



A Pilot Self-Care Group Intervention for Low-Income HIV-Positive Women

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A Pilot Self-Care Group Intervention for Low-Income HIV-Positive Women

Abstract

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Keywords

Empowerment; Health disparities; HIV; HIV infections; HIV-positive women; Poor women; Power (Social sciences); Self-care; Health; Social networks; Social status – Health aspects; Women

Cover Page Footnote

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A Pilot Self-Care Group Intervention for Low-Income HIV-Positive Women

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Abstract

This article describes the development of a self-care intervention and examines its efficacy with low-income HIV-positive women (n=34) in the Midwestern United States. Adapted from an individual nurse-led intervention, this effort focused on increasing self-care behaviors through enhancing self-esteem and social support. The investigators used a community-based participatory approach and partnered with three HIV-positive women to adapt and pilot test the new group intervention. A within-group, repeated-measures, pre-/post-test design, together with participant interviews, was used to evaluate the intervention. Mean scores on measures of self-care behaviors, self-esteem, social support and depressive symptoms all changed in the clinically desirable direction. Group interventions, such as the one described here, could be useful if provided in community settings to enhance the mental and physical health of HIV-positive women. Further testing of this intervention with a larger sample is needed to determine its effectiveness.

Key Words: women, HIV, empowerment, health disparities

Introduction

The number of women living with HIV/AIDS is growing, particularly among populations of low-income women and women of color. In the U.S., African American and Hispanic women together account for over 80% of AIDS cases among women.¹ The disparate health outcomes for these women are largely the result of delays in seeking health care after HIV diagnosis and poorer adherence to HIV treatments. In addition, they use health care services inconsistently, which results in poorer survival rates.^{2–8} Depression, anxiety and emotional distress are also common among low-income women living with HIV.⁹

As treatment has advanced and transformed HIV into a chronic and manageable illness, attention must now focus on overall health, consistent health care utilization, and health promotion and prevention strategies to facilitate optimal emotional and physical health.¹⁰ Engagement in healthful self-care management has been shown to positively influence the health of individuals living with HIV disease.¹¹ Further, individuals who actively participate in the management of their physical and emotional health are more likely to experience positive health outcomes.¹² Only one randomized controlled intervention study was found that focused on improving self-care behaviors in HIV-positive women. Miles et al.¹³ explored the efficacy of a home-based, nurse-led, self-care symptom management intervention in low-income African American mothers with HIV. Compared to the control group, mothers in the intervention group reported fewer feelings of stigma and higher physical function. Within-group analyses over time showed a reduction in negative affective state and stigma as well as fewer infections.

Small group intervention is a means of reaching low-income women living with HIV. Small groups provide a more intimate setting in which the women can address their complex lives and share with one another their multiple stressors—e.g., financial limitations, family demands and emotional distress.^{13–15} Such stressors may contribute to lack of self-esteem, depressive symptoms and lack of social support, which can be barriers to healthful self-care behaviors.¹⁶ A small group approach may be even more effective if it also involves peers working together with health professionals.^{17–20}

Several researchers have successfully used group interventions to enhance positive health behaviors in persons living with HIV, including Kalichman et al.²¹ who reduced potential HIV-transmission behaviors among men and women living with HIV/AIDS through a five-session group intervention that enhanced participants' efficacy in employing risk-reduction behaviors. In a second trial, this same group of researchers found that a five-session group intervention again effectively reduced unprotected sexual behaviors by adults living with HIV disease, particularly when the sexual partner was HIV negative.²² Other studies of group interventions, aimed at improving participants' coping mechanisms, found increased social support, perceptions of social well-being, and optimism among the group (n=16) of older adults.²³ Heckman et al. demonstrated improved coping and quality of life among 90 older adults with HIV who participated in a telephone-delivered group intervention.²⁴ Interventions with two other HIV-positive groups that included both men and women found that women were more responsive to the in-

terventions than men. One intervention was a 12-week, cognitive-behavioral, group coping program to decrease grief and depressive symptoms in HIV-positive adults who had lost a loved one to the disease,²⁵ and the other was a 7-session, small group intervention for mentally ill HIV-positive adults aimed at increasing condom use and positive attitudes about condoms.²⁶ Thus, there is good evidence that group interventions are effective in the HIV population and that group interventions may be particularly salient for women.

