Published in final edited form as:
J Assoc Nurses AIDS Care. 2009 ; 20(6): 458–467. doi:10.1016/j.jana.2009.05.003.

Positive Self-Management Program for Women Living with HIV: A Descriptive Analysis

Allison R. Webel [Doctoral Student] and
Department of Community Health Systems, School of Nursing, University of California, San Francisco

William L. Holzemer [Professor and Associate Dean]
International Programs, Department of Community Health Systems, School of Nursing, University of California, San Francisco

Abstract

There is an increasing need for community-based interventions to help women living with HIV better manage their symptoms and self-care. The investigators conducted a small descriptive pilot study to assess whether women living with HIV needed and wanted a community-based symptom management workshop, such as the Positive Self-Management Program (PSMP). A total of 7 HIV-infected adult women participated in 5, 2-hour semi-structured focus groups and completed a brief survey on demographic information, HIV medications, HIV symptoms and self-efficacy. Quantitative and qualitative data are presented. This pilot study suggests that urban-dwelling, HIV-infected women are interested in participating in a community-based, peer-led intervention and that the program may facilitate symptom management. Nurses caring for women living with HIV should consider referring their patients to community-based, peer-led programs that teach symptom management strategies.

Keywords

AIDS; community; HIV; symptom management; women

HIV is the cause of the largest global health epidemic in modern history. In the United States, it is estimated that approximately 1.23 million people were living with HIV or AIDS in 2006. In 2006, women comprised 23% of new AIDS cases, up from 14% in 1992. Additionally, approximately 15,000 women were diagnosed with HIV, which accounts for 27% of all new diagnoses in 2006 (Hall et al., 2008). These women are often poor, undereducated, uninsured, marginalized, and may be the most vulnerable members of our society today (Centers for Disease Control and Prevention [CDC], 2008).

Corresponding Author: Allison R. Webel, University of California, San Francisco, School of Nursing, Department of Community Health Systems, Box 0608, 2 Koret Way San Francisco, CA 94143, Phone: 415-753-0146, Fax: 415-476-6042, allison.webel@ucsf.edu.

Review of the Literature

Symptoms

Symptoms in HIV-infected women are complex and vary depending on the stage of infection. The general symptoms of primary infection in both women and men are best described as a flu-like syndrome characterized by body aches, chills, dry cough, fever, headache, sore throat, and stuffy nose. After a period with few physical symptoms, the disease progresses to a pre-AIDS defining stage. Symptoms at this stage include lymphadenopathy, frequent fevers, night sweats, rapid weight loss without dieting, chronic fatigue, depression, anorexia, and diarrhea (Cohen, 1997).

With the development and widespread distribution of antiretroviral therapy (ART), HIV has become a chronic disease. Accordingly, the symptoms experienced have changed somewhat over the past decade. In a recent secondary analysis, Mannheimer et al. (2008) found that the most commonly reported symptom among persons living with HIV (PLWH) was fatigue, followed by headache, diarrhea, and nausea. They also reported that the most commonly reported symptom category was gastrointestinal symptoms, with 40% of their participants reporting such symptoms.

Several studies have recently explored the relationship between ART and symptoms. Wantland et al. (2008) found that individuals taking ART had a higher than expected report of loose stools, diarrhea, shortness of breath with activity, fat accumulation in the abdomen and back of the neck, wasted arms and legs, prominent leg veins, thirst, and insomnia. Additionally, individuals taking ART that included a protease inhibitor (PI) had significantly higher symptom intensity than those who were not on ART or not on a regimen containing a PI. Specifically, they found that individuals taking ART with PIs had higher than expected reports of weight gain, hump on back of the neck, skinny arms and legs, prominent leg veins, and gas/bloating (Wantland et al., 2008). Additionally, Johnson, Stallworth, and Neilands (2003) found that PLWH were able to identify nausea and vomiting, constipation, and alterations in taste sensation as ART side effects. PLWH in that study identified tender or enlarged lymph nodes/glands, night sweats, unintentional weight loss, fever, and loss of strength as consequences of their HIV infection. The authors also identified that many individuals attributed the cause of the symptoms to both the disease and its treatments, including fatigue; feeling sad, down, and depressed; problems with having sex; and changes in body appearance (Johnson et al., 2003).

