Content Validity of a Scale to Measure Silencing and Affectivity Among Women Living With HIV/AIDS

Rosanna DeMarco, PhD, RN, ACRN, Christine Johnsen, MS, MPH, ANP, Dawn Fukuda, MS, and Odessa Deffenbaugh, BA

This study measured quantitatively and explored qualitatively silencing behaviors and affectivity (mood) in women living with HIV/AIDS and confirmed the validity of the Silencing the Self Scale and the Positive and Negative Affect Scale. Silencing behaviors are interpersonal communication styles that suppress personal needs and feelings to preserve relationships with others. Silencing behaviors serve as protective strategies that allow one to divorce oneself from an overbearing culture. Affectivity is a way of measuring one’s personal mood state by a positive to negative continuum. The results indicate that the women silenced themselves profoundly, especially when it came to putting the needs of their children or dependents before their own. The women also had high levels of negative affectivity. The research findings from this study extend nursing knowledge by addressing the unique social processes of women living with HIV/AIDS within health care service structures and significant social groups. Further exploration of “silencing” as a phenomenon of this group through measurement and experience will help define specific interventions that are meaningful to and for women living with HIV/AIDS.

Key words: women living with HIV/AIDS, Silencing the Self Scale, affectivity, self-advocacy, empowerment

Women with HIV/AIDS historically have been underserved and are increasing in numbers at a rapid rate in large cities in the Northeastern United States (Chisholm, Grindel, Miller, Patsdaughter, & DeMarco, 1998; Johnsen, 1998). African American and Hispanic women in particular are disproportionately affected by HIV/AIDS and represent 77% of women with Center for Disease Control (CDC)-defined AIDS (Casey, Cohen, & Hughes, 1996; CDC, 2000). Women with HIV/AIDS report an inability or a conscious choice not to communicate their needs and feelings to significant others and health care professionals because of the stigma of the disease. Literature on gender differences and health/wellness supports the notion that women learn to silence themselves in their significant relationships to avoid conflict (Jack, 1991). Silencing behaviors complicate an already stigmatized disease experience, making it more difficult for health care providers to identify and provide meaningful services for women living with HIV/AIDS. The problem is a lack of understanding of the spectrum of needs of women living with HIV/AIDS, specifically methods of self-advocacy and the unavailability of gender-sensitive and meaningful instrumentation to measure this phenomenon.

In a correlational study, DeMarco (1997) found female staff nurse self-perceptions of silencing behaviors at home were positively related to the same behaviors at work. “Silencing the self” describes the experiences of women by identifying four types of silencing behaviors.
behaviors. Nonexpression of feelings and needs is itself called silencing the self. The externalized self describes behaviors indicative of influence by external standards of the immediate or more global culture whereas the divided self describes presenting an outer compliant self to live up to feminine role imperatives while the inner self grows angry and hostile. Care as self-sacrifice identifies how women put their needs last in relation to others’ needs. In this study, no significant relationships were found with care as self-sacrifice (Jack, 1991). DeMarco (1997) found that silencing the self, the divided self, and the externalized self were also directly related to negative affectivity. In this nonclinical context, low positive affectivity and low negative affectivity were found to be associated with feelings of the externalized self and the divided self.

These nursing systems findings led to the observation of similar patterns of behavior in a secondary analysis of qualitative data provided by women with HIV/AIDS who were asked how they take care of their health (DeMarco, Miller, Patsdaughter, Chisholm, & Grindel, 1998). The four themes of the theory of silencing the self by Jack (1991) and Jack and Dill (1992) were used in analyzing responses of 14 women diagnosed with HIV/AIDS. Findings suggest that women transitioned from silencing behaviors to action as a reaction to a threat to self (their diagnosis) where societal, gender normative behaviors lose meaning and a self-advocacy role becomes essential for survival.

A series of focus groups and a separate educational series were conducted with health care providers of women with HIV/AIDS and women diagnosed with AIDS, respectively. The focus groups consisting of health care providers addressed their perceptions of research priorities for women living with HIV/AIDS. The participants consistently represented the need to design and use research that identified specific interventions for this population (Chisholm et al., 1998). Program evaluations from the educational series demonstrated that women with HIV/AIDS have experienced gender-specific barriers with the medical care culture (i.e., they learned to “silence” themselves in expressing their needs and feelings about their disease, specifically, side effects of medications; Johnsen, 1998).

