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Identifying HIV-Infected Women's Psychosocial Stressors: Findings from a Qualitative Study

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Abstract

To inform future psychosocial interventions for HIV-infected women, five focus groups were conducted with 29 HIV-infected women (72% African-American). Sessions were audio-recorded, transcribed, and coded by two raters. HIV-specific stressors included difficulties with serostatus disclosure, HIV medication adherence, and HIV-related discrimination. Stressors not directly linked to HIV were described as more concerning and included mental health or substance use problems, relationship challenges, caretaking for children or grandchildren, and financial difficulties. Participants suggested that interventions provide social support from other HIV-infected women, consistent case management and social work services, and forums to acquire additional information about HIV and treatment options.

Keywords

HIV-infected women; stress; coping; psychosocial interventions

Rates of new HIV infections are on the rise among women in the United States (CDC, 2006). The Centers for Disease Control and Prevention estimate that 24% of all new HIV diagnoses in 2009 were among women, with elevated incidence among African-American women (CDC, 2011). Highly active antiretroviral therapy (HAART) has improved the long-term health outlook of HIV-infected individuals and has markedly decreased HIV-related mortality (Palella et al., 1998; Schackman et al., 2006). Despite the improved medical prognosis following an HIV diagnosis, women living with HIV face a number of ongoing

coping challenges. However, few interventions to promote health and coping among this growing segment of the HIV-infected population have been developed or tested (Brown & Vanable, 2008, 2011). To inform future psychosocial interventions and services, this study used qualitative methods to investigate psychosocial stressors experienced by HIV-infected women and solicited women's input regarding core intervention needs.

HIV poses a number of unique psychosocial challenges associated with living with a chronic, stigmatized disease (Bower, Kemeny, & Fawzy, 2002; Bravo, Edwards, Rollnick, & Elwyn, 2010; Kalichman & Catz, 2000). While some HIV-infected individuals effectively manage their care and lead fulfilling lives, a significant proportion report difficulties coping with stress (Heckman et al., 2004). Elevated psychosocial stressors, coupled with poor stress management skills, can exacerbate existing psychiatric illnesses or heighten an individual's risk for a new psychiatric disorder (Catz, Gore-Felton, & McClure, 2002; Griffin & Rabkin, 1997). Heightened distress may also contribute to poor disease management and negative health outcomes (Ironson et al., 2005; Jenkins & Coons, 1996) including accelerated disease progression (Chida & Vedhara, 2009), as indicated by CD4 decline, increased viral load (Ironson et al., 2005), and fewer natural killer cells (Leserman et al., 1999). Further, poor engagement in protective health behaviors including HAART adherence (Mellins et al., 2009; Weaver et al., 2005) and consistent medical appointment attendance (Andersen et al., 2007) may mediate the association between psychosocial distress and disease outcomes (Gore-Felton & Koopman, 2008). Thus, there is increasing evidence that psychological distress is associated with poor health outcomes and less engagement in protective health behaviors among individuals living with HIV.

Qualitative research provides a valuable approach to gather in-depth information, aid the development of intervention strategies, and identify key programming needs (Morgan, 1997). However, to our knowledge, only three studies have qualitatively investigated the psychosocial stressors of HIV-infected women (Hackl, Somlai, Kelly, & Kalichman, 1997; Ndlovu, Ion, & Carvalhal, 2010; Semple, Patterson, Temoshok, & McCutchan, 1993). Two studies assessed the stressors of HIV-infected women and found that HIV-related health concerns and issues central to HIV (e.g., experiences of HIV-related stigma) were the most salient stressors (Hackl et al., 1997; Semple et al., 1993). These studies also highlighted the prevalence of stressors not directly linked to women's HIV serostatus including occupational and economic challenges (Semple et al., 1993), marital and intimate relationship difficulties (Hackl et al., 1997; Semple et al., 1993), and inadequate social support (Semple et al., 1993). However, these studies were done before the widespread availability of HAART. A more recent qualitative study found that inadequate housing and serving as the primary caregiver for children were the most prominent stressors (Ndlovu et al., 2010). However, this study sampled only six HIV-infected women. While these studies provide insights into HIV-infected women's experiences, they were limited by being conducted prior to the widespread availability of antiretroviral medications and HIV medical treatment advances (Ndlovu et al., 2010; Semple et al., 1993), enrolling few HIV-infected women (e.g., $N = 6$ participants; Hackl et al., 1997), and inadequate assessment of desired psychosocial services to address stressors.

Needed is more current and representative research investigating the psychosocial needs of HIV-infected women. Such research will inform programming that is increasingly viewed as integral to the broader goal of assuring that HIV-infected individuals maintain adequate self-care for their illness (Ironson et al., 2002). In so far as psychosocial interventions can reduce distress and, potentially, improve disease management and health outcomes, research to identify priority psychosocial service needs among HIV-infected women is of considerable importance. Thus, this study sought to: (a) identify the most prominent stressors experienced by HIV-infected women; and (b) solicit HIV-infected women's input regarding desired strategies to address their psychosocial challenges. We hypothesized that HIV-specific stressors would be more concerning than general psychosocial stressors and that women would indicate that HIV-related social services were their most pressing need.

