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Peer-Based Interventions to Increase Symptom Management in Women Living with HIV/AIDS

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PEER-BASED INTERVENTION TO IMPROVE SYMPTOM MANAGEMENT IN WOMEN LIVING WITH HIV/AIDS

by

Allison Webel

DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF PHILOSOPHY

in

[redacted]

DEDICATION

This dissertation is dedicated to my parents and to my husband whose love, support, patience and wisdom have allowed me to see further than I ever thought possible.

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ABSTRACT

TESTING A PEER-BASED INTERVENTION TO IMPROVE SYMPTOM MANAGEMENT IN WOMEN LIVING WITH HIV/AIDS

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Women living with HIV/AIDS are challenged to manage the symptoms of HIV/AIDS and its treatment. Peer-based interventions are one strategy that may help women living with HIV/AIDS better manage their symptoms. Peer-based interventions have the potential to enhance health equity in women with HIV/AIDS. It can improve access to health care services, provide support, improve self-efficacy and self-confidence and facilitate involvement in self-care activities. While it has not yet been used with a symptom management intervention in women, recent evidence suggests a peer intervention model may be appropriate to employ in order to change the symptom management behavior in women infected with HIV; but that evidence is needed before wide implementation of it. No studies have been located that have explored the benefits of utilizing a peer-led intervention program to help facilitate symptom self-management for HIV/AIDS in an all-female sample. Therefore, this dissertation presents three papers that address different aspects of the focus of this dissertation, Peer-Based

Interventions to Increase Symptom Management in Women Living with HIV/AIDS.

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Introduction

HIV/AIDS is 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. Approximately 15,000 women were diagnosed with HIV/AIDS, which accounts for 27% of all new diagnoses in 2006 (Hall et al., 2008). Additionally, according to the California Department of Public Health, in December 2008 in California, 14% of all new HIV infections were in women. Additionally, while only 9% of AIDS cases in California are women, 44% of all AIDS-related deaths in California occur in women (Health, 2009). These women are often poor, undereducated, uninsured, marginalized, and may be the most vulnerable members of our society today.

Women living with HIV/AIDS are challenged to manage the symptoms of HIV/AIDS and its treatment. Several studies have described the symptom experience of women with HIV/AIDS and its consequences on the quality of their life and treatment decisions. Peer-based interventions are one strategy that may help women living with HIV/AIDS better manage their symptoms. Peer-based interventions have the potential to enhance health equity in women with HIV/AIDS (HRSA, 2006). It can improve access to health care services, provide support,

improve self-efficacy and self-confidence and facilitate involvement in self-care activities (Doull, O'Conner, Robinson, Wells, & Tugwell, 2004). While it has not yet been used with a symptom management intervention in women, recent evidence suggests (Brown & Vanable, 2008; Doull et al., 2004; HRSA, 2006; Jones et al., 2007) a peer intervention model may be appropriate to employ in order to change the symptom management behaviour in women infected with HIV; but that (more) evidence is needed before wide implementation of it. No studies have been located that have explored the benefits of utilizing a peer-led intervention program to help facilitate symptom self-management for HIV/AIDS in an all-female sample. Therefore, the study hypotheses for this dissertation were:

1. Participants in the experimental group (PRISM-HIV) will report reduced symptom intensity over time, compared to the participants in the control group, as measured by the revised HIV Sign & Symptom Checklist.
2. Participants in the experimental group (PRISM-HIV) will report increased medication adherence and reduced viral load over time, compared to the participants in the control group.
3. Participants in the experimental group (PRISM-HIV) will report increased quality of life over time, compared to the participants in the control group, as measured by the HAT Quality of Life Scale.

This dissertation describes the HIV symptom experience in women and its consequences, the use of peer-based education interventions to improve health-related outcomes around the world and the results of the randomized clinical trial testing the PRISM-HIV intervention in a sample of women living with HIV/AIDS in the San Francisco Bay Area.

Background

Symptom Experience

The symptoms of 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 (Cohen, 1997). After a period without physical symptoms, the disease progresses to a pre-AIDS defining stage. Symptoms at this stage include lymphadenopathy, frequent fevers, night sweats, and rapid weight loss without dieting, chronic fatigue, depression, anorexia, and diarrhea (Cohen, 1997).

With the development and widespread distribution of Anti-retroviral medication (ARV's), HIV has become a chronic disease. Accordingly, the symptoms experienced have slightly changed 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 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 (Mannheimer et al., 2008).

Several studies have recently explored the relationship between anti-retroviral medications and symptoms. Wantland, et al (2008) found that individuals taking ARVs had a higher than expected report of loose stools, diarrhea, shortness of breath with activity, weight gain in the stomach area, hump on back of the neck, skinny arms/legs, and prominent, leg veins, thirst and insomnia. Additionally, individuals taking ARVs that included a protease inhibitor had significantly higher symptom intensity than those who were not on ARVs or not on a regimen containing a Protease Inhibitor. Specifically, they found that individuals taking ARV regimens with Protease Inhibitors had higher than expected weight gain, hump on back of the neck, skinny arms and legs, prominent leg veins and gas/bloating (D. J. Wantland et al., 2008). Additionally, Johnson, et al. (2003) found that HIV-infected individuals were able to identify the symptoms of stomach, nausea and vomiting, constipation, and alterations in taste sensation as side effects of their ARV medication. They also identified tender or enlarged lymph nodes/glands, night sweats, unintentional weight loss, fever, and loss of strength as consequences of their HIV infection. These authors also

identified that many individuals attribute the cause of their symptoms to both the disease and its treatments. These symptoms included: fatigue, feeling sad, down, and depressed, problems with having sex, and changes in body appearance (M. O. Johnson, Stallworth, & Neilands, 2003).

In addition to the general HIV-symptoms experienced by women, they may also experience gender-specific manifestations including sexually transmitted infections, Pelvic Inflammatory Disease (PID), and abnormal Papanicolaou smears or cervical dysplasia (Cohen, 1997(Gilad, Walfisch, Borer, & Schlaeffer, 2003). These conditions lead to painful gynecological symptoms. One research study reported that 58% of women with HIV are infected with human papillomavirus (HPV), marked by sores, blisters or growths on the outer genitals (Levine, 2002). Women infected with HIV are more likely to have persistent HPV infection over time which is associated with invasive cervical cancer (De Vust, 2008). They are more likely to experience symptoms associated with gynecologic infections and malignancies than other, non-infected women. These symptoms are complex, painful and distressing to those who experience them (van Servellen, Sarna, & Jablonski, 1998). Moreover, the care needed to manage these symptoms can be overwhelming for women. However, in order to live

well, a woman with HIV must learn to manage her symptoms in spite of the challenges she faces.

In addition to the physical manifestations of HIV infection, individuals also experience severe consequences affecting their quality of life related to their symptoms of HIV. The symptoms of HIV were identified as the biggest influence on quality of life in 142 HIV positive people (Sousa, Holzemer, Bakken Henry, & Slaughter, 1999). The general HIV symptoms were also associated with worse health-related quality of life and more disability days (K. A. Lorenz, Shapiro, Asch, Bozzette, & Hays, 2001). Finally, nearly one-third of HIV-positive women reported that coping with HIV symptoms and disorders was one of the worst things to happen to them since becoming infected with HIV (K. A. Lorenz et al., 2001). More recently, Lorenz, et al., (2006) found that, among HIV-infected individuals, worsening totally symptoms was significantly associated with decreased overall health and overall quality of life. They concluded that health care providers and organizations share an important responsibility to improve symptom assessment and management (K. Lorenz, Cunningham, Spritzer, & Hays, 2006)

The symptoms of HIV also have an effect on treatment decisions. HIV-positive patients with higher intensity symptoms scores were found to

be less adherent to their medication regimens, to follow their health care provider's advice or to attend their medical appointments (Holzemer et al., 1999). HIV-positive patients who experienced symptoms, but who did not believe the symptoms were associated with HIV, did not seek medical care (Siegel, Schrimshaw, & Dean, 1999). This literature reveals the great effect that symptoms have on quality of life and general health of individuals living with HIV/AIDS. The consequences of unmanaged symptoms are dire and require a more effective management strategy (Portillo, 2007).

There are many symptom management strategies employed by women who experience HIV symptoms. Patients who utilize these strategies perceive them as being helpful in their symptom management. Previous research demonstrates that people living with HIV/AIDS will actively seek and use strategies to manage their symptoms (Chou, Holzemer, Portillo, & Slaughter, 2004; Portillo, 2007). However, this research also demonstrates that there are barriers to symptom management. For instance, many patients with HIV do not obtain their health care information from health care providers, which may prevent them from receiving evidence-based information (Sowell et al., 1997; van Servellen et al., 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/AIDS in the United States.

Peer-Based Interventions

Peer-based interventions have become a common method to increase important health-related behavior changes (M. Doull, O'Conner, Robinson, Wells, & Tugwell, 2005; Posavac, 1999). However, within the literature on peer-based interventions there is not a generally accepted definition of peer, and, consequently, there is lack of a universal model of what a peer-based intervention is. Peers often share a common culture, language and knowledge of the problems that a particular community experience (Szilagyi, 2002). Moreover, in this context, peers must share the experience of a common health problem (e.g. newly diagnosed tuberculosis) or a potential for change in his or her health status (e.g. breastfeeding for new mothers).

Over the past twenty years there has been a growing body of literature that examines the efficacy of peer-based health care interventions to improve health care. These studies have examined a variety of illnesses, conditions, populations and interventions to determine what can be done at the community level to facilitate positive health care outcomes. Additionally, numerous studies have often tested new ways to reach

minority populations and/or to decrease health care spending. Outcome measures that have been studied include: improved quality of life, improved self efficacy, increased self care and symptom management, and a reduction in harmful behaviors (M. Doull et al., 2005). These studies have concluded that peer-based interventions have the potential to enhance health equity in persons living with disease (Campbell & MacPhail, 2002; M. Doull et al., 2005; Szilagyi, 2002; Turner & Shepherd, 1999). Examples of behaviors targeted include physical activity, smoking and self breast exams (Malchodi et al., 2003; Navarro et al., 1998; Sallis et al., 1999). Peer-based interventions have been found to improve access to health care services, provide support, improve self-efficacy and self-confidence, facilitate involvement in self-care activities and improve cost effectiveness (M. Doull et al., 2005).

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 (IVDUs), partners of IVDUs, 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 six-week, small group, chronic care intervention among 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 one 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/AIDS (Gifford, Laurent, Gonzales, Chesney, & Lorig, 1998).

Interventions for Women Living with HIV/AIDS

Recently, the SMART/EST (Stress Management and Relaxation Training/Expressive Supportive Therapy) Women's Project was developed to help meet the growing needs of minority women living with AIDS (Ironson et al., 2005; Jones et al., 2007). This intervention was led by professional therapists. It was a 10-week group therapy intervention that focused on cognitive-behavioral stress management related to HIV/AIDS. In one of their first studies, they tested different

domains of self-efficacy and how they related to biological and behavioral health outcome. The investigators found that increases in AIDS self-efficacy was correlated with increases in CD4 count and a decrease in viral load. However, they also found that increase in AIDS self-efficacy was not associated with a corresponding decrease in depression or anxiety (Ironson et al., 2005). Further analyses found that change in AIDS self-efficacy predicted change in viral load and change in CD4 count controlling for group assignment. An increase in cognitive-behavioral self-efficacy also predicted a decrease in depressive symptoms and anxiety symptoms. The investigators concluded that people who believe they have the skills to "slow down the development of symptoms" had better biological outcomes.

The analysis of the effect of the SMART/EST intervention on HAART medication adherence was completed in 2007 and included 6 month follow-up data (Jones et al., 2007). The results indicated that participants with any exposure to the group sessions had increased medication adherence compared to those participants who only received the educational control. Additionally, the intervention predicted an increase in "emotion-focused coping skills" related to medication adherence(Jones et al., 2007). The investigators attributed these results to an increase in social learning and emotional support which is supported by other recent literature in the field (Brown &

Vanable, 2008). However, other studies have found the positive effect of cognitive-behavioral interventions on HAART medication adherence and stress management is either short-lived (Brown & Vanable, 2008; M. Johnson, Charlebois, E., Morin, S., Remien, R. & Chesney, M., 2007).

This literature demonstrates that women living with HIV/AIDS are challenged to manage the symptoms of their HIV. Furthermore, unmanaged symptoms have a detrimental effect on a woman's quality of life and the overall management of her disease. This literature also revealed that peer-based interventions and interventions based on increasing self-efficacy are a common method to increase health outcomes and may be helpful in facilitating symptom management in women living with HIV/AIDS.

Methods

This dissertation presents three papers that address different aspects of the focus of this dissertation, Peer-Based Interventions to Increase Symptom Management in Women Living with HIV/AIDS. Each paper is presented in the format required by the journal to which it was submitted. The first paper in this dissertation is, A Systematic Review of the Effectiveness of Peer-Based Interventions on Health-Related Behaviors in Adults. This paper describes the current use of peer-based interventions around the world and synthesizes them using the principles of systematic review. It carefully examines the evidence for

and against the use of peer-based interventions in health-related outcomes studies and laid the foundation for the rest of the work presented in this dissertation.

The purpose of this systematic review was to examine the effect of peer-based interventions on health-related behavior change outcomes in adults. This review revealed three common models of peer-based interventions in health care: group-based peer education intervention (group); the use of peers as "buddies" for individuals (dyads) who are matched for health care concern and demographics; and a combination of the group and dyad models. The data provided evidence that peer-based interventions facilitated some positive health related behavior changes in some outcomes but not all.