These studies support a consistent presence of a behavior that seems unique to women (i.e., silencing). In addition, the specific request by health care providers to create and evaluate interventions that are valid and meaningful to this specific group is extremely important. From a research perspective, if the behavior of silencing exists for these women, then it is important to find an accurate and appropriately tested measure of the phenomenon.

Review of the Literature

Jack (1991) traces many issues supporting the contention that depression is a complex, multifaceted illness, influenced by numerous biological and psychosocial factors. The focus of her exploration is women’s mental health. She asserts that developmental, clinical, and psychoanalytic psychologists all agree, “women’s orientation to relationships is the central component of female identity and emotional activity” (Jack, 1991, p. 3). Society, psychologists, measurement tools, and most important, the women themselves have viewed this very healthy capacity for intimacy and maturity as a weakness (Jack, 1991).

Jack (1991) traces the development of a feminine orientation to relationships in this cultural context and states the female caretaking role and male dominance emerge as themes. Women emulate their mothers and the female caretaking role, prevalent in many societies and cultures, inherently developing separate distinctions in society based on gender differences. In other words, to be female is not to be male, and vice versa. Daughters mature to adulthood with many aspects of the mother-child relationship still intact. Sons relinquish the closeness and form an identity separate from their maternal bond (p. 13).

In evaluating women’s mental health, Jack (1991) contends that “women’s vulnerability to depression does not lie in their ‘dependence’ on relationships but in what happens to them within their relationships. . . . Missing from most accounts of depression are the entanglements that result when intimacy occurs within a context of inequality” (p. 21). The traditional theories and measures of depression did not adequately take into account the feminine relational sense of self, gender norms, and societal and cultural inequalities. Therefore, Jack engaged in a personal search for better insight into the nature of depression in
women and concepts that “more adequately reflected women’s emotional realities” (p. 23). She interviewed depressed women so that the feelings and/or emotions of this group would honestly be represented in their own voices rather than be interpreted by others. Her extensive exploratory and longitudinal studies with this group resulted in her development of the Silencing the Self Scale (SSS).

Researchers who have explored the relationship between affectivity (mood) or depression and silencing behaviors have reported mixed findings. Low positive and high negative affectivity (both circumstantial and inherited, state/trait) are considered major distinguishing features of depression and anxiety (Tellegen, 1985). No study that measured silencing, depression, or affectivity together indicated a significant relationship between the two variables in men. Jack and Dill (1992) found a significant relationship between silencing and maternal depression. Silencing in women was significantly related to depression (Carr, Gilroy, & Sherman, 1996; Gratch, Bassett, & Attra, 1995; Hart & Thompson, 1996; Jack & Dill, 1992). Different ethnic backgrounds and cultures were also found to be predictors of depression in two studies (Carr et al., 1996; Gratch et al., 1995). This finding was important in light of the ethnic diversity of the population of women living with HIV/AIDS.

The perspective and concerns of women with HIV/AIDS have been studied mostly through ethnography and descriptive research designs (Mallory & Fife, 1998). Areas of inquiry have focused on what they found important in their care (Meredith, Delaney, Horgan, Fisher, & Fraser, 1997), perceptions of quality of life and coping styles (Rose & Clark-Alexander, 1996), self-care burden (Anastasio, McMahan, Daniels, Nicholas, & Paul-Simon, 1995), and psychosocial issues experienced as partners and mothers (Andrews, Williams, & Neil, 1993; Chung & Magraw, 1992; Rose, 1993; Semple et al., 1993). Isolation, stigma, coping with being ill, and motherhood put women in the position of not sharing their illness with their children and family members (Chung & Magraw, 1992; Semple et al., 1993). However, Andrews, William, and Neil (1993) found in women with HIV a strong sense of social support that moderated the needs of their children. Caring for children before themselves was a significant barrier to health care access and a source of depression (Anastasio et al., 1995; Rose, 1993; Rose & Clark-Alexander, 1996). This is supportive of the construct of the SSS called care as self-sacrifice (Jack & Dill, 1992). Lester, Partridge, Chesney, and Cooke (1995) found that anxiety and depression were significantly greater among HIV-positive women than other women with chronic illness. Those women also experienced more health care discrimination and social isolation. Last, interventions directed to women with HIV/AIDS found that women receiving social skills interventions were more likely to demonstrate direct communication and assertiveness (DiClemente & Wingood, 1995), safe and preventive sexual negotiation (Kelly et al., 1994), and more self-advocating behaviors (Harris, Kavanagh, Hetherington, & Scott, 1992).