Method

Participants

Focus groups were conducted with HIV-infected women ($N = 29$), with 72% self-identifying as African American, 21% as Caucasian, 3% as American Indian, and 3% as Multiracial. Participants' ages ranged between 23 and 64 ($M = 45.9$, $SD = 9.7$). Twenty eight percent were employed, working an average of 34 hours a week ($SD = 11.6$). The typical monthly income among participants was low ($M = \$1,063$, $SD = \$934$). The mean education level was 11 years of schooling ($SD = 1.7$ years). The average number of years since being diagnosed with HIV was 12.3 years ($SD = 5.6$); 44% had one or more previous HIV-related hospitalizations and 28% had been diagnosed with AIDS.

Procedures

Recruitment and informed consent—Patients were recruited during outpatient medical visits at a University-based Infectious Disease (ID) Clinic in a mid-sized Northeastern city. Patients were informed that participation involved engaging in a single focus group with other HIV-infected women and completing a brief paper-and-pencil questionnaire. Eligibility requirements for this study were: (a) receiving outpatient care at the ID clinic; (b) female; (c) 18 years or older; (d) medically able to participate; (e) no evidence of active psychosis; (f) cognitively capable of participation; and (g) able to understand spoken and written English. All participants provided informed consent to participate in the study. All study procedures were approved by the Institutional Review Boards of the participating institutions.

Focus group procedures—Participants first completed a brief, pencil-and-paper questionnaire with demographic and background characteristic questions including time since HIV diagnosis, number of HIV-related hospitalizations, and history of an AIDS diagnosis. Qualitative focus groups were led by the first author, a clinical psychologist with experience working clinically with HIV-infected individuals. The average group size was six members (range: 4–7) across the five groups. In accordance with recommendations for achieving data saturation, we recruited a total sample size between 20 and 30 participants (Creswell, 1998). Each focus group was approximately two hours long and was audio recorded. To structure the focus groups, an interview guide was used.

Qualitative interview guide—Participants were informed that their input was being sought to guide the development of new stress management and educational programs to help HIV-infected women live healthier lives. To identify key psychosocial stressors faced by HIV-infected women, focus group participants were first asked to describe prominent psychosocial stressors in their lives. The operational definition of a stressor was informed by Lazarus and Folkman’s Transactional Model of Stress and Coping (Lazarus & Folkman, 1984). According to this model, to be deemed a stressor, an environmental stimulus must be appraised as taxing, exceeding one’s resources, or endangering an individual’s well-being (Lazarus & Folkman, 1984). Participants were asked to discuss their stressors or “the biggest, challenges, hassles, or things that stress you out, worry you, or demand your time attention.” Follow-up prompts inquired whether participants experienced any unique challenges associated with being an HIV-infected woman. Next, women were asked to describe what information and services would be most helpful to address their psychosocial stressors. Additional input regarding strategies to make such programs successful was elicited along with identification of potential barriers to participating in psychosocial services or interventions.

Data reduction and analysis—Each focus group was audio-taped and transcribed verbatim. After the focus groups were transcribed, the development of a structured codebook and subsequent analyses were guided by the Grounded Theoretical approach (Strauss, 1987; Strauss & Corbin, 1998). The analyses included the identification of key themes in the data, segmenting text and applying codes representing each theme to each text segment, writing annotations about the data content and patterns that emerged over the course of data analyses, and engaging in a systematic retrieval and review of data by theme or sets of themes to characterize themes and relationships between themes. Preliminary analyses were performed relying predominantly on a set of deductive codes representing the initial study objectives as outlined in the focus group interview guide. Using the initial classification system, the first and third authors then coded a randomly selected transcript together. The initial coding classification scheme was refined based on coding discrepancies and discussion of potential revisions for the coding structure using a standard iterative process (MacQueen, McLellan, Kay, & Milstein, 1998; Taylor & Bogdan, 1998). Once the coding classification system was finalized, a structured codebook was created. In depth analyses were based on the emergence of key inductive themes/concepts identified by participants as important. Interpretation of key concepts was based on a thorough and systematic exploration of both inductive and deductive themes, the interrelationships between themes as evidenced in the data, and the development of a conceptual framework that represented and summarized key findings.

The transcripts were then inputted into Analysis Software for Word-Based Records (AnSWR), a qualitative software program designed by the CDC (CDC, 2004). Two independent raters (i.e., the first and third authors) coded the remaining four focus group transcripts using the finalized codebook. Percent agreement between the raters was calculated by the following equation: $\text{Percent Agreement} = \text{Number of Agreements} / [(\text{Number of Agreements} + \text{Disagreements}) \times 100]$. Across the four transcripts, percent

agreement between the two raters was 81%. For the themes identified, illustrative quotes were then selected.