Nevertheless, no self-care management intervention program has been developed that specifically targets the needs of low-income, HIV-positive women living in the Midwest. Consistent with the rest of the nation, the number of women infected with HIV in the Midwest has continued to rise since the mid 1990s, with increasing numbers of HIV-positive women living in smaller Midwestern cities and outlying areas. And while HIV disproportionately affects women of color in this part of the country as well, the population of HIV-positive women in Midwestern communities tends to be more heterogeneous, consisting of mixed groups of low-income African American, Hispanic and white women. As a result, intervention programs developed to target specific ethnic/cultural groups of HIV-positive women may not meet the needs of this population as there may be too few potential participants to sustain enrollment. Further, if insufficient funding precludes offering separate programs for various groups of HIV-positive women, some members of the community may feel excluded. Thus, low-income women living in smaller Midwestern cities often do not have access to the same HIV resources that women living in larger U.S. cities do.

The purpose of this study was to: (a) develop a small group, self-care intervention for low-income women living with HIV and (b) examine the feasibility and efficacy of the intervention in promoting self-care behavior, self-esteem, and social support and reducing depressive symptoms. The study's design and implementation are unique, focusing on women living with HIV in a smaller Midwestern city and partnering with three women from the target population who also live with HIV.

Methods

The Women's Empowerment Program (WEP) Intervention

The intervention was developed using a community participatory model.²⁷ The project grew out of two focus groups conducted to assess the health needs of low-income women living with HIV in a Midwestern city in the United States. The 27 women who participated in the focus groups identified the need for help in taking better care of themselves,

raising their self-esteem, and developing approaches to increase their social support network. The women suggested that an intervention program that used a group format would provide them with additional social support. They further suggested that HIV-infected women be included as co-facilitators because women living with HIV would view a peer-led group as more credible than one led by a healthcare provider alone.

Thus, three women from the focus group phase of the study were selected to work with the investigators on the basis of their interest, positive adaptation to their HIV disease, and willingness to participate. The three women were involved in all aspects of intervention development and implementation in their roles as peer intervention facilitators and program evaluators. As the women collaborated with the researchers, the team determined that the informational modules from the home-based, individual nurse delivered HIV Self-Care Management Intervention¹³ addressed a number of the issues of concern for the focus group women and could be modified into a group intervention format to meet the unique needs of this group of HIV-positive women. The new group intervention was named “Women’s Empowerment Program” (WEP) by the three peer facilitators.