In summary, there are many research studies chronicling women’s experiences with HIV/AIDS. Profound stigma and isolation trigger specific silencing behaviors or the seeking out of social supports that help these women cope with their lives and health. It is obvious that there are many sources of depression and well-being in the midst of the adversity these women feel. Chronic illness and uncertainty are part of an experience that is superimposed on the places in communities where they receive care. Providers of care want to help these patients with specific interventions that are meaningful. What are not known is how the coping behaviors of these women are experienced, how they may be measured with gender sensitive instrumentation or research design methods, and how the validation process of the latter can contribute to specific interventions in health care and other HIV/AIDS support service areas in the future.

**Purpose of the Study**

The purpose of the study was to validate the use of an instrument, SSS and the Positive and Negative Affect Scale (PANAS), with women living with HIV/AIDS. The research questions were as follows:

1. What is the range in scores on silencing and affectivity among women living with HIV/AIDS?
2. What is the relationship between the measures and women’s report of mood and behaviors?
Method

Study Design

This pilot study was descriptive and cross-sectional in design. Two self-report instruments and a semistructured interview were used to address the research questions from two different viewpoints of the participants (method triangulation; Morse, 1991; Sandelowski, 1993). Method triangulation was intended to enhance the unique interpretation of items on the SSS and the PANAS through the participants’ own voices and words. The intent of confirming validity of these measures is to obliterate bias and compensate for deficiencies that are inevitable in single investigator, theory, method, data set, and analysis of the past. Validity as a measure of truth value is acknowledged as a key factor in building nursing science (DeMarco & Friedemann, 1995).

Participants and Setting

The target population was women with HIV/AIDS in the metropolitan Boston area. Inclusion criteria for this study were women who (a) were HIV infected, (b) voluntarily consented to participate in this study, (c) were at least 18 years old, and (d) were English speaking. A convenience sample (n = 5) of women were recruited through the AIDS Action Committee of Massachusetts, Inc., New England Medical Center, and flyers and ads distributed in community and health care facilities directed to patients and providers. An incentive of $25 per instrument completion/interview time was offered to the women.

Procedures

The interviewer sat with each woman, obtained informed consent, and read the instruments to her. The interviewer was able to explain the project and the meaning of phrases or words with which the woman was not familiar. The SSS and the PANAS were administered to the women on two different occasions, 3 months apart. At the second visit, a semistructured audiotaped interview was conducted. The data were analyzed using Statistical Package for Social Sciences for Windows, Version 9.0 (SPSS, Inc. Chicago, IL) and a member-checking theme analysis (Miles & Huberman, 1994).

Instrumentation

Silencing behaviors were measured using the SSS (Jack, 1991; Jack & Dill, 1992). The SSS is a 31-item, self-rating instrument that measures the silencing behaviors Jack (1991) identified in her research. Each of the 31 statements is rated for agreement on a 5-point Likert type scale ranging from strongly disagree to strongly agree. Range of scores for the entire instrument is 155 to 31. The SSS is composed of four subscales. The Externalized Self represents feelings of judging oneself by external standards (six items; range of scores 30-6). Care as Self-Sacrifice represents putting the needs of others before the self (nine items; range of scores 45-9). Silencing the Self (subscale) represents refraining from self-expression and action to avoid conflict and possible loss in the relationship (nine items; range of scores 45-9). The last subscale, the Divided Self, represents the woman who presents with an outer compliant self to live up to feminine role imperatives while the inner self grows angry and hostile (seven items; range of scores 35-7) (Jack & Dill, 1992). The scores represent sums of the Likert-scale ratings. The higher the score (summative rate), the higher the silencing behavior or the particular subscale or the total scale.

The SSS has been tested on three distinct populations of women: women taking an introductory psychology course, residents of three battered women’s shelters, and women who abused cocaine during pregnancy. Internal consistency of the total SSS scores and the individual subscale was examined separately for each of the three groups. Alpha scores of internal consistency ranged from .86 to .94 on the total SSS scores, whereas item-total correlations were .77 to .91. Test-retest reliability ranged from .88 to .93 in the three samples (Politi & Hungler, 1999).

