Journal of Interdisciplinary Feminist Thought

Volume 4 Issue 1 Women and Spirituality

Article 3

Summer 6-2010

Spirituality as a Life Line: Women Living With HIV/AIDS and the Role of Spirituality in Their Support System

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Recommended Citation

Peterson, Jennifer L.; Johnson, Malynnda A.; and Tenzek, Kelly E. (2010) "Spirituality as a Life Line: Women Living With HIV/AIDS and the Role of Spirituality in Their Support System," *Journal of Interdisciplinary Feminist Thought*: Vol. 4: Iss. 1, Article 3.

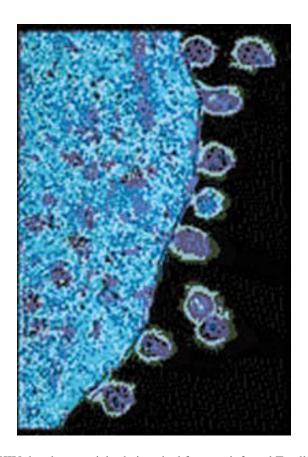
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HIV daughter particles being shed from an infected T cell.

NIH - National Institute of Allergy and Infectious Diseases - Strategic Plan 2000

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Spirituality as a life line: Women living with HIV/AIDS and the role of spirituality in their support system

Women are a rapidly growing population of people living with HIV: 26% of all HIV and AIDS cases in the United States are thought to be among women, with 80% of those attributed to heterosexual sexual contact (CDC, 2008a). According to Center for Disease Control and Prevention (CDC) statistics, AIDS was the leading cause of death in 2004 for black women between the ages of 25 and 34, and the sixth leading cause of death for all women in that age group (CDC, 2008a). In young people between the ages of 13 and 24, 38% of HIV diagnoses were reported among females (CDC, 2008b). HIV primarily affects poor women who often lack

social, financial, and medical resources to deal effectively with the disease (Heckman, 2003), leading women living with HIV to be more depressed than men with the disease, which can lead to immune system decline and increased mortality (Ickovics et al., 2001).

Because HIV is a highly stigmatized illness it can lead to feelings of social isolation, depression, and to delays in seeking health care (Herek, 1999, Berger, Ferrans, & Lashley, 2001, Anthony et al., 2007). Therefore, many women living with HIV report limited social interactions with friends and family as well as a low level of perceived social support (Hudson, Lee, Miramontes, & Portillo, 2001). Women living with HIV exhibit higher levels of depression, lower levels of well-being and functioning, lower quality of life, and experience less social support than men living with HIV (Heckman, 2003, McDonnell, Gielen, Wu, O'Campo, & Faden, 2000, Cowdery & Pesa, 2002, Cederfjall, Langius-Eklof, Ldman, & Wredling, 2001). Mothers living with HIV appear to be at the greatest risk for distress and depression (Murphy, Marelich, Dello Stritto, Swendeman, & Witkin, 2002). Women who report more HIV-related symptoms, perceive more stigma, have greater depressive mood and emotional distress, and experience less family cohesion also report experiencing more suicidal thoughts (Cooperman & Simoni, 2005). This research indicates that HIV is particularly stressful for women.

Because coping effectively with the stress of HIV illness can be associated with better adherence with treatments, improved depressive symptoms, and slower disease progression, understanding what defines "coping effectively" is critical (Vyavaharkar et al., 2007, Remein et al., 2006, Ironson, Stuetzle, & Fletcher, 2006). Some have examined differences between problem-focused and avoidant coping (Vyavaharkar et al., 2007), or between helpful and unhelpful forms of social support (Hays, Magee, & Chauncey, 1994). The mechanisms through which coping (including support) facilitates the management of stress and illness deserve

sustained attention; moreover that effort is likely to enrich our understanding of why different coping strategies or processes are more or less effective (e.g., Brashers, Neidig, & Goldsmith, 2004).

Spirituality is one resource for coping that has been relatively unexplored in communication research (Parrott, 2004). In HIV research, spirituality has been linked to frequency of received social support and psychological adaptation (Simoni, Frick, & Huang, 2006), and relief from stress, uncertainty, and psychological distress (Tuck, McCain, & Elswick, 2001). Exploring connections among spirituality, communication, and coping is important for explaining how, why, and for whom spirituality may be helpful, and how it is enacted for people coping with illness. Spirituality may be a particularly important avenue for coping for women living with HIV. In general, women are more likely to seek religious consolation, tend to have a closer relationship to God, and tend to be more religious than men across cultures (Ferraro & Kelley-Moore, 2000, Feltey & Poloma, 1991, Stark, 2002). The aims of this paper, therefore, are (a) to describe the experience of spirituality for women coping with HIV, and (b) to explore how spirituality is connected to social support in this population. The following section sets the stage for studying spirituality in this population.