In addition, the physical manifestations of HIV infection and the side effects associated with ART can cause severe quality of life issues. The symptoms of HIV and its treatments were identified as the biggest influence on quality of life in a study of 142 PLWH (Sousa, Holzemer, Bakken Henry, & Slaughter, 1999). General HIV symptoms were also associated with an inferior health-related quality of life and more disability days (Lorenz, Shapiro, Asch, Bozzette, & Hays, 2001). Finally, nearly one third of HIV-infected women reported that coping with HIV-related symptoms and disorders was one of the worst things associated with HIV infection (Lorenz et al., 2001). A more recent study found that, among HIV-infected individuals, worsening symptoms were significantly associated with a decrease in overall health and quality of life. The authors concluded that health care providers and organizations share an important responsibility to improve symptom assessment and management (Lorenz, Cunningham, Spritzer, & Hays, 2006).

The symptoms of HIV also have an effect on treatment decisions. HIV-infected patients with higher intensity symptom scores were found to be less adherent to their medication regimens and less likely to follow their health care providers' advice or to attend their medical appointments (Holzemer et al., 1999). HIV-infected patients who experienced symptoms, but who did not believe the symptoms were associated with HIV, did not seek medical care (Siegel, Schrimshaw, & Dean, 1999). The literature reveals the great effect that symptoms have on an HIV-infected woman's quality of life and health. The consequences of unmanaged symptoms are dire and require a more effective management strategy (Portillo, Holzemer, & Chou, 2007).

Women with HIV infection use many symptom management strategies to cope with the symptoms. Patients who use these strategies perceive them to be helpful in symptom management. Previous research demonstrated that PLWH actively sought and used strategies to manage their symptoms (Chou, Holzemer, Portillo, & Slaughter, 2004; Portillo et al., 2007). However, research has also demonstrated barriers to symptom management. For instance, many PLWH do not obtain health care information from health care providers, which may prevent them from receiving evidence-based information (Sowell et al., 1997; van Servellen, Sarna, & Jablonski, 1998). These individuals rely on personal networks and communities to obtain information about managing their symptoms (Chou et al., 2004). A peer-led, HIV symptom-management strategy, managed by a health care professional, has the potential to facilitate the dissemination of effective, evidence-based symptom management strategies to women with HIV and improve the quality of life and health of thousands of women living with HIV in the United States.

Peer-Based Interventions

There has been an increase in the number of research studies employing peer-based interventions in the past 20 years. Historically, peer-based interventions have been employed to “carry out health promotion work among young people” (Backett-Milburn & Wilson, 2000, p. 85). However, that has been changing in the last 10 years. A Cochrane Library search found two reviews that focused on peer-based interventions in chronic disease management (Doull et al., 2004; Halpern, Grimes, Lopez, & Gallo, 2006). While peer-based interventions can be traced back to antiquity (Wagner, 1982), more recently they have been used in health projects targeting reductions in smoking and substance abuse, HIV prevention, and sexual health promotion.

Peer-based interventions that aim to increase sexual health activities in adolescents have been successful at decreasing unprotected sexual activity (Smith & DiClemente, 2000). Among high-risk women, including intravenous drug users (IDUs), partners of IDUs, homeless women, and women who traded sex for money or drugs, a peer-education program that used formal group tutoring and one-to-one discussions with peer advocates improved consistent condom use, increased the perceived advantages of condom use, and increased self-efficacy (Fogarty et al., 2001). These changes were maintained through the 18-month follow-up assessment.

A growing number of studies have focused on group-based interventions to enhance symptom management and self-care. In a study of a 6-week long, small-group, chronic care intervention delivered to 600 individuals with various chronic diseases, participants in the intervention arm reported increased symptom management behaviors, self-efficacy, and health status, and had fewer visits to the emergency department at 1 year compared to those who did not participate in the intervention (Lorig, Ritter, & Plant, 2005). A similar program had comparable effects on symptom management and medication adherence among men living with HIV (Gifford, Laurent, Gonzales, Chesney, & Lorig, 1998).