The PANAS is a Likert scale that lists 10 positive and 10 negative mood descriptors. The time frame for this study was defined as “in general.” For each mood descriptor, the women were asked to respond on a 5-point scale with 1 = very slightly or not at all to 5 =
extremely as degrees of perception of mood states. The possible ranges of scores for negative or positive affectivity is 10 to 50. The higher scores are more indicative of the degree of positive or negative affectivity. Normative mean scores are available for comparison. Populations used to test the instrument have included undergraduates, university employees, and nonmatriculated adults. The positive affectivity items have demonstrated internal consistency of \( r = .86 \) to \( .90 \) (Cronbach’s alpha) and the negative affect items \( r = .84 \) to \( .87 \). It takes fewer than 20 minutes to complete the SSS and PANAS if the participant can read eighth-grade English.

The PANAS measures positive and negative affectivity as two distinct variables. Affectivity describes an arousal of feelings and can be identified by mood descriptors, which have active behavioral consequences (Carlson, Charlin, & Miller, 1988). The term negative affectivity (NA) is a mood disposition dimension. It measures individual differences of negative emotionality and self-concept (Burke, Burke, George, Robinson, & Webster, 1988). Watson, Clark, and Tellegen (1988) defined negative affectivity as maintaining patterns of behavior that focus differentially on negative aspects of self, other people, and the environment. Positive affectivity (PA) represents the extent to which a person has a zest for life. NA is a dimension of subjective distress and unpleasant engagement.

**Semistructured Interview**

The semistructured questions and probes were designed to assist the participants in reflecting on the key variables of silencing behaviors and their prevailing mood in significant areas of their lives. The questions were as follows:

1. How has living with HIV/AIDS affected your relationships with the people that are important to you?
2. How has living with HIV/AIDS affected your relationships with health care providers?
3. How do you feel when discussing any issue with your health care providers?
4. Do you feel that you can take good care of your health at this time?
5. How would you describe your mood related to getting what you need to take care of yourself at this time?
6. Are there any other issues/concerns you would like to share with me?

Analysis of the qualitative interview data was a member-checking reduction of manifest themes imbedded in the recorded and transcribed interviews (Miles & Huberman, 1994). An interdisciplinary research group representing nursing and health education conducted recruitment, data collection, coding, and analysis. The interviews were audiotaped and transcribed verbatim to ensure the reliability of the data collection. Preliminary raw data analysis occurred during data collection through group meetings of the interdisciplinary research group. Checking the accuracy of transcribed data to the audiotapes provided initial hypotheses evolution that was later checked in the process of member-checking analysis providing a validation of themes. Individual members of the research group analyzed the transcribed interviews over 8 weeks. Each member received a copy of the transcribed interviews with no subsample identification. Data were extracted to identify concepts and categories of specific experiences. A codebook was created so that the reliability could be maximized from the interdisciplinary-specific perspectives. The codebook included what statements would be included or not included in identified concepts or categories. The identified and validated categories were then brought to a higher level of abstraction by placing all of them on a blackboard and discussing them to elicit central categories. Coding categories began as descriptions and then progressed to pattern codes or themes between the researchers. To assure that coding and categorizing was not being “pushed” by the invested researchers, an objective third party (a graduate research assistant) was instructed in the research analysis method and analyzed the data independently. The graduate research assistant’s role was to serve as an assurance of representation of the reality of the data (trustworthiness/credibility) (Polit & Hungler, 1999).
Preliminary hypotheses were developed based on these validated categories.

**Results**

**Demographics**

The mean age of the women was 42 years old. Of the 15 women, 10 were African American, 4 were White, and 1 was of mixed Portuguese/Native American origin. Although some of the women indicated a specific marital status, many of them indicated that they were “single.” It was unclear whether the women’s electing “single” had a significant other at the time of the study (see Table 1).

Because of the age of the women, a large percentage had dependent adult children or dependent adults living at home with them. Despite the dependent responsibilities in the family unit, most of the women were legally disabled because of their HIV/AIDS status. In caring for their health care needs the women indicated they primarily received health care and support from major medical center services in the city and HIV/AIDS care centers, respectively (see Table 1).

