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A Qualitative Description of Women's HIV Self-Management Techniques: Context, Strategies, and Considerations

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Abstract

Women living with HIV face unique challenges managing their disease. The purpose of this descriptive, qualitative study was to describe self-management techniques reported by 48 women living with HIV in the United States. Participants were involved in one, 90-minute, digitally-recorded focus group exploring aspects of HIV self-management strategies. Descriptive statistics, qualitative description, and content analysis were used to analyze the data. Participants had been living with HIV for an average of 12 years, most (69%) were engaged in routine HIV care (85%) and were currently prescribed antiretroviral therapy. Participants reported using self-management techniques: taking personal time ($n = 23$; 48%), advocacy ($n = 12$; 25%), sleeping ($n = 17$, 35%); attending support groups ($n = 10$; 21%), and attending medical appointments ($n = 8$; 17%). Nurses can add strategies to enhance HIV self-management to routine clinical care, which may have a positive impact on the health of women living with HIV.

Keywords

HIV; qualitative description; self-management; women

Self-management is a central health goal for people living with HIV (PLWH) and other chronic diseases (Beaglehole et al., 2008) and is defined as the day-to-day decisions and tasks people execute to manage their illnesses (Bodenheimer, Lorig, Holman, & Grumbach, 2002; Lorig & Holman, 2003). As PLWH age, they may develop additional chronic conditions necessitating more self-management skills as they are challenged with adhering to even more medications, health care provider visits, and behavioral changes in order to

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live well. Living with HIV requires many self-management tasks including treatment adherence, daily symptom monitoring (Spirig, Moody, Battegay, & De Geest, 2005), frequent engagement with one's health care provider (Schneider, Castillo-Salgado et al., 2004), managing family responsibilities, dealing with the impact of stigma (Vanable, Carey, Blair, & Littlewood, 2006), preventing sexually transmitted diseases (Jemmott, Jemmott, & O'Leary, 2007), and managing the interaction of HIV and other chronic diseases, including mental health conditions (Pence, Miller, Gaynes, & Eron, 2007). These tasks are critical to successful management of HIV, yet programs to improve self-management of HIV tend to enroll predominantly male participants, leaving a gap in our understanding of the HIV self-management strategies women use and how those strategies can be enhanced (Brown & Vanable, 2008; Scott-Sheldon, Kalichman, Carey, & Fielder, 2008; Swendeman, Ingram, & Rotheram-Borus, 2009).

Women may face unique challenges in managing HIV disease including dealing with family roles, higher levels of poverty, and inadequate access to health care resources (Centers for Disease Control and Prevention [CDC], 2010; Webel, 2010). In the United States, women are increasingly infected with HIV and now account for 25% of all new HIV infections (CDC, 2010). Worldwide, the statistics are even more alarming. Women comprise more than half of all adults living with HIV and almost one half of all new HIV infections (Joint United Nations Programme on HIV/AIDS, 2009). There is also new evidence identifying poverty, lower education levels, and high rates of incarceration in communities as ecological risk factors of infection for American women (Adimora et al., 2006; Magnus et al., 2009). These risk factors also serve as obstacles to the self-management of HIV disease. Lower education levels and living in poverty have been linked to poorer medication adherence and poorer general health in PLWH (Goldman & Smith, 2002). The daily decisions and tasks required for effective self-management necessitate material resources (e.g., telephones, transportation, Internet, and childcare) that may be harder for women living in poverty to access efficiently and consistently.

Women living with HIV are a vulnerable population and in order to develop programs to address the self-management needs of these women, we need a better understanding of the self-management strategies they currently use. Recognizing this need, Tufts, Wessell, and Kearney (2010) qualitatively explored the self-care strategies of 21 African American women living with HIV in the southeastern United States. They found two primary domains: "doing what the doctor said" and "living healthy." Within those domains, several self-care techniques were identified including seeking social support, managing disclosure, engaging in pampering, taking part in religious customs, and maintaining recovery. In our study, we build on this work and expand the body of knowledge on HIV self-management to women from other ethnic groups, geographic areas, and social backgrounds.

The purpose of our study was to describe the self-management techniques reported to be used by women living with HIV in the United States. A better understanding of these techniques will help nurses, advocates, and community members develop better self-management programs that integrate medical and social aspects of HIV self-management.

