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Silent Endurance and Profound Loneliness: Socioemotional Suffering in African Americans Living With HIV in the Rural South

Margaret Shandor Miles, PhD, RN, FAAN¹, Malika Roman Isler, PhD, MPH¹, Bahby B. Banks, MPH¹, Sohini Sengupta, PhD, MPH¹, and Giselle Corbie-Smith, MD, MSc¹

¹ University of North Carolina at Chapel Hill, Chapel Hill, North Carolina, USA

Abstract

We explored how community responses to HIV contribute to distress in African Americans living with HIV in the rural South of the United States. We listened to the voices of community members through focus groups and African Americans with HIV through interviews. Community avoidance of HIV, negative views of HIV, and discriminatory behavior powerfully affected the distress of people living with HIV (PLWH). Ongoing distress, coupled with limited support, led to a life in which many PLWH endured their pain in silence and experienced profound loneliness. We conceptualized their experiences as socioemotional suffering—the hidden emotional burden and inner distress of not only living with HIV, a complex serious illness, but also with the societal attitudes and behaviors that are imposed on the illness and on PLWH. To improve the quality of life and health of PLWH, we cannot focus solely on the individual, but must also focus on the local community and society as a whole.

Keywords

African Americans; HIV/AIDS; minorities; stigma; stress/distress; suffering

About suffering they were never wrong,

The Old Masters: how well they understood

Its human position; how it takes place

While someone else is eating or opening a window or just walking dully along

(“Musee des Beaux Arts” by W.H. Auden, 1938, as
cited in Mendelson, 2007)

The diagnosis of HIV is an emotionally charged experience (Cohen et al., 2002). At diagnosis, individuals feel shock, disbelief, guilt, shame, and deep concerns about being stigmatized (Baumgartner & David, 2009; Gielen, McDonnell, Burke, & O’Campo, 2000; Lee, Kochman, & Sikkema, 2002; Logie & Gadalla, 2009). Many view HIV as a death

Corresponding Author: Margaret S. Miles, School of Nursing, University of North Carolina at Chapel Hill, Carrington CB 7460, Chapel Hill, NC 27599-7460, USA, mmiles@email.unc.edu.

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sentence, express a fear of death, and have thoughts of suicide (Baumgartner & David; Kalichman, Heckman, Kochman, Sikkema, & Bergholte, 2000; Whetten-Goldstein & Nguyen, 2002). Distress continues as people living with HIV (PLWH) worry about disease progression and mortality (Kalichman et al.; Safren, Gershuny, & Hendriksen, 2003; Whetten-Goldstein & Nguyen). Worry about stigma and discrimination persist (Lee et al.). PLWH who do reveal their diagnosis might face negative responses, conflict, and even violence (Black & Miles, 2002; Gielen et al.; Maman, Campbell, Sweat, & Gielen, 2000).

Ongoing emotional distress can place PLWH at risk for intense emotional reactions and even more serious mental health problems (Bing et al., 2001; Orlando et al., 2002). Ciesla and Roberts (2001), in a meta-analysis, identified PLWH as being at high risk for depressive disorders. Intense anxiety, depressed mood states, and posttraumatic stress disorder, as well as suicidal thoughts and risk of suicide, have been reported among PLWH in numerous studies (Cohen et al., 2002; Cook et al., 2004; Kalichman et al., 2000; Miles, Holditch-Davis, Pedersen, Eron, & Schwartz, T., 2007; Safren et al., 2003).

Emotional distress and mental health outcomes have been measured in numerous studies of PLWH but, with the exception of stigma, little is known about how the many sources of distress associated with having HIV impact on suffering. In addition, few researchers have used a broad societal perspective that places the PLWH within their local communities and the responses of these communities to HIV—a perspective that is particularly salient for southern rural minorities. The suffering of people living with HIV in the rural South is imbedded in the historical and current economic, social, and cultural issues within the communities in which they live (Reif, Whetten, Ostermann, & Raper, 2006; Whetten-Goldstein & Nguyen, 2002). The rural South is characterized by historical injustices that continue to cause high levels of unemployment, poverty, and discrimination toward minorities (Jensen, McLaughlin, & Slack, 2003; Tickamyer & Duncan, 1990). Traditional values in the South tend to link HIV with negatively perceived social behavior such as drug addiction and illicit sexual behavior, thereby, placing responsibility for the infection on the PLWH (Bletzer, 2007). Thus, PLWH of color in the South, who have lived with some level of stigma and discrimination their entire lives, face increased discrimination (Heckman, Somlai, Kalichman, Franzoi, & Kelly, 2006; Lee et al., 2002). As a result, many keep the diagnosis a secret, thereby restricting access to support in coping with and managing their illness (Miles et al., 2003). Moreover, political, economic, and institutional policies have left the rural South with limited health, mental health, and social service resources (Heckman et al., 2004; Reif et al., 2006) and seeking health care is also fraught with challenges because of issues with confidentiality in small communities (Cohn et al., 2001; Reif et al., 2006; Whetten-Goldstein & Nguyen, 2002).