The second paper in this dissertation, Community-based, Peer-led Program to Facilitate Self-care & Symptom Management in Women Living with HIV/AIDS: A Descriptive Analysis, describes a small descriptive pilot study that assessed the feasibility of a community-based, peer-led program, the Positive Self Management Program (PSMP), in an all-female sample. This study attempted to gain a better understanding of the symptom experience in women living with HIV/AIDS. It also attempted to understand the role a peer-based intervention could fill in the population and what factors would make

such an intervention more feasible and successful for this urban-dwelling, female population living with HIV/AIDS.

A total of seven, HIV-positive adult women participated in five, two-hour semi-structured focus groups to determine the feasibility of a peer-based intervention to increase symptom management in their community. Results from this study suggest that a community-based, peer-led intervention, similar to the PSMP, has the potential to facilitate symptom management and is feasible for women living with HIV/AIDS.

The final paper in this dissertation synthesized the work of the previous two and tested a peer-based symptom management intervention in women living with HIV/AIDS. This paper, Testing a peer-based symptom management intervention for women living with HIV/AIDS, reports the results of a randomized clinical trial testing the impact of participation in a Peer Based Intervention for Symptom Management (PRISM-HIV) for women living with HIV infection on selected outcome measures including symptom management, medication adherence and quality of life. This study includes 89 HIV-infected women followed over 14 weeks. Results from this study suggest that a peer-based symptom management intervention may not increase symptom management or medication adherence. However, numerous limitations existed.

Conclusion

Each of the three papers presented on the following pages elucidates a different aspect of the topic of this dissertation, Peer-Based Interventions to Increase Symptom Management in Women Living with HIV/AIDS. Each paper has its own distinct research question and methodology and provides a unique contribution to answering this topic and to the larger field of nursing research. These contributions, as well as limitations and recommendations for future work, will be discussed in the final chapter of this dissertation.

A Systematic Review of the Effectiveness of Peer-Based Interventions on Health-Related Behaviors in Adults

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Abstract

Objective: To examine the effect of peer-based interventions on health-related behavior change outcomes in adults.

Methods: Five electronic databases were searched. Randomized clinical trials examining the effect of peer based interventions on health-related behavior changes in adults were selected. Effect sizes were calculated using random effects, DerSimonian-Liard analytic model which examined heterogeneity using a Cochrane's χ^2 test. Effect sizes were calculated either as odds ratios or standardized mean effects.

Results: Twenty-five studies were included. Study sample size ranged from 56 to 2,757 participants with the total sample size representing approximately 8,942 participants. Three intervention models were identified: group-based peer education, peer-provided one-on-one advice and support, or a combination of the two designs. Nine outcomes emerged with effect sizes ranging from -0.50 to 2.86.

Conclusions: The findings indicated that peer-based interventions facilitated important health-related behavior change in adults with a small to medium effect size, including physical activity, smoking cessation and condom use. However, the evidence was mixed. The data provided evidence that peer-based interventions facilitated some

positive health related behavior changes in some outcomes but not all.

Introduction

Peer-based interventions have become a common method to increase important health-related behavior changes (M. Doull et al., 2005; Posavac, 1999). However, within the literature on peer-based interventions there is not a generally accepted definition of peer, and, consequently, there is lack of a universal model of what a peer-based intervention is. Peers often share a common culture, language and knowledge of the problems that a particular community experience (Szilagyi, 2002). Moreover, in this context, peers must share the experience of a common health problem (e.g. newly diagnosed tuberculosis) or a potential for change in his or her health status (e.g. breastfeeding for new mothers). In this review, peer-based interventions are defined as a method of teaching or facilitating health promotion, which asks people to share specific health messages with members of their own community (Szilagyi, 2002).

Over the past twenty years there has been a growing body of literature that examines the efficacy of peer-based health care interventions to improve health care. These studies have examined a variety of illnesses, conditions, populations and interventions to determine what can be done at the community level to facilitate positive health care outcomes. Additionally, numerous studies have often tested new ways to reach minority populations and/or to decrease health care spending.

Outcomes measure that have been studied include: improved quality of life, improved self efficacy, increased self care and symptom management, and a reduction in harmful behaviors (M. Doull et al., 2005). These studies have concluded that peer-based interventions have the potential to enhance health equity in persons living with disease (Campbell & MacPhail, 2002; M. Doull et al., 2005; Szilagyi, 2002; Turner & Shepherd, 1999). Examples of behaviors targeted include physical activity, smoking and self breast exams (Malchodi et al., 2003; Navarro et al., 1998; Sallis et al., 1999). Peer-based interventions have been found to improve access to health care services, provide support, improve self-efficacy and self-confidence, facilitate involvement in self-care activities and improve cost effectiveness (M. Doull et al., 2005).

Despite the importance of these outcomes to one's health, and the rapidly increasing use of these interventions to affect these outcomes, a systematic review of the effect of peer-based interventions on health-related behavior change in adults has not been published in the literature. Systematic reviews synthesize the evidence exploring the effectiveness and appropriateness of interventions in specific circumstances (Collaboration, 2008). These reviews can guide individual health care practitioners and health policy makers to select the best treatment for patients. Given the increasing and diverse

applications of peer-based interventions to health conditions, a systematic review is needed to guide the best use of these interventions. Therefore, this review examined the effect of peer-based interventions on health-related behavior change outcomes in adults in randomized clinical trials.

Methods

Eligibility Criteria

Prospective, experimental studies assessing any health-related behavior change in adults resulting from a peer-led intervention were included in this review. For an article to be included in the analysis, it must have met the following six criteria: 1) participants >18 years of age; 2) subjects randomized to intervention and control groups; 3) a primary outcome of health-related behavior change defined as any measureable behavior change related to a disease or change in an individual's health. 4) independent from other studies; 5) a quality rating greater than 12 out of 18 possible points (Moher, 1998; J. D. Wantland, Portillo, Holzemer, Slaughter, & McGhee, 2004); 6) sufficient information to allow adequate estimate of odds ratios or standardized mean differences and 95% confidence intervals; and 6) a primary population of lay participants, not health care providers.

This systematic review combined all health-related behavior change outcomes. Prominent theories explaining health behavior change state

that it is not the particular behavior that is being affected by an intervention but rather the process of behavior change (A. Bandura, 1986; Bandura, 2004; C. Janz, and Strecher, 2002). While each individual outcome of each peer-based intervention is different, the process of behavior change and the factors that facilitate that change, are similar for each outcome. Therefore, it is reasonable to propose examining different health-related behavior changes as a group.

Identification of Studies

A search was carried out for clinical trials, and no language or time restrictions were applied. The literature up to October 1, 2007 was searched using the following databases: MEDLINE, CINAHL, EMBASE, PSYCHInfor and Cochrane Library and included non-published studies. To search for a peer-based intervention, the following keywords were used: peer-based interventions, peer-led interventions, peer education, peers, peer support, peer counseling, group support, group education, peer leader and opinion leader. The following keywords were used when searching for method: intervention, control trial, randomized control trial, and experiment. Adult was applied as a limit and a general search was done using combinations of keywords for intervention and method. The searches were conducted between August and November, 2007.

Data Extraction

Identified articles were retrieved and using standardized coding forms, data was abstracted from the published articles. Each study was blinded and coded for study, sample and intervention characteristics. Two independent reviewers assessed inclusion criteria for the review and rated the quality of each study, according to the established criteria (Moher, 1998; J. D. Wantland et al., 2004). A total of 909 abstracts were retrieved. Each abstract and, if necessary, the full study was reviewed for inclusion in this analysis. After reviewing these articles, 27 were judged to meet the inclusion criteria. However, two articles did not provide the data necessary to calculate effect sizes. The corresponding authors were contacted and asked to provide this information. They were unable to do so and consequently the articles were removed from the final analysis (Auslander, Haire-Joshu, Houston, Rhee, & Williams, 2002; Merewood et al., 2006). Therefore, a total of 25 articles were included in the final analysis (Figure 1).

Data Analysis

Several studies reported multiple behavior change outcomes with varying endpoints. When several outcomes were measured in one study, the most relevant and clinically meaningful outcome that could be themed with other studies was selected. The outcome data from the final end point was used, when available, because it would yield the most conservative estimate of the effect. Information on dose was

recorded verbatim from the article. If it was not provided in the printed article or unclear, the author was contacted and asked to provide precise information on dose.

Effect Size Calculation

Each study-specific effect size was calculated and if appropriate, a group effect size was calculated. The outcomes in all studies were reported either as a dichotomous outcome using odds ratios or as continuous outcome using a standardized mean difference score.

For studies reporting their dichotomous outcomes in odds ratios, the study effect and the themed group effect sizes were calculated by applying the random effects of DerSimonian & Laird analytic model (M. Egger, Smith, G.D. & Altman, D.G., 2001; Mosteller & Colditz, 1996). This model assumes that the findings from the individual studies are estimates of a true effect size and have some random error. The study effect sizes were calculated as odds ratio (OR) from the raw data provided in each article. An OR >1 indicates participants in the intervention arm were more likely to achieve a health-related behavior change than participants in the control arm. The summary effect sizes across different studies were calculated as the weighted mean of the individual odds ratios, with weights equal to the inverse of the study variance and the summary effect estimate (M. Egger, Smith, G.D. & Altman, D.G., 2001; Mosteller & Colditz, 1996).

The studies reporting their continuous outcomes as mean difference scores, the study effect sizes were calculated as standardized mean difference also using random effects, DerSimonian & Liard analytic model. This statistic was calculated as the mean outcome between the two groups divided by the standard deviation of the outcome measure in the study. The summary effect size across the different themed studies was calculated as the weighted average of the study-specific effect sizes, with weights equal to the inverse of the estimated variance (M. Egger, Smith, G.D. & Altman, D.G., 2001; Mosteller & Colditz, 1996).

Homogeneity of the individual study effect sizes was evaluated by calculating the Q statistic. This is the weighted average (M. Egger, Smith, G.D. & Altman, D.G., 2001) of the squared difference between summary and study-specific effect sizes and comparing it with an appropriate chi-square distribution. A significance value of 0.10 was selected to determine if heterogeneity was present (A Bandura, 1986). Homogeneity was evaluated for each outcome subgroup and the overall grouped studies. Additionally, subgroups were analyzed by intervention model, intervention setting, sample size, and publication year. This analysis still yielded statistically heterogeneous effects and thus could not explain the heterogeneity in the overall effect size. All analyses were completed with Stata SE v 9.0 (StataCorp, 2005).

Publication bias was assessed by inspection of a funnel plot of the standard error estimates versus effect size estimates from individual samples and by a linear regression test (M. Egger, Smith, G.D., Schneider, M. & Minder, C., 1997).

Results

Description of Studies

Nine hundred and nine abstracts were retrieved and 25 met the final inclusion criteria. Within the 25 articles, 27 individual health-related behavior change outcomes were documented. However, the assumption of independence for statistical analysis requires that each study be counted only once in the calculation. To address this, the studies were grouped by outcome, thematically. Nine themes emerged in this analysis: 1) an increase in breast feeding, 2) an increase in physical activity, 3) an increase in medication adherence, 4) an increase in women's health preventative behaviors (cancer screenings), 5) an increase in self-care activities, 6) smoking cessation, 7) an increase in condom use, 8) completing advance directives, and 9) a decrease in weekly drinking. Twenty-three of the outcomes were separated into these groups with no repeated studies. However, the outcomes from two additional studies (Fromme & Corbin, 2004; Perry et al., 2005) could not be separated into the thematic groups and were analyzed separately. The sample sizes of the included articles ranged from 56 to

2,757 participants with the total sample size representing approximately 8,942 participants. The studies (Table 1) took place in eight countries.

Intervention Model

This review revealed three common models of peer-based interventions in health care. The first is a group-based peer education intervention. This model uses peers as group leaders to guide people with a related health care concern and/or similar demographics to adopt a new behavior that will facilitate healthy outcomes. This was often noted in the literature on increasing physical activity and decreasing weekly drinking (Dongbo et al., 2003; Fromme & Corbin, 2004; K. R. Lorig, Ritter, & Gonzalez, 2003). The second, more popular model uses peers as "buddies" for individuals (dyads) who are matched for health care concern and demographics. In this model, peers provide one-on-one advice and support about how to achieve a certain health care goal. This was also used to increase breast feeding and medication adherence but also to help decrease smoking and to increase mammography screening among relevant populations (Chaisson et al., 2001; Dennis, 2002; N. K. Janz et al., 1997; Kelly et al., 2006). Some studies adopted a third model, a combination of the group and dyad models. Earp et al. (1998) held community events led by lay advisors to increase mammogram in high-risk communities. The lay advisors then followed up with the women by phone conversations on a weekly basis.

Additional information on the model of intervention can be found in Table 1.

Dose

The length of each session varied from 5.3 minutes (N. K. Janz et al., 1997) to 150 minutes (Dongbo et al., 2003; K. R. Lorig et al., 2003). Two studies reported only one contact by the peer leader and the participants (Hunter et al., 2004; N. K. Janz et al., 1997). One study had varying amounts of time that the peer advisor spent with the participants (Tulsky et al., 2000). The maximum number of contacts by the peer leader was 48 (Tulsky et al., 2000). More complete information on the dose and duration of the peer-based intervention can be found in Table 1.

Outcome Type

Breast Feeding

Six articles used a dyad peer-based intervention to increase breast feeding among new mothers. The odds ratio for this group of studies ranged from 0.583 (Anderson, Damio, Young, Chapman, & Perez-Escamilla, 2005) to 37.03(Haider, Ashworth, Kabir, & Huttly, 2000). Eighty-three per cent (5/6) of these results were positive and three were statistically significant. The overall effect size for this outcome was 2.857 (95% Confidence Interval (CI) 0.769-10.61). The heterogeneity chi-square statistic for this outcome was 126.84 (Degrees

of Freedom (df)=5; p<0.0005) indicating significant heterogeneity among these studies.

