


# Feasibility of a Group-Based Self-Management Program for Ethnically Diverse People With HIV/AIDS in Hawaii

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## Abstract

HIV/AIDS has transformed from a terminal to a chronic health condition affecting individuals for decades rather than years. Yet the development of care models that enhance client-focused HIV disease management skills is still in progress, especially in HIV resource-poor locales. This pilot study tested the feasibility of implementing the group-based Positive Self-Management Program (PSMP) to participants recruited from Oahu, Hawaii. The PSMP is a self-management program developed at Stanford University. A paucity of data exists on the efficacy of implementing the specialized PSMP that addresses unique needs of persons living with HIV. With a focus on enhancing self-efficacy beliefs, examples of topics addressed during seven weekly 2-hr group sessions include managing the physiological and psychological aspects of HIV, adherence to treatment regimes, symptom management, and fostering healthy lifestyle behaviors. Using a randomized waitlist control design, participants were recruited via convenience sampling and active outreach. The manualized PSMP was delivered by trained seropositive lay leaders. The completion rate for those who attended any sessions was 93.5%. The average attendance rate was 85%. The majority of participants reported being comfortable in the PSMP group setting and very satisfied with program activities. Almost all participants reported that the PSMP was a useful and easy method to learn new ways of managing their illness. The majority (93.8%) were most satisfied with skill development in goal setting and action planning. Implementation of the program for persons living with HIV in Hawaii was feasible. Lessons learned for future research and application to practice are discussed.

## Keywords

HIV/AIDS, common disorders, biological, multicultural group work, holistic issues, quantitative research, research, vulnerable/underserved populations, specific populations, biological, self-management and self-care, therapeutic approaches

## Introduction

People with HIV/AIDS are living longer due to the advent and subsequent improvements in antiretroviral therapy. They still, however, must manage the unique symptoms, medical challenges, and sociocultural stressors associated with the illness. While HIV/AIDS has transitioned from a terminal illness to a chronic condition affecting individuals for decades, a change in health care delivery from provider-focused management to client-focused self-management is still in progress (Swendeman, Ingram, & Rotheram-Borus, 2009). Self-management of chronic illness has been defined as a conscious process and as a person's ability to control aspects of the illness, rather than be controlled by it (Thorne, Paterson, & Russell, 2003). Self-management models assume that people strive to optimize aspects of their physical, psychological, and social functioning by taking an active role in health care decision making (Swendeman et al., 2009). HIV self-management emphasizes the informed and engaged client, willing to change behavior and social

interactions to address anticipated complexities of their illness and to optimize health (Coster & Norman, 2009).

In settings where HIV-specific resources are in short supply, creative modalities to augment and strengthen HIV self-management practices are especially important. Seropositive persons without training or support in HIV self-management are alone, or dependent on a health care provider, in facing the sometimes challenging medication side effects, lifestyle changes, stigma, and isolating sense of being HIV-positive in a predominantly HIV-negative community. This dependence may lead to declining self-care practices, emotional distress, and lapses in treatment that go unnoticed for long periods. While individualized interventions for addressing specific

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aspects of HIV management are plentiful (Crepaz et al., 2008; Inouye, Flannely, & Flannely, 2001; Johnson, Dilworth, Taylor, & Neilands, 2011), group-based approaches offer several psychological and socioeconomic advantages. These include peer support, as people work on changing behaviors together (Coday et al., 2002); vicarious learning, as participants learn from others in the group setting (Goepfinger et al., 2009; Leake, Bermudo, Marianela, & Inouye, 2012; Mau et al., 2001); and cost-effectiveness, as group-based programs reach more people and use fewer resources (Lorig et al., 1999). Research and public reports support group-based self-management to improve chronic disease outcomes with arthritis (Goepfinger et al., 2009), cardiovascular disease (Rankin et al., 2012), asthma (Breedland, van Scheppingen, Leijnsma, Verheij-Jansen, & van Weert, 2011), chronic pain (Ersek, Turner, Cain, & Kemp, 2004), diabetes (L. Lorig et al., 2010; Mau et al., 2001), and symptomatic HIV (Gifford, Laurent, Gonzalez, Chesney, & Lorig, 1998; Webel, 2010). Both Webel (2010) and Gifford et al. (1998) offered same-gender programs in the San Francisco Bay area, where HIV is prevalent. Group-based self-management program delivery within a predominantly HIV-negative resource-poor community can be a support service for seropositive persons who feel stigmatized. Gifford et al. implemented the Positive Self-Management Program (PSMP) with an all-male group in 1993, before protease inhibitors or the HIV “cocktail” were on the market. The PSMP has been modified since then, but still needs to be tested for its ability to address aspects of an illness deemed chronic rather than life-threatening. Webel reported that a peer-led 7-week symptoms management group showed some improvement in the quality of life for urban-dwelling, seropositive, HIV women ( $n = 89$ ). However, there was no decrease in symptom intensity, or increase in adherence to medication schedules. Webel, Moore, Hanson, and Salata (2013) also piloted a group self-management intervention for persons living with HIV to improve physical activity.