Theoretical Framework

Recently, Swendeman and colleagues (2009) completed a review of the chronic disease self-management literature and developed an integrative framework of HIV self-management. The authors identified 14 common self-management elements of HIV and other chronic illnesses. They classified these elements into the following three categories: physical health functioning, psychological functioning, and social relationships. The elements in the physical health functioning category included: having a framework for understanding illness

and wellness, health promotion behaviors, adherence to medication (and other treatment) regimens, self-monitoring of physical health status, accessing treatments and services, and preventing transmissions. Elements in the psychological functioning category included: self-efficacy and empowerment, cognitive skills of self-management, reduction of negative emotional states, and identity. Elements in the social relationship category include: collaborative relationships with health care providers, self-disclosure of disease status and coping with stigma, positive social and family relationships, and social support (Swendeman et al., 2009). However, most of the HIV literature cited in building this framework was conducted primarily in studies on men leaving a gap in our understanding of this phenomenon in women. To fill this gap, we used the framework to explore and analyze self-management strategies reported to be used by women living with HIV.

Methods

Study design

We used a descriptive, qualitative research design with focus groups. The use of focus groups was preferable to individual interviews because the participants were able to build upon each other's responses, thus facilitating a deeper understanding of their own self-management activities (Kitzinger, 1995; Morgan, 1998). A semi-structured focus group guide was used to facilitate the discussion of self-management. The focus group guide was developed by searching the HIV and self-management literature to pick out important aspects of the medical and psychosocial management of HIV, as well as important aspects of chronic disease self-management (Lorig & Holman, 2003; Spirig et al., 2005; Tufts et al., 2010). The guide was used as a starting place for initiating the focus group discussion and was iteratively revised after each group to reflect the new issues discussed and to remove the prompts that participants were not identifying as important to self-management. Participants were encouraged to deviate from the prompts if they felt the information was important to HIV self-management.

Setting and Study Sample

We used flyers to recruit participants from HIV clinics and AIDS service organizations in Northeast Ohio. To be included, potential participants had to meet the following inclusion criteria: (a) 18 years of age or older, (b) female, (c) English-speaking, and (d) have a documented HIV diagnosis. Twelve focus groups containing approximately four women each were conducted from January–April 2010. The focus groups were held in private locations that were easily accessible to all participants including community HIV service provider sites and clinics.

Procedures

A trained research assistant screened all potential participants and those meeting the inclusion criteria were sent an informational packet to review. This packet contained an introduction to the study, a copy of the informed consent document, and an appointment confirmation for the scheduled focus group. To increase attendance, participants also received reminder calls the day before the focus group to confirm the appointment.

At the beginning of the focus groups, all participants gave informed consent, completed a short demographic survey, consented to medical chart abstraction, and were given an ID number to wear. To maintain confidentiality, all participants were instructed to only refer to themselves and others in the group by their ID numbers. Focus groups were led by a doctorally-prepared, female, registered nurse who had received formal training in qualitative methodology and experience working with this population. Each focus group lasted approximately 90 minutes. All focus groups were digitally recorded and a research assistant

tracked the comments by ID number. The digital files were downloaded to a secure computer and transcribed verbatim, into an MS Word transcript. At the conclusion of the focus group, participants were compensated for their time with a \$25 gift card. Medical chart abstraction to obtain HIV disease characteristics was completed following the focus groups for 69% of participants; the remaining patients did not have a primary HIV clinic.

All study procedures were approved by the institutional review committee for the protection of human subjects at the University Hospitals, Case Medical Center in Cleveland, Ohio. A Certificate of Confidentiality was obtained from the National Institutes of Health.

Data Analysis

Focus group transcripts, demographic surveys, and medical data were used in the primary analysis for this report. Descriptive statistics were used to analyze the medical record data and to identify the demographic and medical characteristics of cited speakers. Qualitative description and content analysis were used to analyze focus group data. Qualitative description is a dynamic analysis of verbal data, focused on summarizing the informational contents of the data (Neergaard, Olesen, Andersen, & Sondergaard, 2009; Sandelowski, 2000). Content analysis procedures were also used to describe the frequency of similar responses in the data. Two members of the research team independently evaluated the transcripts and sorted through the data to identify patterns and themes. Codes were generated from and systematically applied to the data. Once data collection was complete the two readers met to compare coding. Readers were registered nurses who received formal training in qualitative methods and specific training in focus group coding. Any differences in coding were resolved by discussion. Data coding and sorting was facilitated by the use of Atlas TI software. The percentage of participants responding was determined by summing the number of participants making a quote coded in a particular category, dividing this number by the number of total participants ($n = 48$), and multiplying by 100.