Purpose

Learning more about the distress and suffering of minority PLWH in rural areas of the South is needed to develop interventions and community programs aimed at reducing their distress and enhancing their quality of life. Distress and suffering can limit access to care (Basta, Shacham, & Reece, 2008), place PLWH at risk for poor adherence to treatment and medications (Mellins, Kang, Leu, Havens, & Chesney, 2003; Vranceanu et al., 2008), and lead to higher morbidity and mortality (Cook et al., 2004; Cruess et al., 2003; Farinpour et al., 2003). In this article we explore how community responses to HIV contribute to the distress and suffering of African Americans living with HIV in the rural South.

Our conceptualization of suffering comes from the work of Kleinman (1988), Kleinman and colleagues (Kleinman, Das, & Lock, 1997), and Cassell (1991). Kleinman and colleagues (1997) pointed out that suffering is a reciprocal social experience with close linkages

between individual and societal problems and, as such, the authors defied the idea of categorizing issues as primarily individual or societal (p. ix). Social interactions, shaped by society and culture, enter into an illness experience through relationships and interactions with others and become a central part of the experience of suffering. Cassell viewed suffering on a more personal level, as caused by experiences that threaten the integrity of a person as a complex social and psychological being. Hence, our focus was on socioemotional suffering. Although our focus was on individuals with HIV, we approached our study broadly and interviewed community leaders, service and health care providers, as well as people living with HIV, to have a broad sociocultural perspective.

Methods

Data for this qualitative descriptive inquiry were from a larger study, Project Education and Access to Services and Testing (EAST), in which a community-based participatory research approach was used to explore community, provider, and PLWH perspectives about HIV, research, and HIV clinical trial participation for minorities living in rural areas (Corbie-Smith, Isler, Miles, & Banks, 2010; Corbie-Smith et al., 2010). We listened to the voices of community leaders and service providers through focus groups ($n = 11$) and the voices of African Americans with HIV ($n = 30$) through individual interviews.

Setting and Participants

Project EAST was conducted in six rural counties in the southeastern United States. These counties were selected because of their rural setting and rate of HIV prevalence—30 per 100,000 residents, with a range from 20 to 52 (North Carolina Division of Public Health, 2009). The counties were also characterized by high rates of poverty (17% below the poverty level), low educational attainment (28% without high school diplomas), high numbers of African American residents (33%), and high levels of unemployment because of the loss of manufacturing, textile, and agricultural jobs (U. S. Census Bureau, 2009).

To obtain an information-rich and heterogeneous sample representative of the population, we sampled community leaders, HIV service providers, and PLWH from across the 6 counties. Community leaders ($n = 40$) were those considered to have influence in engaging their respective communities in HIV-related issues. They included administrators or leaders in grassroots community organizations, government agencies, economic and political groups, and churches. These participants were largely ethnic minorities (64% African American; 18% Hispanic) and women (72%). Their education levels ranged from high school diploma to graduate degrees; most had at least some college training (92%). The HIV service providers ($n = 36$) all provided direct care or services to PLWH. They included nurses, case managers, social workers, a variety of public health workers and leaders, and one physician. They were primarily ethnic minorities (58% African American; 11% Hispanic) and women (72%). Most had completed at least some college (94%).

The PLWH were African American men ($n = 19$) and women ($n = 11$) from each of the six counties. Their mean age was 44 years, with a range from 26 to 65. They were primarily male (63%). Many were never married (43%) or were presently separated, divorced, or widowed (37%). Most had no higher than a high school education (83%). Many (67%) were on disability assistance to enable them to obtain Medicaid for health care and medication coverage. About half had annual incomes of less than \$5,000 (54%). Most (73%) had been diagnosed for more than 5 years. Not all participants were receiving care for their HIV, and only 57% were in HIV specialty care. Nevertheless, most (89%) reported they were taking HIV medications.

Data Collection Method

Data for both focus group participants and PLWH were collected using semistructured interview guides which were based on a conceptual framework that placed the PLWH within their community and social networks (Flaskerud & Winslow, 1998; Gelberg, Andersen, & Leake, 2000). Questions focused on topics such as how communities and individuals thought about HIV/AIDS and how people living with HIV/AIDS were treated, as well as questions related to research and clinical trials. Project East community advisory board (CAB) members provided input into the interview guides. The focus group and interview guides were intentionally similar to allow for triangulation of data; however, the PLWH were also asked about their own experiences in being diagnosed with and living with HIV. Brief demographic information was obtained prior to the focus groups and interviews.

Focus groups were moderated by a trained moderator accompanied by a note taker. They were trained according to focus group methods delineated by Kreuger and Casey (2009). Strategies such as rapport building, use of ground rules, listening, and probing were used. To achieve saturation, we conducted a total of 11 focus groups, each of which included between 4 and 10 participants. The groups lasted an average of 88 minutes (range 67 to 109 minutes). Interviews were conducted by trained interviewers and lasted an average of 46 minutes (range 20 to 104 minutes). The research staff members who conducted focus groups and interviews were African American and had experience working with rural minorities. Focus groups and interviews were audiotaped and professionally transcribed for analysis.

