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## The Challenges of Seeking and Receiving Support for Women Living With HIV

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Human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS) continue to affect a growing number of women. Because social support is essential to both physical and mental health, this study was designed to explore the social support challenges of women living with HIV. Using a grounded theory approach, 45 women were interviewed. In their support experiences, these women encountered numerous challenges in seeking and receiving social support. Challenges seeking support included stigma and a lack of resources. Challenges receiving support included a mismatch of goals, concern for the providers, a lack of independence, and the readiness to accept the support offered. Issues concerning how these specific challenges factor into disclosure, the communication of support, and community are considered in the discussion. Future interventions and the development of support programs guided by this study will have the potential to improve the physical and psychological health of women living with HIV.

The number of women living with human immunodeficiency virus (HIV) has been increasing steadily since 1986, particularly among Black and Hispanic women. In 2005, women accounted for 26% of new HIV/AIDS diagnoses and represented 23% of the estimated number of people living with acquired immune deficiency syndrome (AIDS) in the United States (CDC, 2008). HIV primarily affects poor women who often lack social, financial, and medical resources to deal effectively with the disease (Heckman, 2003).

Living with HIV is particularly stressful for women. Women living with HIV exhibit higher levels of depression (Heckman, 2003), lower levels of well-being and functioning (McDonnell, Gielen, Wu, O'Campo, & Faden, 2000), and lower quality of life (Cowdery & Pesa, 2002) than men living with HIV. Because they may be perceived as a source or potential source of infection or as a member of a stigmatized group (Ciambrone, 2001), women with HIV report limited social interactions with friends and family as well as a low level of perceived social support (Hudson, Lee, Miramontes, & Portillo, 2001). Many women experience difficulty disclosing their HIV status to family members as

well as to partners (Kalichman, DiMarco, Austin, Luke, & DiFonzo, 2003), and those who disclose their status often experience the breakup of a marriage or a relationship, neglect or rejection by family, loss of friends, and even physical or sexual assault (Grinstead, Gregorich, Choi, & Coates, 2001). Many women living with HIV also suffer from guilt and concern about the effect of their illness on their family (Goggin et al., 2001). They experience a number of family-related concerns, including the needs of children and struggles with family finances (DeMatteo, Wells, Goldie, & King, 2002); hence, mothers living with HIV appear to be at the greatest risk for distress and depression (Murphy, Marelich, Dello Stritto, Swendeman, & Witkin, 2002).

Thus, women living with HIV face many psychosocial challenges, including stress on their relationships and challenges finding support to help them cope with their illness. Some describe a lack of support services available to women living with HIV, leading them to experience their illness alone rather than as part of a community (Lichtenstein, Laska, & Clair, 2002). Available research on social support suggests important directions for future investigations: specifically, the need for descriptions of the social support needs and experiences of women living with HIV (Siegel & Schrimshaw, 2005).

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The specific aim of this study, therefore, is to identify the challenges associated with seeking and receiving support, and how those challenges might create dilemmas of support.

## SOCIAL SUPPORT AS A COPING RESOURCE

Social support is one resource that women can use to cope with the stresses of HIV illness. Social support generally can be defined as the various ways in which interactions and social relationships affect physical and psychological well-being (Burlinson, Albrecht, Goldsmith, & Sarason, 1994). More specifically, social support has been defined as “an interpersonal transaction involving one or more of the following: emotional concerns, instrumental aid, information, or appraisal” (Cutrona, Suhr, & MacFarlane, 1990, p. 30).

Research suggests that social support and strong social networks are important resources and possible buffers against stress for women with HIV (Serovich, Kimberly, Mosack, & Lewis, 2001). Women report that they choose to disclose their HIV status because they desire social support (Kalichman et al., 2003). High levels of stress can suppress the immune system, whereas social support can help control stress (Livingston, 1988) and enhance immune function (Gore-Felton & Koopman, 2008). Receiving social support is related to less depressive symptomatology and better well-being scores (Simoni & Cooperman, 2000) for women with HIV. Women with high levels of social support have a higher level of adherence (Gonzalez et al., 2004), practice more health promoting behaviors (Gielen, McDonnell, Wu, O’Campo, & Faden, 2001), and adopt better coping strategies (Heckman, 2003).