Spirituality and Social Support as a Lifeline

By definition, spirituality has been associated with personal faith, meaning and purpose, connectedness, and a connection of mind, body, and spirit (Hill, et al, 2000, Koenig, 2008, & O'Brien, 2002). Within the realm of HIV and AIDS research, Siegel and Schrimshaw (2002) found that the perceived benefits of spirituality include that it:

(1) evokes comforting emotions and feelings; (2) offers strength, empowerment, and control; (3) eases the emotional burden of the illness; (4) offers social support and a sense of belonging; (5) offers spiritual support through a personal relationship with God; (6) facilitates meaning and acceptance of the illness; (7) helps preserve health;

(8) relieves the fear and uncertainty of death; and (9) facilitates self-acceptance and reduces self-blame (p. 91).

Researchers have associated spirituality with mental and physical health outcomes. For example, people with life-threatening illnesses may have higher level of distress about death without the comfort of spirituality (Chibnall, Videen, Duckro, & Miller, 2002). Previous research has indicated that spirituality has been a robust variable in predicting health-related outcomes including higher odds of survival (Hill & Pargament, 2003). For people living with HIV or AIDS, spirituality and/or religious coping has been positively associated with better quality of life, greater social support, more effective coping (Tuck et al., 2001), lower levels of depression (Yi et al., 2006), longer survival (Ironson et al., 2006), and purpose in life (Ironson & Hayward, 2008). It also has been found to be a resource that enhances personal control and provides a source of comfort, as well as a way of understanding and ordering the AIDS experience (Belcher, Dettmore, & Holzemer, 1989). Prayer and spirituality have also been linked with increased adherence to medication regimens (Konkle-Parker, Erlen, & Dubbert, 2008). While HIV disproportionately affects African-American women, African-Americans tend to have higher levels of religiosity (Yancey, 2006) and utilize more spiritual coping (Cotton, Puchalski et al., 2006). In particular for African-American women living with HIV, spirituality leads to a reduction in depressive symptoms (Braxton, Lang, Sales, Wingood, & DiClemente, 2007) indicating the potential for spirituality to be an important coping mechanism. Because of the potential of spirituality to promote positive health outcomes and serve as a lifeline to vital support resources (Musgrave, Allen, & Allen, 2002), researchers even have begun to encourage practitioners to incorporate spirituality into treatment (Cotton, Tsevat et al., 2006).

These benefits of spirituality are similar to definitions and benefits of instrumental, emotional, informational, and appraisal social support (see Albrecht & Goldsmith, 2003; Goldsmith, 2004), suggesting that intersections between the concepts of spirituality and social support might provide useful theoretical explanations for health outcomes. By examining aspects of spirituality that connect with the communication of support, a better understanding of the role of spirituality in the support systems of women living with HIV can lead to more effective services and treatment.

Social support has been defined as "an umbrella term for a variety of pathways linking involvement in social relationships to well-being" (Goldsmith, 2004, p. 12). For example, the perception that support is available may foster less threatening appraisals of stressful events. Feeling valued and affirmed by others not only gives confidence in times of stress but also fulfills basic human needs. Social support may function as assisted coping, providing information, resources, and encouragement for solving problems and managing emotions in constructive ways. Involvement in a network of relationships can also regulate behavior and give meaning to life. These linkages between social support and well-being mirror some of the benefits of spirituality.

Although some have suggested comparisons between social support and spirituality (Taylor & Chatters, 1988), there is need to further explore these concepts. There are at least two ways in which juxtaposing spirituality and social support may be useful. First, the comparison may encourage us to see social dimensions of spirituality. In contrast to viewing spirituality as primarily a system of beliefs, considering the similarities between spirituality and social support draws our attention to spirituality as relational (e.g., as a relationship to God or to a higher power, as relationships to a community of others who share this experience). This, in turn, yields

opportunities to understand how spirituality is enacted in communication. Second, examining spirituality and social support may suggest interrelationships in the experiences of women with HIV/AIDS. For example, can a strong spirituality help one cope with a lack of social support and with rejection from others? Does spirituality facilitate seeking and giving social support? To further explore issues such as these, we ask the following research question:

RQ1: What is the role of spirituality in the social support experiences of women living with HIV/AIDS?