Procedures

All procedures for the study were approved by the university institutional review board (IRB). Local community and health care agencies who assisted in recruitment also approved the study and agreed to accept the review of the university IRB. Community outreach specialists (COS) knowledgeable about local services and resources recruited the community leaders and service providers. The COS created a master list of potential leaders from across various community segments. This included leaders in political, education, grassroots, economic, media, religious, social welfare, service, and health agencies. A purposive sample of leaders who represented a cross representation across community segments and provider types were selected from the list by the research team. The COS then contacted them. The COS used an IRB-approved script to tell the leaders about the study and determine whether they were willing to have the research team contact them. If the leaders agreed, the research team telephoned them and assigned them to a focus group. Staff at local HIV/AIDS case management and clinical care programs in each community helped to recruit PLWH. They contacted prospective participants using an IRB-approved recruitment script that emphasized the voluntary nature of participation. If PLWH indicated an interest, the staff member made an appointment for the PLWH to meet with the research team. At first contact with both focus group members and PLWH, the research staff reviewed the purpose of the study in detail and answered questions. IRB-approved consent processes were followed with all participants. All focus groups took place in neutral and familiar community locations. Interviews were conducted in a private room in a local case management facility or health clinic on days that participants had scheduled appointments to avoid the barrier of multiple trips to the facility.

In transcripts, code names were used for all participants, any individuals or agencies that were named, and for the county. Actual names of participants were kept in a separate locked file. All printed transcripts were kept locked and computer files were password protected. These data were collected in 2007.

Data Analysis

Data were analyzed using methods of content and thematic analysis (Boyatzis, 1988; Saldana, 2009). The first step in data analysis for the overall project involved an extensive process of content analysis to code data from the focus groups and individual interviews. Using a deductive process, a preliminary code book was developed based on the interview guides. Focus group data were coded first. Teams of two coders independently reviewed each transcript, developed and applied codes to the text, and together reconciled the development and application of the codes. To ensure the iterative development of the codebook, the entire team of six coders met weekly to review, revise, and expand the codes. In addition to the question-related codes, conceptual codes that inductively emerged in analysis were identified (i.e., fear, isolation). The PLWH interviews were then coded using the same code book, which was expanded to include additional codes based on questions unique to PLWH guides and any additional conceptual codes that emerged. Coders managed the text data using a computer software program

The next step in analysis for this article involved examining the coded data from the PLWH interviews regarding their experiences of being diagnosed and living with HIV, as well as their perceptions about the views of the community about HIV and PLWH, to identify key themes. Coded data was collapsed and categorized into three broad themes: (a) community responses to HIV, (b) PLWH distress associated with being diagnosed with and living with HIV, and (c) the availability of social support to ameliorate this distress. Subthemes were then identified within these broader themes. The next step in analysis was triangulating the PLWH interview data with the focus group data to identify key themes related to perceptions about HIV and PLWH. Each focus group transcript was also read and inductively summarized by an investigator who was not involved in the coding so as to summarize key themes from each group. These data were used to check and elaborate on the analysis of PLWH interviews regarding community responses to HIV and PLWH. Data checking and verification of themes was then done by reading PLWH interviews and identifying quotes of respondents that captured the essence of the identified themes. The interpretative process of analysis involved making inferences about the data through further synthesis of the themes while reading key literature related to suffering and distress associated with living with HIV. During this analytic phase, two additional salient themes emerged that described critical outcomes for PLWH: silent endurance and intense loneliness. The final step was to interpret the data as a whole and identify theoretical linkages among the major themes and how they contributed to socioemotional suffering for PLWH. The findings were also presented to the CAB, who verified the conceptual model and provided ideas regarding strategies helpful in overcoming socioemotional suffering.

Findings

Figure 1 displays the theoretical linkages between the sociocultural context of these southern rural communities, community responses to HIV, and the distress of PLWH. The sociocultural context of the communities shaped community views of HIV and behavior toward people living with HIV and, along with limited support in these rural communities, powerfully affected the lives of the participants living with HIV. The end result was that many PLWH in our study endured in silence and experienced profound loneliness, which we define as key components of their socioemotional suffering.

Sociocultural Context

Data were interpreted within the broader sociocultural characteristics of these rural southern communities. In two related articles, we describe the perspective of residents about the communities we were studying based on analysis of the focus group and interview data and

a mapping and photoessay exercise with our CAB (Corbie-Smith, Banks et al., 2010; Corbie-Smith, Isler et al., 2010). Of importance to this article were themes related to geographic isolation of small towns; high unemployment and low educational levels resulting in poverty; limited recreational, health, and educational resources; traditional values and religious beliefs; and historical and current racism (Corbie-Smith, Banks et al., 2010).

Community Responses to HIV

Community leaders, service and health care providers, and PLWH all described their communities as avoiding and denying HIV as a problem, which contributed to negative views of HIV. They also described numerous ways in which PLWH were discriminated against.