Few studies have examined strategies to improve symptom management and self-care for women living with HIV. Specifically, peer-based strategies have not yet been used with a symptom management intervention in women. The experience with other populations suggests that a peer intervention model may be appropriate to facilitate symptom management behavior in women living with HIV; however, more research is needed prior to widespread implementation. The objective of this small pilot study was to assess whether HIV-infected women were interested in participating in a community-based, peer-led program called the Positive Self-Management Program (PSMP).

PSMP was designed at Stanford University in 1997. This intervention was developed using Social Cognitive Theory, emphasizing the role of self-efficacy, as its guiding framework. The program contains seven, 2-hour scripted modules to be delivered by peer leaders each week for 7 weeks. The skill-building curriculum contains modules that address symptom self-management strategies (emotional, cognitive, and physical), symptom monitoring, problem-solving, medication adherence, communicating with health care providers, diet, and exercise. It uses lectures, action plans, brainstorming, discussion, and other teaching techniques to help participants learn the skills that will help them become better self-managers of their HIV symptoms. The intervention was pilot tested in 72 HIV-infected men in southern California in 1997. The investigator found a significant relationship between the intervention and decreased symptom intensity, decreased viral load, and increased medication adherence (Gifford et al., 1998).

Method

Design, Sample, and Setting

This descriptive, qualitative study was designed to assess the feasibility of using the PSMP, a community-based, peer-led program, in an all female sample. All study procedures were approved by the Institutional Review Board at the University of California, San Francisco. Participants for this study were recruited from HIV-care clinics affiliated with the Positive Health Program at the University of California, San Francisco. HIV case managers or primary HIV care providers referred women to the study; other women were directly recruited with flyers posted in the clinic. Potential participants were screened by the study coordinator in a private clinic room or by telephone. Eligible participants were at least 18 years of age, infected with HIV, English speaking, and self-identified as female. A letter of diagnosis from the participant's primary care provider and corresponding picture identification verified HIV diagnosis.

Procedure

The study coordinator obtained informed consent from each participant prior to initiation of study procedures. Each participant participated in five, 2-hour semi-structured focus groups to assess whether members of the community needed and wanted a community-based symptom management program, such as the PSMP. The study coordinator called each of the participants a day before the group session to remind her about the session's time and location and to encourage attendance.

Focus groups were chosen over individual interviews in this study because of the ability of participants to build upon each other's responses in order to provide a deeper understanding of the topic (Morgan, 1997). The study coordinator, who is a nurse, facilitated the focus groups. To fully ascertain the participants' beliefs about the feasibility of a community-based symptom management program, such as PSMP, the concept was deconstructed into four themes based on a literature review. Each of the group sessions were organized around these themes: (a) significance of commonly experienced symptoms (Dodd et al., 2001; Lorenz et al., 2001; Lorenz et al., 2006; Portillo et al., 2007; Spirig et al., 2005; van Servellen et al., 1998), (b) symptom management (Chou et al., 2004; Dodd et al., 2001; Portillo et al., 2007), (c) barriers and facilitators to symptom management (Chou et al., 2004; Dodd et al., 2001), and (d) potential symptom-management interventions (Gifford et al., 1998). During the first session, participants focused on common symptoms experienced by the women and how the symptoms had affected their lives. The second session focused on the importance of symptom management. The third session focused on barriers and facilitators to self-care. During the fourth session, participants were given an outline of the PSMP and asked to share their opinions on its appropriateness for the community. Interactions were recorded on paper by the study coordinator. A summary of the comments was prepared for the participants and they were asked to verify the accuracy of the data.

During the final session, participants completed a brief survey on demographic information, HIV medications, HIV symptoms, and self-efficacy. The groups included 3-7 women and were held in a secure, private, unlabeled room once per week for 5 weeks. Food was provided. Participants were compensated with $25 for each completed session for a total of $125.

Measures

Demographics

Demographic variables were assessed by self-report. Age, race/ethnicity, work/income, education level, health insurance, marital status, number of children, date of HIV diagnosis, other health conditions, and current HIV medication use were collected.

