A Qualitative Description of HIV-Infected African American Women’s Experiences of Psychological Distress and Their Coping Strategies

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HIV-infected individuals are at risk for psychological distress, including depression, sadness, and suicidality. The purpose of this qualitative descriptive study was to examine 22 HIV-infected African American women’s experiences of psychological distress and use of coping strategies. Data were collected through in-person one-on-one interviews until conceptual saturation was reached. Data were analyzed using inductive content analysis. Four themes were found: (a) psychoemotional suffering, (b) contextual factors negatively influence the everydayness of living with HIV infection, (c) HIV-related stigma perpetuates isolation and loneliness, and (d) creating a safe haven. Implications for nurses and other health care providers include (a) holistic assessment to include evaluation of emotional and mental state, and (b) coping strategies. Integration of spiritual practices into plan of care is also important. Development and evaluation of individualized coping interventions that address stigma and psychological distress through holistic modalities is warranted.

HIV infection remains a significant health concern, particularly in African American women. HIV infection disproportionately affects African American women, who make up 13% of the U.S. female population yet represent 62% of HIV-infected women (Centers for Disease Control & Prevention [CDC], 2016a). One in 32 African American women is likely to be diagnosed with HIV infection during her lifetime, compared to 1 in 106 Latina women and 1 in 526 White women (Kaiser Family Foundation, 2014). Antiretroviral therapy (ART), by suppressing the virus, has changed HIV from a fatal to a chronic disease. However, in 2013, only 51% of African Americans were retained in health care and only 37% were prescribed ART (CDC, 2016b).

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Additionally, in comparison to mortality rates among Latina and White women, HIV has consistently remained one of the 10 leading causes of mortality for African American women between the ages of 20 and 54 years (CDC, 2015).

HIV-infected African American women face unique challenges in managing their disease. The same factors that have influenced African American women’s risk for HIV infection have also shaped their lives while living with the disease, including racism, violence, sexual victimization, and lower socioeconomic status. Residential segregation and discrimination (Watkins-Hayes, 2008) and poverty (National Alliance of State and Territorial AIDS Directors, 2008; Watkins-Hayes, 2008) are significant issues that HIV-infected African American women may face, challenging their abilities to self-manage their disease. The complex interplay of sexual and physical abuse may precipitate an environment in which women are ill prepared to engage in health-promoting self-care practices, including holistic management of their disease (Hurst, Montgomery, Davis, Killion, & Baker, 2005).

Psychological distress further complicates African American women’s management of HIV infection. Psychological distress is defined as “the unique discomforting, emotional state experienced by an individual in response to a specific stressor or demand that results in harm, either temporary or permanent, to the person” (Ridner, 2004, p. 539), and encompasses feelings of depression, sadness, anger, and other negative emotions and thoughts. Psychological distress, including depressive symptoms, is associated with decreased ART adherence (Schuster, Bornovalova, & Hunt, 2012; Simoni et al., 2011) and decreased viral suppression (Leserman, 2008; Schuster et al., 2012). Although psychological distress, including experiences of anxiety, suicidality, anger, and other negative feelings and thoughts, is common in individuals living with HIV infection, our focus is on depressive symptom experiences following the diagnosis of HIV infection.

Depression, which contributes to psychological distress, is a common and significant symptom experienced by HIV-infected individuals (Pence, O’Donnell, & Gaynes, 2012), with a lifetime prevalence of 22% to 45% (Jones et al., 2010). There is an association between depression and the complex pathways that influence negative health outcomes in HIV-infected individuals, including decreased immune responses (Leserman, 2008; Schuster et al., 2012), decreased adherence to treatment regimens (Schuster et al., 2012; Simoni et al., 2011), and increased risky behaviors (Cook et al., 2006; Schuster et al., 2012).

Women have higher rates of depression compared to men (Cook et al., 2006; Jones et al., 2010) and African American women have higher rates compared to other racial/ethnic women (Shacham, Basta, & Reece, 2008). Factors that contribute to HIV-related psychological distress, including depression, experienced by African American women include stigma (Miles, Gillespie, & Holditch-Davis, 2001; Waite, Brawner, & Gipson-Jones, 2008), consequences of disclosure (Miles et al., 2001), isolation (Miles, Isler, Banks, Sengupta, & Corbie-Smith, 2011), and low socioeconomic status, unemployment, and lower levels of education (Lennon, Huedo-Medina, Gerwien, & Johnson, 2012; Miles, Holditch-Davis, Pedersen, Eron, & Schwartz, 2007).