Some of the identified challenges to a group-based intervention include the logistical challenges of attending classes, limited resources for travel, or concerns that their HIV-positive status would be revealed (Swendeman et al., 2009). This article describes the feasibility of implementing the PSMP, a group-based program for chronic diseases, to ethnically diverse people living with HIV/AIDS on the island of Oahu, Hawaii.

## Background

There is a lack of published research on group-based self-management models for HIV-positive people. This reflects a delay in adopting this approach, compared with other disease conditions such as arthritis, cancer, or diabetes. Recruitment challenges for individualized self-management programs in the HIV population have been reported (Inouye et al., 2001).

Further application and testing of the PSMP is needed to explore the efficacy of this self-management model. Offering the PSMP within the multicultural setting of Hawaii serves a population that is underrepresented in self-management research and includes a disproportionately high rate of Asian Americans and Pacific Islanders with HIV/AIDS (24%), compared with the mainland United States (1.0%; Centers for Disease Control and Prevention [CDC], 2013). In recent years, Native Hawaiians and other Pacific Islanders were more than twice as likely (2.6%) to be diagnosed with HIV compared with Caucasians (U.S. Department of Health and Human Services, 2012). In 2010, Native Hawaiians/Pacific Islanders were 2.6 times more likely to be diagnosed with an HIV infection than the White population (CDC, 2013; U.S. Department of Health and Human Services, 2012). Like many other areas with a low prevalence of HIV, funds are in short supply, so HIV services need to be creative as well as economical. As this is a pilot study testing feasibility, a detailed description of study methods is provided for replication purposes.

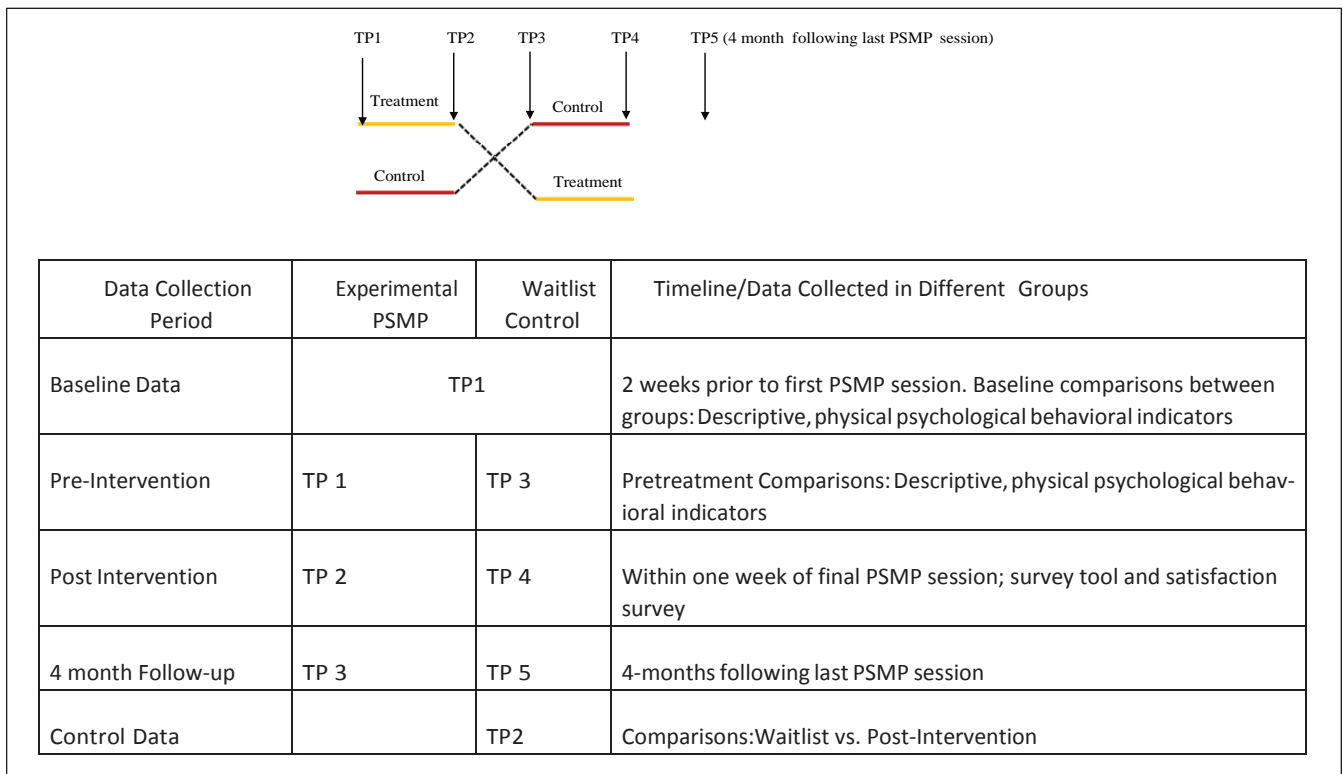
## Method

### Design

We used a randomized experimental design with a waitlist control. A convenience sample of 40 individuals with HIV/AIDS was enrolled. This sample size allowed for assessment of the methodology, acceptability of the intervention, and identifying problems with logistics and data-collection strategies (Hertzog, 2008). The sample size also ensured that at least 10 individuals in each cohort group ( $n = 20$ ) would complete the feasibility study, even with an attrition rate of 50% (Gucciardi, DeMelo, Offenheim, Grace, & Steward, 2007).