HIV Symptoms

To assess symptom intensity, participants completed the Revised Sign and Symptom Checklist for Persons with HIV Disease (SSC-HIVrev), which consists of three parts and seeks to identify current symptoms and symptom intensity. The checklist includes 72 symptoms and each is scored on a 0-3 scale with *0 = has not experienced that symptom* in the previous 24 hours and *3 = severely experienced that symptom* in the previous 24 hours. The overall mean daily symptom intensity score was computed by summing each symptom intensity and dividing by 72. The mean distress score was calculated for the most frequently reported symptoms as the total intensity score of the symptom divided by the number of participants who reported each symptom. The total score reliability estimate (Cronbach's alpha) was 0.97 (Holzemer, Henry, Portillo, & Miramontes, 2000).

Self-Efficacy

Each participant completed the Chronic Disease Self-Efficacy Scale (Lorig, Stewart, & Ritter, 1996) to assess her own perception of her ability to manage her chronic HIV disease. This instrument is a measure of selected components of chronic disease self-efficacy including self-efficacy to perform self-management behaviors, general self-efficacy, and self-efficacy to achieve outcomes. Aspects of self-efficacy measured by the instrument include regular exercise, ability to obtain help from family and friends, communication with a physician, disease management, chores, social/recreational activities, symptom management, and management of depression. It has reliability estimates ranging from 0.82-0.92 (Lorig et al., 1996).

Data Analysis

The study coordinator recorded the qualitative data manually. The study coordinator then reviewed the data to identify common phrases, patterns, themes, and important features and extracted them for further consideration and analysis. Codes were generated from the literature review and were systematically applied to the data. These codes included: (a) symptoms experienced, (b) symptom management, (c) barriers and facilitators to symptom management, and (d) potential symptom-management interventions. All quantitative data were analyzed using descriptive statistics. Microsoft Excel was used to analyze the data. The coordinator provided a summary of verbal feedback at the final session and asked the participants to review the summary and clarify any discrepancies. This strategy is known as member checking and is used to enhance the trustworthiness of the qualitative data (Lincoln, Y.S & Guba, E.G, 1985). Since the data were not digitally recorded, comments are not presented in quotation marks.

Results

The characteristics of the women who participated in the focus groups are shown in Table 1. Eighty-seven percent were African-American. The mean age was 45 years. Half had not completed high school. All were unemployed, and all were on Medi-Cal. Approximately half of the participants had children, and half were taking ART. None of the women withdrew over the course of the study.

The overall mean symptom intensity was 0.70 with the most prevalent symptoms being muscle aches and gas/bloating. See Table 2 for more information on the most commonly reported symptoms. Participants also reported a moderate level of self-efficacy to care for their chronic disease.

In the first week, participants were prompted to discuss their experiences with symptoms related to HIV. In accordance with previous qualitative work on the burden of HIV (van Servellen et al., 1998) we found that symptoms continued to be distressing to women living with HIV. One especially telling comment described the symptom experience:

> People think that the meds make it okay to live with HIV, that it's okay to have sex without condoms. What I tell them is to live with my neuropathy and diarrhea for one day. Taking extra underwear and always looking for the bathroom when I go out. And the pills, I take so many pills I can barely keep track of them. It's not okay and I wouldn't wish this on anybody.

In response to the open-ended questions around symptom management, the women acknowledged that they tried to manage their symptoms by following the advice of their health care providers. However, the participants were often prevented from fully managing their most distressing symptoms, as noted in the following comments:

> Even though I take my medications for depression, I still feel depressed most days. I pray a lot in order to make me less depressed and I try to have a good support system because I know its important, but I'm still depressed.

> I just don't have the energy to do everything I need to do. I try to exercise and eat right and take my medications but I just don't have the energy.

During the third week, participants discussed facilitators and barriers to symptom management. They disclosed their experiences with stigma from health care providers and a perceived unhelpful emphasis on medications by their health care providers. They identified these as barriers to symptom management:

> I feel like I am not a person since I got this virus. Nobody respects me. When the ambulance picks me up (in the Tenderloin) they yell at me: “You've got HIV.” And in the hospital when the doctors come in they talk real loud about my HIV. They don't respect my confidentiality.