Social support can be a highly beneficial resource that should be more available and accessible for women with HIV (Simoni & Ng, 2000). Even when women living with HIV report having adequate social support, they often question whether that support will be present throughout the illness trajectory (Ciambrone, 2002). This lack of adequate support is a significant predictor of distress (Hudson et al., 2001) and depression (Richardson et al., 2001). There is insufficient research currently to help determine the causes and consequences of inadequate support. The result is that we know social support can be helpful for women with HIV, but do not know what is helpful, how women can most effectively seek support, and how to deliver that support. This need for additional research with women with HIV or AIDS led to the following research questions:

- RQ1: What are the challenges associated with seeking support for women living with HIV?
- RQ2: What are the challenges associated with receiving support for women living with HIV?

## METHOD

Because relatively little research specifically describes social support experiences of women living with HIV, I employed a qualitative grounded theory approach (Corbin & Strauss, 2007). Following approval by the Institutional Review Board for the Protection of Human Subjects, participants were recruited. In this study, audiotaped in-depth interviews ranging approximately from 45 minutes to 1.5 hours were used to examine the social support experiences as well as the communicative strategies and behaviors women living with HIV utilize to seek or enact support. Before the interview, participants were asked to complete a brief survey and sign an informed consent document. An additional researcher conducted eight of the 45 interviews and participated in the data analysis.

### Instruments

**Survey.** Respondents were asked demographic questions such as their age, ethnic group, sexual orientation, and employment status. Health-related information (i.e., how long they had been diagnosed with HIV or AIDS, whether they were on medication for their illness or depression, and their current CD4 count and viral load) provided a health profile of the women. The survey also included the Center for Epidemiological Studies Depression Scale (CESD). The CESD is a 20-item scale that has been used extensively in HIV/AIDS studies.

**Interview schedule.** An interview schedule was generated from the needs expressed in the literature on women living with HIV as well as the literature on social support and HIV (the interview schedule is available from the author upon request). The first section of the interview schedule was designed to elicit information about the challenges the participant has experienced as a woman with HIV or AIDS. The remainder of the interview questions focused on how social support functions for participants, what their experiences were seeking support, and what support has been the most helpful and the most unhelpful.

### Participants

Study participants were 45 women living with HIV or AIDS. They were each reimbursed \$25 for their participation. Participants were recruited in three Midwestern cities at (a) an HIV care facility, (b) an AIDS service organization, and (c) an AIDS clinical trials unit (ACTU). Intentional efforts were made to recruit a sample that reflected the wide variety of ages, races, and backgrounds of women with HIV. The average age of the participants in the sample was 39 years old (range 19–64,  $SD = 8.79$ ). Three (7%) women reported being employed, 26 (58%) women reported being on disability, and five (11%) women identified themselves as

students. Twenty-six (58%) of the women reported having a partner with whom they were in a committed relationship. Thirty-nine (87%) of the women indicated that they had children (number of children ranged from one to seven). Of these 39 women, 13 had children who did not live with them, and 11 had children under 18 years of age who did not live with them.

Black women and Hispanic women account for approximately 82% of AIDS cases in women (CDC, 2008a). The sample for this study reflected these numbers. Thirty-six (80%) of the women reported their racial identity as African American. Four (9%) women reported their racial identity as Latina. Two (4%) women reported their racial identity as Caucasian. One woman (2%) identified herself as biracial. Two women (4%) did not answer the question.

The average time since diagnosis with HIV was 7 years (range = 0–16,  $SD = 3.96$ ). Eleven (24%) of the women reported being diagnosed with AIDS. Those with AIDS reported an average time since diagnosis with AIDS of 5 years (range = 1–7,  $SD = 2.12$ ). The mean CD4 count was 506 (range 8–1,200,  $SD = 289.21$ ). An additional indicator of the progression of HIV is the viral load, or the amount of virus in the blood stream. A viral load of 50 or less is considered to be undetectable for the purposes of this study. Because the range of viral loads was so large (50–590,400), the median of 59 is a more accurate representation of the sample than the average of 29,437 ( $SD = 107,079.72$ ).