Physical Activity

Five articles used a combination of all three types of peer-based interventions to increase physical activity in adults. They were employed in a variety of settings and the results were mixed. Three studies reported their outcomes as mean differences between the intervention and control groups and these scores ranged from -0.0951 (Carroll & Rankin, 2006) to 0.208 (K. R. Lorig et al., 2003). The overall effect size for this outcome was 0.1578 (95% CI 0.047-0.269) . The heterogeneity statistic for this analysis was 1.699 (df=3; p=0.57) indicating no heterogeneity among the three studies.

Medication Adherence

Three articles used a combination of peer-based interventions to increase medication adherence. Two studies reported odds ratios which included 0.305, (a statistically significant difference) (Chaisson et al., 2001) and 0.926 (Tulsky et al., 2000). Additionally, Simioni et al., 2007 reported a mean difference of -0.1972 between the intervention and control group(Simoni, Pantalone, Plummer, & Huang, 2007). These results indicate that the control group had better medication adherence than the peer-based intervention groups. The overall effect size for this outcome was 0.502 (95% CI 0.17-1.48). The heterogeneity

chi-square statistic for this outcome was 3.88 (df=1; p=0.049) indicating significant heterogeneity among these two studies.

Women's Health Cancer Screening

Three articles were classified as having women's health outcomes. These outcomes included an increase in mammography screening (Allen, Stoddard, Mays, & Sorensen, 2001; N. K. Janz et al., 1997) and an increase in gynecological cancer screening (Hunter et al., 2004). These studies reported their outcomes in odds ratios which ranged from 1.05 to 3.33, all of which indicated an increase in women's health activities in the peer-based groups. The overall effect size for this outcome was 1.88 (95% CI 0.82-4.30). The heterogeneity chi-square statistic for this outcome was 19.25 (df=2; p<0005.) indicating significant heterogeneity among these three studies.

Smoking Cessation

Two articles used dyad, peer-based interventions to increase smoking cessation. Their reported odds ratios were 1.26 (Malchodi et al., 2003) and 1.79 (Emmons et al., 2005) . These results indicate that the intervention group had higher levels of smoking cessation than the control group. The overall effect size for this outcome was 1.64 (95% CI 1.09-2.46). The heterogeneity chi-square statistic for this outcome was 0.470(df=1; p=0.470) indicating no heterogeneity among these studies.

Participating in General Activities

Two articles examined whether peer-based interventions could increase general activities in participants with chronic disease. They both used dyad peer-based interventions and reported the mean differences between the groups as being 0.5381 and -0.476. These opposing scores yielded an overall effect size as 0.3043 (95% CI -0.339 to 0.424), indicating that the intervention did not have a significant effect on whether the participants engaged in more general activities compared to the control group. The heterogeneity statistic for this analysis was 6.788 (d1=3; p=0.991) indicating no heterogeneity among the two studies.

Condom Use

Two articles used dyad, peer-based interventions to increase condom use and reported odds ratios of 2.12 (Basu et al., 2004) and 2.39 (Kelly et al., 2006). Both of these articles reported statistically significant and positive outcomes indicating that participants in the peer-based intervention reported more condom use than those in the control group. The overall effect size for condom use was 2.266 (95%CI 1.145-3.54). The heterogeneity statistic for this outcome was 0.07 (df=1; p=0.797) indicating no heterogeneity among these studies.

Non-Themed Outcomes

Two studies reported behavior change outcomes that could not be themed with at least one other article. Perry et al. (2005) employed a dyad, peer-based intervention model to increase the rate of

participants completing advance directives among dialysis patients. They reported a statistically significant odds ratio of 4.89 (95% CI 2.00-11.98), indicating that those who participated in the intervention were more likely to complete advance directives. Frome and Corbin (2004) used a group peer-based intervention to decrease alcohol intake among university students. They reported mean differences between the intervention and control groups and the standardized mean difference was 0.3521 (95% CI of 0.11-0.59). This indicates that the intervention had a significant, yet moderate effect on changing the drinking behavior among intervention participants, compared to the control group. More information on reported effect sizes can be found in Figures Two and Three.

Summary Effect Size

After testing the data for heterogeneity and publication bias, it was decided not to report the overall group effect size for all of the studies due to significant heterogeneity The chi-square statistic for the articles with dichotomous outcomes was 214.65 ($df=16$; $p<0.005$); the Q statistic was 23.26 ($df=7$; $p= 0.0015$) for the articles reporting continuous outcomes. Additionally, the subgroup analyses by intervention model, intervention setting, sample size, and publication year still yielded statistically heterogeneous effects and similar effect sizes, and thus could not explain the heterogeneity in the overall effect size.

Discussion

Peer-based interventions have been increasingly used to facilitate health-related behavior changes in adults around the world. The evidence evaluating the overall effectiveness of these interventions has not yet been systematically synthesized. This review is the first to examine the effect of peer-based interventions on behavior change outcomes in adults.

This systematic review analyzed 25 different studies, attempting to determine whether or not peer-based interventions are effective in promoting health-related behavior changes in adults. Three distinct models of peer-based interventions that were repeatedly used throughout the literature were identified- dyads, groups and a combination of both. Subgroup analyses by intervention model did not reveal whether any one model had better outcomes than another. The majority (72%) of models employed the dyad model; perhaps because it is the simplest intervention model to implement. This model allows the peers to "individualize" the intervention to meet the participant's needs. It permits for flexibility with the participants' schedule and logistical concerns. It can also facilitate a more personal bond with their peer leader and increase his/her legitimacy with the participant and in turn increase the participant's willingness to try and sustain the proposed behavior. Nevertheless, it is difficult to analytically control

for these factors and given the wide variation in study results utilizing this intervention, there was little evidence within this review to determine which model yields better outcomes.

To answer the primary research question, our analyses demonstrated that three of the seven outcomes had significant, positive findings when analyzed as a group (increasing physical activity, decreasing smoking and increasing condom use). Additionally, one individual study had significant, positive outcome of increasing advance directive completion. These are desirable health outcomes which will have a positive impact on the health of the individual, his or her family, and the greater public health care system. That peer-based interventions work in these outcomes suggests that peer-based interventions may be useful with other outcomes. However, the evidence is mixed. The remaining four outcomes did not yield a significant difference between those who participated in the peer-based intervention and those who were in the control group (breast-feeding, medication adherence, women's health, and participating in general activities). This may be related to the variability of each intervention within themed outcomes; for example, the training and experience level of the peers may have varied which can lead to mixed results, even within the same theme. Additionally, the dose of the intervention, even within themed outcomes, was varied. Within the theme of breastfeeding, the peers

spent from 16 minutes to over 2 hours with the participants. This variability in dose may have lead to the heterogeneity among the studies.

Study Strengths

This systematic review has several strengths, which include the use of explicit eligibility criteria, independent reviewers assessing eligibility and the use of the random-effects analytic model. We included only randomized clinical trials to help eliminate confounding from other variables. Yet, even within themes, there was little standardization among the studies. We used subgroup analyses to explore the effect of the varied intervention models, follow up times, settings, training of peer leaders, and doses of intervention among the different studies, even within themes. However, the sub-group analyses did not reveal any variables that can explain the differences in outcomes.

Study Limitations

The main limitation of this review was including study quality as an exclusion criterion. To address concerns about study rigor, quality was assessed by two individual reviewers using a standardized instrument. The use of quality rating scores is controversial but only 18 of 909 studies were eliminated from the analysis due to low quality scores (Balk, 2002). This score was used to facilitate the inclusion of more generalizable studies. For example, one study that was excluded had a

sample size of eight. Other studies excluded did not explain how the investigators collected their data or which instruments they used.

Furthermore, an additional limitation is the heterogeneity of some outcomes. While health behavior change theories suggest that it is appropriate to combine the varied behavior change outcomes, the statistical assumptions of systematic reviews suggest otherwise. We found significant heterogeneity in our overall analysis and among some of our themed outcomes. Although it is possible that a large amount of this heterogeneity is related to the clinical diversity of the studies, there is not enough evidence to determine if this is the case. This limited our ability to answer the overall research question. Subgroup analyses did not reveal the source of the heterogeneity but did eliminate variables such as intervention model, intervention setting, sample size, and publication year . However, in the future this may be avoided by the use of a common definition of peer-based intervention and a common evaluation protocol, including follow up time.

Additionally, most of these outcomes were ascertained by self-report. Given the nature of behavior change, it can be difficult to efficiently assess one's individual behavior change without using self-report. It is better to complement self report with a direct measure of behavior

change, when available. These outcomes could have included the measurement of pediatric diseases, changes in weight, HIV viral control or the levels of cancer, however few of these studies reported these outcomes. Given the low prevalence of some of these outcomes, it may be very challenging to have an adequately powered sample size to answer these questions. In the future it is advisable for investigators to include such clinical outcomes or an accepted proxy in their research protocols.

Finally, we were unable to assess the effect of the dose of intervention on behavior change outcomes because each study reported dose differently. The authors did not report this information in a way that could be combined (i.e. some reported the number of sessions but not total time spent). Peer-based interventions are naturally more flexible and lend themselves to real-world applications. The application of these interventions to community problems is a strength of the intervention but the inability to quantify the dose of the intervention limited our ability to do quantitative statistical analysis. We recommend that future studies report dose in standardized units of time to assist determining the effect of dose.

In conclusion, health-related behavior changes are increasingly important as many health conditions are becoming more chronic and

less susceptible to biomedical interventions. The chronic nature of these diseases will require people to modify their activity level and decrease unhealthy behaviors. There will be an emphasis on prevention of disease. This systematic review found positive evidence that peer-based interventions may help facilitate these outcomes. However, this evidence was mixed. There was not a significant effect on breast-feeding, medication adherence, women's health and participating in general activities-outcomes. Future research on peer-based interventions should be conducted using rigorous methodology, including the quantification of dose in time, to facilitate synthesis of this literature.

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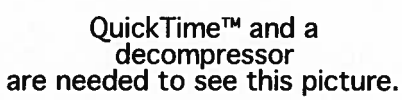
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Table 1: Study Characteristics

Study	Sample Size	Model [a]	Setting	Dose of Intervention [b]	Duration of Intervention	Odds Ratio	Standardized Mean Difference	Country
Breast Feeding								
Muirhead, P. et al., 2006	225	Dyad	Telephone Call	Varied by pair	One Month and if requested 4 months	5.14	-------	Scotland
Anderson, A. et al 2005	135	Dyad	Home & Hospital	Average of Prenatal visits were 2.6 ± 1.9 hrs; Average in-hospital visit was 2.2± 2.0 hrs	Six weeks	0.58	-------	USA
Madeiro-Leite, A. et al 2005	859	Dyad	Home	Average of 30-40 mins per session	Maximum of six visits over four months	1.41*	-------	Brazil
Chapman, D. et al 2004	157	Dyad	Home & Hospital	20 mins per session	One month	1.75	-------	USA
Dennis, C. et al 2002	258	Dyad	Home	Mean duration of 16.2 mins ± 12.22 mins per session	Mean 53.1 ± 30.90 days	2.58*	-------	Canada
Haider, R. et al 2000	573	Dyad	Home	20-40 mins per session	15 sessions	37.03*	-------	Bangladesh
Physical Activity								
Carroll, D. & Rankin, S., 2006	89	Dyad	Telephone Call	Average of 1 call/week	Three Months	------	-0.10	USA
Kramish-Campbell, M. et al 2004	352	Combination	Church	Varied by church	Nine Months	------	0.56*	USA
Dongbo, F. et al 2003	725	Group	Not given	150 mins per session	Six Weeks	------	0.16*	China
Lorig, K. et al., 2003	443	Group	Outpatient clinics	150 mins per session	Six Weeks	------	0.21*	USA
Lamb, S. et al.,2002	250	Combination	Telephone calls	Up to 3 calls	12 months	1.28	-------	United Kingdom
Medication Adherence								
Simoni, J. et al., 2007	136	Combination	Home and clinics	12 hours	Three Months	------	-0.20	USA
Chaisson, R. et al., 2001	201	Dyad	Clinic	Two connections in the 1st month and one connection per month thereafter	Six Months	0.30*	-------	USA
Tulsky, J. et al., 2000	73	Dyad	Not given	Varied by pair	Six Months	0.93	-------	USA

Study	Sample Size	Model [a]	Setting	Dose of Intervention [b]	Duration of Intervention	Odds Ratio	Standardized Mean Difference	Country
Women's Health Cancer Screening								
Hunter, J. et al., 2004	101	Dyad	Home	1 home visit	Not Given	1.99	-------	USA
Allen, J. et al.,2001	2757	Combination	Workplace	20 minutes per session	16 Months	1.05	-------	USA
Janz, N. et al., 1997	460	Dyad	Telephone call	Mean of 5.3 mins per call	Once	3.33*	-------	USA
Smoking Cessation								
Emmons, K. et al., 2005	796	Dyad	Home	Up to 6 calls	Seven Months	1.79*	-------	USA
Malchodi. et al. , 2003	118	Dyad	Home and Telephone call	Mean of 45 ± 15 mins per session	Median of Six Contacts	1.26	-------	USA
Condom Use								
Kelly, J. et al., 2006	275	Dyad	Community	Mean of 6.8 mins per session	Three Months	2.39*	-------	Bulgaria
Basu, I., et al., 2004	172	Dyad	Workplace	One session a month	16 Months	2.12*	-------	India
Participate in General Activities								
Riegel, B. & Carlson, B., 2004	88	Dyad	Telephone Call	Varied by pair	Three months	------	-0.49	USA
Parent, N. & Fortin, F., 2000	56	Dyad	Hospital	3 visits	One Month	------	0.54	USA
Complete Advance Directives								
Perry, W. et al., 2005	203	Dyad	Home and Hospital	Varied by pair	Four Months	4.90*	-------	USA
Weekly Drinking								
Frome, K. & Corbin, W., 2004	357	Group	University Health Center	Two hours per session	Two Sessions	------	0.35*	USA

*; Significant with a p-value ≤ 0.05

a ;Model refers to the model of intervention used. Dyad is a one-on-one peer counseling method. Group is a group peer education sessions. Combination is a both the dyad and group models

b ;All information on dose was recorded verbatium from the article. If it was not provided in the printed article or unclear, the author was contacted and asked to provide precise information on dose.