Avoidance of HIV—Overall, the communities were described as coping with the HIV epidemic by avoidance. There was a general taboo regarding talking about and acknowledging HIV as a community-wide health and social problem. As a result, little attention was paid to prevention of the disease or to providing needed services to PLWH. Avoidance was fueled by fear. Residents were afraid of catching HIV and thought of it as a death sentence. Avoidance was also a way of distancing the community from these fears, as well as from the stigma associated with HIV. Successful treatments for people with HIV supported the attitude of avoidance and denial because people with HIV were no longer visibly ill:

Because they don't really accept it. They accept it but they don't accept the knowledge that's been given about HIV and AIDS. You know? Most people with HIV and AIDS [used to be] skinny . . . and they don't see any of those things with me, so they just don't receive it. . . . Why talk about something that we don't see and that's how it goes. It's kind of like a rejection of it.

Negative views of HIV—Negative views of HIV resulted from lack of information, misinformation, and fear. Moreover, HIV was viewed by many as transmitted by casual touch. Community members had an intense fear of catching HIV, and avoided people with the disease. One participant noted,

They don't want [people with HIV] to come in their house . . . don't want to touch them . . . don't want to sit beside them. Hearing comments like that . . . I want to explain to them and tell them what's going on, but I don't. I just back down because I think that they're going to say the same thing about me.

Lack of information also caused HIV to be viewed as a “dirty disease” caused by personal lifestyle choices such as homosexuality, illicit or unprotected sex, and drug use. One woman sorted out her concerns about how others might view her:

I never tried drugs in my life. I never drank alcohol. I have never experienced like what they call the wild life. It was just that experience that I had with this monogamous partner that had a life of that stuff. You know? And, uh, so my family knew that I hadn't been . . . What do you call it when you're just very sexually active? Promiscuous.

Even among risk groups, the disease was thought of as “nasty,” as illustrated by this comment: “So gay people amongst themselves think if you've got AIDS that means . . . you didn't watch yourself. You didn't do the right thing. You got it by being nasty.” Traditional religious beliefs led some community members to view PLWH as being punished for perceived sinful behavior. This was especially evident for homosexual men: “It's God's way of beating you for your sexual preference . . . your punishment.”

Discriminatory behaviors toward PLWH—As a result of incomplete knowledge about HIV and the resultant community beliefs and attitudes, PLWH faced discrimination in all aspects of their lives. For example, discrimination took the form of blame and gossip. One participant described how people with HIV were treated like they had leprosy: “They talk about you like a dog. People are just uncaring, insensitive . . . point their fingers and look down on PLWH [like] modern day leprosy.” PLWH also felt they were labeled: “They’re stigmatized because of the fact that they got HIV . . . people look down . . . I guess they figure we’re, how do you say it, degenerates.” The discrimination sometimes occurred in health care settings, as a result of both having HIV and being Black: “The White person will get more . . . attention than I . . . because they always look at us like we [are] dirt.”

Because of their intense fear of getting HIV, community members marginalized PLWH by avoiding physical contact or close proximity. PLWH report being shunned and avoided: “People say she got AIDS . . . just stay away from that person.” PLWH were acutely aware of behaviors that represented this fear: “They look at you funny . . . they scared to touch behind you, sit behind you.” In addition, PLWH often experienced discrimination in jobs and seeking housing, as others attempted to avoid contact and therefore exposure to the virus: “They think people with HIV should live in separate houses.” Such discrimination even occurred with family and friends. One PLWH reported that her sister was distressed when she used her bathtub: “When I go take me a bath in the tub . . . they keep saying, ‘You need to clean that tub out,’ . . . and someone will say, ‘I ain’t bathing behind [after] so and so.’” Another told the story of a friend’s experience: “She wouldn’t let her [the friend with HIV] back in the house . . . spoons and dishes she ate off, she threw them away.” Community fear and discrimination sometimes resulted in physical threats or even violence to people with HIV: “In [town], you might get jumped on if they find out.”

Distress of PLWH

Community avoidance of HIV as a problem, negative and erroneous views of HIV, and discriminatory behavior powerfully affected the distress of people living with HIV as they observed and personally faced these community responses and behaviors. In addition, distress was shaped by the PLWH’s own personal struggle to cope with the diagnosis and manage health care.

Devastation about being diagnosed—PLWH described being devastated and highly distressed at the time of diagnosis: “I was devastated and numb . . . cried for two weeks.” Given the negative views and taboos regarding talking about HIV, many newly diagnosed PLWH experienced a time of disbelief of the diagnosis:

I’ll never forget it. I just wanted to die. I just felt like I was useless and I shouldn’t live, and I felt real disgraced, shamed. I just felt bad. Other than feeling bad mentally I felt bad physically. I just, it took me a long time. I stayed in denial for a long time.

One participant said, “It went through one ear and out the other. I didn’t want to hear the words.” A few reported getting retested. The community taboo of acknowledging HIV was reflected in newly diagnosed persons who refused to face their diagnosis and experienced long-term denial leading to delays in seeking treatment: “So for three or four years, I just didn’t even think about it, didn’t deal with it. I went on with my life.”