Method

This study employed a qualitative grounded theory approach (Corbin & Strauss, 2007). Interviews used for this analysis were conducted as part of a larger study of mothers living with HIV. Following approval by the Institutional Review Board for the Protection of Human Subjects, participants were recruited. Audio taped interviews of approximately 60 minutes each were used to examine the social support experiences as well as the communicative strategies and behaviors of women living with HIV/AIDS. Before the interview, participants completed an informed consent document and a brief survey. Interviews were conducted in a private office by one of three interviewers. The data was then coded by one of the interviewers, as well as an additional researcher.

Instruments

Survey. Respondents were asked demographic questions such as their age, ethnic group, sexual orientation, and employment status. Several health-related questions provided a health profile of the women in the study. The survey also included the Center for Epidemiological Studies Depression Scale (CESD). The CESD is a 20-item scale that has been used extensively in HIV/AIDS studies.

Interview schedule. A semi-structured interview schedule was generated from the literature focused on mothers living with HIV. The first section of the interview schedule elicited information about the challenges the participant experienced as a woman with HIV or AIDS. The remainder of the interview focused on how social support functions for participants, and their relationships with their children. Although there were no specific questions about spirituality, it spontaneously developed as a theme for many of the participants.

Participants

Participants included 46 women living with HIV or AIDS who were reimbursed \$25. They were recruited through two agencies, which serve a large Midwestern metropolitan area. The average age of the participants in the sample was 43 years old (range = 27 - 60, SD = 8.442). Women reported their ethnic identity as African-American (n = 28, 61%), Caucasian (n = 10, 22%), Latino American (n = 5, 11%), or other (n = 3, 7%). Twenty seven (59%) of the women reported having a partner with whom they were in a committed relationship. Because this study focused on mothers, all but one of the women had living children (n = 45, 98%). The number of children ranged from 0 to 11, with an average of three. Eleven (24%) of the women reported being diagnosed with AIDS.

Thirty-five (76%) of the women were taking medication to treat HIV. Twenty-nine (63%) of the women were taking medication for depression. In this sample, the average score on the CESD was 24 (range 7 - 50, SD = 11.56). Scores on the CESD of 16 or above out of a possible 60 are considered to indicate significant depressive symptoms. Other studies have used a score of 23 to indicate significant depressive symptoms in people living with HIV (e.g., Richardson et al., 2001). In this sample, using the cut off of 23, the number of women experiencing significant depressive symptoms was sixteen (35%).

Data Analysis

After transcribing the tapes, the transcripts were verified with the audiotapes. During the verification process, notes about general themes were taken. Once the transcripts were verified, they were re-read to look for specific themes and important issues by two researchers. These themes were then examined for similarities and differences to group them under larger categories. The larger categories were then reviewed to make sure there were no overlapping or duplicated categories and that both coders agreed on them. These categories were then compared to the categories found in a previous study of spirituality and coping for women living with HIV (Peterson, 2009).

The transcripts were then coded according to the categories that were labeled with headings. The transcripts were re-examined to define and explain the categories in more detail. Quotations that were particularly representative of the categories were selected from the transcripts and reviewed by the additional researchers. All names associated with the quotations were changed to protect the identity of the women. The data analysis was then written and tied to relevant literature to explain the findings. Content validity of categories and themes was assessed through procedures that Lincoln and Guba (1985) described: (a) participants in the later interviews were used to validate categories and themes from earlier interviews and (b) a fellow HIV researcher reviewed transcripts to match categories and themes.

Results

This study grew out of a larger project focused on mothers living with HIV and their support experiences. From the interviews, it became clear that religion or spirituality was intertwined with their experiences of social support. Those who spoke of spirituality described a strong sense of faith that they would be taken care of no matter what happened to them. The

interviewees seldom differentiated spirituality from religion; consequently, in the analysis that follows, we interpret "spirituality" quite broadly to include both relationships to things spiritual in nature as well as involvement in particular religious communities.

This strong sense of spirituality had several functions described through the roles that God and the church played in the support system. In particular, spirituality or a connection to God offered the women an opportunity to develop meaning and perspective taking, to have a source of support, to provide control through a more powerful being, and to offer a path to community.

