"I Should Know Better": The Roles of Relationships, Spirituality, Disclosure, Stigma, and Shame for Older Women Living With HIV Seeking Support in the South

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The population of older people living with HIV in the United States is growing. Little is known about specific challenges older HIV-infected women face in coping with the disease and its attendant stressors. To understand these issues for older women, we conducted semi-structured in-depth interviews with 15 women (13 African American, 2 Caucasian) 50 years of age and older (range 50–79 years) in HIV care in the southeastern United States, and coded transcripts for salient themes. Many women felt isolated and inhibited from seeking social connection due to reluctance to disclose their HIV status, which they viewed as more shameful at their older ages. Those receiving social support did so mainly through relationships with family and friends, rather than romantic relationships. Spirituality provided great support for all participants, although fear of disclosure led several to restrict connections with a church community. Community-level stigma-reduction programs may help older HIV-infected women receive support.

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Approximately one quarter of the estimated 1.2 million people living with HIV in the United States are over the age of 50 years (Centers for Disease Control and Prevention [CDC], 2008; CDC, 2012). By 2015, the proportion of HIV-infected individuals older than age 50 is estimated to increase to 50% (Effros et al., 2008). This increase is due in part to the rising number of new HIV diagnoses among this group (15% of new HIV cases in 2009; CDC, 2012; Stark, 2007), and in part to decreased mortality as a result of successful treatment with antiretroviral medications, allowing more HIV-infected people to live into old age (Sankar, Nevedal, Neufeld, Berry, & Luborsky, 2011).

Research has suggested that older people may experience living with HIV differently than those who are younger. Generally, older patients have been found to be more adherent to their antiretroviral medications than younger patients, but their adherence is more sensitive to weakened cognitive function and substance abuse problems (Barclay et al., 2007; Ettenhofer et al., 2009; Hinkin et al., 2004). Similarly, the experience of aging may differ between those who are living with HIV and those who are not. For example, Rabkin, McElhiney, and Ferrando (2004) found that rates of depression and substance use, which typically decline with increasing age in the general population (Byers, Yaffe, Covinsky, Friedman, & Bruce, 2010; Gum, King-Kallimanis, & Kohn, 2009; Lincoln, Taylor, Chae, & Chatters, 2010), do not similarly decline for individuals infected with HIV. Research has suggested that social support may be particularly important for older HIV-infected people. Social support confers benefits for older adults living with HIV, helping to mitigate distress and improve mood (Schrimshaw & Siegel, 2003), while stigma and loneliness are associated with increased depressive symptomatology (Grov, Golub, Parsons, Brennan, & Karpiak, 2010; Yi et al., 2006).

The particular challenges of older women living with HIV have not been separated from those of men. More specifically, the psychosocial experiences of older women living with HIV have not been fully described. Yet older women are at increased risk of contracting HIV as the likelihood of using condoms decreases with age and, accordingly, the estimated annual percentage of older women who acquired HIV heterosexually has been rising (Nguyen & Holodniy, 2008). These trends indicate the increasing need to understand the experiences of older women living with HIV. The purposes of the project were to (a) investigate the important psychosocial factors impacting older women's living and coping with HIV infection, particularly in social and spiritual relationships, and (b) explore relationships between those factors. To achieve these purposes, we conducted a qualitative study with 15 HIV-infected women ages 50 years and older receiving HIV care in the southeastern United States.

Methods

Design

In-depth, semi-structured, qualitative interviews were conducted with 15 women, with each interview lasting about 1 hour. The interview guide was designed to elicit information from the women on psychosocial aspects of their lives, particularly related to the diagnosis and management of their HIV, that would yield a thematic description of older women's experiences living with HIV (Sandelowski & Barroso, 2003). Examples of the general questions used to invite exploration of these issues included, *What are some challenging aspects of your day-to-day life?* and *How has your life changed since you were diagnosed with HIV?* Women were also asked more specific probes to provide opportunities to elaborate on specific psychosocial factors such as social stressors and support, emotional reactions to aspects of living with HIV, perceptions of faith, and personal and social responsibilities. These probes were refined continuously during data collection to ensure exploration of relevant themes emerging in the interviews. Examples of such probes included, *Tell me about your home and the people who live there. Are you responsible for the well-being of any of these individuals? and How has being HIV-infected affected any relationships in your life—with friends, family, sexual partner(s)?*

Study Sample and Setting

This study took place at a public-hospital-based infectious diseases clinic. All women who were