

Program to Enhance Health Literacy and Treatment Adherence in Low-Income HIV-Infected Latino Men and Women

GWEN VAN SERVELLEN, R.N., Ph.D.,^{1,2} FELIX CARPIO, M.D., M.P.H.,^{3,4}
MONICA LOPEZ, M.A.,^{3,4} LORRAINE GARCIA-TEAGUE, R.N., Ph.D.,²
GILBERTO HERRERA, F.M.G.,² FLOR MONTERROSA,⁴ ROBERTO GOMEZ,⁴
and EMILIA LOMBARDI, Ph.D.⁵

ABSTRACT

This paper reports the initial results of a pilot study to evaluate the acceptability and effectiveness of a program to enhance health literacy in low-income HIV-infected Latino men and women receiving antiretroviral therapy. Participants rated the program highly on measures of satisfaction, providing evidence of its acceptability. The effectiveness of the program was assessed in comparisons of the intervention ($n = 41$) and standard care only ($n = 40$) groups at baseline and 6-week intervals. Program participants showed significant improvement over comparison group participants on measures of HIV/AIDS and treatment-related knowledge and recognition and understanding of HIV terms. Although there were no significant changes in adherence mastery and behaviors during the 6-week follow up period, there were significant changes in program participants' knowledge about medication adherence. Future steps to examine the sustainability of the program in the medical management of patients are planned in addition to determining its long-range relative impact.

INTRODUCTION

Programs aimed at improving individuals' health literacy and communications with health care providers have the potential to maximize antiretroviral treatment adherence. This dual approach with a focus on enhancing health literacy and maximizing communications with health providers is particularly important in communities in which HIV infection rates are increasing and individuals' ability to adapt to stringent treatment regi-

mens might be impaired by a multitude of factors that interact in complex ways to impede the delivery of high-quality health care. This paper describes an HIV health literacy and adherence enhancement program for low-income Latino men and women living with HIV/AIDS and receiving antiretroviral therapy in community-based clinics. The initial results of this evaluation are presented with implications for further examination of the sustainability and long-range effectiveness of the program.

¹Acute Care Section, ²School of Nursing, UCLA, Los Angeles, California.

³HIV Division, ⁴Alta Med Health Services Corporation, Los Angeles, California.

⁵Integrated Substance Abuse Programs, UCLA, Los Angeles, California.

Background

Achieving close to perfect adherence to anti-retroviral therapy can be difficult for systems of care under any circumstance. Maximizing high levels of adherence is especially challenging in the delivery of services to low-income minority populations with low levels of health literacy and limited knowledge of the health care system. Both system and individual factors impact the probability that maximal adherence will be achieved and sustained in these populations. While some of these factors are common to all HIV-infected populations, others are unique and require attention in the formulation of culturally sensitive adherence enhancement programs.^{1,2}

Prevalence of HIV/AIDS in ethnic minority populations

As with other illnesses, the burden of HIV disease is not borne equally by all population groups in the United States. Issues of disease prevalence, morbidity, and mortality in HIV exist as a function of race/ethnicity and socioeconomic status,³ placing impoverished minority populations at increased risk for HIV infection and greater morbidity.

Recent national data on the incidence and prevalence of HIV infection indicate that HIV is increasing most rapidly among African American and Latino populations.⁴ African American and Latino populations represent more than three quarters of all women and heterosexuals with AIDS, and nearly half of men who have sex with men living with HIV (1999–2000). California ranks second in the nation for total number of AIDS cases and Los Angeles is the second largest epicenter. In California, the percentage of new AIDS cases among Latino men in 2000 was 42% and among women, 41%.⁵ Recent data depicting time to AIDS diagnosis revealed that 38% of those Latinos participating in the Los Angeles County surveillance survey (1997–2001) learned of their AIDS diagnosis within 1 month of their learning their HIV status, compared to 26% of whites and 22% of African Americans.⁶ These data have drawn concern to the fact that Latinos are at greater risk for AIDS and represent a significant population of recent immigrants

making their access to care and utilization of services more complex.