Develop Meaning and Perspective Taking

For some of the women in this study, spirituality served as a context for perspective shifts. They believed that God had a plan for their lives, and that connecting spiritually to God as a higher being provided them a way to make sense of, and make changes to, their lives. For example, Michelle explained, "I think actually when I found out that I was positive, a lot of positive things came into my life, I had began to seek out a relationship with God, and I learned, and began to build my faith in my higher power." Katie discussed how her approach to everyday life changed, "God made it a reason -- and I look at life different now. I woke up and I'm going to enjoy the day." Toni explained what God brings to her life, "I put a lot of trust in God too. I believe in God. That kind of gave me hope." Not only did spirituality provide the mothers with a way to find meaning and a new perspective, but it also was a tool they used to help their children do the same.

By involving their children in their religious practices, the mothers provided their children with the spiritual tools to process their diagnosis. Michelle said, "I had been taking my kids to church for awhile, and they were listening to what the pastor was saying, so when I told

them what I told them they were not afraid at all, they did not look at that as something to be afraid of, that God is much more higher than HIV is." Sylvia had a similar comment, "We're a God-fearing family, so with his help you can get through anything." Gabby had told her daughter, "Maggie, I'm still here and I'm going to be here for a long time. I trust God on this one, and you better trust him too." As much as spirituality played a role in the perspective of the mothers, it also played a role in the experiences of their children in processing the diagnosis and coping with HIV.

Becomes a Source of Emotional Support

Women in the study also described the practice of spirituality as a source of support. Just as communication with a supportive friend might be comforting, spiritual communication practices such as daily prayer and meditation were common ways the women calmed their stress and rejuvenated their mood. Wendy explained the importance of prayer in her life, "so I have to pray all the time and I have to ask God for guidance and hope and pray that he lead me in the right direction." Jane also regularly used prayer for support, "I don't like to talk about it, I just pray and do what I do everyday." In addition to prayer, reading the Bible also provided some of the mothers with a sense of support. Robin explained, "but here lately I've just been every morning picking up the Bible, just read out the Bible and study in the best way I know how." Mothers also involved their children in these practices as well. Toni explained her encouragement of her son, "I make him read the Bible to a lot. Trust in God for everything." Spiritual activities such as these have been negatively correlated with feelings of emotional distress (Sowell et al., 2000) – this relief from emotional distress was clear in many of the women's explanation of the role of spirituality in their lives.

For some of the women, God provided a consistent/stable presence in their lives. No matter what the situation, their spiritual resources were always present. That meant a sense of security in some cases, as Toni said, "But I manage it as long as I got God." Samantha explained her constant reliance, "If I didn't have God in my life, I don't think I would have made it through. I had to put everything on God." Laura summarized the supportive role of God in her life by saying, "My God. He is the thing that helps me deal with this madness."

Provides Control through a More Powerful Being

For some of the women, God was a powerful force who could control elements of their lives that they could not, akin to perceived available instrumental support. Perhaps the most obvious way this was discussed was in terms of control over their health. Nancy explained, "thank God for the mercy of the Lord. He must have something planned for me because little by little, I started getting better." Lindsay commented, "But I, but by the grace of God, I've never had a AIDS related illness." In these cases, the women believed that God had a direct, positive impact on their physical health.

For other women, God was the giver of life. As the giver of life, God is the one who has the power to decide who lives and dies. Sometimes this was an explanation for still being alive. Nancy said, "God don't want me yet and I'm not gonna die." Sometimes it was a reflection about being alive as Jan explained, "I'm grateful for the life that God has given me." Mandy said, "I just thank God when he wakes me up every morning."

In addition to the larger issues of life and death, God was also portrayed with power to direct various aspects of daily life. For example, God was seen as having the power to direct the women to resources, or provide sources of support. Nancy explained, "Well, thank God, again, for places like this because through my ordeals, I have met beautiful, beautiful people and I felt

comfortable." Karen felt that God had led her to disclose her status to her children. She said, "I think God just put it on my heart to let them know."

Offers a Connection to Community

For some participants, ties to spirituality and to God meant church attendance and participation in church activities. For these women living with HIV, churches provided not only an environment to commune with God, but also offered opportunities for numerous types of social ties that might provide support opportunities; that is, churches are social networks where one can readily find access to potentially supportive people. Although not all churches will react positively toward people living with HIV, some of the women in this study found churches that were a source of support. When first diagnosed, some women went to churches looking for help coping with their diagnosis. Toni declared, "The only way I was able to cope with it was getting involved in the church. Going to church. Praising the Lord. That's it. That's the only way I felt I could cope with it." In addition, church also provided some women with the opportunity to talk about it as Michelle explained, "I began to speak in the church and I would give my testimony and part of my testimony was sharing how God has preserved my life." These experiences provided the mothers with a sense of comfort and relief.