Thirty-four (76%) of the women were taking HIV medication. Twenty-five (56%) of the women were taking depression medication. In this sample, the average score on the CESD was 23 (range 0–51,  $SD = 12.18$ ). Scores on the CESD of 16 or above out of a possible 60 are considered to indicate significant depressive symptoms. Of the 42 women who completed both the CESD and the information on depression medication, 29 scored above 16 on the CESD. Twenty-one of those 29 whose scores indicated significant depressive symptoms reported taking medication for depression.

### Data Analysis

After the tapes were transcribed, the transcripts were verified with the audiotapes. Once the transcripts were verified, they were reexamined to look for specific themes and important issues. These themes were then compared for similarities and differences to group them under larger categories. The larger categories were reviewed to make sure there were no overlapping or duplicated categories. The additional researcher who had interviewed participants reviewed the transcripts and the categories. The transcripts were then coded according to the categories. The transcripts were reexamined to define and explain the categories in more detail. Quotations that were particularly representative of the categories were selected from the transcripts and reviewed by the additional researcher. Content validity of categories

and themes was assessed through procedures described by Lincoln and Guba (1985): (a) Participants in the later interviews were used to validate categories and themes from earlier interviews and (b) a fellow HIV researcher reviewed transcripts to match categories and themes.

## RESULTS

The results of this study demonstrated that social support was a key factor in coping with HIV illness. Jill, a 43-year-old Caucasian woman, explained, "Support is a very important part of dealing with this. Don't isolate yourself. When you are alone, your mind is a very dangerous place. When you are dealing with something as devastating as HIV and AIDS, or any fatal illness, it's hard to deal with it on your own." These women encountered numerous challenges in seeking and receiving social support. Challenges seeking support included stigma and a lack of resources. Challenges receiving support included a mismatch of goals, concern for the providers, a lack of independence, and the readiness to accept the support offered.

### Challenges of Seeking Support

**Stigma.** The process of disclosing their HIV status to other people is one major concern that the women had that affects support-seeking behavior. Although 43 (96%) of the women had disclosed their HIV status to another person, deciding when and to whom to disclose took a lot of thought. Edna, a 43-year-old African-American woman, explained, "When I sit down and talk to a person I just don't tell them right out about my diagnosis. I have to fish my way through that to know when to say and when not to say something."

Many women were afraid that disclosing their status might mean losing a relationship with the confidant. Elaine, a 40-year-old Caucasian woman, explained that this was the worst thing about disclosing her status: "Being afraid. There is always that fear that someone will turn their back on you." The women expressed particular concerns about disclosing their status to their family. There was a clear need for support surrounding disclosure to their children, as well as to other family members. Rachel, a 25-year-old African-American woman, discussed her concern:

How to tell my family? What would my family think about me? Would they change or would they be the same? I was scared to tell them because I didn't know how they would react. Would I get that warm look from them or would I get that cold look?

In addition to the fear of abandonment by family members, women also worried that family members would not keep the information private. Many expressed concern that telling their family meant that other people would find out about their diagnosis.

When asked about what was difficult for her, Cindy, a 51-year-old African-American mother of four, answered that it was being around her family: "It's very hard for me because they know you have these illnesses and they are scared of you and scared that it's going to rub off on them. It's the hardest thing when I go see them." For some, encounters with family members were painful with constant reminders that they have a chronic illness. Many women had restrictions when they visited family members, such as a specific place to sit, separate eating utensils, and limited or no physical contact with children. Cindy explained her family's reaction:

My family knows and they really let you know that you have HIV and herpes. They throw your clothes out and you're not allowed to go in the refrigerator. They give you a special spoon and plate to eat out of. It's really hard. They think they caught something from you and they are not very nice.

Although it was difficult to seek support in light of these experiences with stigma, these difficulties were compounded by a lack of available support resources.