### Recruitment

Participants were recruited over a 2-month period from health care clinics, private physicians, and HIV-related social service sites on Oahu, Hawaii. Participants enrolled in the study were also asked to refer others who might be interested. Criteria for inclusion included the following: Participants must be 18 years of age or older; have a diagnosis of HIV/AIDS or a history of at least one AIDS-related complex (Centers for Disease Control and Prevention [CDC] CDC, 1999); have been continually enrolled in care for HIV with a primary provider for at least 6 months; have been taking antiretroviral medications for 1 year or more, with an agreement to remain on these medications for the duration of the research; and be competent in English (able to read a screening form out loud). Persons with evidence of dementia, as determined by a score of below 20 on the Mini-Mental State Exam (MMSE) were excluded from enrolling (Folstein, Folstein, & McHugh, 1975). The 2-month recruitment and



**Figure 1.** Timeline for survey administration, including time period (TP) 1-5.

enrollment period began in January 2011, with all other survey and intervention procedures occurring between March 2011 and February 2012.

### Pre-Enrollment Screening

Personal interviews were scheduled with individuals interested in participating in the study. If they met the inclusion criteria, the MMSE was administered by a mental health specialist. Individuals with an MMSE score below 20 were excluded from the study and given the test results to take to their primary care provider. Participants who met the inclusion criteria completed the enrollment process. This included a baseline height and weight and demographic information. Participants were also required to obtain copies of recent laboratory work from their health care provider(s) at baseline and at the 4-month follow-up.

Enrolled participants were randomly assigned to either the treatment ( $n = 18$ ) or waitlist control group ( $n = 18$ ) for the 7-week PSMP. Surveys were administered at pre- and post-intervention and at 4 months following the PSMP sessions (Figure 1). Participants in the treatment group took part in a 7-week PSMP run by two lay instructors with HIV who were trained in the use of this model. The waitlist control group received their usual medical treatment during this period. The PSMP was then offered to the control group, who became part of the experimental cohort (waitlist treatment

control). Survey data (described below) were collected at four time points: enrollment, pre-intervention, post-intervention, and at the 4-month follow-up. Participants received a US\$20.00 gift card following each survey and each PSMP session attended.

### Recruitment and Training of PSMP Lay Leaders

After posting layperson recruitment flyers, those interested in becoming a layperson leader were told about the role of the PSMP facilitator and the schedule for the group sessions. A brief, open-ended interview questionnaire was used to explore their views about HIV self-management and their own management practices. Two laypersons were selected based on descriptions of their personal success with HIV self-management (undetectable viral loads, consistent medication adherence, regular visits to a primary care provider), and comfort with speaking in front of others and leading a group. The leaders selected both had previous experience with facilitating groups of HIV-positive persons. The lay leaders then underwent formal training for 4.5 days by master trainers of the PSMP, at Stanford University in Palo Alto, California.

### Intervention

The PSMP is a structured, manualized, 7-week program offered in a workshop format, lasting 2 hr/session. It is built upon the

Feasibility Indicator	n/total (%)		
Recruitment Rate	40/54 (74.0)		
Screening Rate	37/40 (92.5)		
Enrollment Rate	36/37 (97.3)		
Retention Rate	29/36 (80.6)		
Randomization to Groups	36/36 (100)	Intervention (n = 18)	Waitlist (n = 18)
Drop out before start of sessions	5/36 (13.8)	2	3
Drop out after start of sessions	2/36 (5.6)	0	2
Retention Rate	29/36 (80.6)	16/18 (88.9)	13/18 (72.2)
Completion Rate (those attending any sessions)	29/31 (93.5)	16/16 (100)	13/15 (86.7)
Average Attendance	85%	83%	88%

**Figure 2.** Recruitment screening, participation, retention and completion rates (N = 54).

social cognitive notion of reciprocal interplay between physiological states, thoughts, behaviors, and the environment, which can influence health-related outcomes. Self-efficacy and behavior change are enhanced through supportive group environments, vicarious learning, role modeling, guided mastery, verbal persuasion, and goal setting. Sessions are highly interactive with facilitators leading six to eight activities, including brainstorming, role-play, and interactive feedback (Figure 2). The PSMP model typically uses trained layperson leaders or “expert clients,” who are HIV-positive themselves (Gifford et al., 1998). Lay leaders who have used HIV self-management successfully, and are experienced at coping with the disease serve as role models when training others. They can facilitate participant learning about how to evaluate symptoms and to build confidence toward implementing healthy behaviors.