The women in this study were also able to assert their independence and affirm their ability to help others through participation in the church community. The opportunity to participate in groups and offer others support through church programs enables women to reciprocate support, affirming their worth and preventing a sense of dependence. Sarah explained her participation, "Being there to mentor to other people, newly diagnosed people and people living with this. That's very healing for me, because I want to give back." Others participated in

traditional church activities such as Tamara who said, "I'm Christian in church now. I belong to the church. I sing in the choir."

Underscoring the importance of spirituality in the support systems of these mothers, were women who looked to the church as one of their only sources of support. For example, Toni said, "Really, I don't have any support but my children or my church that I go to." Even if the church was not the sole source of support, it provided an important assurance that support would be available. Sylvia had not disclosed her status to her church, but she was confident that the support would be there if she needed it. When asked if the church provided her with support, she explained, "But I believe they would if I were to ask, I believe they would."

Discussion

At a basic level spirituality, particularly church attendance, provided these women with opportunities to participate in a community with others independent of their HIV diagnosis. This participation provided an outlet to help them focus on spirituality and the role it plays in their lives. However, these women experienced spirituality in a much more relational way as well, creating a lifeline to vital resources for their quality of life as well as their survival. It was a supportive relationship with a higher power for themselves, reflecting the intimate relationship between self and God that is sometimes associated with spirituality (Mattis, 2000; Shambley-Ebron & Boyle, 2006). However, it also provided these mothers with a way to ensure that their children would also have the same unconditional love and support that their spirituality had provided for them. In this way, spirituality presented itself as a force that bonded mother and child together in an environment where illness was not the focus.

Spirituality is not a resource that is connected exclusively or specifically with HIV/AIDS.

Support derived from spirituality may also be useful for coping with the range of life stresses

experienced by women in this sample. It is also more significant than, and independent of, the medical concerns that the women are experiencing, which may be a reason the women find it to be so vital. Likewise, supportive spiritual communities are not based on the common experience of living with HIV so membership is not limited by diagnosis. They are communities that family members and friends can engage in as whole members. Spiritual communities not only offer women the opportunity to find support for themselves, but also offer the women opportunities to care for and include family members, particularly children, in the support experiences at the same time.

Based on the data in this study there appears to be a strong connection between social support and spirituality. At a very basic level, the definition of social support and the perceived benefits of spirituality include similar concepts. Each of the four main themes that emerged from this analysis of spirituality are also main themes in research on social support. Through their relationship to God, women reported developing new meanings and perspectives on HIV, a function that resembles the processes of re-appraisal (e.g., Burleson and Goldsmith, 1998) and uncertainty management (e.g., Brashers et al., 2004) through which social support improves coping. The women in this study spoke of spirituality as a source of emotional support and control. Prayer and meditation entailed communication with a stable, supportive, affirming presence and a spiritual connection could be a powerful force capable of intervening to affect cures, extend life, and improve relationships. These themes resemble the provisions of social relationships, including emotional support and instrumental aid (e.g., Cutrona, Suhr, & MacFarlane, 1990). Finally, connection to a spiritual community provided opportunities for participation in a social support network. A spiritual connection to God facilitated entry into reciprocal ties of mutual aid and support with diverse others. Access to resources, reciprocity,

and diversity have all been identified as important in theories of social support networks and they were also evident in women's talk about their participation in church.

For the mothers in this study, the experience of spirituality was a relational experience. For some people, God is an entity who provides comfort, and God is a safe haven because he or she is a being who offers caring and protection in times of stress. Research indicates that a relationship with God will lead to greater comfort in stressful situations and greater strength and confidence in everyday life (Hill & Pargament, 2003), which is very similar to the buffering theories of social support. People who report a closer connection to God experience a number of health related benefits including less depression and higher self-esteem (Hill & Pargament, 2003).