Coping strategies to address psychological distress are important to support HIV-infected African American women’s engagement in the treatment cascade. Adaptive coping responses, particularly positive reappraisal and spiritual methods, promote psychological relief in HIV-infected women (McIntosh & Rosselli, 2012). In order to develop nursing-facilitated coping interventions to ameliorate psychological distress in HIV-infected African American women that are culturally appropriate, patient-centered, and individually tailored, researchers and providers need to understand how this population defines, experiences, and manages HIV-related psychological distress. The purpose of this qualitative descriptive study was to examine HIV-infected African American women’s experiences of psychological distress and their use of coping strategies. The specific research questions were:

1) How do HIV-infected African American women describe psychological distress?
2) What are HIV-infected African American women’s perceptions of how psychological distress influences their everyday lives?
3) What trigger events increase the symptoms of psychological distress among HIV-infected African American women?
4) What coping strategies do HIV-infected African American women use for decreasing symptoms of psychological distress?

**Research Methods**

Qualitative descriptive methods guided data collection and analysis. Qualitative descriptive method is a research method used to describe participants’ experiences of a phenomenon (Sandelowski, 2000). This method allowed the researchers to gain in-depth insight into the phenomenon of HIV-related psychological distress staying close to the data without deconstructing the data to reconstruct the findings (Knaff & Howard, 1984; Miles & Huberman, 1994; Sandelowski, 2000; Sullivan-Bolyai, Bova, & Harper, 2005). Although there is always some level of interpretation in qualitative methods, in qualitative description the purpose is to describe the facts (Sandelowski, 2000), therefore, the analysis stays closer to the surface.

**Sample, Setting, and Data Collection**

The research team purposively sampled 22 HIV-infected African American women who self-reported psychological distress. Fliers were given out by Ryan White Case Managers and a Program Director in two clinics in two metropolitan cities in the Midwest. Ten women were recruited through an internal medicine clinic that served a large population of HIV-infected individuals in a metropolitan city in the southwest region of Kansas, and 12 women were recruited through an infectious disease clinic that served a large population of HIV-infected individuals in an eastern city in Missouri. Women interested in the study contacted the Principal Investigator (PI), who explained the study purpose and participation, including data collection procedures and the process for maintaining confidentiality. Inclusion criteria included: older than 18 years of age, African American race, HIV-positive serostatus, ability to speak and read English, and self-report of psychological distress (anxiety, depression, sadness). Exclusion criteria included born outside of the United States. The PI established that the inclusion criteria were met through self-report by the participants during the telephone call. Questions about psychological distress included if the potential participant had experienced feelings of depression, sadness, anger, or other negative feelings and thoughts at any time point after her diagnosis of HIV infection. The PI asked each woman if she would prefer to meet in a personal interview with the PI or a focus group session. All participants preferred to meet individually with the PI. Data collection continued until there was conceptual saturation of the experiences of psychological distress and coping strategies in the stories provided by 18 participants. Four additional women were interviewed to ensure that no new data were obtained and to ensure we had captured the experiences of psychological distress in this population of HIV-infected women. We also completed informal member checking of the preliminary findings with the last four participants.

The women were given the option to meet in a setting that would provide the greatest amount of privacy. Fifteen participants preferred to meet in their homes, three in a private room at an ambulatory care clinic, and four in a meeting room at a public library. Written informed consent and demographic data, including age, year of diagnosis, self-report of CD4+ T cell count and viral load, education level, employment, and number of children, were obtained prior to the semi-structured interview. The PI also explained that the participants could stop the interview at any time or did not have to answer any questions that made them uncomfortable. The PI had resources, such as information for 24-hour crisis lines, available in case a participant reported experiencing severe symptoms of psychological distress, specifically suicidality, that warranted referral to psychological services. None of the participants reported being actively suicidal.

The PI began the interview with a general prompt, Tell me about the feelings you experienced at any time point after your diagnosis of HIV. Additional questions also included: How would you describe these feelings? How do these feelings affect your daily life? How do you cope with these feelings? The questions were framed in the context of living
with HIV infection rather than general feelings of distress. However, several women described emotional issues unrelated to HIV infection that did impact how they lived with HIV infection. These data were included in the data analysis and subsequent findings. The interviews lasted from 30 to 90 minutes and were audio recorded. The participants were provided a $25 gift card after completion of the interview.