Results

Forty-eight adult women living with HIV attended 1 of 12 focus groups. This sample was middle-age (mean = 42 ± 8 years), mainly African American ($n = 33$, 69%), unemployed ($n = 40$, 83%), and single ($n = 28$, 58%). Additionally, most of the participants were mothers ($n = 43$, 83%). Our sample had a mean HIV diagnosis year of 1998 (median = 2000), indicating that this sample was experienced with this disease. Eighty-five percent of the patients were currently receiving prescriptions for antiretroviral therapy (ART), 80% had an AIDS diagnosis, and 73% had an undetectable viral load at the time of the study. The mean CD4+ T cell count was 577 cells/mm³ (SD $\pm$ 345) and for those patients with a detectable viral load, the mean viral load was 27,595 copies/mL. Participants reported many co-morbidities including depression ($n = 15$, 45%), hypertension ($n = 13$, 39%), obesity ($n = 9$, 27%), herpes simplex virus ($n = 5$, 15%), and cervical dysplasia ($n = 4$, 12%). Additional demographic and medical characteristics of the participants can be found in Tables 1 and 2.

The female participants in this study reported using self-management techniques that were congruent with those described by Swendeman's review of studies mainly conducted with men living with HIV (Swendeman et al., 2009). The prominent self-management techniques congruent with the framework included: taking personal time, advocacy, sleeping, attending support groups, and attending/making medical appointments. The theoretical framework category and common elements found are listed as subheadings below. Representative quotes from the participants and the numbers of participants reporting use of the techniques are listed below and in Table 3.

Physical Health Functioning

The daily self-management techniques our participants reported were congruent with the elements of physical health functioning in Swendeman's Framework (Swendeman et al., 2009). Participants reported that they had faith beliefs to help them understand illness and wellness, engaged in health promotion activities, reported strategies to enhance medication adherence, accessed treatment, and prevented HIV transmission through advocacy. Swendeman and colleagues (2009) found that PLWH also did not report disease-specific self-monitoring, compared with those with other chronic conditions. The women in our focus groups did not report any strategies to self-monitor their HIV disease. The two most common techniques in the physical health functioning category reported by participants were health promotion techniques and preventing transmission of HIV/STDs through advocacy.

Health Promotion Techniques

Participants discussed several health promotion behaviors including adopting a healthy diet and increasing physical activity. The most common health promotion behavior was sleep. Thirty-five percent ($n = 17$) of women identified sleep as an important self-management technique. The following quote exemplifies its centrality, the consequences of disturbed sleeping, and the technique the participants used to overcome sleeping problems.

You know if you really want to sleep, Ambien will let us, 'cause we need our rest with this disease, and I call it during the day I get my HIV nap. It's like, "Girl, I'm getting my HIV nap. Call you later," you know, and I have to take a nap during the day because I'm really tired and I have to take it. It's one of the major symptoms of our disease, so I make sure I get that extra nap. (46-year-old African American female, living with HIV for 17 years)

The participants in this study also reported techniques women can use to enhance the quality and quantity of sleep. These techniques may be enhanced through appropriate self-management interventions.

Preventing Transmission Through Advocacy

Another self-management technique mentioned often by participants was being an advocate to prevent HIV transmission in others and also to promote a positive or normal perspective of HIV. This was largely reported as a positive strategy, but only widely adopted by women living with HIV for a long time (range of years living with HIV for participants reporting this strategy was 7–20 years).

I'm open about it now (because) it doesn't matter to me. I can't change a person's feelings and I can't change the way they think. (But) I start bringing out flyers, (I'll say), "Wait, wait, wait. Don't go no where. I've got something in my car," and I'll start bringing out information, and I'm like, "Go on this website. This website will explain everything to you. Or call me on this number and I'll give you whatever you need to know about it, but stop judging, 'cause you don't know." So I just started giving out information (to) anybody who wants to know. (My daughter's) friends will come in, they're all sitting down and I'm like. "All right, how old are you, 15, 16, 18, 19? All of you, have you used condoms this week?" and they'll look at me like "What the heck?" I need to know, because look what happened to me. (36-year-old Latina female, living with HIV for 20 years)

Also noteworthy was that fear of stigma for themselves, but also for their family members, tended to prevent women from adopting this strategy.