To maintain fidelity with the PSMP model, the nurse researcher was trained as a PSMP leader as well. The three PSMP leaders used the *Stanford Self-Management Fidelity Toolkit* (Stanford Patient Education Research Center, 2010). These tools were used for all aspects of implementing and evaluating the PSMP. The principal investigator (PI) debriefed the lay leaders after each 2-hr session. They then reviewed portions of the training manual (Gifford, Lorig, Laurent, & Gonzalez, 2005) covered that day. Data collection checklists

were maintained and all data entries were reviewed by the PI. The study was approved by the University of Hawaii Committee on Human Subjects (Institutional Review Board).

## Instrumentation

### *Feasibility Measures*

We documented recruitment rates, screening completion, and participation. The retention rate was calculated as the number of participants who completed the PSMP and the postintervention survey. A “drop-out” was defined as one who failed to participate in at least four PSMP sessions. Persons who dropped out did not complete the 4-month follow-up survey. PSMP attendees completed a program evaluation survey immediately following the final PSMP session. The evaluation included questions pertaining to program structure and curriculum, and the group experience.

### *Program Structure*

Using a 5-point Likert-type scale, participants rated the degree of importance of nine program features on the decision to participate in the PSMP. Items measured included

logistics of the program delivery (e.g., dates, times and number of sessions, setting) and incentives. The scales ranged from *not at all important* to *very important*. The Cronbach's alpha for reliability analysis was .92.

### Program Curriculum

Satisfaction with learning activities (e.g., role-play, goal setting, action planning, homework) were measured using a 5-point Likert-type scale ranging from *very dissatisfied* to *very satisfied*. Cronbach's alpha for the seven activity types was .87. The curriculum was also evaluated based on self-reports on the importance of eight distinct module topics presented in the weekly sessions. These topics included taking medications, exercise and strength improvement, symptom evaluation, communication with care providers and with significant others, the physical and psychological aspects of HIV, alternative treatments, and end-of-life directives. The 5-point scales for these topics ranged from *not important at all* to *very important*.

### Group Experience

We asked the participants whether they had attended other chronic disease self-management groups and, if so, how many. The perceived comfort level and usefulness of the group as a means for learning were assessed using a 3-point scale ranging from *not comfortable/useful* to *very comfortable/useful*. We used a 10-point semantic differential scale (Chin, Diehl, & Norman, 1988) to assess the participants' overall reaction to PSMP group dynamics. The scale consisted of opposing terms, such as terrible or wonderful, difficult or easy, frustrating or satisfying.

### Statistical Analysis

Feasibility analyses for enrollment and retention included all persons enrolled in the study ( $n = 36$ ) rather than those who completed the sessions ( $n = 29$ ). Attendance was calculated as an average of the seven sessions attended by the participants who completed the program. The averages for the intervention and waitlist control groups were compared. Comparative analyses between descriptive data for the intervention and waitlist groups included frequencies, cross tabs, and comparison of means. Data from the postintervention satisfaction surveys were similarly compared between groups. A chi-square analysis was used to determine whether there were significant differences between items evaluating program structure, curriculum, or group factors. Significance was determined to be a  $p$  value less than .05

## Results

### Recruitment Efficiency

An estimated 450 people considered to be eligible for screening were included in a distribution of flyers via a listserv for

people with HIV/AIDS, a pharmacy newsletter sent to people who receive HIV/AIDS medications, and by word of mouth at an AIDS walk. Of 54 respondents interested in the study, 49 were eligible based on our criteria (Figure 2). Of these, 40 were scheduled for a screening session. Those not screened cited scheduling conflicts ( $n = 9$ ) or disinterest in the group format ( $n = 4$ ), or were lost during the follow-up ( $n = 1$ ). Four people were excluded during screening with 1 unable to complete the MMSE, 1 admitting to not meeting the inclusion criteria, and 2 citing other commitments. A total of 36 of the 40 (92.5%) people completed the screening, enrolled in the study, and were included in the enrollment analyses.

Those enrolled included 30 men (83.3%) and 6 women (Table 1). Enrollees were mostly Caucasian (61.1%), or Asian/Pacific Islanders (25.0%), with 1 African American and 4 categorized as Other Ethnicity (13.9%). Nearly three quarters of those enrolled identified as homo or bisexual (74.4%,  $n = 25$ ), and most never married (52.8%). Most reported some college education (72.2%,  $n = 26$ ), while nearly all (94.4%,  $n = 33$ ) reported incomes below US\$20,000 per year. The mean age was 47.0 years old and the range of time since testing HIV-positive was 1 to 30 years ( $M = 13.9$ ,  $SD = 6.9$ ). More than two thirds of those who enrolled (69.0%,  $n = 20$ ) reported no prior group experience for disease self-management.