**Group Silencing**

**Behaviors and Affectivity**

Comparisons were made between mean scores of each of the SSS and total scores of the women after the educational intervention (see Table 2) with a group of women living in a domestic violence shelter \( (n = 140) \) (Jack, 1991). The mean total score was higher for the 15 women in this study than the domestic shelter group. In particular, “care as self-sacrifice” representing putting the needs of others before oneself and “silencing” representing the restraint from self-expression and action to avoid conflict and possible loss in the relationship were higher than the comparable means of the domestic shelter group. Although women in this study had somewhat higher scores for the subscales Care as Self-Sacrifice, Divided Self, and total scores, no statistical significance was found due to the small sample size of 15. Data suggest scores are comparable between the two groups.

Comparisons were also made between mean scores of women in this study on the PANAS with the scores of a normative group of undergraduate students and a mixed adult group of men and women (see Table 3). The mean score of the 15 women living with HIV/AIDS was higher than the normative group. This was especially true for NA, which was previously defined as patterns of behavior that focus differentially on negative aspects of self-concept, other people, and

---

**Table 1.** Descriptive Statistics

<table>
<thead>
<tr>
<th>Variable</th>
<th>n</th>
<th>M</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Portuguese/Native American</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>11</td>
<td></td>
</tr>
<tr>
<td>Divorced</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Significant other</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Individual with/mean number</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dependent children at home</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Dependent nonchildren at home</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Other dependents at home</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>None</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Employment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disabled</td>
<td>11</td>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Descriptive statistics</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neighborhood</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Medical center</td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>Place for support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HIV/AIDS center</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Medical care area</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Family/friends</td>
<td>2</td>
<td></td>
</tr>
</tbody>
</table>

**Table 2.** Comparison of Study Sample Means on the SSS With Comparison Group

<table>
<thead>
<tr>
<th>Comparison Group:</th>
<th>Study Sample</th>
<th>SSS</th>
<th>M</th>
<th>SD</th>
<th>Range</th>
<th>M</th>
</tr>
</thead>
<tbody>
<tr>
<td>Women in a Domestic Shelter</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Externalized</td>
<td></td>
<td></td>
<td>18.42</td>
<td>6.64</td>
<td>26-8</td>
<td>20.30</td>
</tr>
<tr>
<td>Care/self-sacrifice</td>
<td></td>
<td></td>
<td>29.40</td>
<td>7.38</td>
<td>39-17</td>
<td>25.50</td>
</tr>
<tr>
<td>Silencing</td>
<td></td>
<td></td>
<td>33.28</td>
<td>8.29</td>
<td>37-12</td>
<td>28.70</td>
</tr>
<tr>
<td>Divided</td>
<td></td>
<td></td>
<td>25.00</td>
<td>4.28</td>
<td>31-15</td>
<td>25.40</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
<td>102.40</td>
<td>15.72</td>
<td>133-63</td>
<td>99.00</td>
</tr>
</tbody>
</table>

Note: SSS = Silencing the Self Scale.
the environment. The comparison indicates that there was a ratio of both positive affectivity and negative affectivity that was part of the study as well as comparison group.

**Individual Silencing Behaviors and Affectivity**

Although qualitative analysis was completed on all 15 participants to expand the quantitative findings, a subsample of nine women’s interview theme patterns and instrument scores were randomly selected to represent the connection between the two types of data. The data represented the mean scores of the total SSS, subscales Externalized Self (EXT), Care as Self Sacrifice (CARE), Silencing (SS), and Divided Self (DS); PANAS subscales Positive Affectivity (POS) and Negative Affectivity (NEG); and the ranges of the mean scores of the entire group studied. Each of these scores demonstrated acceptable internal consistency (.82 to .96 Cronbach’s alpha) for this particular sample (Polit & Hungler, 1999). They were paralleled with exact quotes of manifest themes analyzed from the interview data.