I've never really told a whole lot of people. The only people that do know are my husband, my sister, and one of my good, longtime friends. Other than that, my parents don't know, my kids don't know, my friends don't know. Nobody knows, so that's how I deal with it. I act like it's not there.... The only thing that I think that makes me take my medicine is my daughter. I choose not to tell people because of her... I know it's going to define who she is and society will take it and rip her apart. I mean she's done nothing wrong to deserve that.... And she has to go through school. She has to go through life, and I have to just try to keep her in some sort of normalcy so her life doesn't get thrown out of proportion. I try to let her live the life that she can, as I lived mine.... So for me to manage, that's how I manage. I manage by keeping her world safe as I can. (38-year-old Caucasian female, living with HIV for 12 years)

Advocacy was reported to be a helpful self-management technique, and is one that has much potential to increase the health of the women living with HIV and those around them. Women employed advocacy in their everyday lives to help manage HIV transmission to members of their communities and to pursue opportunities to enhance the health of others.

Psychological Functioning

Our participants provided rich data on psychological functioning congruent with Swendeman's Framework (Swendeman et al., 2009), but our results diverge from the framework in that our participants did not report using strategies to enhance cognitive skills of self-management, perhaps because this question was not specifically asked in the focus groups. In the psychological functioning category, the most commonly reported self-management technique was taking personal time as a way to reduce negative emotional states.

Reduction in Negative Emotional States

The most commonly cited day-to-day self-management technique ($n = 23$, 48%) was finding a way to increase personal time and to use it effectively to alleviate the stress of their disease. The centrality of this was best illustrated in the following quote:

Having time for ourselves is very important. We need that because we're always taking care of everybody and everything around us, and some of us don't have that where anybody (will) take care of us....My alone time sometimes is getting in the car ... and just staying out there, sitting in a restaurant and eating by myself. I don't care if I do that. I used to do it way back in the day, and I enjoyed it. ... or I'll take long rides. Instead of coming home the quick way, I take a way long way. Turn my music on and just sing, because I love singing. ... My music always relieves me. (51-year-old Latina female, living with HIV for 9 years)

What the participants did during the personal time varied, but some of the common themes included, reading, watching television, and journaling. The following quote captures this:

I'll go to the movies or go to the little matinee and I'll chill by myself, and I say that I was gon' go eat by myself. I could do it. I'm a have to do this, you know what I'm saying, it's that I can do this myself, you know. So I don't need my kids to do whatever, and it feel good when I did go to the movies myself. (44-year-old African American female, living with HIV for 20 years)

And I think it's very important that you take time out for yourself to meditate or just to be in a clear area ... because our bodies go through a lot and it's up to us and the doctors to get it right. (47-year-old African American female, living with HIV for 17 years)

The women in our study described the need to balance their own personal and health needs with the daily needs of their families, friends, and other social responsibilities. Finding a way to take more personal time was an essential technique to help them reduce their negative emotional states.

Social Relationships Functioning

Our participants also reported self-management techniques that were congruent with the four social relationship functioning elements described in the Swendeman framework (Swendeman et al., 2009) including attending support groups and developing a collaborative relationship with their health care providers. Most of these techniques were not employed on a day-to-day basis, but the effects of these strategies were felt each day. The most common self-management strategies reported in this category were attending support groups and attending/making medical appointments.

Social Support

Consistent with Swendeman's model (Swendeman et al., 2009), 21% of women participating in our focus groups identified support group attendance was one of the most common self-management strategies. Participants discussed how support group attendance facilitated the adoption of new self-management techniques.