### Retention and Completion

The vast majority of PSMP group attendees were retained for the entire study period, for both the initial PSMP intervention (88.9%,  $n = 16/18$ ) and for the waitlist group (72.2%,  $n = 13/18$ ; Figure 2). The overall retention rate was 80.6%. Five enrollees (13.8%) dropped out before attending any group sessions, and two from the waitlist group (5.6%) dropped out after the PSMP sessions started. The completion rate for those who attended any sessions was 93.5%, as two enrollees in the waitlist group dropped out early. The average attendance for the PSMP sessions was 85.0% ( $M = 6.0$  sessions, range = 4-7 sessions). Most participants (75.8%,  $n = 22$ ) attended either six or all the seven sessions. There was no significant differences between the two trial groups for PSMP session attendance ( $p = .41$ ) or for program withdrawal ( $p = .22$ ). No make-up sessions were offered for those who missed a class.

### Feasibility of Protocol Implementation

A summary of scores measuring the importance of PSMP program features, as reported by participants who completed the PSMP ( $n = 29$ ), is included in Table 2. The mean score for the importance of monetary incentives was higher than any other factor related to the participants' decisions to enroll in the PSMP. When comparing mean scores for pooled data on the importance of program features in the decision to participate in the PSMP, there was a significant

**Table 1.** Demographic Characteristics of Participants Overall and by Intervention Group (N = 36).

Participant characteristics	Overall percent	Intervention	Waitlist control	p
	n (%)	n (%)	n (%)	
Sex				.55
Male	30 (83.3)	83.3 (15.0)	83.3 (15.0)	
Female	6 (16.7)	3 (16.7)	3 (16.7)	
Race/ethnicity				.35
Caucasian	22 (61.1)	10 (55.6)	12 (66.7)	
Asian/Pacific Islander	9 (25.0)	4 (22.2)	5 (27.8)	
Other	5 (13.9)	4 (22.2)	1 (5.6)	
Sexual preference				.69
Homosexual	16 (45.7)	7 (38.9)	9 (52.9)	
Bisexual	9 (25.7)	5 (27.8)	4 (23.5)	
Heterosexual/straight	10 (28.6)	6 (33.3)	4 (23.5)	
Relationship status				.84
Never married	19 (52.8)	10 (55.6)	9 (50.0)	
Married/domestic partner	9 (25.0)	3 (16.7)	6 (34.4)	
Divorced/separated	8 (22.2)	5 (27.8)	3 (16.7)	
Education level				.19
Some college	26 (72.2)	11 (61.1)	15 (83.3)	
High school/GED	4 (11.1)	2 (11.1)	2 (11.1)	
Less than high school	6 (16.7)	5 (27.8)	1 (5.6)	
Income				.79
≤US\$20,000	33 (94.4)	17 (88.8)	16 (91.6)	
≥US\$20,000	3 (5.6)	1 (11.2)	2 (8.4)	
Prior chronic disease group experience				.98
No	20 (69.0)	11 (68.8)	9 (69.2)	
Yes	9 (31.0)	5 (31.3)	4 (30.8)	
Mean years of age (SD)	47.0 (9.8)	45.7 (9.2)	48.5 (10.5)	.42
Range	20-69	29-66	20-69	
Mean years since diagnosis	13.8(6.9)	14.2 (7.8)	13.6 (6.3)	.82
Range	1-29	1-30	2-24	

**Table 2.** Importance of Program Features in Decision to Participate in PSMP (n = 29).

Program features	Overall M(SD) Range = 1-5	Intervention group	Waitlist group	Comparison of group means	
		M (SD)	M (SD)	t	p
Monetary incentives	3.8	3.6 (1.6)	4.2 (0.8)	-1.3	.21
Geographic location	3.5	3.1 (1.7)	3.8 (1.5)	-1.1	.28
Having an HIV+ leader	3.3	3.3 (1.5)	3.3 (1.4)	-0.11	.92
Setting environment	3.1	3.1 (1.7)	3.2 (1.4)	-0.16	.87
Day of week	3.1	2.6 (1.6)	3.8 (1.5)	-2.1	.04*
Number of sessions	3.0	2.9 (1.6)	3.1 (1.4)	-0.26	.80
Lesson materials	3.0	3.2 (1.5)	2.7 (1.4)	0.94	.36
Time of day	2.8	2.3 (1.5)	3.3 (1.8)	-1.5	.14
People you know	2.5	2.8 (1.7)	2.2 (1.4)	1.0	.32

Note. PSMP = Positive Self-Management Program.

different between the importance of monetary incentives ( $M = 3.8$ ,  $SD = 1.3$ ), compared with the importance of people that you know ( $M = 2.5$ ,  $SD = 1.6$ ;  $t = 2.4$ ,  $df = 23$ ,  $p = .024$ ). When comparing groups, the mean scores for the

importance of day of the week for the PSMP sessions to be held were significantly higher for the waitlist group ( $M = 3.8$ ,  $SD = 1.5$ ) compared with the PSMP group ( $M = 2.6$ ,  $SD = 1.6$ ;  $p = .04$ ).