Data Analysis

Descriptive statistics were used to analyze the demographic data. Inductive content analysis was used to analyze the narratives (Creswell, 2013; Elo & Kyngas, 2008; Graneheim & Lundman, 2004; Miles & Huberman, 1994). The audio-recorded narratives were transcribed verbatim, with all identifying information removed by a professional transcriptionist. The narratives were read simultaneously while listening to the audio recordings by the PI, the lead author, and two graduate students to make sure the narratives were transcribed accurately. The narratives were then entered into N-Vivo (version 10.0; QRS International, Doncaster, Victoria, Australia, 2012) qualitative data management software for organization and management. The narratives were then read several times by three members of the research team and two graduate students to gain a sense of each woman’s story. Reading each narrative line by line, they each independently highlighted phrases relevant to the research questions. The lead author and the two graduate students met via telephone conference to discuss the highlighted phrases and extracted meaning units, condensing the content-rich text to a grouping of words that retained the core meaning (Graneheim & Lundman, 2004). Two other team members independently extracted meaning units. The meaning units were then independently labeled into codes by the three team members and the two graduate students. The codes were reviewed for consistency in code development and revised through consensus by three team members during in-person meetings. These three team members then used an iterative process to independently reduce the codes into categories. This process included reviewing the codes for commonality and grouping codes that belonged together into categories, again during in-person meetings. Finally, four themes were developed that interconnected the underlying meanings within and between the categories (Graneheim & Lundman, 2004) during a final in-person meeting. The themes were provided to the other team members as a method of confirmability through a secure e-mail platform. A code book was developed and maintained by the PI, which documented the dynamic process of developing and revising the codes, categories, and themes, as a method of credibility.

Ethical Considerations

The research team obtained institutional review board approval at their academic medical centers prior to commencement of the study. The research team and graduate students completed the requisite training and conflict-of-interest documentation prior to data collection and analysis. Data were stored on a secured network at the PI’s institution and password-protected networks were used by the graduate students. Paper documents were stored in a locked file in the PI’s office, per her academic medical center’s institutional policy. Pseudonyms, created by either the participants or the PI, were created to ensure confidentiality of the study participants.

Results

Sample Characteristics

Twenty-two women with a mean age of 48 years (SD = 12; range 25–73 years) participated in the study (Table 1). They had lived with HIV infection, on average, 12.7 years. Fifteen of the women knew their recent CD4+ T cell counts and 16 women knew their recent viral loads. All of the participants reported being on ART, and four reported being on an antidepressant or anxiolytic treatment. Of the 14 participants who provided their education background, most had at least a high school diploma. Less than one-third of the participants were employed and almost half were unemployed. Twenty-one women had children and one was pregnant with her first child at the time of the interview.
Themes

Analysis of the narratives resulted in the identification of four themes: (a) psychoemotional suffering, (b) contextual factors negatively influence living with HIV infection, (c) HIV-related stigma perpetuates isolation, and (d) loneliness and creating a safe haven. Psychoemotional suffering was present in all of the narratives. It encompassed the many and varied negative emotions, including pervasive depression, anxiety, and suicidality, that contributed to the participants’ significant, negative, and at times, disabling emotions about self, including negative feelings of self-esteem and self-worth. Contextual factors negatively influence living with HIV infection described the complex contextual factors that impacted the women’s lives prior to and after the diagnosis of HIV infection, contributing to their experiences of distress. HIV-related stigma perpetuates isolation and loneliness exemplified the stigma that resulted in isolation and loneliness and described the participants’ feelings of vulnerability and loneliness as well as, for some, having to keep up a guard when in public, with friends, and sometimes with family to protect themselves from stigmatizing experiences. Creating a safe haven explained the coping strategies used by women to try to create a safe environment to care for themselves emotionally, psychologically, physically, and spiritually. More detailed information and exemplar quotations for each theme are provided below.

Psychoemotional suffering. Psychoemotional suffering was developed to explain the significant distress experienced by all of the participants following the diagnosis of HIV infection. They described how distraught they were at that life-changing moment from which many had not recovered. Tricia, a young woman in her early 30s, stated, “Two weeks after we got married is when he informed me, so I went into the marriage not knowing he was HIV positive … And when I found out … I was devastated. I mean actually just floored, flabbergasted.” Another participant, Yvonne, a 50-year-old woman who lived with her boyfriend, said, “See I knew my husband was … went both ways, female and male, but I didn’t think that he would hurt me in any way. He kind of stole my life.”