I think being able to talk about it with people, other women that have it or just people that have it is helpful. For the longest time ... I worked and I didn't know anybody else with it. I stayed depressed ... and my T cells finally, slowly went down, down, down, down, down, (and I) started getting sick all the time. I had to quit work and then I found the Women's Group and I got better, a little bit better. (51-year-old African American female, living with HIV for 19 years)

It was hard for me to go in there in front of all these people that I did not know, and tell them my life story. ... It was hard as hell for me to do that. So when I first went, I would just sit. I wouldn't say anything, and then the more I went, the more comfortable I became because here I'm in a room with all these people and half of them know my life and don't even know me. They are going through and have been through the things that I'm going through now, so maybe if I just open up to somebody, let them know that "I am hurting on the inside, I don't know how to share this with anybody, can you help me get this off my chest? That's all I need." Once you make that first step, then God will do the rest. (47-year-old Caucasian female, living with HIV for 1 year)

A particularly powerful component of these groups was listening to other women's journeys with HIV, and finding strength and inspiration in those stories. A 43-year-old African American female, living with HIV for 17 years said, "You're listening to another person's testimony. See what I went through, somebody else went through, and it gives me strength. It relaxes me." A 45-year-old African American female, living with HIV for 9 years, said:

You will find that even though you may not (be) saying nothing at first (in the groups), you have to keep going. You can't just go once and then stop. You have to keep going so that you will allow other people's testimonies to touch your heart because it's, you're not the only one that's going through what you're going through.

These quotes reinforced the notion that stories of survival from those who live with HIV are powerful and that similar groups or peer relationships may be helpful for women struggling with their own HIV diagnoses.

Collaborative Relationships with Health Care Providers

The actions of scheduling and attending physicians' appointments were identified as important self-management tasks.

For me, keeping up with your doctor's appointments and you know for covering all aspects of your life because for me, you know, with my doctor's appointment I also see a therapist and you know I have counseling and stuff and that helps me to help maintain doing the things that I need to do. (40-year-old Caucasian female, living with HIV for 17 years). I find that being a successful manager of HIV is to be in treatment, to take your medication, to follow up with your doctors and to be active in your treatment. So it's like a total process, and with the support of other women that are HIV-positive also, that's how I manage it, 'cause we do have other stressors, like relationships and children and just normal things. (45-year-old African American female, living with HIV for 10 years)

These tasks allowed the women to manage the tangible aspects of the disease and may serve as a way to monitor health status when daily biomedical monitoring is not available. These self-management tasks also reinforced to participants that this disease is controllable. These quotes also highlighted ways to deliver better, integrated HIV care for women.

Discussion

Self-management is a broadly recognized goal for all PLWH (Gifford, Laurent, Gonzales, Chesney, & Lorig, 1998), yet the strategies employed by and the factors that facilitate self-management in women living with HIV are less known than those in men. Swendeman's framework (Swendeman et al., 2009) did not address potential differences in self-management between women and men. This differentiation is important as a person's ability to balance his or her illness needs is challenged by his or her many roles. A woman is often a mother and the primary caregiver of her family. In these roles, someone is depending on the woman for support, time, resources, and energy. However, women living with HIV also have increased physical and emotional needs that require them to escape from these competing demands and find time to care for themselves (Iwelunmor, Zungu, & Airhihenbuwa, 2010; Tufts et al., 2010). Almost half of the women in our study ($n = 23$; 48%) reported that making sufficient personal time, on a daily basis, was a critical self-management strategy. Participants reported that this strategy was a way to balance the many competing needs of their families and social and work responsibilities, with their own personal health needs. In our study, taking and effectively using personal time was a way to reduce negative emotional states, which is an important self-management task for anyone with a chronic condition (Swendeman et al., 2009). As the quotes illustrate, the women in our study recognized that HIV added physical and emotional stress to their lives and they needed time to deal with that stress. Our findings are similar to two of the themes that Tufts and colleagues (2010) described in their study of African American women living with HIV: "me first" and "pampering." These findings, combined with the findings in our study, suggested that the increased need for personal time is pervasive among all women living with HIV and that it transcends ethnic and geographic boundaries. Health care providers should consider their patients' experiences with and successes in obtaining and effectively using personal time in order to offer appropriate assistance, including respite services when possible.

Health care providers and others caring for women living with HIV should note that the acquisition of personal time should not result in social isolation. Social isolation has been linked to increased suicide and increased health care utilization in other populations (Löfvenmark, Mattiasson, Billing, & Edner, 2009; Manoranjitham et al., 2010). For women living with HIV and perhaps vulnerable to social isolation, recent research has described

promising interventions. Investigators found that a computer-delivered intervention could decrease loneliness in rural women living with chronic illness, leading to increased self-management skills (Weinert, Cudney, & Hill, 2008). Such novel interventions using technology are hopeful strategies and may enhance HIV self-management in marginalized populations. However, additional research on the prevalence and consequences of social isolation, as well as the effect of social isolation on self-management practices, would be useful in developing interventions to increase effective personal time and HIV self-management.