Fear of dying and thoughts of suicide—Because HIV was viewed as a “death sentence” in the community, PLWH experienced intense fear of dying: “My whole life flashed before me. I was thinking, ‘Death, death, I’m gonna die.’” Lacking knowledge about HIV as a chronic illness for which there are treatments, many PLWH had no hope and

became despondent. One man described it as like having a loaded gun to his head. Some reported thoughts of suicide, especially if they became depressed: “It worried me, that thing worried me. . . . I wanted to kill myself.” Their concern about dying was sometimes reinforced by family responses: “The first thing [my sister] said was, ‘You better go get some life insurance and get your burial and stuff straightened out.’”

Anger and self-blame—Lack of community dialogue about how HIV is transmitted and prevented caused many PLWH to feel confused and angry about how they got infected. This was especially true if they were in a long-term relationship. One man was told by his long-time male partner to get an HIV test just before the partner died. Anger and loss of trust in relationships was common. A woman said her boyfriend of 15 years did not tell her he had HIV/AIDS. She said she “felt like killing him.” Some blamed themselves: “I still fault myself. . . . I was naïve [in thinking] this person really cared for me.”

Concerns about discrimination—Major, ongoing sources of distress were concerns about discrimination, about being stigmatized, perceived negatively, ostracized, or blamed. This reinforced feelings of shame, hurt, and embarrassment in having HIV: “So I don’t want to tell. It’s in the closet. You can’t tell because they’ll run out all over the world telling others, ‘This is nasty. She’s nasty.’” If they told others of the diagnosis, they were often shunned, pointed at, and rejected: “People scared to be around me, afraid of catching it.” A few PLWH reported physical abuse and violent acts by others in the community. One man described a particularly painful and violent experience: “So they came over and jumped on me. They left me for dead.”

Living in secrecy—The concerns about how they would be treated led many participants to live a life of secrecy in which their diagnosis was revealed to only a few people or to no one. Lack of knowledge about HIV was also a contributing factor, as noted by one man: “My family and friends and church family . . . are unknowledgeable of it [lack knowledge about HIV], so I keep it hid[den].” Even years after the diagnosis, many participants still had not told more than a few people. Keeping this secret resulted in emotional strain and an erosion of support: “So you keep your mouth shut. If you tell, you’ll be ostracized and left alone. If you don’t tell you are alone.”

Struggles to find health care—Ongoing struggles for most participants in these rural communities were the challenge to find adequate and affordable health care and the challenge of getting access to medications. Lack of health insurance, limited access to health care in rural communities, and long distances to HIV clinics in tertiary care centers all contributed to the challenges of finding health care: “I’m supposed to be in the greatest country in the world but . . . I got to worry about health care and drugs. It’s crazy.” To get funding for medications, many had to apply for state disability benefits, a complex and lengthy procedure. Being on disability brought additional loss of self-esteem and lowered income because of restrictions placed on employment:

When I became disabled [was awarded disability status to get health benefits], I was training at a bank. . . . I went from making \$2,500 a month to \$800, and no chance for advancement. . . . I can only stay, for the rest of my life in one place. . . . It’s never going to be to the point where I’ll be able to succeed.

Another aspect of finding health care was concern about maintaining confidentiality and avoiding discrimination within local health care systems. PLWH worried about staff gossiping about them and revealing their diagnosis. Several described incidents in which their diagnosis was revealed to family or friends during a health care visit.

The stresses and challenges faced by PLWH were chronic and ongoing. Feelings experienced at diagnosis sometimes continued for years: “Like I thought it would get different or better, but it doesn’t. Each day it still feels the same like the first time he told me . . . and it’s been years now.” Major causes of ongoing distress were avoiding and coping with discrimination and working hard to keep the secret. Over time, some PLWH became more open about their diagnosis, and even used this as an opportunity to teach others the importance of prevention. Other PLWH reported using alcohol, drugs, or sex to help cope with their distress. A few participants reported that they had thoughts of suicide

Living With Limited Support

Even though PLWH reported numerous sources of distress and experienced this distress for years, they had limited sources of support and few people who would listen to their pain. Secrecy of the diagnosis limited their potential support network. Family members who knew of the diagnosis were not always supportive, as evidenced by their avoiding, ostracizing, or blaming the PLWH. Many participants even kept their secret from friends and acquaintances known to have HIV, thereby losing another potential source of support: “It’s the oddest thing, most of my friends are positive but we don’t talk about it. It’s the stigmatism.”

Additionally, there was inadequate professional counseling available. Health care providers whom they saw for their illness focused mostly on the physical aspects of disease and treatments, and not on the emotional responses and needs of the person living with HIV. In these rural towns, there were limited mental health services available, and these were perceived as only available to the severely mentally ill or those who are threatening suicide:

So you’ll never find a time that you have a place to talk to anybody about HIV/ AIDS. We have a mental health center but unless it’s related to alcohol, drugs, or you say, “I feel like killing myself,” that’s the only way they’ll listen, and then once you say that they’ll fill you up with medications to keep your mouth closed.