**Lack of support resources.** These women living with HIV reported that there are not enough support services, and the available services are difficult to find. They offered multiple explanations for this lack of services. One fundamental reason the women felt that there were not enough support services was that they felt that HIV is not as salient a public issue as it should be. Frustration at the lack of attention was clear when Emma, a 46-year-old African-American woman, said:

HIV is on the back burner if it is on the stove at all. You don't hear that much about it but yet it is more devastating than September 11th. Osama Bin Laden does not have a thing on HIV—September 11th is over with. HIV is not over with.

This frustration is compounded by the feeling that if they had a more socially embraced illness they would be able to get the support they need. For example, Emma drew a comparison to breast cancer: "If we were talking about breast cancer we could go on TV and I would get the support that I need that I still need now, but not with this." In addition to these support seeking challenges, the women also reported challenges receiving support.

## Challenges of Receiving Support

**Mismatch of goals.** One challenge that occurs in supportive interactions is that support provision may or may not match the support seeker's goal; for example, "an individual with HIV may simply want emotional support, which may come at the cost of being subjected to new information" (Brashers, Neidig, & Goldsmith, 2004, p. 317). The mismatch of goals in a support-seeking situation can undermine adaptation (Brashers et al., 2004; Goldsmith, 2004). Most unhelpful support experiences the women in this study

had experienced were related to a mismatch of goals. Of the nine (20%) women who provided an example of an unhelpful support experience, five (55%) offered instances of mismatched goals. For example, one woman wanted to talk with her daughter-in-law, whereas her daughter-in-law wanted to encourage her to be more active. Sara, a 49-year-old African-American woman, explained:

My daughter-in-law one day was trying to get me to go out and I didn't want to go out. This was in the beginning when I got out of the hospital and she wanted me to go out instead of staying in all the time. She thought I was getting very depressed and stuff. But she didn't want to talk to me, she just wanted me to get out of the room.

*Interviewer: How did it affect you when she did that?*

I started crying because I wanted her to talk to me and not tell me to get out of the room. I just got more depressed.

It is clear in this example that the mismatch of goals led to an unhelpful attempt at support, leaving the woman living with HIV more depressed. Sometimes, an unhelpful experience not only causes more distress, but can also affect future interactions. For example, Amy, a 29-year-old African-American woman, commented:

I've got one who is a "Mr. Know-it-all" about HIV and AIDS. I really don't like talking to him when something is going on. I feel worse after talking to him. There is no sympathy there and I guess that's what I'm looking for. He says, "get off the pity, you're not going to have a pity party." There is no sympathy or empathy there, so rarely do I call him.

Amy was looking for emotional support, but "Mr. Know-it-all" only wanted to provide informational support. Not only did Amy have a support experience that left her feeling worse, she also decided that this support provider was not someone to whom she wanted to turn for support in the future. The mismatch of goals in these support situations left the women feeling more stress and affected their relationships with the support provider. Further complicating this process for the women was their concern for support providers.

**Concern for support providers.** The women in this study also faced the challenge of balancing their needs for support with their concern of overburdening their families. Because the women were concerned with the burden they were placing on their family, both to provide support and to cope with stigma, some did not disclose their HIV status to family members. Some who had disclosed to their families limited the conversations they had about their diagnosis. Bonnie, a 41-year-old African-American woman, explained her concerns about going to her family: "My family is 100% behind me but they don't want me to keep talking about it. This is part of my life. I don't know if I make them sad along with me." Ella, a 64-year-old African-American woman, had similar views about talking with family. "I try not to talk to



my family. They always take a double meaning on things. I don't want to bother them because they worry about me."

Not wanting to worry or cause sadness for others is also a factor for the women when it comes to disclosing their status to their children. Particularly when the women had small children, they did not want the children to be worried or scared of a situation they might have trouble understanding. Maggie, a 28-year-old African-American mother of three, explained:

I'm trying to help my oldest understand it. She knows Mom is sick and I try to explain to her what it is. She's ten and the other two just know that Mommy is sick and Mommy has to take medicine every day. That's all they know.

Some women had not told their children, or had told them very little, about their HIV status. In addition to their concern about support providers, the women were also concerned with their lack of independence.