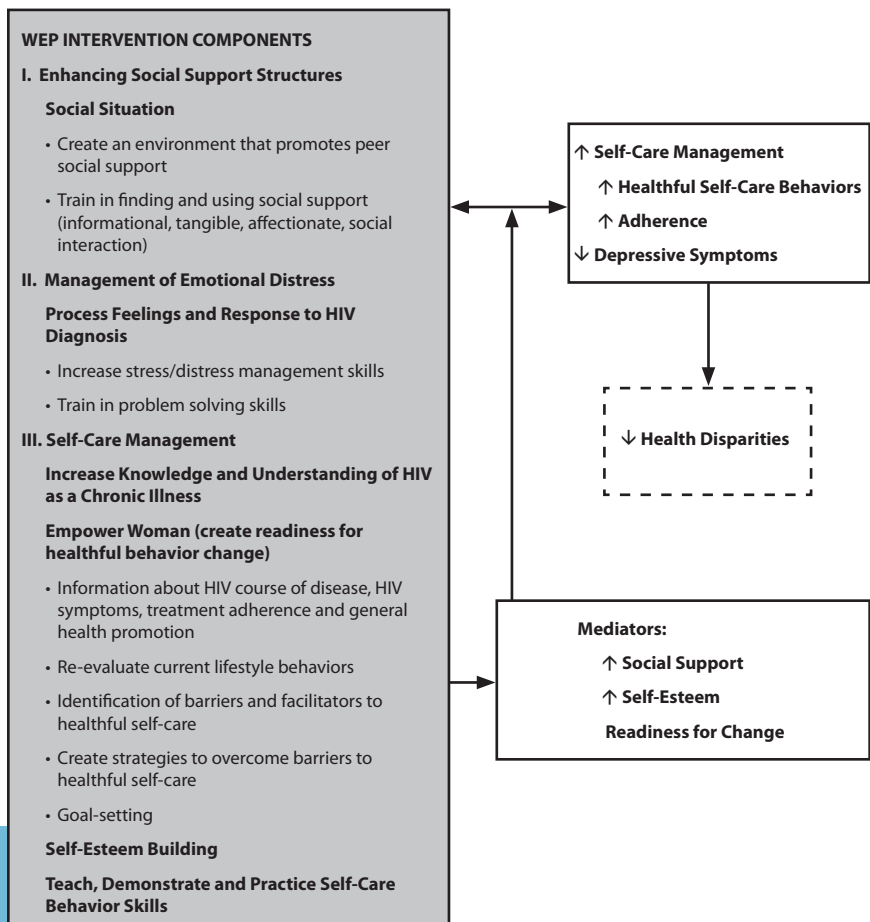
Theoretical Framework of the Intervention

Miles’s original intervention was based on the Self-Management of HIV Framework¹⁵ and used cognitive reframing within a therapeutic relationship to help African American women enhance their social situation, process their feelings about having HIV, view HIV as a chronic illness and learn how to prevent and manage HIV-related problems. In the WEP program, Miles’s intervention was adapted from an individual-level intervention to a group intervention, and content was revised to incorporate input from the focus groups and recent changes that had occurred in the management and treatment of HIV. Fleury’s²⁸ Wellness Motivation Theory of empowerment together with Coopersmith’s²⁹ theory of self-esteem were used together to guide the adaptation and development of the new intervention’s format and content. Fleury’s theory purports readiness as a necessary phenomenon that precedes individual behavior change, and Coopersmith’s theory states that high self-esteem is a critical component of confidence and effective functioning. Within Coopersmith’s theory, the evaluation of one’s self-esteem is based on beliefs about successes, values, aspirations and defenses. Significant contributors to high self-esteem include (a) acceptance by others who are considered important; (b) acceptable group norms that are associated

with personal worthiness; (c) belief that goals are attainable; and (d) the ability to deal with stress and anxiety.

By adapting Miles’s framework, and using Wellness Motivation Theory and self-esteem theory to provide an understanding of how the intervention components would work, we conceptualized the Women’s Empowerment Program (WEP) as shown in Figure 1. The goal of the newly developed WEP intervention was to empower women living with HIV to improve self-care management of their health, particularly HIV-related treatment issues, through social support, informational support, self-esteem building, and self-care skills training. Decreasing depressive symptoms was a secondary aim of the intervention.

Figure 1. Women’s Empowerment Program (WEP) Intervention: Under Miles’s (1996) HIV Self-Management Framework, Guided by Wellness Motivation Theory (Fleury, 1991) and Self-Esteem Theory (Coopersmith, 1967)



WEP Format

The WEP intervention was provided to participants in four group sessions held once monthly. Each session was held on a Saturday and lasted approximately four hours with a meal included. The meal gave everyone the opportunity to interact with each other and build relationships. The intervention sessions were held at a community fitness center in a central location with easy access to public transportation. The choice of the facility where WEP intervention sessions were held was based on information gained in the focus group formative phase of the study. Focus group participants indicated that a location that had “nothing to do with HIV” would increase participation. The participants came together at the beginning of each session as a larger group and were then subdivided into groups of approximately 10 women for small group work. Groups were co-facilitated by pairs of women: one woman living with HIV together with a nurse who was experienced in HIV/AIDS care and women’s health care. Facilitators used participants’ baseline readiness scores, as measured by the Index of Readiness, to help drive intervention format.