Even where mental health service or counseling was available, PLWH often did not access these services for fear of more discrimination as a result of entering the mental health system. One important source of support for many PLWH was their respective case manager, someone most PLWH trusted and to whom they had relatively easy access.

Silent Endurance and Profound Loneliness

Ongoing distress in living with HIV, coupled with limited support or counseling, led to a life in which many PLWH endured their pain in silence and experienced profound loneliness. Silent endurance describes their experience of sustaining themselves emotionally and physically amid prolonged distress, with few or no individuals with whom they could share and process these intense feelings safely. Silent endurance involved a silence of voice. This was aptly described as, “You throw your feelings under the rug and keep going.” Another PLWH noted, “I keep it all balled up inside me. I just keep it to myself. Sometimes I feel I need to talk but I don’t know who I can talk to.” Keeping feelings inside can increase the distress. One woman described her anger:

And I get up with all this on my back. I go through the day angry, really pissed off. I think if I was able to let some of the pressure off and talk about it and deal with it, I would do better.

Silent endurance was also scary: “I lay up there and think, suppose I get bad, was sick. Ain’t got nobody to call. I just lay there and die, right? That bothers me but I just stick to myself. I’ll battle this all myself.”

Enduring in silence was coupled with profound loneliness. Many PLWH made weighty statements about their social isolation and loneliness. One PLWH summed it up as follows: “Feel like nobody wants you, very alone, lonely.” Another participant shared a story of profound loneliness briefly mitigated by a television commercial:

Then I saw the little, a commercial [on television] where the man on the airplane, and told [a girl] . . . he had AIDS and stuff like that . . . and I didn’t feel alone you know. [It was] a big help.

For some, loneliness was harder than having HIV: “Yeah it hurts me. . . . I’m not saying it hurts because I have it. HIV is stressful. It [the hurt] comes from being abused, being lonesome, being by yourself all the time.” Loneliness was especially profound for those living in remote, rural areas: “Don’t know anyone yet with HIV. Not where I stay . . . out in the country. I ain’t really been around no people [with HIV].”

Many participants indicated that a major source of strength amidst their silent endurance and loneliness was talking to God:

You ain’t got no other choice in life as far as terms of relationships and stuff like that but, you know, so that’s why I just try to keep a close relationship with God. ‘Cause, um, He don’t look at you like that.

Prayer and talking to God mitigated the loneliness:

Nobody. I just keep it to myself. I really do. I just, I pray about, I talk to God about it. That’s who I talk. . . . I put my faith in Him. So I get in my little quiet place and I talk to Him and my days get lighter and easier through prayer.

Socioemotional Suffering

Silent endurance and profound loneliness, in our model, are key components of socioemotional suffering. We conceptualize socioemotional suffering as the hidden emotional burden and inner distress of not only living with HIV—a complex, serious illness—but also the loss of voice in silent endurance and the resultant intense loneliness so as to protect the self from societal attitudes and behaviors that are imposed on the illness and PLWH. Although we identified a number of sources that contributed to the socioemotional suffering of the PLWH in our study, only a few participants directly described their experiences as “suffering.” Our focus on suffering came from the stories they shared with us about living with HIV:

It has been really hard, rough. I felt like I just wanted to give up on life because of the community that I was in. I just felt like there was nowhere else to go. There was nobody to understand. I felt like everybody was going to be like that in the whole world. It made me feel isolated and confused and panicky . . . I just wanted to give up.

One participant, however, described it succinctly: “A lot of people out there are not in positions that we are in . . . suffering.”

Discussion

These findings extend previous research that has largely focused on being stigmatized, emotional distress, or mental health problems in PLWH. Our findings suggest a more complex model that incorporates linkages between multiple levels of influence leading to socioemotional suffering in PLWH living with HIV in the rural South. The findings support the views of Kleinman and colleagues (1997), who pointed out that suffering is a social experience with close linkages between personal suffering and societal problems. The

current and historical sociocultural context of the rural South is a force that influences how rural southern communities cope with the HIV epidemic and, ultimately, how these societal responses affect persons with HIV. Although the community contributes to the socioemotional suffering of PLWH, they also turn their backs to that suffering. This is profoundly expressed in W. H. Auden's poem, "Musee des Beaux Arts," which depicts how individuals, when faced with suffering, find their own lives more immediate and absorbing, or perhaps turn away to avoid being disturbed and threatened (Auden, 1938, 2007).

The findings also fit with Cassell's (1991) interpersonal aspects of suffering. He noted that suffering is the consequence of perceived, impending destruction of the person or some essential part of the person that affects personal integrity. For our participants, suffering was the result of internal perceptions about how the local community viewed HIV and persons with HIV, and their observations or actual experiences of how PLWH were treated. These collective perceptions were internalized, adding to the challenges of living with HIV and profoundly affecting their social relationships, leading to a loss of needed support.