**Table 3.** Satisfaction With Topics of PSMP Program.

PSMP program topics	Overall <i>M</i> (range = 1-5)	Intervention group	Waitlist group	Comparison of group means	
		<i>M</i> ( <i>SD</i> )	<i>M</i> ( <i>SD</i> )	<i>t</i>	<i>p</i>
Physical/psychological aspects of HIV	4.5	4.3 (1.2)	4.8 (0.44)	-1.4	.17
Communication with care providers	4.5	4.3 (1.2)	4.8 (0.44)	-1.6	.12
Symptom evaluation	4.5	4.4 (1.1)	4.6 (0.78)	-0.7	.49
Exercise, strength improvement	4.4	4.3 (1.1)	4.5 (0.78)	-0.63	.53
Medication adherence	4.4	4.1 (1.4)	4.8 (0.44)	2.9	.08
Communication with significant others	4.3	4.3 (1.2)	4.4 (1.2)	-1.7	.87
End-of-life directives	4.2	3.9 (1.6)	4.5 (0.78)	-1.5	.15
Evaluation of alternative treatments	4.2	3.8 (1.3)	4.6 (0.65)	-2.2	.03*

Note. PSMP = Positive Self-Management Program.

**Table 4.** Satisfaction With Curricular Activities.

Curricular activities	Overall (range = 1-5)	Intervention group	Waitlist group	Comparison of group means	
		<i>M</i> ( <i>SD</i> )	<i>M</i> ( <i>SD</i> )	<i>t</i>	<i>p</i>
Goal setting	4.4	4.6 (0.6)	4.1 (1.0)	1.8	.09
Action plan	4.4	4.6 (0.6)	4.1 (1.0)	1.9	.09
Homework	4.2	4.3 (0.8)	4.0 (0.8)	1.0	.31
Relaxation	4.2	4.2 (0.8)	3.9 (0.8)	1.8	.09
Flip charts	4.1	4.3 (0.9)	3.7 (1.0)	1.5	.14
Role-plays	4.0	4.4 (0.7)	3.5 (1.0)	2.4	.03

**Table 5.** Satisfaction With Group Experience (*n* = 29).

Experience	Overall <i>M</i> range (4-10)	Waitlist control		<i>t</i>	<i>p</i>
		<i>M</i> ( <i>SD</i> )	<i>M</i> ( <i>SD</i> )		
Meeting in a group setting (frustrating–satisfying)	9.2	9.6 (0.81)	8.7 (1.5)	2.0	.05
Exploring HIV topics in a group (difficult–easy)	8.8	8.9 (1.9)	8.7 (2.2)	0.24	.81
PSMP overall (terrible–wonderful)	8.7	8.9 (2.2)	8.5 (1.3)	0.52	.61

Note. PSMP = Positive Self-Management Program.

### Satisfaction With PSMP topics

Mean scores for the eight PSMP topics ranged from 4.2 to 4.5 (scale range = 1.0-5.0; Table 3). For the program topic, evaluation of alternative treatments, the waitlist group scored significantly higher for satisfaction with this program measure compared with the intervention group ( $M = 4.8$  and  $3.8$ , respectively). However, evaluation of alternative treatments was the lower of the mean scores for satisfaction with PSMP program topics ( $M = 4.2$ ,  $SD = 1.1$ ) and was significantly lower when compared with mean satisfaction scores for the topic of symptom evaluation ( $M = 4.5$ ,  $SD = .95$ ,  $t = 2.5$ ,  $df = 15$ ,  $p = .023$ ).

### Satisfaction With Curricular Activities

Satisfaction scores for curricular activities were compared between groups (Table 4). Mean scores indicate that the intervention group was more satisfied with role-play than

was the control group ( $t = 2.4$ ,  $df = 1$ ,  $p = .03$ ). In addition, pooled data analysis indicates that of all the curricular activities, satisfactions scores for role-play were significantly lower than for other activities including goal setting, action planning, homework, or relaxation.

### Dynamics of the PSMP Group Experience

Mean satisfaction scores for meeting in a group setting were high ( $M = 9.2$ ,  $SD = 1.3$ ; Table 5). More than half of the participants rated exploring HIV-specific topics in the PSMP group setting as *easy* ( $M = 8.8$ ,  $SD = 1.8$ ) and rated the PSMP as *wonderful* ( $M = 8.7$ ,  $SD = 1.8$ ). For measures of the group approach for learning (Table 6), most participants reported feeling *very comfortable* about learning in a group setting (82.8%,  $n = 24$ ), and no one reported feeling *not comfortable*. The group setting was rated by most participants as a *very useful* way to learn (69%,  $n = 20$ ), and no participants reported the PSMP to be *not useful*.