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Table Two: Outcome Characteristics

Outcome	Number of Studies	Total N	Range	Overall Effect Size
Breast Feeding	6	2,207	OR[a]: 0.58-37.03	OR: 2.86
Physical Activity	5	1,117	SMD[b]:-0.10-0.56 OR:1.9	SMD: 0.16[c]
Medication Adherence	3	410	SMD: -0.29 OR:0.31-0.93	OR: 0.50
Women's Health	3	2,855	OR:1.05-3.33	OR: 1.88
Smoking Cessation	2	826	OR:1.26-1.79	OR: 1.64[c]
Condom Use	2	447	OR:2.12-2.39	OR: 2.27[c]
Participating in General Activities	2	144	SMD:-0.49-0.54	SMD: 0.30
Completing Advance Directives	1	144	OR:4.89	OR: 4.89
Decrease Weekly Drinking	1	357	SMD:0.35	SMD: 0.35

a OR: Odds Ratio

b SMD: Standardized Mean Difference

c;Significant with a p-value ≤ 0.05

Community-based, Peer-led Program to Facilitate Self-care & Symptom Management in Women Living with HIV/AIDS: A Descriptive Analysis

Abstract Word Count 119
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References 34

Key Words: HIV, AIDS, Community, Symptom Management, Women

ABSTRACT

There is an increasing need for community-based interventions to help women living with HIV/AIDS better manage their symptoms and self-care. The investigators conducted a small descriptive pilot study was to assess the feasibility of a community-based, peer-led program, the Positive Self Management Program (PSMP), in an all-female sample. A total of seven, HIV-positive adult women participated in five, two-hour semi-structured focus groups to determine the feasibility of the PSMP in their community. They also completed a brief survey on demographic information, HIV medications, HIV symptoms and self efficacy. Quantitative and qualitative data are presented. Results from this study suggest that a community-based, peer-led intervention has the potential to facilitate symptom management is feasible for women living with HIV/AIDS.

Introduction

HIV/AIDS is 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/AIDS, 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.

Symptoms

The symptoms of 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 (Cohen, 1997). After a period without physical symptoms, the disease progresses to a pre-AIDS defining stage. Symptoms at this stage include lymphadenopathy, frequent fevers, night sweats, and rapid weight loss without dieting, chronic fatigue, depression, anorexia, and diarrhea (Cohen, 1997).

With the development and widespread distribution of Anti-retroviral medication, HIV has become a chronic disease. Accordingly, the symptoms experienced have slightly changed 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 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 (Mannheimer et al., 2008).

Several studies have recently explored the relationship between anti-retroviral medications and symptoms. Wantland, et al (2008) found that individuals taking ARVs had a higher than expected report of loose stools, diarrhea, shortness of breath with activity, weight gain in the stomach area, hump on back of the neck, skinny arms/legs, and prominent, leg veins, thirst and insomnia. Additionally, individuals taking ARVs that included a protease inhibitor had significantly higher symptom intensity than those who were not on ARVs or not on a regimen containing a Protease Inhibitor. Specifically, they found that individuals taking ARVs with PIs had higher than expected weight gain, hump on back of the neck, skinny arms and legs, prominent leg veins and gas/bloating (D. J. Wantland et al., 2008). Additionally, Johnson, et al. (2003) found that HIV-infected individuals were able to identify the symptoms of stomach, nausea and vomiting, constipation, and alterations in taste sensation as side effects of their ARV medication. They also identified tender or enlarged lymph nodes/glands, night sweats, unintentional weight loss, fever, and loss of strength as

consequences of their HIV infection. These authors also identified that many individuals attribute 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 (M. O. Johnson et al., 2003).

In addition to the general HIV-symptoms experienced by women, they may also experience gender-specific manifestations including sexually transmitted infections, Pelvic Inflammatory Disease (PID), and abnormal Papanicolaou smears or cervical dysplasia (Cohen, 1997(Gilad et al., 2003). These conditions lead to painful gynecological symptoms. One research study reported that 58% of women with HIV are infected with human papillomavirus (HPV), marked by sores, blisters or growths on the outer genitals (Levine, 2002). Women infected with HIV are more likely to have persistent HPV infection over time which is associated with invasive cervical cancer (De Vust, 2008). They are more likely to experience symptoms associated with gynecologic infections and malignancies than other, non-infected women. These symptoms are complex, painful and distressing to those who experience them (van Servellen et al., 1998). Moreover, the care needed to manage these symptoms can be overwhelming for women. However, in order to live well, a woman with HIV must learn to manage her symptoms in spite of the challenges she faces.

In addition to the physical manifestations of HIV infection, individuals also experience severe consequences affecting their quality of life related to their symptoms of HIV. The symptoms of HIV were identified as the biggest influence on quality of life in 142 HIV positive people (Sousa et al., 1999). The general HIV symptoms were also associated with worse health-related quality of life and more disability days (K. A. Lorenz et al., 2001). Finally, nearly one-third of HIV-positive women reported that coping with HIV symptoms and disorders was one of the worst things to happen to them since becoming infected with HIV (K. A. Lorenz et al., 2001). More recently, Lorenz, et al., (2006) found that, among HIV-infected individuals, worsening totally symptoms was significantly associated with decreased overall health and overall quality of life. They concluded that health care providers and organizations share an important responsibility to improve symptom assessment and management (K. Lorenz et al., 2006)

The symptoms of HIV also have an effect on treatment decisions. HIV-positive patients with higher intensity symptoms scores were found to be less adherent to their medication regimens, to follow their health care provider's advice or to attend their medical appointments (Holzemer et al., 1999). HIV-positive patients who experienced symptoms, but who did not believe the symptoms were associated with

HIV, did not seek medical care (Siegel et al., 1999). This literature reveals the great effect that symptoms have an HIV-positive woman's quality of life and their health. The consequences of unmanaged symptoms are dire and require a more effective management strategy (Portillo, 2007).

There are many symptom management strategies employed by women who experience HIV symptoms. Patients who utilize these strategies perceive them as being helpful in their symptom management. Previous research demonstrates that people living with HIV/AIDS will actively seek and use strategies to manage their symptoms (Chou et al., 2004; Portillo, 2007). However, this research also demonstrates that there are barriers to symptom management. For instance, many patients with HIV do not obtain their health care information from health care providers, which may prevent them from receiving evidence-based information (Sowell et al., 1997; van Servellen et al., 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/AIDS 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 twenty years. Historically, peer-based interventions have been employed in countries other than the United States, specifically the United Kingdom countries, to "carry out health promotion work among young people" (Backett-Milburn & Wilson, 2000). However, that has been changing in the last 10 years. We recently reviewed the Cochrane Library and found two reviews that have focused on peer-based interventions in chronic disease management and (Doull et al., 2004; Halpern, 2006). While peer-based interventions can be traced back to antiquity (Wagner, 1982),, more recently they have been used in health projects targeting a reduction in smoking, a reduction in 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 (IVDUs), partners of IVDUs, 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 six-week, small group, chronic care intervention among 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 one year compared to those who did not participate in the intervention (Lorig et al., 2005). We also found a similar program that had comparable effects on symptom management and medication adherence among men living with HIV/AIDS (Gifford et al., 1998).

As for women living with HIV/AIDS, few studies have examined strategies to improve symptom management and self-care. 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 behaviour in women

living with HIV; however, more research is needed prior to wide-spread implementation. The objective of this small pilot study was to assess the feasibility of a community-based, peer-led program called the Positive Self Management Program (PSMP), in an all-female sample.

The Positive Self Management Program (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 PSMP program contains seven, two-hour, scripted modules that will be delivered by peer leaders each week for seven weeks. This skill-building curriculum contains modules that address: symptom self-management strategies (emotional, cognitive and physical), symptom monitoring, problem-solving, and 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 to become better self-managers of their HIV symptoms, as a chronic disease. This intervention was pilot tested in 72 HIV positive 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 was a descriptive qualitative study that assessed the feasibility of a community-based, peer-led program, the Positive Self Management Program (PSMP), in an all-female sample. Participants for this study were recruited from HIV care clinics affiliated with the Positive Health Program at the University of California, San Francisco. Their HIV case manager or primary HIV care provider either referred participants, or they were directly recruited with flyers posted in the clinic. Identified persons were screened by the study coordinator in a private clinic room or by telephone. Eligible participants were at least 18 years of age, HIV positive, English speaking and self-identified as female. Only those participants who met these criteria were included. A letter of diagnosis from the participant's primary care provider and corresponding picture ID verified HIV diagnosis.

Procedure

The study coordinator obtained informed consent from each participant prior to initiation of study procedures. Each participant participated in five, two-hour semi-structured focus groups to assess the feasibility of implementing the Positive Self-Management Program in this community. Specifically, feasibility was defined as the belief that members of the community needed and wanted a community-

based symptom management program, such as the Positive Self-Management Program. The study coordinator called each participant the day before each group session to remind her about the session's time and location and to encourage her to attend.

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 symptom management (Morgan, 1997). The study coordinator, who is a nurse, facilitated the focus groups. To fully ascertain the participant's beliefs of the feasibility of a community-based symptom management program, such as the Positive Self-Management Program, the concept was deconstructed into four themes based on a literature review. Each of the group sessions were organized around these themes: 1) significance of common symptoms experienced, 2) symptom management, 3) barriers and facilitators to symptom management, and 4) potential symptom-management interventions. During the first session, participants focused on common symptoms women experienced and how it 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, the participants were given an outline of the Positive Self Management Program and asked to share their opinions on its

appropriateness for the community. These 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 their accuracy.

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 a week for five weeks. Food was provided. Participants were compensated with $25 for each completed session for a total of $125.

All study procedures were approved the Institutional Review Board at the University of California, San Francisco.

Measures

Demographics

Age, race/ethnicity, work/income, education, health insurance, family, date of HIV diagnosis, other health conditions, and current HIV medication use were self-reported.

HIV symptoms

To assess symptom intensity, participants completed the Revised Sign and Symptom Checklist for Persons with HIV Disease (SSC-HIVrev). This instrument consists of three parts and seeks to identify current symptoms and symptom intensity. There are 72 symptoms and each scored on a 0-3 score. A score of 0 indicates that the participant is has not experienced that symptom and a score of 3 that the participant severely experienced that symptom, in the past 24 hours. The mean daily symptom intensity score is computed by summing every symptom intensity and dividing by 72.The total score reliability estimate (Cronbach's alpha) was 0.97 (Holzemer WL, Henry SB, Portillo CJ, & Miramontes, 2000).

Self-Efficacy

Participants completed the Chronic Disease Self-Efficacy Scale (K. Lorig et al., 1996) to assess their own perception of their ability to manage their 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 which are measured by the instrument include: regular exercise, ability to obtain help from family and friends, communication with the physician, disease management, chores, social/recreational activities, symptom management, and management of depression. It has reliability estimates ranging from 0.82-0.92 (K. 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: 1) symptoms experienced, 2) symptom management, 3) barriers and facilitators to symptom management, and 4) 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. Since the data was not digitally recorded, the comments will not be presented in quotation marks.

Results

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

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

In the first week, participants were prompted to discuss their experience with the symptoms of HIV/AIDS. In accordance with previous qualitative work on the burden of HIV/AIDS (van Servellen et al., 1998) we found that symptoms continue to be distressing to women living with HIV. One especially telling comment describing 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, women acknowledged that they tried to manage their symptoms by following the advice of their health care providers. However, something always prevented the participants from fully managing their most distressing symptoms. Some of the comments included:

> 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 it's 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. Some comments included:

I feel like I am not a person since I got this virus. Nobody respects me. When the ambulance picks me up (in the TL) 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 Positive Self Management Program 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. 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 the final focus group, a copy of the group summation 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 Two.

Discussion

This was a descriptive qualitative study that assessed the feasibility of a community-based, peer-led program, the Positive Self Management Program (PSMP), in an all-female sample. 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).

The participants in these focus groups are a representative cross-section of the most vulnerable woman living with HIV in the United States today. They are minority women who are often marginalized from society. They are poor and unemployed, and they must frequently balance the competing roles of caregiver and patient. Additionally, they represent various stages of HIV disease and suffer from distressing chronic co-morbidities. Their daily symptom experiences were quite diverse—some women reported no symptoms while others reported moderate to severe symptoms. Their self-efficacy scores were similarly varied.

Despite 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: 1) Women living with HIV/AIDS may experience a great deal of distress related to the symptoms of their HIV disease and its treatments; 2) The management of these symptoms is very challenging for women because of numerous barriers; 3) A symptom management intervention for women living with HIV/AIDS such as the Positive Self Management

Program is needed and wanted; and 4) Peers should be used in all aspects of the intervention (including selecting community sites and recruiting participants).

Previous studies have reported similar findings of women struggling to manage their distressing HIV-related symptoms (Spirig, 2005; van Servellen et al., 1998). In this 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 can be applied across acute and home-care settings that the patient, family and friends can successfully implement. Several studies have explored the mechanism of symptom management in individuals infected with HIV.