Silent endurance is a key component of our model of socioemotional suffering. We view silent endurance as privately bearing the distress of living with HIV by the repression of voice. Morris (1997), in an essay on suffering, examined Auden's famous poem, "Musee des Beaux Arts," and pointed out the poet's view of suffering as "absolute and insurmountable otherness" in which voice is silenced or repressed and becomes inaccessible (p. 29). Wilkinson (2005) suggested that the inability to outwardly express suffering "may well be one of its most essential attributes" (p. 16). He, too, viewed suffering as taking place amidst personal estrangement and social isolation. Ferrell and Coyle (2008) suggested that one of the tenets of suffering is that it occurs when an individual feels voiceless, or when his or her words are unheard. Based on our study, we might add that it occurs when giving words to distress associated with living with HIV might put the person at risk for further anguish and suffering because of stigma and discrimination (Duffy, 2005).

For many participants, silent endurance involved prolonged exertion. This is similar to descriptions of silent endurance in Egyptian women suffering from reproductive disabilities from pregnancy and childbirth (Khattab, 1989), as well as the experience of Vietnamese women victims of domestic violence (Shiu-Thornton, 2005). Our findings are similar to Morse's (2001) view of enduring as the shutting down or suppression of emotions. However, our model also differs from Morse in that we view silent endurance as a component of socioemotional suffering, and not as diametrically opposed to it. Silent endurance might be related to the phenomena of "being strong" that has been found to be a characteristic of African American women (Beauboeuf-Lafontant, 2007), including women with HIV (Shambley-Ebron & Boyle, 2006). Recently, Woods-Giscombé (2010) described suppression of emotions as one of the characteristics of the syndrome of being strong so as to preserve the self. She labeled this the "Superwoman Schema." Given that our sample included men and women, further research is needed about silent endurance and its possible linkage to the phenomena of being strong for minorities with HIV.

Silently enduring their distress with limited access to social support or counseling left PLWH socially isolated and, ultimately, profoundly lonely. The limiting of disclosure to avoid discrimination and the resultant social isolation and loneliness has been reported by other investigators (Black & Miles, 2002; Heckman et al., 2006; Logie & Gadalla, 2009; Mayers & Svartberg, 2001; Miller, Kemeny, Taylor, Cole, & Visscher, 1997). Authors of only one article, however, placed loneliness, defined as existential loneliness, within a broad psychosocial context (Mayers & Svartberg, 2001). To our knowledge, no researchers have previously conceptualized profound loneliness of PLWH within a larger sociocultural perspective and linked it to socioemotional suffering.

Social isolation and loneliness have long been identified as common human experiences across the ages (Peplau & Perlman, 1982; Weiss, Bowlby, & Reisman, 1973). Given the sociocultural context of the rural South, particularly poverty and racism, PLWH might experience stigma, social isolation, and loneliness not only because of their HIV diagnosis but also related to their social position. Most of the PLWH in our study had a low educational level and were poor. Reutter and colleagues (2009) identified poverty stigma as an aspect of social isolation. Participants in their study perceived their social identities as negative and felt they were labeled, treated differently, blamed, and viewed as a burden on society. Duffy (2005), in an ethnographic study in Zimbabwe, also found that the diagnosis of HIV/AIDS within the context of poverty resulted in shame, silence, and considerable suffering. The Health and Society Scholars Working Group on Stigma, Prejudice, Discrimination, and Health examined the dynamic link between stigma, prejudice and discrimination, and health (2008). In particular, the authors argued that even though stigma and prejudice are conceptually similar and have root causes that stem from exploitation and dominance, the justification for stigmatization relates to norm enforcement and disease avoidance (Phelan, Link, & Dovidio, 2008). Thus, societal discrimination toward PLWH could be related to both prejudice as a result of poverty as well as race, and stigma that arises from both norm enforcement of traditional values and distancing themselves from PLWH. Research is needed to explore how norm enforcement prejudice might lead to even higher levels of silent endurance, profound loneliness, and socioemotional suffering, especially for homosexual African American men living in the South.

The finding that PLWH, while suffering emotional distress, had limited or no access to professional counseling has been pointed out recently in a number of publications. Heckman et al. (2006) reported higher barriers for obtaining mental health care or finding psychological support groups for rural compared to urban PLWH. Reif and colleagues (2006) found that rural PLWH were less likely to report seeing a mental health provider, despite reporting distress. Both authors indicated the need to address mental health needs of PLWH in rural areas. In the rural communities we studied, both mental health- and HIV-related health services were limited, and access was exceedingly difficult for PLWH because of lack of public or private transportation. In addition, accessing mental health services is also compounded by cultural issues and stigma that affect acceptability (Ward, Clark, & Heidrich, 2009). HIV case managers, however, were a source of support for many participants. The case management system, which is largely funded by federal Ryan White HIV/AIDS funds (U. S. Department of Health and Human Services, 2010), needs to be strengthened, and case managers should receive ongoing training in counseling. Unfortunately, state and federal budget cuts are limiting rather than reinforcing this system of care.