**Table 6.** Program Evaluation: Aspects of Group Approach for Learning (*n* = 29).

	Overall	Intervention	Waitlist control	<i>p</i>
	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	
Feel of group learning				.81
Very comfortable	24 (82.8)	13 (81.3)	11 (84.6)	
Somewhat comfortable	5 (17.2)	3 (18.8)	2 (15.4)	
Not comfortable	0 (0)	0 (0)	0 (0)	
Usefulness of group learning				.13
Very useful	20 (69)	13 (81.3)	7 (53.8)	
Somewhat useful	9 (31)	3 (18.8)	6 (46.2)	
Not useful	0 (0)	0 (0)	0 (0)	

## Discussion

This study adds to our knowledge about the feasibility of implementing the PSMP with two cohorts of persons with HIV/AIDS in a community setting, where no such program currently exists. The targeted recruitment goal of having 40 people with HIV screened for enrollment was achieved using a variety of outreach methods. The waitlist control design did not deter attendance significantly and most feasibility indicators between the groups were similar. Nearly one quarter of the participants were of Asian or Pacific Islander descent. Therefore, this study adds new knowledge about self-management of HIV in these populations for which information is scarce (Ro & Yee, 2010). The question of whether HIV-positive persons in diverse ethnic groups in Hawaii would attend group sessions for self-management of their disease was answered; only 2 people withdrew from the classes once they started. Retention rates were robust and similar to rates noted in cognitive behavioral group programs for persons with HIV/AIDS (Crepaz et al., 2008). Generally, the HIV-positive participants in this study were older, with years of experience living with the disease, yet they were still motivated to attend a self-management program. This may be a reflection of the growing population of aging persons living with HIV/AIDS in Hawaii. Long-term survivors may also have self-management requirements that differ from those of younger seropositive persons and include loneliness, ageism, or both (Vance et al., 2011). This unique population has also experienced the transformation of HIV treatment as the disease prognosis evolved from terminal to chronic. Older people with HIV may seek additional support from specialized HIV care services such as a PSMP program.

The highest scores for decisions to participate in the PSMP was the monetary incentive for attendance. Not all self-management programs pay participants for attendance and some charge a small fee to cover the costs of implementation. The likelihood of the program's success, however, may be linked to its cost. Therefore, it is important to note that the Centers for Medicare and Medicaid Services (CMMS) are currently testing the effectiveness of programs to provide financial and nonfinancial incentives to Medicaid

beneficiaries who participate in prevention programs and who demonstrate changes in health risk and outcomes. Ten states have received CMMS grant funding to implement such programs (Centers for Medicare & Medicaid Services, 2015). Outcome efficacy analyses should explore whether incentive payments contribute to changes in behavioral indicators of attendance, retention, and survey completion.

Having HIV-positive layperson leaders was the third most frequent factor rated as important in decisions to participate. It may be that having a peer role model supports a belief in one's ability to make lifestyle changes. The lay leader approach is commonly utilized when addressing risk, and has shown promising results among men for modifying condom use and smoking behaviors, and for promoting physical activity (Lyles et al., 2007; Webel, Okonsky, Trompeta, & Holzemer, 2010). However, outcomes related to symptom management among women with HIV/AIDS are equivocal (Webel et al., 2010).

The methods used to obtain most outcome measures were feasible. Survey return rates were robust, and most likely due to regular meetings with the PSMP group members and the research staff. The surveys were administered in person, immediately prior to or following a group session, and a monetary incentive was paid if the surveys were returned before leaving. Having a digital scale for weighing was also very useful. However, the feasibility of obtaining client copies of clinical laboratory results was questionable because the rates of return decreased as the study progressed. Accepting copies of serum laboratory reports reduced the need for the participants to have extra blood tests. The failure of many participants to provide the copies, however, affected the outcome analyses of biomedical markers.

One challenge to providing HIV/AIDS support in resource-poor locales is fewer available clinicians, or clinicians unable to offer HIV-specific care for individuals or groups. Typically, clinician-driven models of care focus on the clinicians attempts to help people change behaviors. This approach does not fully fit the client-driven chronic disease self-management model presented by Swendeman et al. (2009), wherein self-management emphasizes participant empowerment and strengthening of personal beliefs about



the ability to change one's behavior. The approval of the PSMP lay leader format by participants in the present study supported the use of lay leaders as role models and may have motivated participants to attend.

This study's utilization of a group setting to address the personal challenges of living with HIV/AIDS was supported by the robust retention and participation results. The uncertainty of interacting with others was the least important factor in the decision of whether or not to participate in the program (Table 2). These findings go against the assumption that people with HIV/AIDS are fearful of disclosing their status and deterred from seeking available health care services. This supposition is especially prevalent regarding Asians and Pacific Islanders (Kang, Rapkin, Remien, Mellins, & Oh, 2005). The PSMP includes a 2-hr session on communicating effectively with family, friends, and health professionals. This provides a safe avenue for learning how and when to disclose their illness. It also stresses a person's responsibility in managing his or her own illness. By disclosing their illness to their sex partners, a solid link can be made between HIV care and prevention. Group attendance remained high despite the ethnocultural and demographic diversity of the PSMP group members. The focus groups were held at a university setting. This may have lessened the participants' fears of social rejection because they were attending classes at an educational institution rather than a health clinic.