Brianna, a single mother diagnosed 10 years earlier, described her experience of learning she was HIV infected, stating:

Well the thing that kind of messed with me the most at first is my children and sister … being in the room and then the nurses coming in, here is your AIDS medicine. I feel like that was a breach of confidentiality ’cause I hadn’t even, you know, let that set in with me, to let me get used to that idea and then you’re letting everyone around to know my status and I didn’t think that was right at the time … am I going to die before my kids even have a chance to grow up?

The participants discussed their experiences of pervasive, negative emotions and thoughts that had affected their daily lives. Suicidality was common among the participants following the diagnosis of HIV infection. Tricia tried to commit suicide six times, stating, “I tried to run out in the street and get hit by a car … I tried three times to slit my wrists.” Ayana, a 42-year-old mother of one and living with an abusive boyfriend, stated, “I became suicidal, depressed. I got on crack cocaine. I said within the first year of me knowing that I had it I tried to commit suicide and was in [psychiatric hospital] about 12 times within the first year.” Although none of the participants were actively suicidal, several spoke about continued ideas of suicide from diagnosis to the present time. Yvonne stated, “I think about suicide … So at one time I was shooting myself with syringes for my insulin.”

Table 1. Participant Demographics

<table>
<thead>
<tr>
<th>Demographic Information</th>
<th>n</th>
<th>M/Frequency</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Years living with HIV</td>
<td>22</td>
<td>12.7 (SD = 8)</td>
<td>1-31</td>
</tr>
<tr>
<td>CD4+ T cell count</td>
<td>15</td>
<td>744</td>
<td>134-1700</td>
</tr>
<tr>
<td>Undetectable viral load</td>
<td>16</td>
<td>73%</td>
<td></td>
</tr>
<tr>
<td>Number of children</td>
<td>21</td>
<td>2</td>
<td>0-6</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some high school</td>
<td>2</td>
<td>14%</td>
<td></td>
</tr>
<tr>
<td>High school diploma</td>
<td>7</td>
<td>50%</td>
<td></td>
</tr>
<tr>
<td>Some college</td>
<td>5</td>
<td>36%</td>
<td></td>
</tr>
<tr>
<td>Employment status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>7</td>
<td>31.8%</td>
<td></td>
</tr>
<tr>
<td>Retired</td>
<td>2</td>
<td>9.1%</td>
<td></td>
</tr>
<tr>
<td>On disability</td>
<td>3</td>
<td>13.6%</td>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
<td>10</td>
<td>45.5%</td>
<td></td>
</tr>
</tbody>
</table>
Some participants seemed reticent to discuss their experiences of psychological distress, downplaying their feelings until further prompts used by the PI elicited information that provided important information about their experiences of distress. For example, Yvonne initially denied experiencing depression or other negative thoughts. However, upon further questioning, she reported sleeping all day to avoid the negative thoughts she had about living with HIV infection.

Contextual factors negatively influence living with HIV infection. Although specific questions about current or previous life experiences were not central to this study, contextual factors, such as poverty and addiction, had influenced the women’s experiences of psychoemotional distress. One young participant, Tricia, described living with her older male partner who often asked her to trade sex for money to support their household. Providing a story of significant physical, emotional, and sexual abuse from childhood to present, this young woman was unable to move away from her history of abuse because, at least in her present situation, she had a regular place to stay and regular income. She stated, “My mother told me that my dad molested me … he got me pregnant when I was 14.” Ayana shared, “I done had a hard life growing up and been through all this and abused in relationships and lived on the street and had to deal with men touching me and I don’t understand why and couldn’t run to momma, cause when you’re scared you go to momma and they comfort you, my momma beat me.

Another participant, Beverly, reported her continued intermittent use of alcohol and illicit drugs, acknowledging that the interaction between alcohol, illicit drugs, and psychotropic medications would not be effective to decrease her depressive symptoms. She said, “I don’t take my pills when I’m drinking, cause they don’t work.” Sandra, diagnosed in the mid-1980s, shared, “I was still in my addiction for another 10 years before I became a Peer Educator. I stayed high all the time because of low self-esteem and depression.”