> All they want to do is give me meds. I tell them that these meds don't work for me that they make me sick, but they don't listen.

> I don't want to take 26-30 pills a day. It's hard on me and makes me physically sick, and I sleep too much. They just wake me up and make me take more meds, like clockwork.

In the fourth week, participants discussed potential symptom-management interventions and had the opportunity to review the PSMP and provide feedback. The participants focused on the benefits of a peer-led program and offered pragmatic suggestions. Participants stated,

> Facilitating as a group gives us more self-esteem. Having them get the information from us will be more effective. But it needs to be comfortable and fun. Maybe we can do activities outside the group too, like go to the zoo.
>
> People who have been through recovery can help the new women being diagnosed with the virus. We can tell them not to overdo it, and to reserve their energy because the meds drain it, [and] about how you can't control your bladder on some meds and the need to take disposable underwear with them when they go out. We've been through that and we know what it feels like.
>
> People who don't have the virus can't give me a format; they cannot tell me how to live with the virus.

In addition, participants suggested topics that should be covered but did not appear in the curriculum. These included the relationship of HIV to aging, menopause, and the role that families can play to help women manage symptoms.

In the final focus group, a copy of the group transcript was presented and the participants had a chance to correct or elaborate on their comments. Additionally, all of the women expressed interest in being involved in the proposed intervention and signed consents to be contacted for future research. More information on the results can be found in Table 3.

Discussion

This was a descriptive, qualitative study that assessed whether HIV-infected women were interested in participating in PSMP, a community-based, peer-led program. Qualitative content analysis was used for several reasons: it describes experiences in everyday terms thus facilitating understanding of the phenomenon by the general community; it is often used in combination with quantitative methods; and it has been used in both instrument and intervention development (Sandelowski, 2000).

Participants in the focus groups represented the most vulnerable women in the United States today. They were minority women who were often marginalized from society. They were poor and unemployed, and they frequently had to balance the competing roles of caregiver and patient. Additionally, they represented various stages of HIV disease and suffered from distressing chronic co-morbidities. Their daily symptom experiences were quite diverse—some women reported no symptoms while others reported moderate to severe symptoms. The participants' self-efficacy scores were similarly varied.

Because of this heterogeneity, the participants revealed rich qualitative information that will help develop an intervention that best meets the needs of this community. Four conclusions can be drawn from the information yielded in the focus groups: (a) women living with HIV may experience a great deal of distress related to the symptoms of their HIV disease and its treatments; (b) management of these symptoms is very challenging for women; (c) a symptom management intervention for women living with HIV such as PSMP is needed and wanted; and (d) peers should be used in all aspects of the intervention (including selecting community sites and recruiting participants).

Previous studies have reported similar findings for women struggling to manage their distressing HIV-related symptoms (Spirig et al., 2005; van Servellen et al., 1998). In our study, the participants not only reported difficulty with symptom management but also expressed the hope that better symptom-management skills would increase their quality of life. However, it can be difficult to develop symptom management strategies that apply across acute and home-care settings and that the patient, family, and friends can successfully implement.

Several studies have explored the mechanism of symptom management in individuals infected with HIV (Chou et al., 2004; van Servellen et al., 1998; Nicholas et al., 2002). PLWH used many self-care strategies that they perceived to be helpful to manage HIV-related symptoms (Chou et al., 2004). While the study didn't directly assess barriers and facilitators to symptom management in women living with HIV, the investigators reported that a majority of PLWH did not learn symptom management strategies from their health care providers; rather, they learned these strategies through experience and experimentation. The results were comparable to other research findings and suggested that peer-modeling or education could facilitate use of symptom management strategies (Nicholas et al., 2002; Siegel, Brown-Bradley, & Lekas, 2004). Additional studies found that participants were reluctant to follow the advice of a health care professional (Sowell et al., 1997; van Servellen et al., 1998).

Participants in this study felt that peer-led programs could provide unique contributions to effective self-management skills, which is also consistent with previous research findings. Peer-led programs offer women a chance to develop a strong support network through mentoring and allow them to learn more effectively by others' examples (Doull et al., 2004). Furthermore, participants suggested that a community-based program had the potential to attract more participants than a clinic-based program.