A limitation of this study is that we did not directly explore with PLWH their isolation, loneliness, or perceptions of suffering. However, the strength of our findings is that these concepts arose from the analysis of interviews focused on what it was like living with HIV in their rural communities. As noted by Kleinman (1988), the only way of learning more about suffering is listening through illness narratives. Wilkinson (2005) indicated how difficult it is to truly represent a highly personal phenomenon like suffering, which cannot easily be shared with others. Frank (2001) suggested that the most significant part of suffering concerns that which remains largely unspeakable and concealed. Nevertheless, more research is needed on the life experiences of PLWH living in the rural South, using methods that allow them, as well as community residents, to give voice to their experiences and lives. Of importance is learning more about the process through which community responses and behaviors affect the lives of PLWH in rural communities, and factors that ameliorate or reduce isolation and suffering.

We also did not explore how the passage of time might have affected the participants' adaptation to HIV (Baumgartner & David, 2009) and perhaps changed their lives in a positive direction (Berger, 2004; Bletzer, 2007; Milan, 2006; Siegel & Schrimshaw, 2000). However, many participants indicated that they continued to live in silence years after their diagnosis. Many of our participants who shared stories of distress, lack of support, and loneliness, however, also discussed strategies they used to overcome their suffering. This included being open about their diagnosis; eliciting support, especially from family; using spirituality, especially talking to God; and reaching out to others. PLWH who did report getting support from their families noted that this was crucial in reducing their distress and coping with their illness.

These findings have many implications for clinical practice. Loneliness, social isolation, and psychological distress have all been found to impact on quality of life and have a negative impact on health, such as limiting engagement in HIV care (Basta et al., 2008; Mellins et al., 2003) and lowering adherence to medication (Catz, Kelly, Bogart, Benotsch, & McAulit, 2000). Loneliness has been associated with declines in CD4 levels indicating a decrease in immunologic status and increase in risk for infection (Miller et al., 1997; Straits-Troster et al., 1994). Psychosocial risk factors in general are associated with higher HIV morbidity and mortality (Farinpour et al., 2003; Ickovics et al., 2001; Logie & Gadalla, 2009; Vranceanu et al., 2008).

To improve the quality of life and the health of people living with HIV, we cannot be solely focused on the individual, but must also focus on the local community and society as a whole. Systems of care that include a focus on psychosocial issues and issues of trust are especially important in the South (Cohn et al., 2001; Whetten, Reif, Whetten, & Murphy-McMillian, 2008). Interventions are needed that help rural PLWH overcome barriers to disclosure and barriers to social support and counseling to reduce isolation and loneliness. Given the issues of distance for rural PLWH, interventions should be delivered to PLWH in their own communities through mechanisms such as home visits (Miles et al., 2003) or telephone contact (Heckman et al., 2004; Ransom et al., 2008). On reviewing our manuscript for this article, the CAB for Project EAST suggested strongly that we mention the importance of spirituality as a resource for strength in coping, and the importance of HIV support groups as a vehicle for sharing feelings and gaining the courage to disclose to others who can provide support. One model they found helpful was a 1-day state-wide retreat sponsored by a church-based agency. During this retreat, PLWH gained insight into their suffering and explored strategies important in living with HIV. The CAB also noted the importance of helping PLWH establish a strong, trusting relationship with a health care provider. In their comprehensive review of suffering, Kahn and Steeves (1996) found that a caring environment can influence suffering positively.

Our findings support the overarching socioecological model which guided the Project EAST study. As such, we explored how factors at the societal, community, and personal levels affected responses to HIV and people with HIV (Corbie-Smith, Isler, et al., 2010; Flaskerud & Winslow, 1998; Gelberg et al., 2000). This perspective strengthens the importance of working with local rural communities toward a better understanding of HIV as a chronic, treatable disease and improving negative attitudes and behaviors toward PLWH. Such interventions can only be done through collaborative partnerships that involve community leaders, health providers, and PLWH (Corbie-Smith, Isler et al., 2010).

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Biographies

Margaret S. Miles, PhD, RN, FAAN, is a professor, School of Nursing, The University of North Carolina at Chapel Hill in Chapel Hill, North Carolina, USA, and a consulting professor at Duke School of Nursing, Durham, North Carolina, USA.

Malika Roman Isler, PhD, MPH, is a research assistant professor, Department of Social Medicine, School of Medicine, and assistant director, Community Engagement Core of the North Carolina Translational and Clinical Sciences Institute, The University of North Carolina at Chapel Hill, North Carolina, USA.

Bahby Banks, MPH, is a project coordinator of Project EAST, Cecil G. Sheps Center for Health Services Research, and a doctoral student, Department of Health Behavior and Health Education, UNC Gillings School of Global Public, The University of North Carolina at Chapel Hill, North Carolina, USA.

Sohini Sengupta, PhD, MPH, is a research coordinator, the Center for Faculty Excellence, The University of North Carolina at Chapel Hill, North Carolina, USA.

Giselle Corbie-Smith, MD, MSc, is an associate professor, Departments of Social Medicine and Medicine, School of Medicine; Director of Program on Health Disparities, Cecil G. Sheps Center for Health Services Research; and Director of the Community Engagement

Core, North Carolina Translational and Clinical Sciences Institute, The University of North Carolina at Chapel Hill, North Carolina, USA.