Results

HIV-related stressors

Disclosure of HIV serostatus—Serostatus disclosure to children, family, friends, and sexual partners emerged as a prominent stressor. Deciding on optimal timing of disclosure to children and grandchildren was described as being particularly challenging. A few participants reported that they believed the best time to disclose their HIV status was when their children or grandchildren could be sexually active because they could use this as an entrée into discussing the importance of safer sexual practices. The following quote by a 47-year-old African-American woman illustrates this point:

It's something that needs to be told to them because when they become sexually active, I feel like it will give them the tools to cover up [protect themselves]. You understand what I'm saying? Be careful, know who you're sleeping with and put something on.

Disclosure to family and friends was also a source of stress. Women described hesitancy in disclosing their HIV serostatus due to fears that family or friends would react negatively, as seen in the following quote from a 58-year-old Caucasian woman.

If my brother or sister knew, I mean my brother is like Archie Bunker Jr., you know, and I think it was just the way that I was brought up and my family history and so forth, nobody, even my aunts, my nephews, my nieces, nobody knows. It's just my kids and I think that's my stressor because I'm afraid that if they find out what am I going to say? What am I going to do? How am I going to explain to them that it really was, it was my fault in a way, I had unprotected sex...

Indeed, women stated that they had not disclosed their HIV serostatus to family or friends, and were worried that they might inadvertently learn of their diagnosis. Other participants reported that they had purposely decided not to share their HIV serostatus because of potential negative reactions. In what follows, a 60-year-old African-American woman described her decision to not disclose her HIV serostatus to a close friend.

I have a close friend in [State] and I want to go visit so bad, but I haven't told him. He knows I'm sick, but he doesn't know what's wrong with me and I don't want to tell him.

Similarly, challenges surrounding HIV serostatus disclosure to sexual partners and fears of negative reactions were common among participants. For instance, one participant (48-year-old, African-American) shared her concerns about disclosing to her current partner.

We've been together for a while, but I mean we try to make plans to stay together and stuff like that. I think this is the appropriate time to tell him and if I don't tell him now he's going to be hurt.

As illustrated by this quote, women struggled with disclosure decisions and fears that disclosure would negatively impact their relationships with family, friends, and sexual partners.

Adherence to HIV medications—A second prominent HIV-related psychosocial stressor was medication adherence, particularly among women who had been taking medication for longer periods of time. Participants experienced “medication fatigue” from taking multiple pills over several years. As a result, participants took “vacations” from their HIV medications as illustrated by the following quote from a 40-year-old African-American woman:

...I've been on meds since 1990...and I lapse sometimes, I do. You know I like take them one day and then 2 days I won't take them, but then they say that it's kind of dangerous cause then your body can become resistant to the medications.

Some women also made personal decisions about when they took their medications, rather than taking them as prescribed. One woman stated, “I'll be honest. I take it when I feel like it because I don't want to take too much or something's going to happen.” In addition, women experienced a variety of HIV medication side effects, which undermined their medication adherence; the following quote from a 47-year-old African-American woman illustrates this point.

I take 1 pill a day and sometimes I just get sick of taking them. I've never been a medicine taking person and I'm sick of taking it! You know what I'm saying? And then I'm getting little fatty deposits and my teeth are weak and there's always something with the medicines...you know I read on the net that the HIV meds ages your body from the inside. So you know are you taking these meds to keep you alive or are they actually killing you? Sometimes I get to the point where I go for weeks at a time without taking any of them.

Thus, prominent challenges for HIV-infected women are adherence to complicated medication regimens over the course of many years, fatigue with taking the HIV medications, and side effects, all of which undermine their adherence to HIV medication regimens.

HIV stigma and discrimination—Women also identified experiencing HIV-related discrimination as a prominent stressor. Participants described direct discrimination in employment and healthcare settings and indirect discrimination by their friends, families, and others in the community. Some women reported instances where they had not been hired for jobs or experienced negative consequences at work because of their disease. Other women described negative experiences in the health care context. For instance, a 40-year-old Caucasian woman describes being isolated from other patients in the ER for a long period of time because she was HIV-positive:

...like if I had a high fever and I was coughing or something like instead of sitting in the Emergency Room like where everybody sits you know where they wait to be seen, they had me like way, way in the back. I had to put a mask on.

Particularly stressful for participants were instances where their relationships with significant others were negatively impacted following disclosure of their HIV serostatus. As illustrated by the following quote from a 43-year-old African-American woman, participants experienced discrimination by their family members.

I have a sister, but she looks at me like I'm a monster, you know, like oh my God I can't go to the store with you or I can't go with you. You know like at the table when I'm eating I get that feeling like ooh you've got HIV or you know she'll sit far away from me. I'm your sister, you know.