WEP Content

Each session contained four components: (1) creating social support networks; (2) providing informational support; (3) building self-esteem; and (4) training in self-care behaviors. The focus of each session can be found in Table 1. Topics included in the WEP intervention sessions were selected based on findings from the formative phase focus groups conducted prior to the development of the WEP intervention, and role-play scenario content was selected by the peer facilitators.

Evaluation of the Intervention

The purpose of the pilot study was to examine the feasibility of the intervention and to explore whether WEP was effective in increasing self-care behaviors, self-esteem, and social support and in reducing depressive symptoms. A repeated-measures, one-group, pre-post test design was utilized. In addition, individual interviews were conducted with selected participants to further evaluate the intervention.

Procedures

Women were recruited in one Midwestern city through the Ryan White Case Management System and from medical practices that focus on the treatment of women with HIV infection. Physicians, nurses and case managers distributed flyers to potential participants in their respective settings. Potential participants were given additional information

Table 1. WEP Intervention Content

Session	Social Support	Informational Support	Self-Esteem Building	Self-care Skills Training
I.	<p>Introductions of facilitators and participants</p> <p>Peer facilitators share their "success" stories, helpful strategies and challenges faced related to finding and using social support as an HIV-positive woman</p>	<p>HIV: Overview of pathogenesis, transmission, treatment</p> <p>Sexually transmitted diseases, sexual health</p>	<p>Discussion about barriers and facilitators to self-care, evaluation of current life-style, goal setting, modeling of goals, healthy lifestyle, values, aspirations, defenses related to sexual health and self-care</p>	<p>Sexual self-care: Prevention of sexually transmitted infections, male and female anatomy, use of barrier protection</p>
II.	<p>Participants share their "success" stories and challenges since the last meeting related to finding social support and use of skills learned at the previous meeting</p>	<p>HIV and personal relationships</p> <p>Management of emotional distress</p> <p>Financial planning</p>	<p>Discussion and modeling: HIV and relationship issues with family, children, co-workers, boyfriend/spouse</p>	<p>Emotional self-care: Disclosure strategies and relationship negotiation skills through role-play</p> <p>Problem solving and stress management skills role-play</p>
III.	<p>Participants share their "success" stories and challenges since the last meeting related to finding social support and use of skills learned at the previous meeting</p>	<p>General health promotion, women's health, reproductive health, emotional health management</p>	<p>Discussion and modeling: healthy living behaviors, healthy eating, exercise, health screening activities to prevent chronic illness, HIV symptom management</p>	<p>General self-care stations training specific self-care behaviors such as breast self-exam, mental health care, skin care, smoking cessation, physical activity/exercise, PAP screening.</p> <p>Management of finances</p>
IV.	<p>Participants share their "success" stories and challenges since the last meeting related to finding social support and use of skills learned at the previous meeting</p>	<p>HIV care, health maintenance, significant laboratory markers of HIV, symptom management, HIV treatment, relationship between HIV treatment adherence and drug resistance</p>	<p>Discussion and modeling: engagement in HIV health care interventions, HIV medication adherence, accessing health care, advocating for health care needs</p>	<p>HIV self-care strategies/tips to enhance adherence, use of medication taking reminders, ensure regular health care.</p> <p>Each participant receives tote bag, contents reinforce all WEP content (i.e., recipes for healthy meals, water bottle, reference book of local HIV care agencies)</p>

about the study by phone or by mail and asked for a commitment of interest. If a woman agreed to participate, she was given details about the first meeting session. At the first session, the study was again explained and the woman signed a consent form prior to the start of the intervention. Childcare and transportation assistance was provided to all participants for each intervention session. In addition, each participant received \$10 for her time in completing questionnaires at each data collection point. The study was approved by the University of Missouri–Kansas City’s Social Sciences Institutional Review Board.