Our findings indicated that sleep was an important self-management technique, often used as a health promotion strategy. Sleep has long been recognized as an important health promotion technique, although exact mechanisms remain unclear. A recent study (S. Patel and A. Webel, personal communication, July 9, 2010) found that otherwise healthy women who sleep too much (> 9 hours/night) or too little (< 5 hours/night) were at an increased risk for developing pneumonia (RR = 1.39 and 1.38, after adjusting for potential confounders). The authors discussed a strong link between inadequate and excessive sleep and immune dysregulation and subsequent morbidity; and suggested that the effects of poor sleep habits on immunocompromised individuals should be concerning. Moreover, previous studies have indicated that PLWH often have less than recommended amounts of sleep leading to negative outcomes (Reid & Dwyer, 2005). However, few interventions have examined how to increase healthy sleep in this population. One study found that decreasing caffeine consumption significantly predicted increased sleep quality in PLWH (Dreher, 2003). A more recent study found that an individually-tailored sleep hygiene intervention minimally increased nighttime sleep in 30 women living with HIV (Hudson, Portillo, & Lee, 2008). Our data supported the prevalent and distressing consequences of disturbed sleep in women living with HIV. Effective interventions targeted at increasing sleep quality in this population are desirable.

Our study has several strengths that enhance the usefulness and transferability of results. We used audio recordings and verbatim transcription to ensure accurate capture of the participants' comments. Our sample was demographically diverse and representative of the HIV epidemic in women. We also had access to medical chart information for approximately 70% of the participants, which allowed us to have a more complete picture of the participants' competing health, and ultimately their self-management, needs.

However, the following limitations should also be considered when evaluating the usefulness and transferability of our results. None of our participants reported the use of cognitive techniques to enhance self-management. However, we did not specifically ask about the use of cognitive techniques. We did ask about the general components of self-management and other broader questions that could have led to elicitation of this information. Other research in this area may want to consider specifically asking about the cognitive aspects of self-management. Our sample represented a group of women who were experienced with HIV, but 30% were not currently engaged in HIV primary care. Perhaps women who are newly diagnosed or engaged in primary care would provide different responses.

Future research should consider recruiting HIV-infected women from alternative sites including non-HIV support service providers, because our recruitment was from established HIV clinics and AIDS service organizations. Investigators may consider using both individual interviews and focus groups to minimize the impact that group dynamics have on the data. Future research on HIV self-management in women should also consider including women from multiple geographic areas, where local culture, support services, and laws/norms may have a relevant or substantial impact on HIV self-management strategies. We

only sampled women from northeast Ohio and our results are likely not generalizable to other populations of women living with HIV. Finally, we did not analyze the data by age, nor did we stratify enrollment by age. As this is an aging population with unique, age-associated health considerations, future work should also consider the role of age-associated factors in HIV self-management strategies.

Conclusion

As the framework developed by Swendeman and colleagues (2009) illustrated, the strategies involved in HIV self-management were similar to other chronic diseases, of which these women had many, but they did not completely overlap. Our study described self-management techniques in women living with HIV. Our findings confirmed and extended the work of others in the field by including a diverse population of women living with HIV. Women face unique challenges to managing their illnesses as they balance their work as a mother, wife, employee, and caregiver. Our study found that an additional challenge for these women was the burden of managing multiple chronic conditions. Self-management skills for multiple chronic diseases require similar skills; however, HIV-specific skills are also necessary, including managing the impact of HIV stigma on one's social and psychological functioning. Future work to address these challenges and to help develop the specific skills required for women living with HIV is needed. The Swendeman integrative framework can be used to develop specific HIV self-management interventions, and design and deliver HIV medical and support services to both men and women living with HIV (Swendeman et al., 2009).

Current self-management programs need to consider the unique circumstances of women with HIV and to tailor interventions to meet their needs. In a time of gross budget cuts, when services are cut globally, we have an opportunity to promote cost-effective HIV self-management in this highly marginalized population—women living with HIV.