Participants shared similar stories of their friends or families treating them poorly after learning of their HIV diagnosis. Women who experienced repeated forms of discrimination felt socially isolated and hesitant to disclose to others for fear of negative consequences. Thus, women often were hesitant to disclose their HIV serostatus to avoid potential discrimination from others, a prominent psychosocial stressor.

General Life Stressors

Mental health and substance use difficulties—Across participants, a history of depression was a key struggle. As shown in the following quote, a 64-year-old African-American woman described severe depressive symptoms and prior suicide attempts:

...I'm going to tell you all what happened to me. I almost took my own life. I almost OD'ed and why, I have no idea. I took more pills than I what I should have and my daughter was there and I'm sorry she ever came. I almost took my life...

Participants described ongoing, chronic difficulties with other depressive symptoms; a 55-year-old Caucasian participant characterized her depressive symptoms as follows:

I get days when I just don't want to go out. I don't want to see anybody. I'll just stay home for like 3 days in a row and that's not good.

For several participants a history of childhood trauma or abuse resulted in persistent mental health challenges. One 38-year-old African-American woman described her struggles dealing with childhood abuse as follows:

Somebody did some stuff to me [as a small child], that I don't cry about anymore, because I've talked about it and it's lifted, you know. Before it was lifted, it would hurt so bad, because the pain was so great.

Thus, for a number of focus group participants, ongoing mental health difficulties were cited as important challenges.

Many participants also reported substance abuse as a stressor, with a negative impact on a variety of domains in their lives. For several participants, their substance abuse had damaged important relationships in their life, especially those with their children. Others experienced a variety of other health complications as the result of substance use. Women also reported difficulty abstaining from alcohol and drugs and noted frequent relapses. A number of participants described ongoing difficulties resisting cravings as illustrated by this quote from a 37-year-old Caucasian woman:

I want to go out there and get high every day. Every day I wake up I want to get high. I just choose not to today. That's all [day], every day, you know.

Some women noted that substance use contributed to them contracting HIV initially and that substance use continued to interfere with safer sexual practices. In this quote, a 38-year-old African-American woman described how she engaged in prostitution and did not always disclose her HIV serostatus in order to obtain drugs.

There was a time when I prostituted for the drugs and I would dance around telling them that I was HIV-positive once that I found out that I was 'cause I've always known, right. But I needed the money to do drugs. So I had to trick, right...

Thus, for many participants, the challenge of abstaining from using drugs and alcohol was a daily stressor. In addition, women identified their substance use as contributing to unsafe sexual practices, creating further distress.

Relationship stress—In addition to complications posed by navigating romantic relationships as an HIV-positive person, women identified ongoing challenges with establishing and maintaining romantic relationships. Related stressors included disagreements with romantic partners and the ending of relationships. In order to avoid stress associated with romantic relationships, some women decided to abstain from such relationships. One woman stated, "I think it's easier to just be by myself." Several women also described challenges meeting partners that were suitable for long-term relationships. One 58-year-old multiracial woman conveyed this point as follows:

...the guys of today, okay, the good ones are either married or dead. The other ones are either in jail or on their way, so you've got to find a very good person to sit down and discuss this with so they won't go running for the streets immediately, so it's easier just to be celibate...

Some described constant worry that they would infect partners, even when using risk reduction measures. One 44-year-old African-American woman relayed a related concern of having to disclose her HIV status to a partner whom she is dependent on financially as shown below:

This stresses me out a lot. I have this male friend that I've been seeing for about 3 years and we use condoms and stuff, but I haven't, I mean it's hard for me to tell him cause this is my bread and butter in a sense.

Thus, a key stressor for women was establishing and maintaining romantic relationships, further complicated the need to practice safer sex.

Caretaking for children and grandchildren—Most participants were the primary caregivers for children and/or grandchildren. Women often cited their parenting responsibilities as their *most* pressing psychosocial stressor. Many noted fears about who would care for their children or grandchildren if their health were to deteriorate due to HIV or related medical complications. This point is illustrated by the following quote from a 41-year-old African-American woman:

My biggest stress is my kids. I have an 18 and 19 year old and they stress me out because I don't know how long I'm going to be here for them...

Other women reported daily stress associated with caring for their children. For example, many described frequent arguments with their children as being particularly stressful. Women also had difficulties balancing childcare needs with finding and maintaining their employment, as described by a 47-year-old African American woman, "I'm a single parent and it's hard, especially finding a job." For women with teenagers, concerns that their children's or grandchildren's sexual behavior would put them at risk for HIV were especially stressful. Many stated their fear that their children would become HIV-positive because of behaviors they were engaging in. One 51-year-old African-American woman illustrated this point by describing stress associated with her grandchildren's sexual behavior.

My stress is that my grandkids are hot in their ass. I don't want to curse, but hot in their behinds. You talk condoms. I go to the clinic and I take a bag of condoms and I give them to my grandsons, my granddaughters who are hot in their behinds with their sexy little butts. I say you think you're cute, you don't know what anybody's got, but you should be smart and hitting those books and you're thinking about sex. I got to make sure they're safe, not sorry.