Participants

Participants in this study were low-income women (n=34) living with HIV who were African American (70%) or Caucasian (30%). The average age of women who participated was 42 (SD=10.5) with an average of 12 years (SD=2.6) of education. Low-income was defined as qualifying for public assistance, consisting of either state Medicaid or Ryan White Title I, III or IV assistance. Most participants (75%) had children living at home. The average length of time that participants had been living with HIV disease was eight years; mean CD4 cell count was 442 (range 74 to 1,124); mean HIV1 RNA by PCR was 12,207 (range <50 to 100,000); and 68% (n=23) of the women were taking antiretroviral medications at the time of study participation. In addition to HIV disease, nearly half (45%) of the study participants in this group had another chronic health problem, such as diabetes.

Data Collection Methods

Data were collected at baseline (pre-intervention), mid-intervention (weeks 8 and 16) and post-intervention (week 24) on self-care behaviors, self-esteem, social support, readiness for healthful behavior change and depressive symptoms. In addition, demographic and health information was collected at baseline.

Self-Care Behaviors. The Self-Care Index for Women (SCI) was developed by Miles¹⁵ to assess self-care management strategies and use of self-care behaviors by women living with HIV. The original 35-item instrument was developed based on a literature review of self-management strategies used by older adults with chronic disease, a literature review of HIV care and treatment, and interviews with African American women living with HIV. The instrument was found to have a reliability of .75 in a study with 44 African American women living with HIV.¹⁵ Later, the scale items were reduced based on factor and item analysis in a study examining self-care by 109 African American women living with HIV.¹³ In the study described here, three subscales of the SCI were

used: (1) preventing/treating infections, (2) advocating for own health care needs and (3) use of general health promotion behaviors, including one item that examined adherence to HIV treatment, if prescribed, for a total of 17-items. Higher mean subscale and total scale scores indicated greater use of self-care behaviors.

Self-esteem. The Perlow Self-Esteem Scale (PSES) was developed to provide a short and simple tool to assess self-esteem.³⁰ The scale is based on seven constructs from Coopersmith's²⁹ theory, which maintains that self-esteem is related to success. The PSES has 17 items, uses a 5-point Likert scale, and has been shown to be reliable with Chronbach's alpha of .86 and .81.³¹ Item values are summed with a higher score indicating a higher perception of individual self-esteem.

Social Support. The Medical Outcomes Survey–Social Support Scale (MOS–SSS) consists of 21 items with subscales that measure four types of social support: tangible, affection, positive social interaction, and emotional/informational support. In previous HIV studies, internal consistency has been high with Chronbach's alpha of .97 overall and subscale alpha ranges from .91 to .96.³²

Readiness for Healthful Behavior Change. The Index of Readiness (IR) measures motivation for health-related behavior change and was developed by Fleury³³ based on Wellness Motivation Theory. The original IR consisted of 30 items with three subscales: re-evaluation of life-style, identification of barriers/creation of strategies, and goal commitment. Higher baseline readiness has been associated with greater use of self-care behaviors—specifically, adherence to HIV treatment, in a study conducted with HIV-positive males where reliability estimates for the IR were .89 for the total scale and .80, .81 and .67 for the three IR subscales respectively.³⁴ A short-form, 9-item version of the IR containing the same subscales as the original scale³⁵ was utilized in the present study to assess participants' levels of readiness for health behavior change and to help tailor the delivery of WEP intervention content.

Depressive Symptoms. The Center for Epidemiologic Studies Depression Scale (CES-D) is a measure of depression symptoms in the general population. The scale has been found reliable with Cronbach's alpha >.85 in previous research³⁶ (Hann, Winter & Jacobsen, 1999) and has been used extensively with populations of individuals living with HIV. The CES-D consists of 20 items which are summed with a total score of greater than 16, indicating depressive symptoms in an individual.

Individual interviews. The feasibility and usefulness of the WEP intervention was further evaluated through individual interviews with

selected participants. Most participants ($n=26$; 76%) chose to voluntarily take part in a semi-structured individual interview with a nurse researcher. Each interview lasted 30–45 minutes and was audio-taped. Participants were asked to discuss what ‘worked/didn’t work’ in the WEP intervention and also to give suggestions about how to improve the intervention.