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Table 1

Demographic Characteristics of Participants (n = 48)

	Frequency (%)	Mean ($\pm$ SD)	Range
Age		42 (8)	23–57
Have Children	43 (90)		
Pregnant	2 (96)		
Children living with them		1.5 (1.3)	0–5
Race			
African American	33 (69)		
White/Anglo	10 (21)		
Hispanic/Latina	5 (10)		
Marital Status			
Single	28 (58)		
Divorced	7 (15)		
Married	5 (10)		
Separated	4 (8)		
Other	4 (8)		
Education Level			
11th grade or less	19 (40)		
High School or GED	17 (35)		
2 years college/AA	10 (21)		
4 years college/BS/BA	2 (4)		
Annual Income		\$7,442 (4,969)	\$0–20,000
Work for Pay	8 (17)		
Has Permanent Housing	43 (90)		
Has Health Insurance	44 (92)		
Type of Health Insurance			
Medicaid	27 (61)		
Medicare	7 (16)		
Private, not by work	4 (9)		
ADAP	3 (7)		
Private, provided by work	2 (5)		
Veteran's Benefits	1 (2)		

Note. GED = General Equivalency Diploma; AA = Associate of Arts; BS = Bachelor of Science; BA = Bachelor of Arts; ADAP = AIDS Drug Assistance Program

Table 2Medical Characteristics of Participants (n = 33)¹

	Frequency (%)	Mean ($\pm$ SD)	Range
Year Diagnosed with HIV		1998 (6.4)	1986–2009
Years Between Diagnosis and Seeking Care		1.2 (2.6)	0–10
Prescribed Antiretroviral Therapy		28 (85)	
AIDS Diagnosis	26 (79)		
Undetectable Viral Load	24 (73)		
CD4+ T cells/mm³		577 (345)	16–1400
Comorbidities²			
Depression	15 (45)		
Hypertension	13 (39)		
Obesity	9 (27)		
Asthma	8 (17)		
Hyperlipidemia	7 (21)		
Herpes Simplex Virus	5 (15)		
Cervical Dysplasia	4 (12)		
Bipolar Disorder	4 (12)		
Admitted to Emergency Department in Previous 12 months	16 (48)		
Admitted to Hospital in Previous 12 months	10 (30)		
% of Missed HIV Primary Care Appointments in previous 12 months³		21 (28)	0–100

Note.

¹We were only able to obtain medical chart data on 33/48 participants;²Comorbidities are not mutually exclusive;³This statistic was obtained by dividing the number of missed HIV primary care appointments by the number of scheduled appointments

Table 3

Report Self-Management Strategies Organized by Swendeman et al. (2009) Framework

Swendeman et al. (2009) Integrative Framework	Results		Number of women citing (%)
	Identified Self-Management Strategies	Example Quotes	
Physical Health Element	Faith Belief	If it wasn't for God I wouldn't be here today. My gospel music, like you were saying, I play my music all the time. I sing, I praise him, and I cannot sing, but I praise him anyway singing, and I love the Lord, 'cause if it wasn't for him, I wouldn't be here.	18 (38%)
	Healthy Diet	I started eating more yogurt, started drinking more water and I cut out the sugary drinks like pop and lemonade and things like that, and the weight started falling off me.	3 (6%)
	Physical Activity	I live on the 12th floor. Okay, I'll come in in the afternoon. Instead of taking that elevator, I'll push myself to go up the steps and I do it twice a week. I will actually push myself, coat on, pocketbook loaded, heavy boots and I'll push myself to go up the steps.	8 (7%)
	Sleep	It seems like the more active I am that day the more restful I'll have as far as sleep, and I'll sleep through and I'll feel so much better the next day when I get up. I'll feel like 'Wow, I slept good.'	17 (35%)
	Medication Adherence	I'm a diabetic. I have asthma, so basically I'm taking 25 pills a day. My HIV meds I take in the morning at 10. If I'm not up, my old man will wake me up to take my medicine. Sometimes I forget and that makes me have to wait another day. I have seizures. My back goes out, I'm basically really confined to a wheelchair or a walker, but I'm dealing with it. But I take my medicine at 10 in the morning and 10 at night, and other than that, that was it.	9 (19%)
Self-monitoring of health status	None reported		
	Medical Appointments	In 12½ years my doctor has never cancelled an appointment, and in 12½ years I've missed one. She's never ever cancelled, and she talks. I don't care how many patients is there, she sits and talks and listens, offer advice, you know. So I've never, ever, ever had a problem.	8 (17%)
	Advocate Role	I have two of my girlfriends. I have tons of condoms, tons of condoms, and they'll come ask for condoms. "Give me some condoms." I say, "You're out of them already?" and it's like, "Yeah," but I don't care, as long as you're protecting yourself, and that's part of us having this disease. You know we're not responsible for our disease, (but we are) responsible for our recovery, and then also God gives us the strength to help other people.	12 (25%)
Psychological Functioning Element			
	Priority Setting/Goal Setting	I don't care if I forget anything else, first thing I do is take my medication, 'cause I know if I don't take it I'll die.	3 (6%)
	Staying Busy	I have to stay busy. I can't just sit in the house. Like my car is down right now and I got up and walked to (the store) this morning. I can't just sit around. I have to be doing something.	3 (6%)
Cognitive skills of self-management	None reported		
	Positive Attitude	I'll say my key thing is just keeping a positive attitude to stay stress free, because my whole concept on everything is today, even though I have this, if there's not a cure, if there is a cure, God is gon' keep me going until I'm able to get that cure, you know. Like I say, I don't stress out about nothing like I used to. I don't let nobody bother me. I go to meetings, and when people get on my nerves, I get up, get dressed and I go to a meeting, you know, and a lot of people don't	6 (13%)