Many participants also described significant socioeconomic constraints that affected the ability to engage in holistic self-management strategies, which further influenced their feelings and thoughts about living with a complex and potentially life-threatening disease. Additionally, attending support groups specific to women living with HIV infection were not considered an effective self-care strategy to address psychological distress because many of the participants believed that confidentially would not be guaranteed. When asked about attending support groups, Ayana shook her head no and said, “I’m a one-on-one.” Brianna also stated, “I feel like even though people say that they are confidential, they still let it slip to they friends and then they friends tell they friends.”

HIV-related stigma perpetuates isolation and loneliness. This theme reflected the stigmatizing experiences described by most of the participants, influencing how they lived with HIV infection, isolated from family, friends, and other important individuals in their lives, resulting in profound loneliness. Relationships between the participants and their families, friends, and within the broader community, were often impacted by the participants’ diagnoses of HIV infection. Participants described how relationships had changed based on knowing their diagnoses and not feeling able to disclose to their families, friends, or other members of their communities. Relationships also changed when the participants took a risk and disclosed to their family, friends, potential sexual partners, and within the broader community. Some participants described the negative reaction of their families to the diagnosis; other participants described negative reactions from potential sexual partners. Jada, a young pregnant woman in her early 20s and diagnosed at birth, stated, “I’ve had friends turn on me … But I just know I felt, you know, really bad because you feel like you can trust people … and you can’t. But I don’t get the stigma … it’s the same thing as cancer … If I came and tell you I have leukemia, first thing you’re going to say is, “How can I help you? What do you need?” But I come and say I have HIV and the first thing you ask is, “How’d you get it? What did you do?” … and I think a lot of the depression
comes from knowing what to expect … just the thought of the rejection is what a lot … brings on a lot of the depression.

Multiple experiences of HIV-related stigma and discrimination resulted in the participants creating public personas separate from their private personas. This helped to ensure that they could protect themselves from unnecessary negative experiences and to try to live well with HIV infection. The inability to be authentic with family, friends, and, more broadly, the community negatively impacted the participants’ living with HIV infection, increasing their psychological and emotional distress. The experiences of stigma and discrimination reinforced that living with HIV infection “diseased” the women, influencing their everyday lives. Margaret, a married grandmother, described casual conversations with friends and neighbors that had reinforced her desire and need to maintain privacy, stating,

“I hear people talking and now I’m skeptical to tell them … I’ve tried to offer her [lady] clothes and I tried to offer somebody else clothes, she said, “Well I don’t want their clothes, you know, cause you never know … they could have AIDS.”

Kiara, a home health assistant, articulated her desire to be honest with her social network, but was concerned about the repercussions,

“I think I would feel better if I could just open up to … to my friends and they’d accept me. And I just feel like … I don’t know if I have a need to … to be more open, but I just kind of put that to the back of mind and don’t …

Janelle, a 44-year-old mother of two, stated, “I’m not open, even after all this time; I’m not open with my diagnosis due to stigma and the ignorance.”

All of the women expressed feeling as though people had judged them or they feared they would be judged. Therefore, they refrained from fully disclosing this significant component of their lives, inadvertently affecting their social relationships and the way they felt about themselves. Kiara reported, “I wasn’t me anymore, you know. I felt like I was a disappointment to my family … I would feel ‘nasty’ … I still do sometimes.” Alicia, an addictions counselor, said,

I didn’t want to be here anymore because the stigma that comes along with that was just like, you know everybody’s going to be looking and pointing and I’m feeling like everybody’s looking at me, you know … Yes. I felt very, very exposed.

Creating a safe haven. Creating a safe haven described the personal strategies employed by the participants to ameliorate psychological distress and negative factors that influenced their psychological and emotional distress, including stigmatizing experiences in their interpersonal (family and friends) and social (health care organizations, faith-based organizations) networks. For the majority of the participants, spirituality and religion provided a place of unconditional acceptance from a higher being that also promoted positive self-worth and acceptance of the diagnosis. Brianna stated, “I believe that this is the Lord, you know, the Lord helped me come to terms with it and praying for strength, ‘cause you have to have strength dealing with this.” Yvonne articulated, “Well God is my higher power … supports me in everything I do … God is the one who has given me my strength, besides my boyfriend, to get up every morning, to do what I got to do … He’s my God.” Tricia said, “I gave it all to him [God]. That’s the only way I can cope.”