Data analysis. A repeated-measures design was utilized to examine changes in the mean scores on pre- and post-test quantitative data in this study (Table 2). Changes in mean scores for self-care behaviors, self-esteem, social support, readiness and depressive symptoms were examined using data from 34 persons who completed the intervention (the actual n varied on each measure due to missing data). One participant dropped from the study after the first session. Pair-wise, within-subject comparisons were conducted on pre-test/post-test mean scores to determine if any of the score gains reached a level of statistical significance ($p<.05$). Analyses utilized a one-directional level of significance based on a priori hypotheses with regard to the direction of change for each measure. Specifically, pre-intervention (baseline) measurement was compared to measures at time points during the intervention (weeks 8 and 16) and post-intervention (week 24).

Table 2. Pre-to-Post Intervention Changes in Outcome Measures (n=34)

Variable	Pre-test mean (sd)	T2 mean (sd)	T3 mean (sd)	T4 mean (sd)	<i>p</i>
Use of self-care behaviors					
Prevent/treat infections	2.3 (.49)	2.3 (.45)	2.4 (.44)	2.4 (.45)	<i>ns</i>
Advocate for health needs	2.6 (.38)	2.6 (.42)	2.7 (.34)	2.8 (.32)	$<.05$
General health promotion	2.1 (.49)	2.3 (.36)	2.1 (.49)	2.3 (.40)	$<.05$
Total self-care score	2.3 (.38)	2.4 (.34)	2.4 (.33)	2.5 (.35)	$<.05$
Self-esteem	65.5 (11.4)	65.6 (9.7)	62.5(12.6)	69.0(9.8)	<i>ns</i>
Social support					
Emotional support	3.5 (1.1)	3.4 (1.1)	3.8 (.94)	4.2 (.85)	<i>ns</i>
Tangible support	3.4 (1.2)	3.4 (1.2)	3.5 (1.3)	2.8 (.35)	<i>ns</i>
Affectionate support	3.6 (1.3)	3.8 (1.3)	3.7 (1.1)	3.7 (1.1)	<i>ns</i>
Positive social interaction	3.4 (1.2)	3.4 (1.1)	3.8 (1.1)	3.8 (1.0)	<i>ns</i>
Total social support score	3.45 (.99)	3.46 (.96)	3.78 (.88)	4.04 (.85)	$<.05$
Depressive symptoms	18.0 (16.5)	23.1 (18.4)	22.5 (16.1)	10.1 (8.8)	<i>ns</i>

Pre-test=baseline; T2=8 weeks after baseline; T3=16 weeks after baseline; T4=24 weeks after baseline; *ns*=not significant

Qualitative data collected during individual interviews were examined using content analysis and the constant comparison method.³⁷ The audio-taped interviews were transcribed verbatim and then transcriptions were read and coded with the components of the WEP intervention as guiding themes. Groupings of data by similarity of content were made independently by two researchers (one with participant contact and one without participant contact) and discrepancies in groupings were resolved through discussion. Data displays were constructed with identified themes and supporting data.³⁸ To increase validity, significant themes elicited from the analysis were reviewed with selected WEP participants.

Findings

Examination of Use of Self-Care Behaviors, Self-Esteem, Social Support and Depressive Symptoms from Pre- to Post-Intervention

Although we did not expect to be able to detect statistically significant score improvements given the very small sample sizes used in this study (*n*'s ranged from 13–25 participants), we did observe significant increases on measures of self-care behaviors (total scale score effect size $d=.40$; use of general health promoting behaviors effect size $d=.30$; and advocate for health needs effect size $d=.25$) and total social support scores (effect size $d=.25$) from pre-test/post-test. While not statistically significant, the changes that occurred with regard to depressive symptoms and self-esteem scores were in the clinically desirable direction.