However, participants also indicated real barriers that would prevent women from achieving these goals. These women living with HIV struggled to communicate with their health care providers. They felt their providers were stigmatizing them and that the treatment prescribed reflected the providers' preferences instead of their own. Participants felt that they did not hold equal weight in making health-related decisions and this had caused them to disengage from that part of their symptom management. Participants in our study acknowledged that the stigma associated with HIV in the larger community prevented women from attending any sort of group that identified them as having HIV, a concern that has been reported previously (Sandelowski, Lambe, & Barroso, 2004).

Despite these barriers, the participants were excited about the PSMP. They not only felt that it was feasible, they wanted to help make it happen. The participants offered topics that should be covered but did not appear in the curriculum, namely the interaction of HIV with aging, menopause, and family. Any peer-led, small-group, self-management program should take advantage of the above-mentioned strengths and the benefits may extend beyond the scope of symptom management. However, the program must also consider barriers to self-care and offer solutions to overcome them.

Limitations

The qualitative methods used in this study do not allow the findings to be generalized beyond this group of women. Additionally, the group sessions were not tape-recorded. The comments of the participants were manually recorded and then analyzed in the methods described above. However, at the last group session participants were given a copy of the transcript and asked to verify the validity of the comments and to make any necessary corrections. This strategy helped decrease the risk of inaccurate recording of participant comments.

Conclusions

Symptom management is an increasingly distressing, yet important, issue for women living with HIV. A community-based, peer-led intervention has the potential to facilitate symptom management and is feasible for women living with HIV. However, the success of such a program will depend on many factors including the extent of peer involvement, applicability of the topics to the participants, and the assurance of a safe, convenient environment in which to deliver the intervention. Nurses caring for women living with HIV should consider referring their patients to community-based, peer-led programs that teach symptom management strategies. If such programs do not exist in their communities, nurses should consider developing programs that teach symptom management strategies similar to the PSMP for their patients.

Clinical Considerations

Nurses caring for women with HIV can …

- Adequately assess symptom burden of HIV and its related treatments.
- Assess current symptom management techniques.
- Recommend appropriate symptom management strategies.
- Create an environment where women can communicate effectively with health care providers.
- Consider developing community-based, peer-led programs that teach symptom management strategies.

Acknowledgments

This project was funded by training grants from the National Institutes of Health 1T32RR023259 & 1F31NR009910. The training grant 1T32RR023259 was used to fund the design of the study and data collection of this systematic review. The training grant 1F31NR009910 was used to fund management, analysis, and interpretation of the data, and preparation and review of the manuscript. Both authors had full access to all of the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis.

References

Backett-Milburn K, Wilson S. Understanding peer education: Insights from a process evaluation. Health Education Research 2000;15(1):85–96. [PubMed: 10788205]

Centers for Disease Control and Prevention. HIV/AIDS among women. 2008. Retrieved April 27, 2009 from http://www.cdc.gov/hiv/topics/women/resources/factsheets/pdf/women/pdf

Chou F, Holzemer WL, Portillo CJ, Slaughter R. Self care strategies and sources of information for HIV/AIDS symptom management. Nursing Research 2004;53(5):332–339. [PubMed: 15385870]

Cohen M. Natural history of HIV infection in women. Obstetrics and Gynecology Clinics of North America 1997;24(4):743–758. [PubMed: 9430165]

Dodd M, Janson S, Facione N, Faucett J, Froelicher ES, Humphreys J, et al. Advancing the science of symptom management. Journal of Advanced Nursing 2001;33(5):668–676. [PubMed: 11298204]

Doull M, O'Conner A, Wells G, Tugwell P, Welch V. Peer-based interventions for reducing morbidity and mortality in HIV-infected women. Cochrane Database of Systematic. 2004 Reviews (2) Art. No.: CD004774. 10.1002/14651858.CD004774

Fogarty LA, Heilig CM, Armstrong K, Cabral R, Galavotti C, Gielen AC, et al. Long-term effectiveness of a peer-based intervention to promote condom and contraceptive use among HIV-positive and at-risk women. Public Health Reports 2001;116:103–119. [PubMed: 11889279]