Even when participants were provided psychotropic medications to alleviate depression or anxiety, spiritual practices were suggested as more effective and important strategies for addressing negative thoughts and emotions experienced after the diagnosis. Linda, a peer educator and mother of two, described her experiences of addressing her depression with her primary care provider, stating,

[Physician] asked me when I was going through, she said … and she could tell I was really down … she said, “You want some pills?” I said no [laughing]. I can get through this with the man upstairs, we can get through this.

Jada used poetry as a strategy to deal with her inner angst, voicing,

I write poetry … so that’s really been my outlet … [Ryan White Case Manager] wants me to write a book. I’m thinking about it. I don’t know. But yeah, poetry and singing and just, you know, stuff like that, really gets me through.
Discussion

In this qualitative descriptive study, we found significant psychoemotional suffering experienced by African American women following the diagnosis of HIV, and that this experience persisted to the time of the interview. Psychoemotional suffering pervaded every narrative provided by the participants. It negatively influenced their daily lives, their abilities to attend to their health, and their relationships with significant others, families, and, more broadly, their communities. HIV-related stigma and discrimination were the most important factors in shaping how the women engaged in their social and interpersonal worlds, contributing to their experiences of suffering. Stigma and discrimination also resulted in disparate perceptions and presentations of self within public and private venues, influencing how the women viewed themselves as individuals and as members of their communities. Faith, through spiritual and religious practices, was the most common and effective measure to ameliorate psychoemotional suffering.

Facing a chronic and potentially life-threatening disease, the participants with children have had to re-evaluate life goals for their proposed futures and to further contemplate the futures of their children, possibly without their presence. The potential reality of not being present for their children’s significant life events was distressing for all of the participants who had children. Additionally, the past experiences of the participants impacted their present lives and how they looked toward the future. Several participants shared their experiences of sexual and child abuse that had influenced their perceptions of self-identity and self-worth, contributing to their emotional suffering.

Psychological distress is not unique to the HIV-infected African American women who participated in our study. Researchers have found that distress was common in African American women (Miles et al., 2007), HIV-infected African Americans living in the South (Miles et al., 2011), and HIV-infected adults living in Spain (Leyva-Moral, Sánchez, Lluva-Castaño, & Mestres-Camps, 2015). The participants in our study reported profound experiences of distress on learning their diagnoses. Miles and colleagues (2011) also reported that participants in their study reported being devastated about being diagnosed.

HIV-related stigma was reported as the most concerning factor that influenced participants’ experiences of suffering. For many, stigma resulted in self-imposed isolation or shielding certain parts of themselves from their families, friends, and the broader community. Additionally, changed relationships, real or perceived, with family, friends, significant others, and the broader community impacted their engagement in self-management, including navigation of the health care system. Self-imposed isolation, based on fear of stigma and concerns about disclosure contributing to suffering, was also found in African Americans living in the South (Miles et al., 2011). Grodensky and colleagues (2015), in a qualitative study of older HIV-infected women, reported that depression was influenced by concerns about stigma and feelings of isolation. Vyavaharkar and colleagues (2011) reported, however, that disclosure actually reduced symptoms of depression in a sample of African American women. They posited that disclosure meant that individuals no longer had to maintain a secret diagnosis, and that this could explain the reduction in depressive symptoms as a result of reduction in psychological distress and increased opportunities for social support.

Spiritual and religious practices were the most common and effective strategies used by the participants in our study to cope with psychological distress. Our findings align with other research that supported the positive relationship between spiritual practices and emotional and mental well-being for African American women (Braxton, Lang, Sales, Wingood, & DiClemente, 2007; Dalmida, Holstad, Diirio, & Laderman, 2009; Dalmida, Holstad, Diirio, & Laderman, 2012). The majority of women in our study discussed private spiritual practices, such as prayer and reading the Bible rather than public practices, such as attending religious services. This has not been unique to our study. Dalmida and colleagues (2009) also found that participants preferred private practices. Spiritual and religious practices have also been identified as important coping strategies for psychological distress in older women living with HIV infection (Grodensky et al., 2015) and African American HIV-infected mothers (Casarez & Miles, 2008). Participants in our study
who talked about their relationships with God suggested that this relationship was most central to self-management. Casarez and Miles (2008) also reported in their study that a strong relationship with God was also central to their self-care.