*Lack of independence.* The women often were frustrated because they were not able to maintain their independence from friends, family members, and various governmental organizations. One cause of this feeling of dependence was that some women had lost the ability to work. For some, not working was frustrating because of the lack of activity. Marci, a 41-year-old African-American woman, commented that her frustration was "Not being able to go to work. I'm a worker and I like to do things. I'm not able to do things like I used to." Losing her job reinforced for Marci that she could not do everything on her own anymore, causing her to need support to accomplish the tasks she could not, as well as needing support for this loss of a piece of her identity. For some women, not being able to work removed them from an environment in which they had constant contact with other people. Their need for support increased because they were not able to help people and provide support for others. Helen, a 45-year-old African-American woman, had worked in the health care field before her diagnosis and was particularly discouraged that she could no longer care for people. She said:

I had to stop working and that was torment for me. I really enjoyed working. I really enjoyed what I did; I took care of patients. I tried very hard to continue to work even though the doctors told me I shouldn't work. I kept trying to go back and even when I couldn't wear shoes because I had neuropathy so bad.

Not being able to work also left the women with financial struggles. These challenges forced them to give up possessions such as homes or cars and forced them to seek support from friends or family members. These threats to independence were very difficult for them to adjust to, and were a source of on-going stress. Sara, a 49-year-old Hispanic woman, said that for her the most difficult part of life was

that I can't do any thing for myself and I have to depend on everybody else. I lost my apartment and I am just with one son now. His wife takes care of me. I want to be on my own again. I want my own apartment and my own car.

Whether it be a direct need for assistance due to the financial burden or losing their job, or need for greater support due to the loss of identity or physical ability, these changes all contributed to a feeling of greater dependence on others. The women's concern about relationships further complicated the situation.

*Relationship concerns.* Another challenge to support seeking is the disruption of current and future relationships. In addition to their feelings toward the person who infected them, the women also mourn the loss of future relationships. Some women believed that their HIV diagnosis meant that they would not be able to have another relationship with a partner. Briana, a 40-year-old African-American woman, experienced both the frustration and the loss of future possibilities and said:

I felt I would never catch that and when I found out I had it, I just couldn't believe. I went to see two or three doctors. I'm not very happy that I got this stuff. It's hard to get into a relationship. How can you tell someone that you have HIV? The man would run off and probably beat you up because you didn't tell him in the beginning when you had sex with him. So I stay single.

The debate over whether to have relationships, and how to handle relationships if they had one, often was a divisive issue for the women. Because the women had strong opinions about the subject, and disagreements were common, they did not like to discuss relationships with peers. Even if a woman felt she had a strong, supportive relationship, her inclination was to keep that from her peers. For some, this meant not sharing positive relationships with peers. For others, it meant not being able to seek support for negative or stressful relationship situations. Regardless of the relationships involved, the women felt they had to be ready for the support in order for it to be beneficial.

*Readiness to accept support.* For many of the women, it took some time to react and adjust to their HIV diagnosis. During this time, many of them refused support. Andrea, a 38-year-old African-American woman, explained, "You have to be at a place where you want it. I turned it down because I wasn't ready." In particular, some of the women had encountered what they called a "know-it-all" who had provided little sympathy and large amounts of information early in their experience with HIV. Not only was this type of support not helpful to them at the time, it overwhelmed them. This reflects the dilemma that advice may be experienced as helpful and caring or as butting in or an intrusion (Goldsmith & Fitch, 1997). The women indicated that some were not open and willing to listen to the support others were offering because they wanted to feel sorry for themselves. Lisa, a

43-year-old African-American woman, said that it was bad “to feel that you want support but you aren’t willing to take suggestions. I want the support but I’m not receptive to the answer because I want to dwell on my problem.” Regardless of their reason for not being ready, support offered to women who are not ready to receive it was not effective.