Gifford A, Laurent D, Gonzales V, Chesney M, Lorig K. Pilot randomized trial of education to improve self-management skills of men with symptomatic HIV/AIDS. Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology 1998;18(2):136–144. [PubMed: 9637578]

Hall HI, Song R, Rhodes P, Prejean J, An Q, Lee LM, et al. Estimation of HIV incidence in the United States. Journal of the American Medical Association 2008;300(5):520–529. [PubMed: 18677024]

Halpern V, Grimes DA, Lopez L, Gallo MF. Strategies to improve adherence and acceptability of hormonal methods for contraception. The Cochrane Database of Systematic Reviews 2006;1 Art. No.: CD004317. 10.1002/14651858.CD004317.pub2

Holzemer WL, Henry SB, Portillo CJ, Miramontes H. The client adherence profiling-intervention tailoring (CAP-IT) intervention for enhancing adherences to HIV/AIDS medications: A pilot study. Journal of the Association of Nurses in AIDS Care 2000;11(1):36–44. [PubMed: 10670005]

Holzemer WL, Corless IB, Nokes KM, Turner JG, Brown MA, Powell-Cope GM, et al. Predictors of self-reported adherence in persons living with HIV disease. AIDS Patient Care and STDS 1999;13 (3):184–197.

Johnson MO, Stallworth T, Neilands TB. The drugs or the disease? Causal contributions of symptoms held by HIV-positive adults on HAART. AIDS and Behavior 2003;7(2):109–117. [PubMed: 14586196]

Lincoln, YS.; Guba, GE. Naturalistic Inquiry. New York: Sage; 1985.

Lorenz K, Cunningham W, Spritzer K, Hays R. Changes in symptoms and health-related quality of life in a nationally representative sample of adults in treatment for HIV. Quality of Life Research 2006;15 (6):951–958. [PubMed: 16900276]

Lorenz KA, Shapiro MF, Asch SM, Bozzette SA, Hays RD. Associations of symptoms and health-related quality of life: Findings from a National Study of Persons with HIV Infection. Annuals of Internal Medicine 2001;134(9 Part2):854–860.

Lorig K, Ritter P, Plant K. A disease-specific self-help program compared with a generalized chronic disease self-help program for arthritis patients. Arthritis and Rheumatism 2005;53(6):950–957. [PubMed: 16342084]

Lorig, K.; Stewart, A.; Ritter, P. Outcome measures for health education and other health care interventions. Thousand Oaks, CA: Sage; 1996.

Mannheimer SB, Wold N, Gardner EM, Telzak EE, Huppler Hullsiek K, Chesney M, et al. Mild to moderate symptoms during the first year of antiretroviral therapy worsen quality of life in HIV infected individuals. Clinical Infectious Diseases 2008;46(6):941–945. [PubMed: 18279044]

Morgan, D. The focus group guidebook (focus group kit). 1st. Thousand Oaks, CA: Sage; 1997.

Nicholas PK, Kemppainen JK, Holzemer WL, Nokes KM, Eller LS, Corless IB, et al. Self-care management for neuropathy in HIV. AIDS Care 2002;14(6):736–771.

Portillo C, Holzemer WL, Chou FY. HIV symptoms. Annual Review of Nursing Research 2007;25:259–291.

Sandelowski M. Whatever happened to qualitative description? Research in Nursing and Health 2000;23 (4):334–340. [PubMed: 10940958]

Sandelowski M, Lambe C, Barroso J. Stigma in HIV-positive women. Journal of Nursing Scholarship 2004;36(2):122–128. [PubMed: 15227758]

Siegel K, Brown-Bradley CJ, Lekas H. Strategies for coping with fatigue among HIV-positive individuals fifty years and older. AIDS Patient Care and STDs 2004;18(5):275–288. [PubMed: 15186711]

Siegel K, Schrimshaw SW, Dean L. Symptom interpretation: Implications for delay in HIV testing and care among HIV-infected late middle-aged and older adults. AIDS Care 1999;11(5):525–535. [PubMed: 10755028]

Smith MU, DiClemente RJ. STAND: Peer educator training curriculum for sexual risk reduction in the rural South. Students Together Against Negative Decisions. Preventative Medicine 2000;30(6):441–449.