Changes in the Use of Self-Care Behaviors. Score changes for self-care behavior measures were significant ($p<.05$) with the exception of one subscale. The total self-care score increased significantly with pre-test mean total scale score of 2.3 ($SD=.38$) compared to 2.4 ($SD=.34$) at week eight, 2.4 ($SD=.33$) at week sixteen, and 2.5 ($SD=.35$) post-test. While the prevention/treatment of infection subscale score changes were not significant with means of 2.3 ($SD=.49$) pre-test, 2.3 ($SD=.45$) week eight, 2.4 ($SD=.44$) week sixteen and 2.4 ($SD=.45$) post-test, there were statistically significant changes for the other two subscales. The mean scores for the “advocate for own health needs” subscale were 2.6 ($SD=.38$) pre-test, 2.3 ($SD=.36$) week eight, 2.1 ($SD=.49$) week sixteen and 2.3 ($SD=.40$) post-test; and for the “use of general health promotion,” subscale means were 2.1 ($SD=.49$) pre-test, 2.3 ($SD=.36$) week eight, 2.1 ($SD=.49$) week sixteen and 2.3 ($SD=.40$) post-intervention.

Changes in Perception of Self-Esteem. Participants reported increases in self-esteem scores over the course of the intervention. Pre-intervention self-esteem score mean was 65.5 (baseline) compared to 65.6

(8 weeks), 62.5 (12 weeks) and 69.0 (24 weeks) post-intervention. Again, changes in self-esteem were in the clinically desirable direction, but statistical significance was not achieved likely due to the small sample size.

Changes in Perception of Social Support. Increases in the total score for the measure of social support were significant ($p < .05$); however, the changes in subscale scores for the social support measure were not significant. Nevertheless, most score changes did occur in the desirable direction. With regard to the emotional support subscale, the mean pre-intervention score was 3.5 (SD=1.1) compared to 3.4 (SD=1.1) at week eight, 3.8 (SD=.94) at week sixteen, and 4.2 (SD=.85) post-intervention. Tangible support subscale mean score pre-intervention was 3.4 (SD=1.2) compared to 3.4 (SD=1.2) at week eight, 3.5 (SD=1.3) at week sixteen, and 2.8 (SD=.35) post-intervention. Affection subscale pre-intervention mean score was 3.6 (SD=1.3) compared to 3.4 (SD=1.1) at week eight, 3.8 (SD=1.1) and 3.8 (SD=1.0) post-intervention. For the positive social interaction subscale, the pre-test mean score was 3.4 (SD=1.2) compared to 3.4 (SD=1.1) at week eight, 3.8 (SD=1.1) at week sixteen, and 3.8 (SD=1.0) post-test. And for total social support scale scores, the pre-intervention mean was 3.45 (SD=.99) compared with 3.46 (SD=.96) at week eight, 3.78 (SD=.88) at week sixteen, and 4.04 (SD=.85) post-intervention ($p < .05$).

Changes in Depressive Symptoms. Depressive symptoms decreased over the course of the intervention, although the decrease was not statistically significant. At pre-intervention, the mean depression score was 18.03 compared to 23.1 (week 8), 22.5 (week 12), and 10.1 (post-intervention). Again, changes occurred in the desired direction, but statistical significance was not reached in this small sample.

Examination of Readiness for Healthful Behavior Change

With regard to readiness, scores observed over the course of the intervention were consistent with the postulates of Wellness Motivation Theory²⁸—that is, one's readiness must be high prior to incorporating healthful behavior change. Thus, for example, a participant should indicate a higher Likert scale response to the question, "I think that I need to change some of the ways I take care of myself" early in the WEP intervention, indicating higher readiness for change, and accordingly, a lower response to that same question post-intervention once healthful behavior changes have already occurred. While indeed our findings indicated that readiness scores were higher during the WEP intervention than post-intervention (see Table 3), we noted that, in this particular group of participants, readiness scores were already high at baseline.