## DISCUSSION

The aim of this study was to learn more about the challenges of seeking and receiving support for women living with HIV. This research serves as an initial step in the development of a normative model of social support for women living with HIV. To develop a normative model, it is important to look at the challenges of support that these women experience, as well as their strategies for coping with these challenges. For these women living with HIV, support experiences have been limited by the challenges associated with seeking and receiving support. In general, these challenges created dilemmas of support (i.e., when to disclose, how to construct messages, and how to develop community) that can hinder the effectiveness of seeking or providing support. The following subsections highlight these dilemmas.

### Dilemmas of Difficult Disclosures

The most predominant support challenge facing these women living with HIV is that of disclosure. This creates a dilemma—if people do not disclose their status, they cannot seek support. People living with HIV face the choice of disclosing their status, which has implications for support, the experience of stigma, and changes in relationships (Greene, Derlega, Yep, & Petronio, 2003). People living with HIV have reported, for example, that stigma influences whether they disclose to friends and family because of “concerns about self-blame, fear of rejection, communication difficulties, and a desire to protect the other person” (Derlega, Winstead, Greene, Serovich, & Elwood, 2002, p. 415). For these reasons, disclosure of HIV may be a slow, gradual, judicious, and strategic communication process (Greene et al., 2003; Yep, 2000). The women in this study managed this dilemma by being extremely selective about to whom they disclose their status, and in turn, from whom they seek support.

Support-seeking behaviors are based partially on concerns about the control of information and confidentiality. The discloser has to decide how important it is to control the information (Derlega, Winstead, & Folk-Barron, 2000). Many people with illnesses engage in what is called protective disclosing (Charmaz, 1991). In this case, the person with the illness has control over the form and timing of the information provided to others. This allows people time to soften the information, prepare others for the information, or

prepare themselves for the possible reactions to the disclosure (Charmaz, 1991). The women in this study attempted to engage in protective disclosure by being selective and strategic about how and to whom they disclosed their status; however, in some cases disclosure resulted in greater stress. Research indicates that fear of disclosure may be increased because it can result in the loss of control over the information (Brashers et al., 2004). Participants in this study feared they would lose control over information about their health. Potential sources of support were carefully evaluated for their potential for stigmatizing reactions, as well as the level of threat that source would be to their control over the confidentiality of their status. The women were even cautious about HIV-related resource centers or support sources because of the potential that someone would see them, know about their diagnosis, and share that information with others.

Support-seeking behaviors also are affected by concerns about stigma. People living with AIDS make distinctions in how they balance private information and to whom they choose to disclose. Stigma is a crucial factor in this balance (Greene, 2000), which was clear from the experiences of the women in this study. The target or recipient of disclosure is significant in explaining disclosure decisions (Greene, 2000), and different people may have radically different responses (how a person is treated by the recipient of the disclosure might be changed, or unaffected; see Greene & Faulkner, 2002). In some cases, a significant other is an important resource for support (Haas, 2002). For women in my study, their HIV infection is many times connected to their significant other in some way, making disclosure to them problematic. For some, there were feelings of anger and confusion toward their significant other, primarily because that person was the most likely source of their HIV infection. For others, disclosing to their significant other was complicated because they were forced to reveal additional information about themselves that could cause tension in the relationship, such as previous sexual behaviors, drug use, affairs, or abusive or violent experiences such as rape. Because of these relational tensions with significant others, this relationship that many people would count on when a stressful event occurs can become an additional source of stress (Harvey & Wenzel, 2002). Because the needs of both the recipient and the provider are important in a supportive interaction, disclosure of an illness can lead to a struggle over who is responsible for supporting whom (Coyne, Ellard, & Smith, 1990). For these reasons, it was important to the women in this study to consider how the other person would co-manage knowing their HIV status (Derlega, Winstead, Greene, Serovich, & Elwood, 2004). The women in this study were concerned about overburdening family members and spouses with their needs for support, complicating their decisions about disclosure.