Sousa KH, Holzemer WL, Bakken Henry S, Slaughter R. Dimensions of health-related quality of life in persons living with HIV disease. Journal of Advanced Nursing 1999;29(1):178–187. [PubMed: 10064297]

Sowell RL, Seals BF, Moneyham L, Demi A, Cohen L, Brake S. Quality of life in HIV-infected women in the South-Eastern United States. AIDS Care 1997;9(5):510–512.

Spirig R, Moody K, Battegay M, De Geest S. Symptom management in HIV/AIDS: Advancing the conceptualization. Advances in Nursing Science 2005;28(4):333–344. [PubMed: 16292019]

van Servellen G, Sarna L, Jablonski KJ. Women with HIV: Living with symptoms. Western Journal of Nursing Research 1998;20(4):448–464. [PubMed: 9686523]

Wagner, L. Peer teaching: Historical perspectives. Westport, CT: Greenwood; 1982.

Wantland DJ, Holzemer WL, Moezzi S, Willard SS, Arudo J, Kirksey KM, et al. A randomized controlled trial testing the efficacy of an HIV/AIDS symptom management manual. Journal of Pain and Symptom Management 2008;36(3):235–246. [PubMed: 18400461]

Table 1
Baseline Characteristics of Study Participants

	***N* = 7**
Age	*M*[a] = 45 (*SD*[b] = 7, Range: 35-55)
Race	87% African American 13% Latina
Education	50% 11th grade or lower 13% High school diploma 25% 2 years of college 13% College degree (4 years)
Employed	0
Insurance	100% Medi-Cal
Children	4 (57%) had children (Range: 1-7 children)
Year diagnosised	*M*[a] = 1992 (Range: 1984-2000)
HIV Medications	4 (57%) on ART[c]
Comorbidities	Depression, hypertension, hepatitis
Symptom Intensity	*M*[a] = 0.70 (*SD*[b] = 0.84, Range: 0-2.30)
Self-efficacy to Manage Chronic Disease	*M*[a] = 5.14 (*SD*[b] = 4.34)

[a] Mean;

[b] Standard Deviation;

[c] antiretroviral therapy

Table 2
Frequency and Mean Distress Score for the Most Commonly Reported Symptoms

Symptom	**Frequency[a] Experienced Range (1-7)**	**Mean Distress [b] Range (0-3)**
Muscle Aches	4	2.75
Gas/Bloating	4	2.75
Thirsty	4	2.5
Depression	4	2.5
Numbness in arms	4	2.5
Dry Mouth	4	2.25
Difficulty Concentrating	4	2.25
Lack of Appetite	4	2.25
Itchy Skin	3	3
Shortness of Breath with Activity	3	3

[a] Number of participants who reported experiencing symptom

[b] Mean distress score was calculated as the total intensity score of the symptom divided by the number of participants who reported each symptom.

Table 3

Weekly Topic and Results

Week	Topic	Participant Feedback	Results
1	Symptom Experience	… What I tell them is to live with my neuropathy and diarrhea for one day. Taking extra underwear and always looking for the bathroom when I go out.	• Each woman experiences different, yet equally distressing symptoms related to her HIV disease • Symptoms are often attributed to medications
2	Experience with Symptom Management	I just don't have the energy to do everything I need to do. I try to exercise and eat right and take my medications but I just don't have the energy.	• Symptom management is very challenging for women • Symptom management is important and desirable
3	Barriers/Facilitators to symptom management	I feel like I am not a person since I got this virus. Nobody respects me… They don't respect my confidentiality.	• Women experience distressing stigma from health care providers • It is difficult for women to communicate effectively with their health care providers
4	Potential Interventions	… We can tell them not to overdo it, and to reserve their energy because the meds drain it…. We've been through that and we know what it feels like.	• Women who are experienced with HIV can help newly-diagnosed women with their symptom management • The Positive Self-Management Program is feasible
5	Feedback on focus-group summation		• Not applicable