People living with HIV utilize many self-care strategies to manage their symptoms of HIV (Chou et al., 2004). Participants perceive that these strategies helpful in managing their symptoms of HIV. While this study didn't directly assessed barriers and facilitators to symptom management in women living with HIV/AIDS, the investigators reported that a majority of individuals with HIV did not learn their symptom management strategies from their health care providers; rather they learned them through experiences and experiments. These

results are compatible with other research findings and suggest that peer-modeling or education may facilitate utilization 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)

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

However, participants also indicated that there are real barriers that prevent women from achieving these goals. Women living with HIV/AIDS struggle to communicate with their healthcare providers. They feel their providers are stigmatizing them and that the treatment prescribed reflects the provider's preferences instead of their own. Participants felt that they do not hold equal weight in making health-related decisions and this has caused them to disengage from that part

of their symptom management. Participants in our study acknowledged that the stigma associated with HIV/AIDS in the larger community will stop women from attending any sort of group that identifies them as having HIV, a concern that has been reported previously (Sandelowski, Lambe, & Barroso, 2004).

Despite these barriers, the participants were excited about the Positive Self Management Program. 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, group self-management program should take advantage of the above-mentioned strengths; however, it must also consider these important barriers and offer solutions for overcoming them.

Limitations of this study include its small size. While this sample demographically reflects the most vulnerable population living with HIV in the United States today (CDC, 2006), there is not enough power to extrapolate these findings to a larger sample. Additionally, because women self-selected into this study, the results may have been biased. Finally, the group sessions were not tape-recorded. The comments of

the participants were manually recorded and then analyzed in the methods described above.

Conclusions

Symptom management is an increasingly distressing, yet important, issue for women living with HIV/AIDS. A community-based, peer-led intervention has the potential to facilitate symptom management and is feasible for women living with HIV/AIDS. 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/AIDS 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 community-based, peer-led programs that teach symptom management strategies, similar to the Positive Self-Management Program, for their patients.

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Table 1: Baseline Characteristics of Study Participants

	N=7
Age	Mean =45 (SD=7, 35-55)
Race	87% African American 13% Latina
Education	50% 11th grade or less 13% High school degree 25% 2 years of college 13% College degree (4 years)
Employed	0
Insurance	100% Medical
Children	57 (4/7) % have children (Range:1-7 children)
Year diagnosised	Mean = 1992 (Range: 1984-2000)
HIV Medications	57 (4/7)% on Antiretroviral Therapy
Comorbidities	Depression, hypertension, hepatitis
Symptom Intensity	Mean=0.70 (SD=0.84, 0-2.30)
Self Efficacy to Manage Chronic Disease	Mean=5.14 (SD=4.34)

Table 2: Weekly Topic and Results

Week	Topic	Participant Feedback	Results	Clinical Considerations
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."	• Every women experiences different, yet equally distressing symptoms related to her HIV disease; • Bad symptoms are often attributed to medications;	• To adequately assess symptom burden of HIV/AIDS and its related treatments;
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."	• The management of these symptoms is very challenging for women; • Symptom management is important and desirable;	• To assess current symptom management techniques; • To recommend appropriate symptom management strategies;
3	Barriers/Facilitators to symptom management	"I feel like I am not a person since I go 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	• To create an environment where women can communicate effectively with her health care provider; and
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/AIDS can help newly diagnosed women with their symptom management; • The Positive Self Management Program is feasible	• To refer patient to community-based, peer led symptom management interventions
5	Feedback on focus-group summation		• Not applicable	

Table 3: Clinical Considerations for Nurses Working with Women Living with HIV/AIDS

To adequately assess symptom burden of HIV/AIDS and its related treatments;
To assess current symptom management techniques;
To recommend appropriate symptom management strategies;
To create an environment where women can communicate effectively with her health care provider;
To consider developing community-based, peer-led programs that teach symptom management strategies

RESEARCH ARTICLE

Testing a peer-based symptom management intervention for women living with HIV/AIDS

Short title: Peer-based symptom management

Abstract

Objective: To test the impact of participation in a Peer Based Intervention for Symptom Management for women living with HIV infection on selected outcome measures including, symptom intensity, medication adherence, viral control and quality of life.

Design: Randomized Clinical Trial

Methods: Participants were recruited using a convenient, consecutive sampling method. Those participants randomized to the experimental condition attended seven, peer-led sessions over seven weeks. Participants randomized to the control condition received a copy of HIV Symptom Management Strategies: A Manual for People Living with HIV/AIDS. Participants completed four surveys assessing change over time in the aforementioned outcome variables.

Results: Eighty-nine HIV-infected women were followed over 14 weeks and there were no differences between the two groups on baseline demographic variables. Mixed-effects regression indicated no significant difference between groups across time in total symptom intensity score, viral control and medication adherence. There was a significant difference between groups across time for two of the nine

quality of life scales- HIV Mastery (χ^2=25.08; p <0.005) and Disclosure Worries (χ^2=24.67; p <0.005).

Conclusions:

In urban-dwelling women living with HIV/AIDS, results suggest that a peer-based symptom management intervention may not decrease symptom intensity or increase medication adherence. There is some positive evidence that suggests that the intervention may increase some important aspects of quality of life. However, further research is warranted to elucidate the effect of peer-based interventions in achieving positive self-management outcomes

KEY WORDS

HIV; peer; medication adherence; quality of life; clinical trial

Introduction

Women, particularly vulnerable women, in the United States are increasingly infected with HIV (CDC, 2006; Hall et al., 2008). As a chronic disease, women living with HIV must learn to manage their symptoms and care. This must occur in the face of numerous challenges including stigma which can prevent women from seeking HIV testing and treatment (Gupta, 2002; Sandelowski, Lambe, & Barroso, 2004); lack of economic power (Gupta, 2002; Hunter, 2002) fear of violence (Garcia-Moreno, 2000; Amman et al., 2002); the growing burden of care of infected family members (Ogden & Esim, 2003; Steinberg, Johnson, Schierhout, & Ndewa, 2002) and lack of equal access to health care resources (UNAIDS, 2001). These challenges can prevent women from tending to their own, much-needed care. One important area of self- management in chronic diseases is symptom management. The symptoms of HIV and its treatments are complex, painful and distressing to the women who experience them (M. O. Johnson, Stallworth, & Neilands, 2003; Mannheimer et al., 2008; Sowell et al., 1997a; van Servellen, Sarna, & Jablonski, 1998). Moreover, the care needed to manage these symptoms can be overwhelming for women. These symptoms affect all aspects of a woman's life, including her quality of life (K. Lorenz, Cunningham, Spritzer, & Hays, 2006; K. A. Lorenz, Shapiro, Asch, Bozzette, & Hays, 2001; Sousa, Holzemer, Bakken Henry, & Slaughter, 1999), her adherence to HIV therapy

(Holzemer, Henry, Portillo, & Miramontes, 2000) and her treatment decisions (Portillo, 2007; Siegel, Schrimshaw, & Dean, 1999).

Peer-based interventions have the potential to increase symptom management (Chou, Holzemer, Portillo, & Slaughter, 2004a; A. Gifford, Laurent, Gonzales, Chesney, & Lorig, 1998; Lorig, Ritter, & Plant., 2005; Sowell et al., 1997b; van Servellen et al., 1998) and enhance health equity in women with HIV/AIDS (HRSA, 2005). Peer-based interventions have been found to improve access to health care services, provide support, improve self-efficacy and self-confidence and facilitate involvement in self-care activities (Doull, O'Conner, Robinson, Wells, & Tugwell, 2004; Higgins, Thompson, Deeks, & Altman, 2003; Van Rompay, 2008). Consequently, a peer intervention model may facilitate change in the symptom management behavior in women infected with HIV. To date, no studies have been located that have explored the benefits of utilizing a peer-led intervention program to help facilitate symptom self-management for HIV/AIDS in an all-female sample. Therefore, the main objective of this study was to test the impact of participation in a Peer Based Intervention for Symptom Management (PRISM-HIV) for women living with HIV infection on selected outcome measures including symptom management, medication adherence and quality of life.

Methods

Participants

Eligible participants were HIV-infected adults who self-identified as female and spoke fluent English. Anyone not meeting these criteria was excluded. Recruitment occurred from January to November, 2008. The last participant completed follow-up through 12 weeks after randomization on January 12, 2009. Participants were recruited from San Francisco Bay Area outpatient HIV outpatient clinics, HIV/AIDS specific housing and HIV/AIDS related community-based support/peer groups.

Intervention

The intervention tested was a peer-based, HIV symptom management intervention. The content of the curriculum for the peer-led sessions is the Positive Self Management Program (PSMP) designed at Stanford University in 1997 (Gifford, 1999; A. Gifford et al., 1998). This intervention was developed using Social Cognitive Theory, emphasizing the role of self-efficacy, as its guiding framework. The PSMP program contains seven, two-hour, scripted sessions that were delivered by two trained peer leaders each week for seven weeks. The topics for each of the seven sessions are presented in Table 1. A registered nurse was present at all group sessions to provide any necessary information and in case of any emergencies. This

intervention was pilot tested in 72 HIV positive men in southern California in 1998. A significant relationship was found between the participation in the intervention and decreased symptom intensity, decreased viral load and increased medication adherence (A. Gifford et al., 1998).

Peer Leaders

Three peer leaders were identified as leaders by HIV case-managers, community leaders and health care workers. These women participated in a five-week pilot study to assessing the community's need for and interest in a peer-based intervention to enhance self-care and symptom management in women living with HIV/AIDS. Two of the women have been trained as peer advocates by community-based organizations and all had experience giving presentations on living with HIV/AIDS prior to involvement with this proposed study.

Each peer leader completed a five-day (total of 36 hours) standardized training on the Positive Self Management Program (PSMP) by the investigator and another trained master leader. This scripted training introduced the leaders to the material, taught them how to deliver the intervention, provided experiences to teach the material in teams, introduce teaching techniques (brainstorming, action plans, lecturettes, modeling, discussion and others) and strategies to deal with difficult group members Each participant presented two PSMP

modules and the other peer leader and trainers offered constructive feedback on the presentation (A. Gifford, Lorig, K., Laurent, D. & Gonzalez V. 1995)

Study Design

Participants were randomized after completing a baseline survey and returning the following week. Participants were recruited in blocks of 36 women. After 36 participants, who met the inclusion criteria, volunteered for the study, they were called and invited to participate in the study, give informed consent and complete the baseline surveys. The baseline surveys included demographic questions, general health status questions and questions on HIV management. Participants returning the following week were randomized into either the experimental or control condition. Those randomized to the experimental condition received information on when and where the group sessions would take place, the importance of attending each session, what to expect during the sessions. They attended seven, peer-led sessions over the next seven weeks.

Participants randomized to the control condition also received information about when to return to complete surveys and a copy of HIV Symptom Management Strategies: A Manual for People Living with HIV/AIDS (Wantland et al., 2008). Both groups received phone calls by the investigator reminding them to attend each session in order to

complete four additional surveys at week two, week six, week 10, and week 14. These four surveys described any change the participants' symptom intensity, medication adherence and quality of life throughout the intervention and follow-up period. Participants were paid $15 for completing each survey for a total of $75. An additional $40 bonus was paid to participants in the intervention group who completed all intervention sessions. The Institutional Review Boards at the University of California, San Francisco, Alta Bates Medical Center and Alameda County Medical Center approved all study procedures.

Study Outcomes

The main study outcomes were change in HIV-related symptom intensity, HAART medication adherence, viral control and quality of life.

Symptom Intensity

Symptom Intensity was assessed by the HIV Sign and Symptom Check-List-Revised (SSC-HIVrev). This checklist identifies the 72 most commonly experienced symptoms, and their intensity, among HIV infected adults on the day of data collection. The SSC-HIVrev has three parts: Part I consists of 45 HIV-related physical and psychological symptoms; Part II consists of 19 HIV-related symptoms that do not cluster into factor scores but may be of interest from a clinical perspective; and Part III consists of eight items related to

gynaecological symptoms for women. (Holzemer WL et al., 1999). Each of the 72 symptoms is scored on a scale of 0 to 3. A score of 0 indicates that the participant has not experienced that symptom and a score of 3 that the participant severely experienced that symptom, in the past 24 hours. The mean daily symptom intensity score is computed by summing every symptom intensity and dividing by 72.The total score reliability estimate (Cronbach's alpha) was 0.97 in previous studies(Holzemer WL et al., 1999) and was found to be 0.9701 in the present study.

Medication Adherence

Medication adherence was assessed by administering the Revised AIDS Clinical Trials Group (ACTG) Reasons for Non-Adherence to Medications (ACTGrev) and through change in CD4 cell count and HIV Viral Load. The ACTGrev is a self-report measure of reasons for missing medications (Chesney et al., 2000) that was revised through a large randomized clinical control study on adherence (Holzemer W. et al., 2006). The revised instrument has 2 factors with a total of nine items: Pill taking problems (5 items) and Forgetfulness (4 items). Each factor or subscale can be summed separately and then collectively to create the total score. Cronbach's alphas for the 2 subscales and the total score ranged from 0.8-0.9 (Holzemer W. et al., 2006). Additionally, 3 items were added to the scale to quantify the extent of each participant's HIV-medication adherence within the past seven days.

The reliability of these items was found to be 0.903 in the present study.

Additionally, all participants were asked to bring in their current CD4 and viral load values at baseline and at the 14-week follow up. These lab values were done at the request of their primary care provider.

Quality of Life

Quality of life was assessed with the HIV/AIDS Targeted Quality of Life Instrument (HAT-QoL). This 34-item instrument is a disease-specific quality of life measure assessing nine dimensions: Overall function, life satisfaction, health worries, financial worries, medication worries, HIV mastery, disclosure worries, provider trust, and sexual function. All dimensions are scored so that the final dimension score is transformed to a linear 0 to 100 scale, where 0 is the worst score possible and 100 is the best score possible. Internal consistency reliability coefficients ranged from 0.83 to 0.88 for all nine dimensions (Holzemer WL, Henry SB, Portillo CJ, & Miramontes, 2000). The reliability of the total scale in this study was found to be 0.898

Qualitative Data

Each participant in the intervention group completed a post-intervention qualitative survey which asked the following questions; Please list two things you liked and did not like about the program;

Please list two things you would change about and add to the program; Please list two things you learned from the program; and did you have any questions that did not get asked during the program.