Another common disclosure target for people living with HIV is the nuclear family (Greene & Serovich, 1996; Serovich, Greene, & Parrott, 1992). For the women in this

study, family members provided a sense of belonging and unconditional support on which they could always count. The risk of losing that constant source of support by disclosing an HIV diagnosis was magnified by the closeness of these relationships. In addition, losing family as a source of support would also force the women to seek support elsewhere, requiring disclosure to others who might not be as close or might have less predictable reactions. Because family was so important to the women, rejection by family members was particularly devastating. Further complicating the disclosure decision to the nuclear family were the experiences of other people living with HIV who had been mistreated by their families. Stories of outright rejection, abuse, or mistreatment by family members upon hearing of an HIV diagnosis made many of the women nervous about the possible reactions of their own families. In some cases, research has indicated that “just the anticipation of bad responses might be more crucial to the decision to disclose an HIV diagnosis than whether or not they actually get bad responses” (Greene et al., 2003, p. 125). The potential loss of relationships, family support, and the experience of stigma complicate the process of disclosure for women living with HIV. These challenges of disclosure are further complicated by the lack of community for women living with HIV.

#### Dilemmas of How Support Is Communicated

Throughout the experience of challenges seeking and receiving support, there were several issues that centered on how the support was being communicated. How support is communicated can have an impact on the recipient's coping, on the person's identity, and on the person's relationship with the giver (Goldsmith, 2004). Support can be communicated in more or less helpful ways (Goldsmith, 1994; Goldsmith & MacGeorge, 1997). For example, support is most likely to be helpful when there is a match between the support that is given and the recipient's view of the situation (Goldsmith, 2004). When there is a mismatch of goals, as many of the women in this study experienced (e.g., when a person wants emotional support, but a family member wants to provide advice), the support will not be perceived as helpful.

How supportive messages are provided can change how they are received. For example, direct messages are clear but can also threaten a person's sense of autonomy or self-esteem (Goldsmith, 2004). Support that is too direct or blunt can have harmful effects. The overwhelming amount of information provided to some by a “know-it-all” was very direct, but was perceived as unhelpful by the women. Not only were some overwhelmed to hear such direct information, but the unsuccessful support attempt also decreased the chances that the recipient would seek support from that provider in the future.

The women faced a loss of independence by seeking support. Their physical sense of independence is threatened

because many of them cannot continue to work and have to rely on family members for transportation and shelter. To seek additional support, the women risk losing their emotional independence, because they have to rely on others for comfort, which can be a self-threatening situation (Coyne et al., 1990). Although indirect support may lessen the risks to autonomy, it can also be misinterpreted (Goldsmith, 2004). It may not be perceived as a support attempt at all, or may be interpreted as unsympathetic. Because the message may not directly address the issue the receiver is focused on, the support being offered might be missed.

#### Dilemmas of Community

Community is an important source of support and comfort for people living with HIV, because it provides material and/or psychological safety and security (Adelman & Frey, 1997); however, feeling like they lack community made some women in this study avoid, or not take advantage of, social resources. For gay men living with HIV, developing a supportive community has been shown to enhance social well-being (Somlai & Heckman, 2000) and a sense of belonging (Kraft, Beeker, Stokes, & Peterson, 2000). Community membership also has an impact on individual-level behaviors (Brashers, Haas, Klinge, & Neidig, 2000). It is clear that community provides gay men living with HIV important support resources. Community facilitates accommodation to HIV status and helps educate people who are newly diagnosed about the illness and treatment options. Peer interactions also can provide a basis for social comparison, which may be an important factor contributing to how well individuals cope with their illness (see Derlega, Greene, Henson, & Winstead, 2008). Although this was true for some of the women who were involved with women's peer groups, many women in this study did not feel they had community resources.

The women felt that there were many resources for people living with HIV that were not meant for, nor helpful to, women. They said it was difficult for them to find tangible resources that addressed family-related needs like school items for children or help finding or maintaining safe housing for families. The women spent much of their time seeking help to secure food, housing, and financial resources for themselves and their families. It was also difficult for some of the women to find resources such as support groups specifically directed at women's issues. Although some of the women were willing to participate in support groups with men, they acknowledged that the information and topics that were discussed were much different than in all-women groups. Navigating sexual relationships, emotional challenges, and biological issues unique to women were topics that the women did not feel they could talk about in a mixed-sex support group. Community is based on an emotional connection between people who feel a mutual sense of belonging to a particular group (McMillan & Chvis,



1986). In this case, the women often lacked this sense of emotional connection and belonging.