Similarly, some women noted fears that their children would get involved with drugs which in turn could elevate their risk for acquiring HIV. Women often put their children first and at times sacrificed their own needs, particularly their health. One 58-year-old Caucasian participant expressed it this way:

We always put our health on the back burner because we take care, no matter how old our kids are, they could be 50 years old, you know and we still caring for them, caring for their children and everything else and we always put our health on the back burner and we really have to start focusing on ourselves and the stress reduction. You know stress isn't good for [HIV] positive people, you know.

Thus, most participants faced challenges associated with parenting their children or grandchildren. In addition, many expressed concerns about their children's welfare if their health declined. Women also noted instances where they sacrificed their own health or well-being to provide for their children's needs. Related to HIV, participants had additional concerns that their children may be putting themselves at risk for HIV by their sexual or substance use behaviors.

Financial difficulties—Women reported that financial difficulties were a prominent source of stress. Most participants indicated that they were on fixed incomes and had to carefully monitor their expenses so that they were able to pay their bills. This point is illustrated by the following statement by one 58-year-old Multiracial participant, who said, "I mean I'm on a fixed income so you have to learn how to take a dollar and stretch it 20 different ways..." Healthcare expenses also increased this financial challenge. Some women, particularly those who were single parents, reported challenges providing for their children due to financial strains. For instance, one 51-year-old African-American woman

described the stress associated with not being able to pay for things her children want, “The kids want something you can’t give them and you don’t have the money.”

Participants identified financial challenges as a prominent life stressor that they typically worry about. Most were living on fixed income or earned low wages which made additional costs posed by healthcare and providing for their children difficult to manage.

Psychosocial Service Needs

Desire for support groups with other HIV-infected women—Participants expressed frustration that most supportive services for HIV-infected individuals were directed towards men and noted their desire for programming tailored to the unique concerns of women. In particular, participants’ primary desire was to establish regular support groups for HIV-infected women. Participants noted that such groups would provide an important forum to connect with other HIV-infected women who may experience similar challenges and would be helpful in managing stress. One 51-year-old African-American participant described the positive benefits she perceived from participating in a support group as follows:

You know what’s good is when you can talk to other people. That helps a lot, cause like now we’re all sitting here and we all got comfortable with each other. At first we were all looking around, but now I’m comfortable, especially talking with people that are the same way as us. That relieves a lot of stress too, very much so...

Participants noted that the support groups could provide a mechanism for providing additional services to address other concerns including substance use and mental health (e.g., depression). Women also noted that support groups could be used to share information regarding HIV and treatment advances with other women.

Need for consistent case management and social work services—Participants indicated the need for consistent case management and social work services to help address their psychosocial challenges. Women noted that their case managers and social workers had been instrumental in assisting with a variety of stressors, including insurance and billing problems, difficulties arranging transportation for medical appointments, and navigating the health care system. However, participants noted frustration by frequent turnover among case managers; one participant (37 years old, Caucasian) noted, “I don’t want to get used to somebody every other month you know, it’s hard.” Additionally, participants expressed concern about reductions in case management and social work services due to a lack of funding. Thus, participants stressed their desire to have adequate case management and social work services available with a consistent provider.

Potential barriers to utilization of psychosocial services—Women identified several potential barriers of utilization of psychosocial services or interventions. The most frequently cited barrier to utilization of services was lack of available childcare. Indeed, women noted that if free or low-cost childcare was provided in conjunction with services they would be more likely to participate. Participants also indicated that lack of reliable transportation or reliance on public transportation was a key barrier. For example, one participant (37 years old, Caucasian) noted she, “...can’t depend on the bus” and therefore

would only schedule appointments when another transportation option was available. Finally, women noted that when they are experiencing health complications there is a reduced likelihood that they would attend scheduled appointments or participate in other psychosocial services.

Discussion

Consistent with the broader empirical literature on stress and coping among men living with HIV (Bower et al., 2002; Chesney, Folkman, & Chambers, 1996), a significant proportion of the HIV-positive women in the present sample described experiencing a wide range of difficulties related to managing their health and coping with broader life challenges. Whereas HIV-related stressors are often presumed to be of primary concern among persons living with HIV (Bogart et al., 2000; Jenkins & Coons, 1996; Morrow, Costello, & Boland, 2001; Siegel, Karus, & Dean, 2004), our findings suggest that, for many women, other life stressors are often more important than HIV-specific stressors. Indeed, women described experiencing a variety of psychosocial stressors associated with caring for children, difficulties related to establishing and maintaining romantic relationships, and chronic stress related to financial difficulties. High rates of poverty, unemployment, and inadequate housing among HIV-infected women (Hudson, Lee, Miramontes, & Portillo, 2001; Semple et al., 1993), combined with ongoing challenges associated with substance use and mental illness, lead to considerable stress for women living with HIV (Galvan et al., 2002; Morrison et al., 2002).