**LJ**

<table>
<thead>
<tr>
<th>SSS</th>
<th>EXT</th>
<th>CARE</th>
<th>SS</th>
<th>DS</th>
<th>PANAS</th>
<th>POS</th>
<th>NEG</th>
</tr>
</thead>
<tbody>
<tr>
<td>SCORE</td>
<td>72</td>
<td>8</td>
<td>31</td>
<td>18</td>
<td>15</td>
<td>60</td>
<td>38</td>
</tr>
<tr>
<td>RANGE</td>
<td>133-63</td>
<td>26-8</td>
<td>39-17</td>
<td>37-12</td>
<td>31-15</td>
<td>73-51</td>
<td>42-26</td>
</tr>
</tbody>
</table>

LJ stated, “Me and my doctor have a good relationship... and she understands my needs.”

LJ demonstrated a positive perspective related to her relationship with her physician as well as high PA in contrast to an NA score that is lower than the group mean. Overall, her total SSS score was lower than the study group’s and the domestic violence shelter group’s. This means that her efforts toward self-advocacy were better than these groups’ efforts.

**CG**

The SS score of 20 was relatively low. CG comments,

I used to just listen to the doctor and then I’d go home and I would be mad because I didn’t really want to do what the doctor said. But now we talk, so I feel like I’m taking care of me.

CG discussed how she dealt with the societal/community-cultural standard to be “good,” “clean,” and “decent” as a human being by stating, “I didn’t want to leave here as a HIV drug addict and have that be my epitaph so it did affect my determination to clean up my act.”

Her comments were consistent with her higher score on the EXT supporting the notion of external rules being important in behavioral choices.

CG also explained that she feels positive related to her health care provider relationships, which is very significant to her. This is also reflected in POS and NEG scores.

I’m comfortable, confident, and real happy and satisfied with my health care providers right now.

I am more knowledgeable. . . . I have a very good relationship with my current health care provider.

**SJ**

<table>
<thead>
<tr>
<th>SSS</th>
<th>EXT</th>
<th>CARE</th>
<th>SS</th>
<th>DS</th>
<th>PANAS</th>
<th>POS</th>
<th>NEG</th>
</tr>
</thead>
<tbody>
<tr>
<td>SCORE</td>
<td>102</td>
<td>20</td>
<td>27</td>
<td>33</td>
<td>22</td>
<td>56</td>
<td>26</td>
</tr>
<tr>
<td>RANGE</td>
<td>133-63</td>
<td>26-8</td>
<td>39-17</td>
<td>37-12</td>
<td>31-15</td>
<td>73-51</td>
<td>42-26</td>
</tr>
</tbody>
</table>

I have no relationships with HIV because you get rejected a lot. So, I tend to be by myself a lot. Actually, the support from the people where I live and different organizations make it easier.
Otherwise, I would be a hermit and I probably wouldn’t be taking as good care of myself as I have been lately.

SJ’s comments agree with her high SSS score. The metaphor of being a hermit supported the notion of hiding away one’s presence and voice in society.

CS

<table>
<thead>
<tr>
<th>SSS</th>
<th>EXT CARE</th>
<th>SS</th>
<th>DS</th>
<th>PANAS</th>
<th>POS</th>
<th>NEG</th>
</tr>
</thead>
<tbody>
<tr>
<td>108</td>
<td>26</td>
<td>30</td>
<td>33</td>
<td>19</td>
<td>72</td>
<td>34</td>
</tr>
<tr>
<td>133-63</td>
<td>26-8</td>
<td>39-17</td>
<td>37-12</td>
<td>31-15</td>
<td>73-51</td>
<td>42-26</td>
</tr>
</tbody>
</table>

Just being around positive people, you know, I think plays a big part.

I just kind of distant [sic] myself and stay away. I just don’t feel like I can be close.

CS demonstrated moving away from people while exhibiting a high total SSS score, particularly the externalized self, care as self-sacrifice, and silencing. Despite observation, she hinted that she was making an effort to be around a welcoming, positive group of people who were supportive and helpful.

CMV

<table>
<thead>
<tr>
<th>SSS</th>
<th>EXT CARE</th>
<th>SS</th>
<th>DS</th>
<th>PANAS</th>
<th>POS</th>
<th>NEG</th>
</tr>
</thead>
<tbody>
<tr>
<td>66</td>
<td>11</td>
<td>25</td>
<td>12</td>
<td>18</td>
<td>56</td>
<td>36</td>
</tr>
<tr>
<td>133-63</td>
<td>26-8</td>
<td>39-17</td>
<td>37-12</td>
<td>31-15</td>
<td>73-51</td>
<td>42-26</td>
</tr>
</tbody>
</table>

I think it’s the support of other people with the disease is key.