The lack of community contributed to the feeling that support was not always available. The support that a community provides can be thought of as a safety net—when someone rejects an individual, there will always be someone to help. The women felt that it was very important to maintain the support resources they had because they did not have a community on which to rely. The feeling that there would be a community behind them despite what happens with other friends or family members was not something that the women experienced. This meant that disclosing was a very complex decision based on predicted reactions and the degree to which they could trust the other with knowledge about their status.

### Toward a Normative Model

This study examined the social support experiences of women living with HIV as a first step toward developing a normative model. The development of a normative model of social support includes an examination of how social support functions, the dilemmas of seeking and providing support, and the strategies individuals use to adapt to the dilemmas (Brashers et al., 2004). The women in this study were particularly concerned with meeting basic needs such as food and shelter. Other issues that cause stress for the women are issues surrounding how they contracted HIV, the physical changes that had occurred as a result of their diagnosis, and the difficulty keeping up with and dealing with the side effects of medication. Social support facilitated living with HIV by making it easier to cope on a day-to-day basis; however, there were numerous challenges associated with seeking and receiving support for the women.

The primary social support challenge the women face is that of disclosure and stigma. Because the women have experienced, or have been told about, experiences of discrimination and stigma, they are very careful about to whom they disclose their status. The women constantly weigh the advantages of disclosing their status to seek support with the risks of stigma and the fear of losing control over their health-related information. The women also face a loss of independence by seeking support. Their sense of independence is already threatened because many of them cannot continue to work and have to rely on family members for transportation and shelter. While the women face threats to their independence, they also face threats to current and future relationships. As they struggle with these stressors, the women suffer from a lack of support services. Support services that cater specifically to women are rare, which deters some of them from utilizing services that are available. Even when support is available, some women are not ready to accept their status or to disclose their status to others. When the women take advantage of support opportunities, they can experience unhelpful interactions with peers,

a mismatch of goals, and concern about the burden support places on support providers.

A normative model can serve multiple purposes for women living with HIV. Further development of this model will include examining how women deal with the challenges identified in this paper. The unique support sources the women use, along with their recommendations for providing support, can be used to establish mental health interventions. Interventions that facilitate disclosure, provide the women with strategies for dealing with stigma, and provide women with encouragement should be developed to meet these needs. By addressing the issues of disclosure and stigma and providing more opportunities for exposure to other women living with HIV, women may become more empowered to be involved in their health care. This involvement can lead to the reduction of the risk of disease progression. Above all else, making tangible support more available will not only promote quality of life, but will also afford women the opportunity to take advantage of emotional, esteem, and informational support opportunities.

### Limitations

A few limitations of this study should be recognized. Because this method entails interviewing, large numbers of participants are impractical for detailed analysis; therefore, the results of this study are based on a relatively small sample of women. Despite the relatively small size of the sample, conducting interviews in three cities yielded a sample of women with diverse backgrounds and experiences. Another limitation of this research is the lack of some general demographic data. In particular, no information about income or educational experience was collected. This information would have been helpful to further characterize the sample, as well as providing a richer explanation of the women's context. Additional information about the women's physical experience of HIV would have also provided more information about their experiences. Because the interviews were only conducted with the women receiving the support, additional research that involves support providers is needed to provide a more complete picture of the interactions and the challenges surrounding them.

### CONCLUSION

This study was designed to explore the social support challenges of women living with HIV or AIDS. The women in this study faced multiple challenges to finding and receiving the support they needed. Although the women had trouble finding support, the social support they did find was important to their adjustment to, and day-to-day coping with, living with HIV. As the number of women diagnosed with HIV continues to grow, understanding how social support impacts their lives becomes increasingly important. Developing a

normative model of social support for women living with HIV will help practitioners develop more effective interventions and services, which will increase the psychological quality of life of women coping with HIV or AIDS. Much more research needs to be done to provide a clearer picture of what support works and what support does not work for women living with HIV.

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