Statistical Analysis

The sample size was determined by the sample size in Gifford, et al's study in 1998 (A. Gifford et al., 1998). This led to the recruitment of 89 eligible women, which provided an effect size of 0.04 to detect change in symptom intensity between the two groups at follow up (Hedges & Olkin, 1985).

Descriptive statistics were calculated using frequency distributions and appropriate summary statistics. The control and intervention groups were compared on major demographic variables to ensure that potentially confounding variables were equally distributed by the random assignment. Regression models were used to explore the effect of baseline characteristics on the dependent variables.

Multilevel negative binominal regression (Rabe-Hesketh, 2005) and multilevel linear regression analyses (also called random regression models, linear mixed models, and hierarchical linear models) were used to explore changes over time across HIV/AIDS-related symptom intensity, medication adherence, HIV viral load and quality of life between the experimental and control groups. This analytic method

has several advantages: 1) it uses all available data on each subject and the estimates are unaffected by data missing at random (Schafer, 2002); 2) it estimates group and individual trends; 3) it flexibly models time effects; and 4) it uses realistic and efficient variance and correlation patterns. The disadvantages of this model include: 1) it is more complex than traditional analytic methods; 2) assumption violations are harder to ascertain than traditional models (and may lead to erroneous conclusion); and 3) estimates are more unstable with small sample sizes (Gueorguieva & Krystal, 2004; Krueger & Tian, 2004; Vittinghoff, Glidden, Shiboski, & McCulloch, 2005). This analytic method was selected because it can efficiently analyze all of the longitudinal data collected, even if it wasn't collected on each individual at each time point. This resulted in less information lost and a potentially less biased result

Post-intervention qualitative comments were summarized verbatim and themes were identified.

Analyses were performed using Stata version 10.0 (Stata corporation, College Station, Texas, USA) using an intent-to-treat approach. All statistical tests were considered significant if they achieved the 0.05 level with 2-tailed tests.

Results

This randomized controlled study includes 89 HIV-infected women followed over 14 weeks. A total of 18 participants were lost to follow-up from time of enrollment to the survey completed 14 week later (Figure 1). A total of 89 participants were included in the final analysis.

The mean age of participants was 47 years (SD was 8.16 and range was 27-72), 65 (73%) of women were currently taking HAART, with a mean (±SD) total CD4 lymphocyte count of 464.4 ± 257.6 cells/μl. There were no major imbalances in demographic variables between the intervention and control group at enrollment. Baseline characteristics of the participants are displayed in Table 2.

Impact on Symptom Intensity

The SSC-HIV (rev) mean scores with 95% confidence intervals by group at baseline and week 4, 8 and 12 are presented in Figure 2 (a). Higher scores indicate worse symptom intensity in the past 24 hours when 0= no symptoms, 1=mild symptoms; 2=moderate symptoms; and 3= severe symptoms. Error bars indicate 95% confidence interval. Intervention sessions occurred during weeks 2-8.

Random-effects negative binominal regression indicated no significant difference in change between groups across time for total symptom intensity score (Table 3). The mean total symptom intensity score demonstrated a downward linear trend in the intervention group, compared with an upward trend in the control group .This trend was observed when the intervention sessions were occurring (Figure 2). However, this difference between groups over time was not statistically significant.

Impact on Medication Adherence

The mean percent of missed HAART doses in the past week with 95% confidence intervals at baseline and week 6, 10, & 16 is presented in Figure 2 (b). Error bars indicate 95% confidence interval.

Multilevel linear regression indicated no significant difference between groups across time for HAART medication adherence. The mean, self-reported percent of missed HAART doses demonstrated an upward trend in both the control and experimental groups, indicating that more doses were missed (Figure 2). This difference between groups over time was not statistically significant.

Neither the ACTG Reasons for Missed Medications Scale nor the self-reported number of doses missed in the past week changed

significantly over time. Additionally, change in CD4 lymphocyte count or Viral Load did not differ significantly by group.

Impact on Quality of Life

Multilevel linear regression indicated a significant difference between groups across time for two of the nine subscales of the HAT-QOL: HIV Mastery (χ^2=25.08; p <0.005) and Disclosure Worries (χ^2 =24.67; p <0.005). However, further inspection of the mean differences between the experimental and control groups over time revealed that the differences between the two groups were only at baseline. Consequently, the significant results cannot be attributed to the intervention. None of the other quality of life subscales yielded significant results between the experimental and control groups over time (Table 3).

Qualitative Results

Overall, the qualitative comments were very positive about the intervention program. The participants' comments suggested many logistical improvements that could be made to the intervention. However, the three main substantive themes that emerged from intervention group participants included:

(1) Strong sense that intervention taught women how to manage their symptoms; one comment that expresses this theme is:

"I like the program because I have learned more ways to control any negative symptoms I have".

(2) The intervention facilitated a strong sense of community; two of the comments that best exemplify these sentiments are:

"I meet other women who are just like me and I learn about each other; they bring experience and they being lots of information about HIV".

"Being able to speak openly and not be ashamed of my status; seeing old friends and knowing I'm not alone".

(3) Feeling that the peer leaders could be better: One comment that best expresses this theme is:

"I feel the teachers should be more prepared- not just reading off papers; students and teachers should be able to make lesson plans more interesting; they should be more professional in presentation"

Additionally, the participants had many comments about which topics should be included in the group. Suggested topics included more information on discordant couples and relationships, menopause, substance abuse, co-morbidities and dealing with stress.

Discussion

Symptom management for individuals living with HIV/AIDS continues to be an important biomedical goal. However, the results of this study suggest that a peer-based symptom management intervention may not decrease total symptom intensity or improve medication adherence and quality of life in women living with HIV/AIDS, when compared to a control group who received a symptom management guidebook.

The differences between the two groups on symptom intensity was often less than 0.20 mean points at any point in time which yielded a very small effect size. Previous research with this intervention yielded an effect size of 0.61 (A. Gifford et al., 1998). However, they compared the intervention to usual care. A more recent trial testing the effect of the symptom management manual, used as the control condition, in the present study yielded a 0.4 effect size (Hedges & Olkin, 1985; Wantland et al., 2008). This larger effect size for the control condition may explain the diminished effect size in

symptom intensity between the intervention and control groups over time. Several other explanations exist to explain the discrepancies in effect sizes between the original and present study of the Positive Self-Management Program.

The original study was tested in an all-male, relatively well-educated, mainly white sample. Additionally, the original study was completed in 1996. Consequently, the intervention was tested in a very different sample in a time when HIV/AIDS self and symptom management were very different (Chou, Holzemer, Portillo, & Slaughter, 2004b; Portillo, 2007). While the intervention has been updated in the past decade, it was updated based on new medical interventions and not to specifically reflect the needs of women living with HIV/AIDS. For example qualitative findings suggested that the intervention content could be modified to include topics on gynecological symptoms and menopause, childbearing/rearing, stigma and sexual negotiation (HRSA, 2005).

In recognition of these growing needs of minority women living with AIDS, investigators developed and tested the SMART/EST (Stress Management and Relaxation Training/Expressive Supportive Therapy) Women's Project (Ironson et al., 2005; Jones et al., 2007). In contrast to the present study, this intervention was led by professional therapists,

not peers. This two-phase intervention was longer, a 22-week group therapy intervention that focused on cognitive-behavioral stress management related to HIV/AIDS. The analysis of the SMART/EST intervention on HAART medication adherence was completed in 2007 and included 6 month follow-up data (Jones et al., 2007). The results indicated that participants with any exposure to the group sessions had increased medication adherence compared to those participants who only received the educational control. Additionally, the intervention predicted an increase in coping skills related to medication adherence (Jones et al., 2007). The investigators attributed these results to an increase in social learning and emotional support which is supported by other recent literature in the field (Brown & Vanable, 2008). However, other studies have found the positive effect of cognitive-behavioral interventions on HAART medication adherence and stress management is short-lived (Brown & Vanable, 2008; M. Johnson, Charlebois, E., Morin, S., Remien, R. & Chesney, M., 2007).

Qualifications of peer-leaders are also a potential source of effect size discrepancies. In this study, the peer-leaders were representative of the overall sample. They had a high school diploma or GED, identified as African-American or Latina, were single and had a history of substance abuse. While it is desirable to have peer-leaders identify with the participants on these variables, the low education

level was an impediment to delivering the scripted intervention as intended. For example, the peers had a hard time reading parts of the script and would often get flustered during the intervention sessions. Several of the qualitative comments supported this barrier.

Finally, one potential reason for the small effect size is that the dose was not sufficient for this population. While the intervention was ongoing, there was a small, although not significant trend towards a decrease in symptom intensity missed HIV medications in the intervention group. However, this trend disappeared when the intervention sessions concluded. These findings are compatible with recent clinical trials evaluating the effect of behavioral interventions on medication adherence (M. Johnson, Charlebois, E., Morin, S., Remien, R. & Chesney, M., 2007; Parsons JT, 2007; Sampaio-Sa et al., 2008) and is consistent with a recent review suggesting that effective medication adherence interventions tend to last longer than 12 weeks (Sergio, 2006). Of note, the SMART/EST trial did find a significant difference in HAART medication adherence between the intervention and control conditions. However, the dose of their intervention was much longer, both phases lasted 22 weeks, and the measurements were taken immediately after the intervention was complete. (Jones et al., 2007)

The primary limitation of this study is its small sample size which limited the ability to detect significant changes between the two groups over time. While the sample size was based on the original pilot study, the aforementioned factors may have led to a much smaller effect size. Additionally, because women self-selected into this study, the results may have been biased.

Despite the non-significant findings and limitations in this study, previous research does suggest that peer-based interventions may work to help increase symptom management and self-care (Doull et al., 2004). Future work on similar interventions in comparable populations should consider whether the content of the intervention addresses the more general needs of people living with multiple chronic diseases and in poverty. Additionally, future work should consider using a combination of peers and professionals to help efficiently deliver the content when other barriers exist (i.e. limited literacy). It is also advisable to consider a larger intervention dose and longer follow-up period in order to test the long term efficacy of future interventions. Specific recommendations for the Positive Self Management Program include that a diverse sample of women (and men) living with HIV/AIDS should review the intervention and make detailed suggestions on changes to the content of the intervention.

Conclusion

To the best of our knowledge, this is the first study to test an established peer-based symptom management intervention in this sample, compared to an efficacious control condition. In this sample of urban-dwelling women living with HIV/AIDS, results suggest that a peer-based symptom management intervention may not decrease symptom intensity or increase medication adherence. There is some positive evidence that suggests that the intervention may increase some important aspects of quality of life. However, further research is warranted to elucidate the effect of peer-based interventions in achieving positive self-management outcomes using study designs that incorporate heterogeneous HIV+, female populations and longer follow-up periods.

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Figure 1: Flowchart of Participants