I have not found the comfort zone to discuss my HIV status with family and many of the people I socialize with. I’m going to find people in the community, a new ground of people to share this with so that I can work with it.

I realized how important it is to be able to, you know, speak your mind about certain issues and to advocate through yourself when those issues aren’t being met. . . . I always surrendered all of the power to the health care provider and I know that’s not the way to do this. Now you have to participate.

HIV, it consumes your life—it absolutely consumes your life.

I have a person in my life who is my partner and he needs a lot of care right now, so yes, I do put myself aside. I keep promising myself that I am going to level the time out differently and do things differently but you know, being a woman and a caretaker and the type of person that I am, I have a great struggle with that.

CMV’s SSS scores were much lower compared to the mean of her group and comparison group, which means she is trying to advocate for herself. Her CARE subscore supported her statement related to putting herself aside and caring for her partner.

SMD

<table>
<thead>
<tr>
<th>SSS</th>
<th>EXT CARE</th>
<th>SS</th>
<th>DS</th>
<th>PANAS</th>
<th>POS</th>
<th>NEG</th>
</tr>
</thead>
<tbody>
<tr>
<td>63</td>
<td>12</td>
<td>21</td>
<td>13</td>
<td>17</td>
<td>67</td>
<td>42</td>
</tr>
<tr>
<td>133-63</td>
<td>26-8</td>
<td>39-17</td>
<td>37-12</td>
<td>31-15</td>
<td>73-51</td>
<td>42-26</td>
</tr>
</tbody>
</table>

We don’t just talk about my health. We talk about a lot of other stuff because she knows me.

If I need something or something is bothering me, I usually, you know, I go to my doctor and say, you know, I want to get this checked. . . . Pretty much, if I need something, I don’t have a problem asking for it.

SMD’s SSS and PANAS scores indicated that she had created a comfortable, open, and self-advocating relationship with her health care provider.

LC

<table>
<thead>
<tr>
<th>SSS</th>
<th>EXT CARE</th>
<th>SS</th>
<th>DS</th>
<th>PANAS</th>
<th>POS</th>
<th>NEG</th>
</tr>
</thead>
<tbody>
<tr>
<td>95</td>
<td>13</td>
<td>31</td>
<td>28</td>
<td>23</td>
<td>67</td>
<td>37</td>
</tr>
<tr>
<td>133-63</td>
<td>26-8</td>
<td>39-17</td>
<td>37-12</td>
<td>31-15</td>
<td>73-51</td>
<td>42-26</td>
</tr>
</tbody>
</table>

I’m really trying to maintain them too, making sure that my kids are doing the right thing before I leave the world and that’s a big part of my life.

LC reflected a theme consistent with the CARE score. Women with HIV/AIDS are very concerned about their children or other dependents.
[My] Family when they found out, they dis-owned me. Three children, two of them knew about it. They are adults; one accepted all right. The youngest went on a tantrum and quit his job, left the state, and got in trouble. I feel responsible for that because he took off because he found my AZT prescriptions.

And they were rude in the emergency room. They said, “What is this, AIDS day?”

SMD’s high SSS score and NEG score on the PANAS supported the stigma and family/social isolation described in her interview.

Discussion

The first research question of this study was as follows: What is the range of scores on silencing and affectivity among women living with HIV/AIDS? The similarities in mean scores of this study on 3 of the 4 SSS subscales (Silencing the Self, Care as Self-Sacrifice, and the Divided Self) with the scores of the women living in a domestic violence shelter was an important point of comparison. Women in domestic shelters are women in crisis whose lives are actively in upheaval. Women’s responses to battering include physical effects but also psychological and behavioral responses. According to Ratner (1993), battered women are significantly depressed and have physical symptoms of stress, anxiety, and insomnia. They exhibit more social dysfunction than those not abused. Like women living with HIV/AIDS, women in domestic violence shelters are highly influenced by safety and family, friend, and financial support afforded them by their communities, in addition to individual personality characteristics or resources (Campbell & Humphreys, 1993).