While women said that general life stressors were typically more concerning than HIV-specific stressors, participants also described a variety of HIV-specific stressors during the focus groups. Women noted enduring challenges related to disease management, including the challenge of maintaining consistent adherence to medication regimens and coping with medication side effects. This finding is consistent with a recent review of antiretroviral adherence rates across 57 studies indicating a multitude of adherence problems and overall poor adherence rates among HIV-infected women (Puskas et al., 2011). Women also described difficulties associated with HIV-related stigma and discrimination and stress associated with disclosure of their HIV serostatus to family, friends, romantic partners, and children (Ciccarone et al., 2003; Semple et al., 1993; Venable, Carey, Blair, & Littlewood, 2006). Thus, enduring challenges remain for HIV-infected women to manage their illness and navigate relationships in the context of a stigmatizing disease.

To address the full range of HIV specific and general life stressors, women voiced the need for supportive services that are tailored specifically to women. In particular, participants identified the need for regular support groups with other HIV-infected women. Additionally, women desired consistent case management and social work services to manage ongoing psychosocial challenges. There is a growing body of efficacious group-based stress management interventions (Brown & Venable, 2008, 2011) that promise to provide a supportive group forum where coping skills can be improved. Such intervention programs would likely benefit from incorporating case management and social work services. Furthermore, ongoing groups could provide women with information about HIV and treatment advances. Such interventions may also benefit from providing women with

strategies to discuss their serostatus and sexual health with their children or grandchildren. Our findings indicate that providing childcare and addressing transportation challenges would bolster participation in such programming. Such services will likely need to be flexibly administered to accommodate the health challenges faced by HIV-infected women. In the current cost-sensitive health environment, documenting the cost-effectiveness of such services (e.g., fewer high cost hospital re-admissions) may help to provide the rationale for such services.

Study Limitations

Interpretation of findings should be considered within the limitations that are inherent to qualitative research. In particular, caution is warranted in generalizing our findings given our sample size. As a result, findings may not be representative of stressors faced by other HIV-infected women. Because participant input was generated based on a structured interview guide, this format may have shaped the type of input that was obtained. In addition, selection bias may have impacted study results. Women who were willing to participate in the focus groups may have had a unique perspective regarding their experiences with psychosocial stressors. Additionally, this study was conducted in one venue with a sample of middle-aged women; thus, results may not generalize to other geographic locations or age groups.

Conclusions and Practice Implications

Many HIV-infected women experience high levels of distress associated with a variety of general and disease specific stressors. For many of the participants, difficult life circumstances existed prior to contracting HIV, with HIV-related stressors adding further coping challenges. To address the multiple stressors experienced by HIV-infected women, efficacious interventions to address these psychosocial challenges are needed. Such female-focused interventions should be designed to provide social support as well as to improve knowledge and skills needed to cope with the wide range of stressors faced by HIV-infected women.

Given the complex medical and related needs of individuals living with HIV, there is an emphasis on providing comprehensive services through funding programs such as the Ryan White Act ("Ryan White HIV/AIDS Treatment Extension Act of 2009," 2009). Comprehensive HIV care centers offer the potential to provide mental health and social work services within the context of routine medical care. Such centers present a setting that is ideal for implementation and evaluation of psychosocial interventions for HIV-infected women. However, for HIV-positive women who do not have access to comprehensive HIV care centers, findings from this study highlight the need to refer HIV-infected women to available community resources (e.g., public health clinics, community-based organizations) and services (e.g., case management, social work services, substance use, and mental health counseling). Ultimately, an integrated approach to HIV care that addresses the medical and psychosocial needs of HIV-infected women holds the promise of improved long-term health outcomes and psychosocial adaptation.