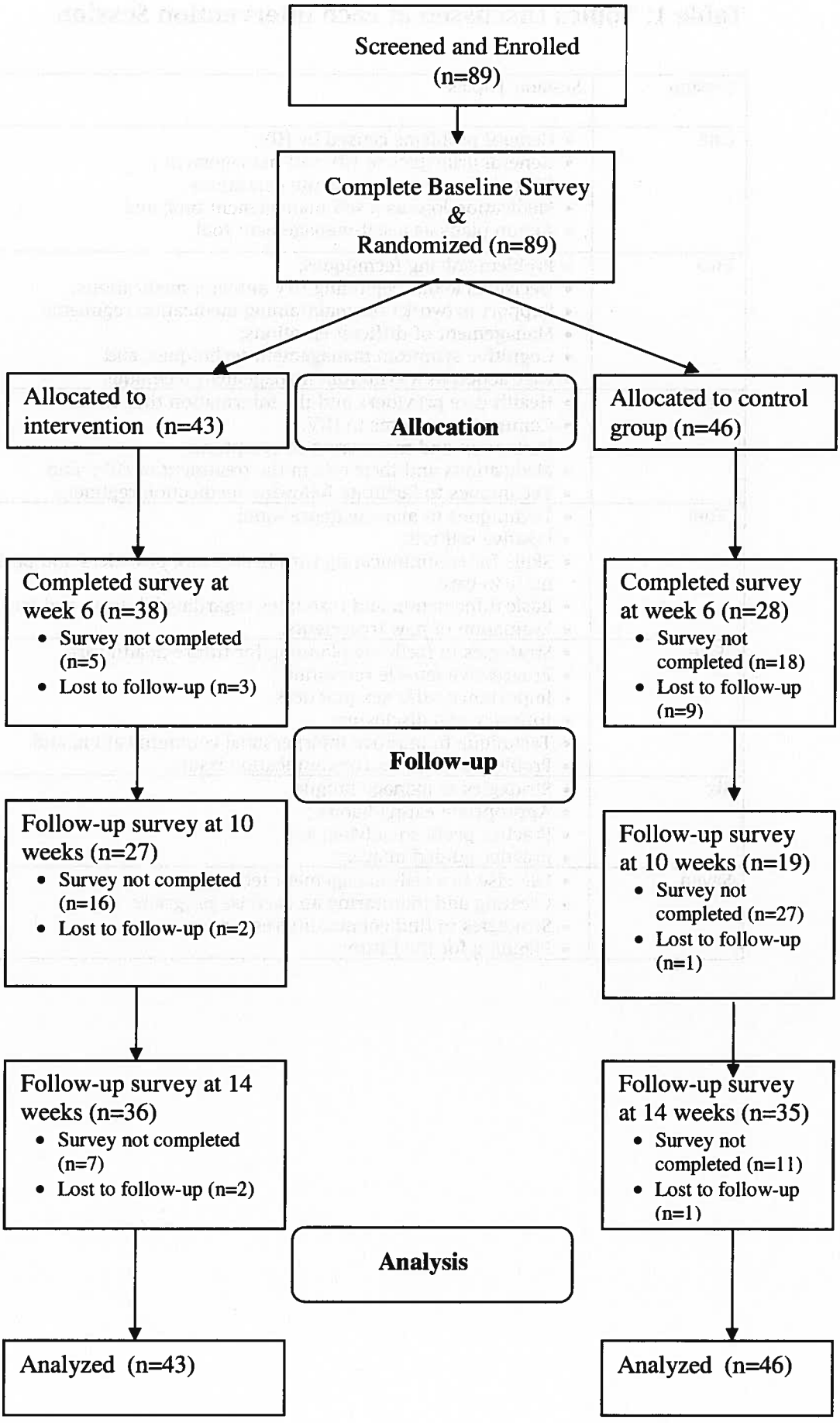


Table 1: Topics Discussed at Each Intervention Session

Session	Session Topics
One	• General problems caused by HIV; • General principles of HIV self-management ; • Chronic conditions vs. acute conditions; • Medication logs as a self-management tool; and • Action plans as a self-management tool
Two	• Problem-solving techniques; • Decisions about beginning HIV antiviral medications; • Support networks for maintaining medication regimens; • Management of difficult emotions; • Cognitive symptom management techniques; and • Distraction as a symptom management technique
Three	• Health care providers and the information they need; • Common symptoms in HIV; • Evaluation and monitoring of symptoms; • Medications and their role in the treatment of HIV; and • Techniques to facilitate following medication regimens
Four	• Techniques to manage depression; • Positive self talk; • Skills for communicating with health care providers and participating more in care; • Basic information and resources regarding lab tests and treatment; and • Evaluation of new treatments.
Five	• Strategies to facilitate planning for future health care; • Progressive muscle relaxation ; • Importance safer sex practices; • Intimacy and disclosure; • Technique to improve interpersonal communication; and • Problem-solving on communication issues.
Six	• Strategies to manage fatigue; • Appropriate eating habits ; • Practice problem-solving; and • Practice guided imagery.
Seven	• Exercise as a self-management technique; • Creating and monitoring an exercise program; • Strategies to find community resources; • Planning for the future.

Table 2: Baseline Demograpic Characteristics by Group

	Intervention Group (n=43)	Control Group (n=46)	P-value[d]
Age at baseline in years (range)	48.0 (27-67)	45.9 (31-72)	.232[a]
Gender (%)			
Female	38 (88%)	36 (72%)	
Transgender	4 (9%)	10 (22%)	.147[b]
Race (%)			
African-American	31 (72)	37 (80.4)	
Hispanic/Latina	5 (11.6)	2 (4.4)	
Caucasian	6 (14)	4 (8.7)	
Native American Indian	0	1 (2.2)	
Asian	0	1 (2.2)	
Other	1 (2.3)	1 (2.2)	.552[b]
Marital Status (%)			
Married	1 (2.3)	2 (4.4)	
Single	28 (65.1)	33 (71.7)	
Separated	3 (7.0)	4 (8.7)	
Divorced	4 (9.3)	2 (4.4)	
Domestic Partnership	3 (7.0)	3 (6.5)	
Other	4 (9.3)	2 (4.4)	.851[b]
Education Level (%)			
11th grade or less	15 (34.9)	19 (41.3)	
High School or GED	18 (41.9)	19 (41.3)	
2 Years of College/AA	8 (18.6)	5 (10.9)	
College (BS/BA)	2 (4.7)	2 (4.4)	
Master's Degree	0	1 (2.2)	
Doctorate	0	0	.797[b]
Currently work (%)	4 (9.3)	5 (10.9)	.806[c]
Income Adequacy (%)			
Enough	12 (27.9)	14 (30.4)	
Barely Adequate	24 (55.8)	26 (56.5)	
Totally Inadequate	7 (16.3)	6 (13.0)	.900[c]
Has Health Insurance (% yes)	41 (95.4)	43 (93.5)	1.00[b]
Pregnant (% yes)	1 (2.3)	3 (6.5)	.617[b]
Has Children (% yes)	27 (62.8)	27 (58.7)	.693[c]
Comorbidities (%)			
Diabetes	16 (37.7)	12 (26.1)	.637[c]
Hypertension	12 (27.9)	11 (23.9)	.940[c]

Depression	12 (27.9)	8 (17.4)	.518[c]
HIV RNA (1000/mL)*	2.061	5.396	.209[a]
Baseline CD4* cells/μl	495.1 (SD=277.9)	434.6 (SD=236.1)	. 319[a]
HIV Duration- years	12.8	12.4	.670[a]
Current HAART Use (%Yes)	30 (69.8)	35 (76.1)	.502[c]
Year started HAART (range)*	1999 (1996-2008)	2001 (1996-2008)	.348[a]

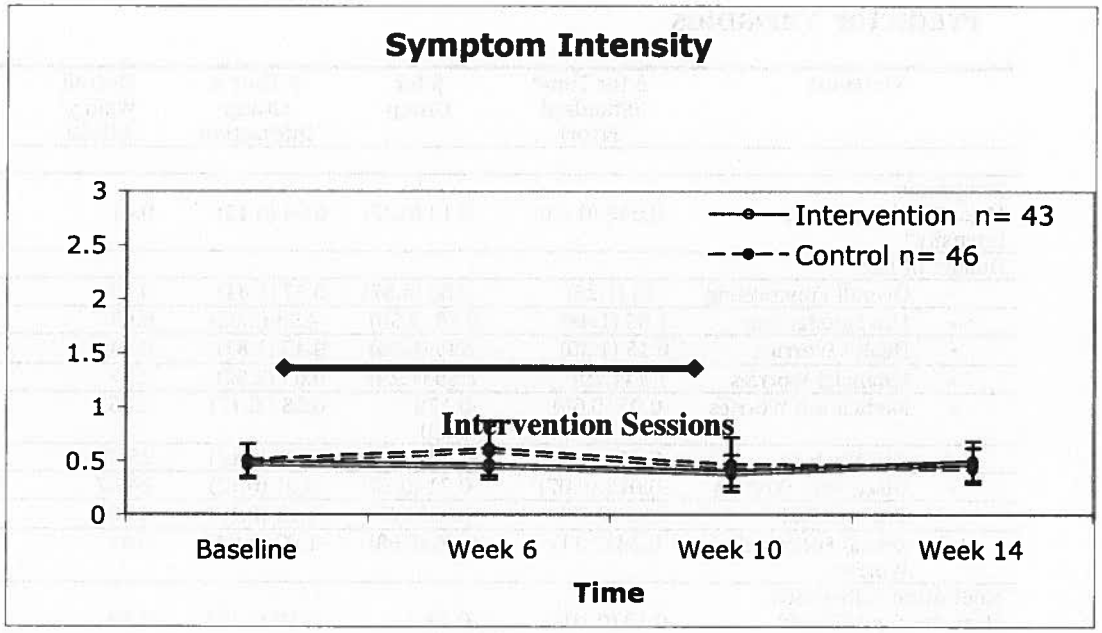
[a:] Student's t-Test: Differences in baseline mean demographics for continuous variables were analyzed using Student's t Test.
[b:] Fisher's Exact Test: Differences in baseline mean demographics for categorical variables when any of the cells had less than 5 occasions, were analyzed using Fisher's exact test
[c:] Pearson chi-square test: Differences in baseline mean demographics for categorical variables were analyzed using Pearson's chi-square test
[d] Statistical tests were considered significant if they achieved the 0.05 level with 2-tailed tests

Table 3: Conditional Linear Growth Model for Selected Outcomes by Predictor Variables

Outcome	β for Time[c] (Standard Error)	β for Group	β Time x Group Interaction	Overall Wald χ^2 (df=3)	P Value[d]
Symptoms: Mean Total Symptom Intensity[d]	-0.048 (0.10)	-0.13 (0.27)	0.04 (0.15)	0.41	0.9378
Quality of Life					
• Overall Functioning	-.25 (1.25)	-0.66 (4.87)	0.57 (1.81)	0.10	0.991
• Life Satisfaction	1.65 (1.44)	6.78 (5.59)	-4.93 (2.02)	6.63	0.085
• Health Worries	0.15 (1.30)	2.45 (6.06)	0.45 (1.81)	0.54	0.909
• Financial Worries	1.4 (1.79)	2.69 (7.24)	0.63 (2.52)	2.37	0.499
• Medication Worries	-0.05 (0.09)	-0.179 (0.23)	0.08 (0.12)	0.66	0.884
• HIV Mastery	-0.11 (0.07)	-0.53 (0.20)	-0.05 (0.12)	25.08	<0.005 [e]
• Disclosure Worries	-0.012 (0.07)	-0.71 (0.22)	-0.01 (0.12)	24.67	<0.005 [e]
• Trust in HCP[a]	0.05 (0.10)	0.45 (0.25)	-0.13 (0.13)	3.98	0.2631
• Sexual Functioning Worries	-0.24 (2.11)	0.66 (7.68)	-1.03 (2.94)	0.41	0.9375
Medication Adherence: Mean Per Cent Missed HAART Medications[b]	0.18 (0.10)	-0.13 (0.428)	-0.10 (0.15)	4.56	0.2068

[a] HCP, Health Care Provider
[b] HAART, Highly Active Anti-Retroviral Therapy
[c] All coefficients analyzed are reported using regression coefficients
[d] Statistical tests were considered significant if they achieved the 0.05 level with 2-tailed tests
[e] Although these tests reached statistical significance, further inspection of the mean scores over time revealed that the difference between the two groups was at baseline and therefore not a result of the intervention

(a)



(b)

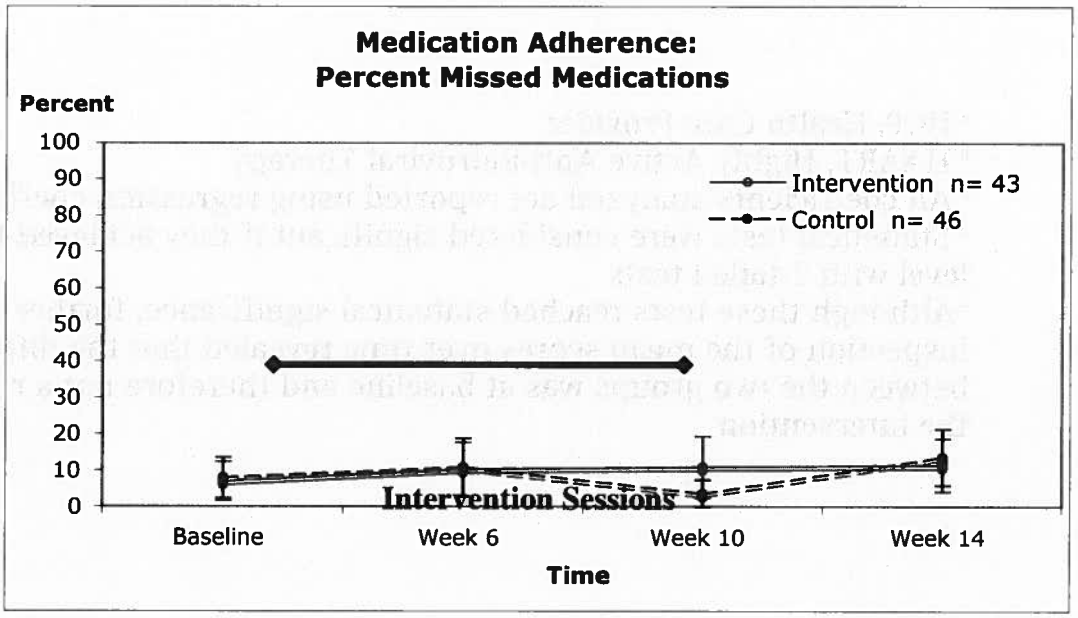


Figure 2. Line graphs of mean scores with 95% confidence intervals for the Sign and Symptom Checklist-HIV revised and the percent of missed HAART doses by group and time period. (a) SSC-HIV(rev) mean scores with 95% confidence intervals by group at baseline and week 4, 8 and 12. Higher scores indicate worse symptom intensity in the past 24 hours when 0= no symptoms, 1=mild symptoms;

2=moderate symptoms; and 3= severe symptoms. Error bars indicate 95% confidence Interval of the mean (Standard Error of the Mean). Intervention sessions occurred during weeks 2-8. (b) Mean percent of missed HAART doses in the past week with 95% confidence intervals at baseline and week 6, 10, & 16. Error bars indicate 95% confidence interval. Intervention sessions occurred during weeks 2-8.