Perhaps the closest similarity between the women in this study and the comparison group was that women who have been victims of abuse were also mothers. Nursing research has documented that mothers worry about their children so much that it dramatically affects their decision making and behavior (Humphreys, 1995; Torres, 1991). Interventions for women who are victims of domestic violence have included the use of empowerment models inclusive of individual and group counseling rather than merely supplying information regarding community resources (Parker, McFarlane, Soeken, Silva, & Reel, 1999). This approach may have key significance for women living with HIV/AIDS.

The second question is highly related to the first in asking what was the relationship between the measures and women’s report of mood and behaviors. Specifically related to the second research question, there was a high correlation between silencing behaviors and depression using the Beck’s Depression Inventory as a diagnostic measure with women living in a domestic violence shelter (Jack, 1991). This was a confirmation of the work completed by Ratner (1993). In our study of women living with HIV/AIDS, although scoring high in NA, the women have high PA scores as well. Women stated that they are energized about their progress in “staying alive” and being able to find meaning in their health care provider relationships, family supports, and especially their children. The women also expressed the opposite feelings of not feeling comfortable in talking about their illness to others, putting their children’s needs before their own, and distancing themselves from others.

The number of women who participated in this study was small (n = 15) but appropriate for a descriptive pilot study including quantitative and qualitative methods of inquiry (Polit & Hungler, 1999). For women living with HIV/AIDS, factors such as stigma, family responsibilities, and how well they feel physically and psychologically on a given day (health appraisal), may contribute to participation in research studies outside of their homes. Other limitations include representation from one geopolitical area and the similar economic level of the women. The sample was predominately African American (n = 10). A group that is underrepresented in the sample is Latina women. The latter group is highly affected by the HIV virus usually through shared drug use with infected...
partners. It is important to translate diversity issues that are defined from different societal and cultural perspectives. To do this would challenge common stereotypes that support the belief that certain groups of women may silence themselves more than others.

Health Provider Implications

During the interviews, only 2 of the 15 women reported receiving support from friends. Thirteen of the women stated they received support from the health care system (i.e., formal facilities or community organizations giving support to patients living with HIV/AIDS). The SSS itself has potential as an intervention in this highly significant context of health care. Women seem to need to tell their story and share their experiences with others for personal growth. During health care visits, the SSS could be administered or given to women patients to complete at home between visits. Conversation about the scores and their experiences could enhance the understanding of the women. Individual items or scores could also be compared to normative data. The PANAS may also be used in combination or singularly to measure the balance between positive and negative aspects of mood that is part of the complexity of HIV/AIDS illness and chronicity.

Conclusion

This study extended nursing research knowledge by quantifying silencing behaviors of women living with HIV/AIDS. The silencing behaviors were also present as manifest themes. These findings identified the need to go beyond offering community resources and/or referrals but to initiate a dialogue about silencing behaviors with women living with HIV/AIDS. When women feel comfortable in a group setting, the use of educational programs and retreats may have high potential to offer a vehicle for entering this conversation. It may help them in expressing needs and feelings with others. If access to care is affected by gender-sensitive barriers, then women will suffer at the health care interface without a definitive plan that helps them articulate what they need and how they feel at many points of care. More research, specifically action research, may help us understand what types of interventions can address these specific behaviors that are highly embedded in women even before they become ill with a chronic illness. Action research as a research method has much to offer the community of people living with HIV/AIDS because it can be used to analyze problems or improve standards of care, carry out and evaluate plans, and teach researchers about the research process while serving patients (Patton, 1990; Van Manen, 1990). This approach is particularly sensitive to the immediate needs of research participants and acts on their needs as a process of understanding and unfolding. It may be a potent response to many research participants’ feelings that health care providers and researchers often ask many questions, leave, and document these data through publications but return little to them in terms of concrete or meaningful assistance.

Acknowledgments

At the time of this study, Rosanna DeMarco, PhD, RN, ACRN, was an assistant professor at Northeastern University, and Christine Johnsen, MS, MPH, ANP, was associated with the New England Medical Center. The authors would like to acknowledge the Massachusetts Health Research Institute and the Northeastern University (Research Scholarship Development Fund) for their grant support. Additionally, the authors would like to thank Jonathan Judy, MS, RN, ACNP, and Linda Burwell for their assistance in the data collection and analysis. The authors also thank all the women living with HIV/AIDS who participated in this study.

References