Svendsen et al. (2009) Integrative Framework	Results		Number of women citing (%)
	Physical Health Element	Identified Self-Management Strategies	Example Quotes
		Personal Time	believe that I keep this attitude, but my glass is always half full. Always, no matter what, and that's just what I do today, and I have more fun today than I've had in my whole lifetime. During the days when my kids are at school and everything's off, except for my dryer or the washer, you know, and it's quiet in the house. I like to be outdoors. My dad has this really nice piece of property that has like a nice waterfall on it, so it's really peaceful. So that's during the summer that's always like an up time anyway 'cause it's sunny and everything's nice and you can go down there and relax. Having time for ourselves, is very important. We need that because we're always taking care of everybody and everything around us, and some of us don't have that where anybody (that) takes care of us....My alone time sometimes is getting in the car ... and just staying out there, sitting in a restaurant and eating by myself. I don't care if I do that. I used to do it way back in the day, and I enjoyed it. ... or I'll take long rides. Instead of coming home the quick way, I take a way long way. Turn my music on and just sing, because I love singing. ... My music always relieves me.
	Forming Identity	HIV Identity	I think that once you find out that you have to be on the medication, you have to change your whole outlook on everything you do. You have to change the way you live. You have to change the way you eat. You have to change the way you think, because if you don't, you're going to let that disease and that not taking that medicine kill you all by yourself before you are ready to die
	Social Relationships Element		
	Collaborative relationships with health care providers	Medical Appointments	I think the most important thing is to make sure you have a good relationship with your doctor, not be afraid to ask questions, be involved in his treatment, what he has to say to make sure you can communicate and make sure you like the doctor that you go to. For me keeping up with your doctor's appointments and you know for covering all aspects of your life because for me you know with my doctor's appointment I also see a therapist and you know I have counseling and stuff and that helps me to help maintain doing the things that I need to do.
	Self-disclosure of disease status/Coping with stigma	Support Groups	We have Healing Weekends there, just for women, and I went last year and it was beautiful. Because of these events, I have women friends today and that helps because they're dealing with the same issues I deal with and it's easier to talk and share with them. I tell the ladies that I'm HIV-positive and I receive big support from them. I can honestly say I have female friends today, which is a big plus for me. I think being able to talk about it with people, other women that have it or just people that have it. For the longest time, well for a while I worked and I didn't know anybody else with it. I stayed depressed all the time and my T cells finally, you know it slowly went down, down, down, down, started getting sick all the time and then I had to quit work and then I found the Women's Group and I got better, a little bit better.
	Positive social and family relationships	Support Groups	Groups that you can go to so you can connect to people that have issues like you and won't be sitting up there judging you, 'cause right now you don't need judgment; you need support.
	Social support	Finding Strength in Others' Testimonies	Coming to these groups, you know when I went to the other group and I heard (that people live) 17 years and 20 years (with HIV), it inspired me you know not only that I'm living with it, I can live with it, you know, and it just made me feel good.