One common way the women in this study engaged in a relationship with God was through prayer. Prayer is the most frequent spiritual behavior (Guillory, Sowell, Moneyham, & Seals, 1997). Prayer can have numerous benefits, similar to that of social support. Women living with HIV, who engage primarily in private forms of religion such as prayer, are less likely to engage in high risk behaviors, are more likely to perceive themselves as healthy, and more likely to feel they were in control of their health (Morse et al., 2000). Prayer offers women the opportunity to talk to someone who will listen without judgment. Many of the women in this study incorporated prayer into a daily routine, as well as used prayer as a way to cope with being upset. Research supports the notion that spiritual activities such as prayer and meditation are useful coping strategies for people living with HIV (Reeves, Merriam, & Courtenay, 1999). One explanation for the effectiveness of prayer is that it is similar to disclosure. Prayers have been found to have similar linguistic characteristics to disclosures and may also be associated with the personal benefits that disclosure provides (VandeCreek, Janus, Pennebaker, & Binau, 2002).

Disclosure can be beneficial because it helps people process events and experiences. The women in this study frequently engaged in prayer and considered it to be an important source of strength and stability. Moreover, their descriptions of prayer and meditation reveal a relational dimension to spirituality as communication with One who accepts, guides, and acts.

Another role God played in the lives of the women in this study was as a "powerful other," that is, God is a powerful being who is in control of events in their lives. Thus they were comforted by their belief that there is an intrinsic benefit of having a relationship with God, because of the power that he/she has to control events and outcomes. Living with HIV/AIDS is a life filled with uncertainties and experiences that reinforce our lack of control as human beings. It is comforting that someone with whom you have a personal relationship through prayer and meditation has control over the events in your life. When life events were too stressful or difficult for the women to think about, they often spoke of giving it to God or letting God work through them. Believing that someone else has control over your ultimate path provides the freedom to focus on the here and now and the care needed at the time. Being able to identify someone who has power over what is going on relieves burdens for some, and provides an outlet for hope. Some research has found that spirituality is positively associated with optimism (Biggar et al., 1999), which is a useful coping mechanism (Brashers, 2007) and can be an important aspect of depression care (Cooper, Brown, Vu, Ford, & Powe, 2001).

Spirituality also serves as esteem support for many of the women in this study. Their faith provided esteem support because everyone is worthy of love and compassion in God's eyes. Spirituality provides a sense of acceptance and belonging that eases emotional tensions caused by their illness and the stigma attached to HIV. In this respect, spirituality can restore identity because it removes blame, provides perspective, and offers opportunities for reappraisal. For

some of the women, spirituality had helped them believe there was a purpose to their diagnosis and that their faith would help them find that purpose, as well as sustain their health until a cure is found. Religion can provide people with a sense of their ultimate destinations in life by providing ultimate purpose and meaning even in disturbing life events (Hill & Pargament, 2003). In this case, the women are sustained in their coping efforts by this spiritual purpose and the support for reappraisal. Not only does spirituality provide network support, but it provides emotional and esteem support as well making it an integral part of the support systems of these women living with HIV/AIDS.

Future Directions

The connections between social support and spirituality warrant further attention. Spiritual resources play such an important role in the lives of these women living with HIV that it seems impossible to separate it from their support experiences. When religion and spirituality have been studied, they typically have been included as secondary variables in the context of other research, primarily measured by church attendance, membership, or some type of religiosity scales (Hill & Pargament, 2003). Further research needs to develop communication specific measures of spirituality (see Egbert, Mickley, & Coeling, 2004) and to explain how and why spirituality affects health.

One avenue for exploration in this case is the connection between spirituality and social support. Additional research to discover what women draw from their spiritual experiences and how those experiences impact their approach to or experience of support may provide insight into this connection. Insight into how and why spirituality functions as social support is important to understanding the support experiences of women living with HIV, as well as to discovering the connection between spirituality and health. In addition, the women in this study

talked exclusively about God and Christianity as their connection to spirituality, but other forms of spirituality and religion (even nonreligious spirituality, see McGrath, 2005) may function differently for people living with HIV (see Persuad, 2007). Future studies, therefore, should investigate a wider range of spiritual and religious beliefs, and how they connect to the management of health and illness. Additional research designed to explore messages about spirituality and health can further enhance our understanding of the role of spirituality and religion in beliefs about health, the connection between faith-based and medical-scientific explanations of health and illness, and the ways in which people manage health and illness.

Conclusion

Spiritual communities provide connections to other people who are potential sources of emotional and tangible support for women living with HIV. Spirituality provides comfort and offers an opportunity for the women to disclose their stresses to an understanding and accepting other, as well as the confidence to cope with life with HIV. The multiple functions of spirituality in the lives of women living with HIV/AIDS make it a vital piece of their support systems.

Author Note

This study was funded by a Research Growth Initiative grant from the University of Wisconsin-Milwaukee.

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