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References

- Andersen M, Hockman E, Smereck G, Tinsley J, Milfort D, Wilcox R, Thomas R. Retaining women in HIV medical care. *Journal Of The Association Of Nurses In AIDS Care: JANAC*. 2007; 18(3):33–41.10.1016/j.jana.2007.03.007 [PubMed: 17570298]
- Bogart LM, Catz SL, Kelly JA, Gray-Bernhardt ML, Hartmann BR, Otto-Salaj LL, Bloom FR. Psychosocial issues in the era of new AIDS treatments from the perspective of persons living with HIV. *Journal of Health Psychology*. 2000; 5(4):500–516.10.1177/135910530000500408 [PubMed: 22049192]
- Bower, JE.; Kemeny, ME.; Fawzy, FI. Group interventions for individuals with serious medical illness. In: Chesney, M.; Antoni, MH., editors. *Innovative approaches to health psychology: Prevention and treatment lessons from AIDS*. Washington D.C: American Psychological Association; 2002. p. 197-218.
- Bravo P, Edwards A, Rollnick S, Elwyn G. Tough decisions faced by people living with HIV: A literature review of psychosocial problems. *AIDS Reviews*. 2010; 12(2):76–88. [PubMed: 20571602]
- Brown JL, Vanable PA. Cognitive-behavioral stress management interventions for persons living with HIV: A review and critique of the literature. *Annals of Behavioral Medicine*. 2008; 35:26–40. [PubMed: 18347902]
- Brown JL, Vanable PA. Stress management interventions for HIV-infected individuals: Review of recent intervention approaches and directions for future research. *Neurobehavioral HIV Medicine*. 2011; 3:95–106.10.2147/nbhiv.s17829
- Catz S, Gore-Felton C, McClure JB. Psychological distress among minority and low-income women living with HIV. *Behavioral Medicine*. 2002; 28:53–60.10.1080/08964280209596398 [PubMed: 12613286]
- CDC. Analysis Software for Web-Based Records (AnSWR) (Version 6.4.x). Atlanta, GA: 2004.
- CDC. HIV/AIDS among women: Fact sheet 2006. 2006. from <http://www.cdc.gov/hiv/topics/women/resources/factsheets/women.htm>
- CDC. HIV Surveillance Report, 2009. 2011. Retrieved July 27, 2011, from <http://www.cdc.gov/hiv/topics/surveillance/resources/reports/>
- Chesney MA, Folkman S, Chambers DB. Coping effectiveness training for men living with HIV: Preliminary findings. *International Journal of STD & AIDS*. 1996; 7(Supplement 2):75–82. [PubMed: 8799801]
- Chida Y, Vedhara K. Adverse psychosocial factors predict poorer prognosis in HIV disease: A meta-analytic review of prospective investigations. *Brain, Behavior, and Immunity*. 2009; 23(4):434–445.10.1016/j.bbi.2009.01.013
- Ciccarone DH, Kanouse DE, Collins RL, Miu A, Chen JL, Morton SC, Stall R. Sex without disclosure of positive HIV serostatus in a US probability sample of persons receiving medical care for HIV infection. *American Journal of Public Health*. 2003; 93(6):949–954. [PubMed: 12773361]
- Creswell, J. *Qualitative inquiry and research design: Choosing among five traditions*. Thousand Oaks, CA: Sage; 1998.
- Galvan FH, Bing EG, Fleishman JA, London AS, Caetano R, Burnam MA, Shapiro M. The prevalence of alcohol consumption and heavy drinking among people with HIV in the United States: Results from the HIV Cost and Services Utilization Study. *Journal of Studies on Alcohol*. 2002; 63(2): 179–186. [PubMed: 12033694]