The PSMP includes the practice of identifying and communicating with a "buddy" from the group between meetings. No data were collected on the number or type of out-of-group communications, but the participants appeared to develop a sense of cohesion. Some even started carpooling together to the site. Further research could focus on social interactions outside the group. Loneliness and the stigma of being HIV-positive have emerged as significant, independent predictors of depression in older adults with HIV (Groves, Golub, Parsons, Brennan, & Karpiak, 2010). A common goal reflected in group-based self-management models is enhancing social functioning. This social contact can include the development of collaborative interactions, supportive relationships, and social role development (Swendeman et al., 2009; Webel et al., 2010). These are important skills for HIV-positive persons. Seeking positive, affirming social networks is considered a form of self-care (Chenard, 2007), and social isolation has been associated with impaired immune functioning (Cohen, Frank, Doyle, Skoner, & Rabin, 1998). Since not all sessions were fully attended, participants may need additional encouragement from care providers to attend the group sessions. Full attendance at the meetings ensures the material is presented to all participants and highlights the message of self-motivation. The topic of end-of-life directives was rated least important (Table 4). This response coincides with a reported negative effect when death and dying is addressed during a PSMP (Sanders et al., 2008). The subject may also be of less interest to the participants, as advancements in

antiretroviral treatments have greatly extended their life expectancy. Age was not correlated to the importance of end-of-life directives. Overall, the PSMP curriculum met the approval of the group members, who were satisfied with the topics presented in the 7-week curriculum.

### *Implications for Research*

Future research can test the PSMP on different age groups (e.g., younger versus older) of people with HIV/AIDS. Testing HIV-positive persons with mental health problems, or persons of similar ethnic backgrounds living in different geographic locales, may produce unexpected, useful results. Creative ways of recruiting and delivering the PSMP and of measuring outcomes can be incorporated into future research designs. This includes online applications, as this approach has proven effective with people suffering from other chronic illnesses (L. Lorig et al., 2010). Distance-based technology for relaying treatment adherence-enhancing methods from researcher to client can be evaluated. These technologies can also be used for conveying data on adherence to medications from researcher to researcher. Further exploration is needed on how acculturation contributes to health care utilization among minority persons living with HIV. Studies including measures of citizenship, years living in the United States, English literacy, and income level could shed light on how these potential barriers contribute to disease self-management behaviors.

### *Application to Practice*

Group-based approaches are familiar to providers who deliver health-related education to populations living with chronic disease. Incorporating trained professionals to oversee the logistics of the PSMP program will support the HIV-positive lay leaders and ensure fidelity to the model. Group sessions can reduce costs in health care systems. They can also help people cope with the stigma, uncertainty, and isolation brought on by their illness. Licensing agreements and the support of additional funding can help a university- or clinic-based center for chronic disease self-management to develop master trainers for the PSMP. Some client costs for the self-management of certain illnesses are currently covered by health insurance, but availability of funds is limited. With the recent allocation of federal dollars to determine whether incentives drive client success for attaining disease prevention outcomes, the future looks promising for support of self-management models such as the PSMP. The cost for implementing the Stanford-based self-management program may be prohibitive for some agencies, as leader training and travel require substantial start-up funding (Stanford Patient Education Research Center, 2012). However, the model emphasizes that master trainers can, in turn, train and certify PSMP leaders from among health care personnel and laypersons.

These program leaders can then continue to develop trainers within the community. Thus, persons with HIV/AIDS can improve their problem-solving skills and strengthen the belief that they can successfully contribute to the management of their condition.

### Limitations

The small sample size of this pilot study limits the application of its results. A larger, statistically significant sample size would improve the evaluation of the PSMP and its ability to produce changes in behavior. The 4-month wait until the control group entered the PSMP was frustrating to some and may have contributed to the decision of other HIV-positive persons not to enroll. In addition, future studies could incorporate make-up sessions for participants who missed some. In spite of the limitations of this study, offering the group-based PSMP to multiethnic persons with HIV/AIDS is a feasible intervention for Hawaii.

### Conclusion

To achieve effective and efficient chronic disease treatment outcomes, primary care providers must compliment patient education with strategies that motivate people to engage in self-management behaviors. Group-based programs give participants opportunities to practice problem-solving skills and to strengthen efficacy beliefs and interactions among people who share similar chronic illnesses. Working with professionals and others to solve health-related issues helps the client actively acquire knowledge and make his or her own decisions.

Aside from monitoring HIV illness and providing treatment recommendations, the role of the current health care system is to help HIV-positive people find ways to foster motivation, develop skills, and enhance beliefs in their abilities to successfully manage their HIV/AIDS. This study provided support for offering the PSMP to persons with HIV/AIDS in Hawaii.

### Authors' Note

The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institute of Nursing Research or the National Institutes of Health.

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