Table 3. Participant Readiness Scores (n=34)

Readiness	Pre-test mean (sd)	T2 mean (sd)	T3 mean (sd)	T4 mean (sd)
Subscale:				
Re-evaluation of lifestyle	3.5 (1.2)	3.7 (1.2)	3.6(.91)	3.2(.91)
Identification of barriers	3.9 (1.0)	3.8 (1.2)	3.8(1.1)	3.5(1.1)
Goal commitment	4.2 (.93)	3.9 (1.1)	4.1(1.1)	3.8(1.2)
Total readiness score	3.85 (.81)	3.8 (.97)	3.8(.86)	3.5(.94)

Pre-test=baseline; T2=8 weeks after baseline; T3=16 weeks after baseline; T4=24 weeks after baseline

Feasibility and Usefulness

Overall, the interview participants were highly positive about the intervention. Three major themes were found in the interviews with regard to ‘what worked’ in the WEP intervention: (1) the majority of women viewed the intervention as a support group rather than an intervention program; (2) the dual facilitation of WEP by a peer and nurse gave the women a sense that information gained and skills learned came from “the best of both worlds;” and (3) being part of a program designed “for (HIV-positive) women by women” gave more credibility to the program and increased enthusiasm about the program. There was only one finding with regard to ‘what didn’t work’ and that was that participants did not find the financial planning component of WEP beneficial. When asked how to improve the WEP intervention in the future, participant suggestions were highly consistent. Participants wanted more content related to coping strategies and more help with emotional problems such as relationship issues, depression, and emotional distress. In addition, some participants suggested including family members (such as children, spouses and significant others) in the WEP intervention.

Discussion

Findings from this pilot study, while preliminary, are encouraging. This study suggests that the self-care behaviors practiced by low-income women living with HIV were enhanced through a 4-session group intervention delivered in a community setting. Participants in this study were very positive about the intervention program and retention was high: only one participant dropped over the six-month study period. In addition, after participating in this pilot intervention study, mean scores on measures of self-care behaviors, self-esteem, social support, and depressive symptoms changed in the clinically desirable directions. Of particular interest were the statistically significant increases that were

observed in measures of social support and self-care behavior practices pre- to post-test. Although sample sizes were small, one could hypothesize that desirable changes observed from pre- to post-test surrounding self-esteem and depressive symptoms might also have reached significant levels given a larger sample size.

While we report encouraging findings here, this pilot study had several limitations that must be addressed. All study participants were recruited from one Midwestern city; therefore, the findings are not generalizable. Because all study participants were recruited through the Ryan White Case Management System and from medical practices, all participants were already engaged in medical care or social services. It is possible we may have recruited a sample of participants who were generally more likely to engage in self-care activities, and thus, the intervention may have appeared more effective in this group of women due to the participants' tendency to already be motivated about self-care. Another limitation of this study was the lack of long-term post-intervention data collection measures, resulting in the inability to evaluate maintenance of the observed healthful behavior changes.

We were moderately surprised to find that the women in this study felt WEP was a support group. However, the fact that WEP was a group intervention designed to enhance participants' social support networks and ability to find/use social support does lend itself to the feelings experienced by the women in this study. We also found it interesting to learn that, despite the fact that women seemed very excited about an intervention that was designed "for women by women," they also wanted to include their significant others in future interventions. The desire to include family members and significant others together with the desire for more coping and mental health components for future interventions speaks to the complex lives of women living with HIV. The fact that these women do lead multifaceted lives may be one reason that a group intervention, such as the Women's Empowerment Program (WEP) with its holistic focus, was well received. Still, post-intervention participant interviews indicated that our intervention needed additional components to more completely address the unique health needs of this group of women. Given the strong sense of social support experienced by women in this study, maintenance of these support networks may be one useful mechanism to sustain the individual healthful self-care behaviors initiated during the intervention period. However, refinement and further testing of the WEP intervention in the form of a randomized, clinical trial with a larger sample size is needed to determine the effectiveness and long-term impact of the intervention.

Conclusion

As the number of low-income women living with HIV continues to rise, interventions are needed that successfully engage these women in positive self-care management of their health. Further, such interventions must strive to eliminate the health disparities that currently face poor women, particularly women living in smaller cities who are greatly affected by the HIV/AIDS epidemic but who have been largely neglected and understudied. Group interventions, such as WEP—delivered in the community by women living with HIV who partner with health care professionals—appear to provide one viable approach to reaching this goal.

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