- Gore-Felton C, Koopman C. Behavioral mediation of the relationship between psychosocial factors and HIV disease progression. *Psychosomatic Medicine*. 2008; 70(5):569–574.10.1097/PSY.0b013e318177353e [PubMed: 18519885]
- Griffin KW, Rabkin JG. Psychological distress in people with HIV/AIDS: Prevalence rates and methodological issues. *AIDS and Behavior*. 1997; 1(1):29–42.10.1023/A:1026261820964
- Hackl KL, Somlai AM, Kelly JA, Kalichman SC. Women living with HIV/AIDS: The dual challenge of being a patient and caregiver. *Health & Social Work*. 1997; 22(1):53–62.10.1093/hsw/22.1.53 [PubMed: 9021418]
- Heckman TG, Anderson ES, Sikkema KJ, Kochman A, Kalichman SC, Anderson T. Emotional distress in nonmetropolitan persons living with HIV disease enrolled in a telephone-delivered, coping improvement group intervention. *Health Psychology*. 2004; 23(1):94–100.10.1037/0278-6133.23.1.94 [PubMed: 14756608]
- Hudson AL, Lee KA, Miramontes H, Portillo CJ. Social interactions, perceived support, and level of distress in HIV+ women. *Journal of the Association of Nurses in AIDS Care*. 2001; 12(4):68–76.10.1016/S1055-3290(06)60218-5 [PubMed: 11486722]
- Ironson, G.; Antoni, MH.; Schneiderman, N.; Chesney, MA.; O’Cleirigh, C.; Balbin, E.; Fletcher, MA. Coping: Interventions for optimal disease management. In: Chesney, M.; Antoni, MH., editors. *Innovative approaches to health psychology: Prevention and treatment lessons from AIDS*. Washington D.C: APA; 2002. p. 167-195.
- Ironson G, O’Cleirigh C, Fletcher M, Laurenceau JP, Balbin E, Klimas N, Solomon G. Psychosocial factors predict CD4 and viral load change in men and women with human immunodeficiency virus in the era of highly active antiretroviral treatment. *Psychosomatic Medicine*. 2005; 97:1013–1021.10.1097/01.psy.0000188569.58998.c8 [PubMed: 16314608]
- Jenkins, SR.; Coons, HL. Psychosocial stress and adaptation processes for women coping with HIV/AIDS. In: O’Leary, A.; Jemmott, LS., editors. *Women and AIDS: Coping and Care*. New York, NY: Plenum Press; 1996. p. 33-86.
- Kalichman, SC.; Catz, SL. Stressors in HIV infection. In: Nott, KH.; Vedhara, K., editors. *Psychosocial and biomedical interactions in HIV infection*. Amsterdam Netherlands: Harwood Academic Publishers; 2000. p. 31-60.
- Lazarus, RS.; Folkman, S. *Stress, appraisal, and coping*. New York: Springer Publishing; 1984.
- Leserman J, Jackson ED, Petitto JM, Golden RN, Silva SG, Perkins DO, et al. Progression to AIDS: The effects of stress, depressive symptoms, and social support. *Psychosomatic Medicine*. 1999; 61(3):397–406. [PubMed: 10367622]
- MacQueen KM, McLellan E, Kay K, Milstein B. Codebook development for team-based qualitative analysis. *Cultural Anthropology Methods*. 1998; 10(2):31–36.
- Mellins CA, Havens JF, McDonnell C, Lichtenstein C, Uldall K, Chesney M, Bell J. Adherence to antiretroviral medications and medical care in HIV-infected adults diagnosed with mental and substance abuse disorders. *AIDS Care*. 2009; 21(2):168–177.10.1080/09540120802001705 [PubMed: 19229685]
- Morgan, DL. *Focus Groups as Qualitative Research*. 2. Thousand Oaks: Sage; 1997.
- Morrison MF, Petitto JM, Ten Have T, Gettes DR, Chiappini MS, Weber AL, Evans DL. Depressive and anxiety disorders in women with HIV infection. *American Journal of Psychiatry*. 2002; 159(5):789–796.10.1176/appi.ajp.159.5.789 [PubMed: 11986133]
- Morrow K, Costello T, Boland R. Understanding the psychosocial needs of HIV-positive women: a qualitative study. *Psychosomatics*. 2001; 42(6):497–503.10.1176/appi.psy.42.6.497 [PubMed: 11815685]
- Ndlovu U, Ion A, Carvalhal A. “My children and my home”: The most recent and challenging stressors of HIV-positive women. *Archive of Women’s Mental Health*. 2010; 13(3):215–222.10.1007/s00737-010-0148-4
- Palella FJ Jr, Delaney KM, Moorman AC, Loveless MO, Fuhrer J, Satten GA, Holmberg SD. Declining morbidity and mortality among patients with advanced Human Immunodeficiency Virus infection. HIV Outpatient Study Investigators. *The New England Journal Of Medicine*. 1998; 338(13):853–860. [PubMed: 9516219]

- Puskas CM, Forrest JI, Parashar S, Salters KA, Cescon AM, Kaida A, Hogg RS. Women and vulnerability to HAART non-adherence: A literature review of treatment adherence by gender from 2000 to 2011. *Current HIV/AIDS Reports*. 2011; 8(4):277–287.10.1007/s11904-011-0098-0 [PubMed: 21989672]
- Ryan White HIV/AIDS Treatment Extension Act of 2009 2885–2903 (2009).
- Schackman BR, Gebo KA, Walensky RP, Losina E, Muccio T, Sax PE, Freedberg KA. The lifetime cost of current human immunodeficiency virus care in the United States. *Medical Care*. 2006; 44(11):990–997. [PubMed: 17063130]
- Sample SJ, Patterson TL, Temoshok LR, McCutchan JA. Identification of psychobiological stressors among HIV-positive women. *Women & Health*. 1993; 20(4):15–36.10.1300/J013v20n04_02 [PubMed: 8171874]
- Siegel K, Karus D, Dean L. Psychosocial characteristics of New York City HIV-infected women before and after the advent of HAART. *American Journal of Public Health*. 2004; 94(7):1127–1132.10.2105/ajph.94.7.1127 [PubMed: 15226132]
- Strauss, A. *Qualitative analysis for social scientist*. 2. London: Sage; 1987.
- Strauss, A.; Corbin, J. *Basics of qualitative research*. 2. London: Sage; 1998.
- Taylor, SJ.; Bogdan, R. *Introduction to qualitative research methods*. New York: John Wiley & Sons, Inc; 1998. *Working with data: Data analysis in qualitative research*; p. 134-163.
- Vanable PA, Carey MP, Blair DC, Littlewood RA. Impact of HIV-related stigma on health behaviors and psychological adjustment among HIV-positive men and women. *AIDS & Behavior*. 2006; 10(5):473–482.10.1007/s10461-006-9099-1 [PubMed: 16604295]
- Weaver KE, Labre MM, Durán RE, Antoni MH, Ironson G, Penedo FJ, Schneiderman N. A stress and coping model of medication adherence and viral load in HIV-positive men and women on Highly Active Antiretroviral Therapy (HAART). *Health Psychology*. 2005; 24(4):385–392.10.1037/0278-6133.24.4.385 [PubMed: 16045374]