Study Limitations

There were several limitations in this study. First, the researchers did not formally assess depression and other symptoms of psychological distress using established reliable and valid instruments, instead relying on self-report. Therefore, the data provided could not be analyzed quantitatively to provide a baseline of distress for this cohort of women. Women were recruited from two clinics, and were, therefore, generally established in care. The findings from our study cannot be transferred to women who are not engaged in care.

Implications

There are several implications for education, practice, and research from our study. First, nursing and health professions students must be educated about HIV infection beyond the pathophysiology and pharmacological modalities. They need a thorough understanding of the experiences of living with a stigmatizing disease, including significant suffering, to provide holistic person-centered care. Nurses and other health professionals need to develop comprehensive and culturally appropriate tools to assess feelings of distress, including depression, anger, anxiety, and sadness, to inform plans of care that optimize health outcomes for HIV-infected individuals.

Another important consideration is disclosure of the diagnosis. Sowell and Phillips (2010) stated that, although there was the risk of stigma and discrimination, thus making disclosure risky, there were many benefits of disclosure. They suggested that mental health nurses could help individuals living with HIV explore the process and consequences of disclosure through role-playing and other nursing interventions. Generalist nurses also were well educated to implement such interventions, particularly in HIV-specialty clinics, where clients are likely to feel safer. Providing targeted opportunities for disclosure may assist with feelings of internalized stigma, as well as providing opportunities to address common myths about HIV infection with patients and their families.

Morse’s (2001) praxis theory of suffering may provide a better understanding of the complex concept of suffering experienced by HIV-infected individuals. Although we did not formally analyze the data using Morse’s theoretical constructs, it was apparent in our study that the participants experienced emotional suffering and enduring. Additionally, other literature has found that HIV-infected individuals experienced emotional suffering and enduring. Within the theory of suffering, reformulation of self is attained through the movement from enduring emotional suffering to reformulation of self. In our study, the majority of the women had, and continued to experience, significant suffering and had not appeared to move beyond suffering to create a new self-identity. This was based on our interpretation of the narratives and was not formally evaluated. Therefore, research to explore if the major constructs in Morse’s theory are present in HIV-infected individuals, specifically the construct of reformulation of self, is warranted. If it is not, there may be opportunities for nurses to intervene to help individuals move beyond suffering and enduring to creating a new and positive self-identity.

Spiritual practices have been identified as important coping strategies to reduce experiences of suffering by the participants in our research and in the literature. Emblen and Pesut (2001) proposed a model of spiritual nursing care to strengthen transcendent meaning during the experiences of suffering. The authors posited that transcendent meaning provided “hope and sustenance for the spirit” (p. 45) to overcome despair and hopelessness. The model incorporated five broad areas of assessment and intervention: (a) authority and guidance, (b) experience and emotions, (c) community, (d) rituals and practices, and (e) vocation and consequences (Emblen & Pesut, 2001). Examples of interventions included prayer, worship, and assisting individuals with positive life-affirming thoughts to replace negative thoughts. This model can be used by nurses in all settings to develop spiritual plans of care, including comprehensive spiritual assessments and interventions, to reduce suffering in African American women living with HIV infection.
Additional research is warranted to evaluate interventions to reduce internalized stigma and psychoemotional suffering experienced by HIV-infected African American women. In our study, psychoemotional suffering was complex and not always alleviated with medication; rather, the underlying issues needed to be addressed. Home-based, one-on-one coping interventions that draw upon spiritual and personal resources that target stigma and psychoemotional suffering should be developed and tested.

Conclusions

Our study reinforced other findings that psychological and emotional distress experienced by HIV-infected individuals is significant and complex. The diagnosis of HIV, despite advances in treatment modalities, has negative connotations that need to be alleviated. HIV-related stigma seems to remain the most significant factor contributing to psychological and emotional health for HIV-infected individuals. Faith-related activities are important self-care practices used by African American women living with HIV infection.

Key Considerations

- Psychological distress should be continually evaluated by nurses, social workers, and providers at every point of care delivery.
- Strategies to safely disclose HIV status are important to alleviate feelings of isolation.
- Coping methods that incorporate individual spiritual practices should be assessed and integrated into the plan of care for HIV-infected African American women.

Disclosures

The authors report no real or perceived vested interests that relate to this article that could be construed as a conflict of interest.

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