Supplemental Table : Mean Outcome Scores Over Time by Group

	Time1 (mean/SD)	Time 2	Time 3	Time 4
Symptom Intensity Experimental	(n=43) 0.493 (0.526)	(n=38) 0.470 (0.438)	n=(19) 0.408 (0.364)	n=(36) 0.499 (0.539)
Control	(n=46) 0.5078 (0.511)	(n=28) 0.613 (0.656)	n=(27) 0.466 (0.524)	n=(35) 0.4556 (0.480)
Overall Functioning Experimental	(n=31) 59.139 (19.407)	(n=35) 60.595 (19.316)	(n=25) 56.833 (22.337)	(n=31) 62.500 (20.972)
Control	(n=37) 58.896(23.818)	(n=27) 61.728 (25.893)	(n=17) 59.559 (24.728)	(n=33) 59.217 (26.347)
Life Satisfaction Experimental	(n=36) 67.188 (21.254)	(n=38) 70.559 (24.415)	(n=27) 57.176 (22.582)	(n=34) 63.419 (32.861)
Control	(n=39) 65.224 (27.796)	(n=27) 60.879 (32.364)	(n=18) 65.972 (24.275)	(n=34) 69.669 (26.298)
Health Worries Experimental	(n=39) 69.088 (22.436)	(n=38) 67.763 (30.115)	(n=27) 62.731 (28.403)	(n=39) 72.569 (28.161)
Control	(n=41) 62.957 (29.027)	(n=28) 72.545 (34.331)	(n=19) 68.75 (29.315)	(n=34) 68.382 (27.044)
Financial Worries Experimental	(n=36) 45.602 (20.045)	(n=27) 53.378 (32.718)	(n=27) 43.210 (32.852)	(n=36) 53.241 (38.590)
Control	(n=41) 46.758 (33.689)	(n=28) 41.964 (37.439)	(n=19) 47.368 (33.913)	(n=34) 53.676 (38.555)
Medication Worries Experimental	(n=34) 73.529 (31.802)	(n=32) 78.593 (23.113)	(n=25) 75.800 (22.531)	(n=34) 73.594 (28.602)
Control	(n=36) 72.361 (27.889)	(n=24) 72.961 (29.632)	(n=17) 81.176 (26.548)	(n=30) 67.667 (35.519)
HIV Mastery Experimental	(n=37) 68.581 (28.047)	(n=37) 66.216 (36.068)	(n=27) 61.574 (34.483)	(n=34) 74.265 (31.070)
Control	(n=40) 44.686 (35.569)	(n=26) 49.520 (35.086)	(n=19) 59.211 (32.501)	(n=34) 57.353 (34.421)
Disclosure Worries Experimental	(n=34) 81.029 (21.669)	(n=33) 81.061 (22.142)	(n=24) 77.083 (25.956)	(n=35) 83.000 (18.756)
Control	(n=39) 63.077 (32.759)	(n=26) 61.731 (31.335)	(n=19) 62.105 (29.451)	(n=34) 68.529 (29.785)

Provider Trust				
Experimental	(n=37) 67.117 (34.244)	(n=35) 61.190 (36.264)	(n=27) 77.160 (32.571)	(n=36) 66.898 (35.606)
Control	(n=41) 79.472 (24.374)	(n=27) 81.173 (26.513)	(n=19) 75.877 (25.594)	(n=34) 73.775 (31.658)
Sexual Function Worries				
Experimental	(n=36) 62.500 (35.72)	(n=34) 69.118 (34.437)	(n=26) 62.019 (39.604)	(n=35) 69.643 (39.678)
Control	(n=38) 62.500 (37.780)	(n=27) 68.981 (35.078)	(n=17) 63.971 (37.208)	(n=33) 66.667 (32.726)
% Missed Meds				
Experimental	(n=43) 6.977 (17.530)	(n=28) 10.150 (22.929)	(n=28) 10.779 (21.769)	(n=36) 11.376 (21.478)
Control	(n=46) 7.919 (18.812)	(n=38) 10.714 (20.619)	(n=20) 3.571 (7.859)	(n=35) 13.537 (22.489)
CD4 count				
Experimental	(n=36) 495.139 (277.904)	N/A	N/A	(n=25) 541.24 (320.511)
Control	(n=37) 434.568 (236.128)	N/A	N/A	(n=32) 447.75 (218.849)
Viral Load				
Experimental	(n=34) 2,000 (62,87.176))	N/A	N/A	(n=25) 236.08 (400.2406)
Control	(n=36) 9,531.194(29,007)	N/A	N/A	(n=32) 1335.625 (3790.126)

Discussion

The purpose of this dissertation was to test if peer-based interventions increase symptom management in women living with HIV/AIDS. Accordingly, three scholarly papers were presented to describe different aspects of this phenomenon. Each had its own research question, methodology, results and conclusions which were discussed above. The final chapter of the dissertation will summarize each study's findings, discuss what each study adds to the literature, its corresponding limitations and finally the implications of each study for future research.

The findings from the first paper, A Systematic Review of the Effectiveness of Peer-Based Interventions on Health-Related Behaviors in Adults, indicated that peer-based interventions facilitated important health-related behavior change in adults with a small to medium effect

size, including physical activity, smoking cessation and condom use. However, the evidence was mixed. There was not a significant effect on breast-feeding, medication adherence, women's health and participating in general activities-outcomes. Future research on peer-based interventions should be conducted using rigorous methodology, including the quantification of dose in time, to facilitate synthesis of this literature. This first paper established critical principles to be included in this dissertation by describing the variables that are instrumental to the success of peer-based interventions and those important variables that are often left out of reports of similar interventions

The second paper, Community-based, Peer-led Program to Facilitate Self-care & Symptom Management in Women Living with HIV/AIDS: A Descriptive Analysis, concluded that a community-based, peer-led intervention has the potential to facilitate symptom management and is feasible for women living with HIV/AIDS 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/AIDS should consider referring their patients to community-based, peer-led programs that teach symptom management strategies. Additionally, if

such programs do not exist in their communities, nurses should consider developing community-based, peer-led programs that teach symptom management strategies, for their patients.

The final paper, Testing a peer-based symptom management intervention for women living with HIV/AIDS, reported the results of a randomized clinical trial testing test the impact of participation in a Peer Based Intervention for Symptom Management (PRISM-HIV) for women living with HIV infection on selected outcome measures including symptom management, medication adherence and quality of life. This study included 89 HIV-infected women followed over 14 weeks. There were no significant difference between the intervention and control groups, across time, on total symptom intensity score, medication adherence or CD4 lymphocyte count and HIV Viral Load. There was a significant difference between groups on two of the nine subscales of the HAT-QOL instrument- HIV Mastery and Disclosure Worries. These results indicate that those who participated in the intervention experienced a positive change over time in their quality of life related to HIV Mastery and Disclosure, compared to those in the control group. These are important findings which support our recommendation to conduct future research in this area.

Contributions

Each study provides the scientific community with their own unique contributions. The first paper presented was the first study to systematically review the entire body of literature on peer-based interventions to increase positive health behavior outcomes in adults. We identified and categorized the dominant models of peer-based interventions. Previously, other authors lumped all models together or disregarded the differences between the types of interventions (Doull et al., 2004). However, this paper identified three distinct models of peer-based interventions that were repeatedly used throughout the literature were identified- dyads, groups and a combination of both. Subgroup analyses by intervention model were conducted to assess whether any one model had better outcomes than another. A majority (72%) of models employed the dyad model. We also discussed the differences between the models and why they may contribute to statistical variation.

Three of the seven outcomes had significant, positive findings when analyzed as a group (increasing physical activity, decreasing smoking and increasing condom use). Additionally, one individual study had significant, positive outcome of increasing advance directive completion. The systematic review of this literature revealed that there is benefit to using peer-based interventions with some very important health outcomes. However, the evidence was mixed for the remaining

health outcomes and suggest theoretical and methodological reasons for these results.

This paper had numerous methodological strengths which add to the contributions of the paper. These strengths included the use of explicit eligibility criteria, independent reviewers assessing eligibility and the use of the random-effects analytic model. Only randomized clinical trials were included to help eliminate confounding from other variables. Yet, even within themes, there was little standardization among the studies. Subgroup analyses were conducted to explore the effect of the varied intervention models, follow up times, settings, training of peer leaders, and doses of intervention among the different studies, even within themes.

The second study was a small pilot study that yielded important information about how to best conduct a peer-based intervention to improve symptom management in women living with HIV/AIDS in the San Francisco Bay Area. Four conclusions were drawn from the information yielded in the focus groups: 1) Women living with HIV/AIDS may experience a great deal of distress related to the symptoms of their HIV disease and its treatments; 2) The management of these symptoms is very challenging for women because of numerous barriers; 3) A symptom management intervention for

women living with HIV/AIDS such as the Positive Self Management Program is needed and wanted; and 4) Peers should be used in all aspects of the intervention (including selecting community sites and recruiting participants). These conclusions were used to directly inform the implementation of the randomized clinical trial testing the Positive Self-Management Program discussed in the third paper, and can be used to inform other research in similar populations.

The final paper discussed an established intervention in a new population compared to a very efficacious symptom management manual. To the best of our knowledge, this is the first study to test a peer-based symptom management intervention in women living with HIV/AIDS. While we found a non-significant difference on the major study outcomes, further exploration of the data yielded a downward trend in the intervention group, compared with an upward trend in the control group. This trend was mainly observed when the intervention sessions were occurring and suggests that with a more robust sample perhaps the differences could have been significant. Similar trends were found in other outcomes lending support to this conclusion.

Additionally, this study had several interesting qualitative comments that address the unique challenges and needs of women living with HIV/AIDS. They highlighted the importance of community to these

women, the sense that they wanted more professional leaders, albeit not necessarily a health care provider, and suggested several important topics to include in similar interventions that are relevant to urban-dwelling women living with HIV/AIDS in the United States today. These findings are the first to be described in this population and should help others hoping to utilize similar interventions in research and clinical practice.

Limitations

Each study employed a different study design and consequently each had its own unique limitations. In the first paper the main limitation was including study quality as an exclusion criterion. To address concerns about study rigor, quality was assessed by two individual reviewers using a standardized instrument. The use of quality rating scores is controversial but only 18 of 909 studies were eliminated from the analysis due to low quality scores (Balk, 2002). This score was used to facilitate the inclusion of more generalizable studies. For example, one study that was excluded had a sample size of eight. Other studies excluded did not explain how the investigators collected their data or which instruments they used.

Furthermore, an additional limitation is the heterogeneity of some outcomes. While health behavior change theories suggest that it is

appropriate to combine the varied behavior change outcomes, the statistical assumptions of systematic reviews suggest otherwise. There was significant heterogeneity in the overall analysis and among some of our themed outcomes. Although it is possible that a large amount of this heterogeneity is related to the clinical diversity of the studies, there is not enough evidence to determine if this is the case. This limited the ability to answer the overall research question. Subgroup analyses did not reveal the source of the heterogeneity but did eliminate variables such as intervention model, intervention setting, sample size, and publication year . However, in the future this may be avoided by the use of a common definition of peer-based intervention and a common evaluation protocol, including follow up time.

Additionally, most of these outcomes were ascertained by self-report. Given the nature of behavior change, it can be difficult to efficiently assess one's individual behavior change without using self-report. It is better to complement self report with a direct measure of behavior change, when available. These outcomes could have included the measurement of pediatric diseases, changes in weight, HIV viral control or the levels of cancer, however few of these studies reported these outcomes. Given the low prevalence of some of these outcomes, it may be very challenging to have an adequately powered sample size to answer these questions. In the future it is advisable for investigators to

include such clinical outcomes or an accepted proxy in their research protocols.

Finally, we were unable to assess the effect of the dose of intervention on behavior change outcomes because each study reported dose differently. The authors did not report this information in a way that could be combined (i.e. some reported the number of sessions but not total time spent). Peer-based interventions are naturally more flexible and lend themselves to real-world applications. The application of these interventions to community problems is a strength of the intervention but the inability to quantify the dose of the intervention limited our ability to do quantitative statistical analysis. This study recommended that future studies report dose in standardized units of time to assist determining the effect of dose.

The limitations of the second study include its small size. While this sample demographically reflected the most vulnerable population living with HIV in the United States today (CDC, 2006), there was not enough power to extrapolate these findings to a larger sample. Additionally, because women self-selected into this study, the results may have been biased. Finally, the group sessions were not tape-recorded., an established methodological principle in qualitative research.

The final study was also hampered by its small sample size, albeit with a larger sample size than the previous study. This limited the ability to statistically detect any changes between the intervention and control groups over time. While the sample size was based on the original pilot study, numerous factors exist that led to a much smaller observed effect size. Additionally, because women also self-selected into this study, the results may have been biased.

These limitations should be addressed in both future research and in clinical practice.

Future Research

Each study had its own implications for both future research which will aid investigators in developing a more rigorous and efficacious studies.

Specific recommendations from the first study included, 1) Future studies report dose in standardized units of time to assist determining the effect of dose; 2) Future research on peer-based interventions should be conducted using rigorous methodology, including the quantification of dose in time; 3) To include such clinical outcomes or an accepted proxy in their research protocols; and 4) To use a common

definition of peer-based intervention and a common evaluation protocol, including length of follow up.

Although not mentioned in the paper, several recommendations for future research can be gleaned from the second paper: 1) Interventions to improve self-management should include content information that the participant's want to learn about; 2) A larger and more diverse sample would better inform the investigators on both logistical and scientific changes; and 3) Qualitative data should be captured via digital audio recordings.

The third paper also suggested several recommendations for future research. These included, 1) Considering whether the content of similar interventions address the more general needs of people living with multiple chronic diseases and living in poverty; 2) To consider using a combination of peers and professionals to help efficiently deliver the content when other barriers exist (i.e. limited literacy); 3) There was a specific recommendation that the Positive Self Management Program convene a diverse sample of women (and men) living with HIV/AIDS to review the intervention and make detailed suggestions on changes to the content of the intervention.

Conclusion

The results from each part of this dissertation add a different piece of evidence answering the question, whether a peer-based symptom management intervention can work in women living with HIV/AIDS. Generally peer-based interventions do work to facilitate some very important health related behavior change outcomes, women living with HIV/AIDS do want to participate and learn from (peer-based) interventions that specifically increase symptom management and self-care; and that the Positive Self Management program may help facilitate those behaviors. However, given the primary limitation of a small sample size, it is hard to ensure it will increase these behaviors. We also concluded that the science evaluating this and similar interventions should be more rigorous. The research designs should ensure each study has clearly defined variables, including what constitutes a peer and quantifies the dose. Future research studies should be large and long enough to ensure the study has enough power to answer whether the intervention will work and whether the effect was sustained over a relevant time period. Finally, peer-based interventions should be updated to include information important to the participants in the circumstances in which they live. With these important modifications the science will advance and inform clinical practice in a way that could greatly improve the health of a woman living with HIV/AIDS, her family and her community.

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