Within-group vulnerability for access to and utilization of services has been reported among poor Latino men and women.⁷ This population is also more likely to consist of recent immigrants who are less likely to understand the complexities of their disease and more likely to have problems understanding and following their prescribed treatment regimen. Poverty, racism, health problems related to poor access to health care, as well as delays in seeking care are factors linked to higher risk of HIV infection and an AIDS diagnosis.⁸ Furthermore, HIV/AIDS and the behaviors associated with becoming infected are highly stigmatized in Latino populations,⁹ which makes coping with HIV and securing adequate support problematic. Finally, Latinos face a number of barriers to receiving supportive services related to medical care,¹⁰ and these factors along with cultural and linguistic barriers place them at risk for receiving inadequate services.² While greater vulnerability can be explained in part by individuals' lack of knowledge and preparation for adherence management, other system related factors (e.g., quality of patient-provider communications) impact the success of existing treatment adherence initiatives.

Need for tailored programs for low-income HIV-infected minority populations

Adequate adherence intervention is that which is most comprehensive and which targets cognitive, behavioral, and affective domains.¹¹ Furthermore, in programs targeting low-income, low-health-literate minority populations, attention to the social, racial, and cultural context of the individual is critical to understanding and intervening in relevant and appropriate ways.⁸ Programs have been designed to address the special needs of HIV-infected impoverished minority populations, but more attention must be given to the multiple complexities of low health care literacy, lifestyle issues, and immigration status that have been shown to affect the health of low-income Latino populations and their ability to utilize available treatments.

Because the design and development of health literacy and adherence enhancement

programs is lagging, data evaluating programs are limited. Controlled randomized trials that examine the effects of enhancement programs on patient preparedness for adherence are critical to the advancement of knowledge about interventions to promote adherence. Fogarty and colleagues¹¹ reporting on their synthesis of data about the effectiveness of patient adherence interventions concluded that little can be said about the effectiveness of interventions reported. Accordingly, reasons for the absence of definitive information included the following: (1) only 11 of the intervention studies reviewed reported outcome results; (2) the samples used to derive evaluation results were small and statistical power was weak; and (3) the majority of the studies reporting evaluation data had no control group. This paper reports the evaluation of a program to enhance health literacy and adherence using a preintervention and postintervention design with comparison group.

Conceptualization and development of the program: Es Por La Vida

The study's health literacy and treatment adherence enhancement program was designed using a multistep process. This process facilitated the integration of the skills and knowledge of community experts, patients, health care providers, and the study's research staff. The program consists of instructional modules aimed at increasing HIV functional health literacy and an individualized approach to follow-up addressing cognitive, behavioral skills, and affective dimensions important for comprehensive adherence enhancement programs. *Es Por La Vida* is tailored to meet the particular needs of monolingual Spanish-speaking clients and those who are bilingual but prefer to speak Spanish.

Content and focus of the program. Preliminary preparation for identifying the essential components for the program included a review of existing literature of the potential predictors of health literacy and treatment adherence, identification of educational and behavioral strategies to improve adherence, and the selection of a conceptual model that would focus on the in-

teraction of individual and system level factors. We examined mutable factors found to be associated with lower levels of health literacy and medication and appointment-keeping adherence in at risk populations. Quality of patient-provider communications has been shown to influence patients' level of awareness and knowledge of their condition and treatment. Many factors have been studied for their impact on adherence to treatment. Fogarty and colleagues¹¹ identified more than 200 separate variables addressed in the adherence literature. These authors grouped variables using the following broad categories, factors related to: (1) treatment regimen, (2) social and psychological factors, (3) institutional resources, and (4) personal attributes.

The health literacy/adherence enhancement program, *Es Por La Vida*, was designed to address some but not all of these categories of potential factors. For example, the commonly reported predictors of low health literacy and nonadherence in this population that could be targeted in a pilot study of this nature were a priority. They included the following individual level factors: functional health literacy,¹² social network support,^{13,14} and mastery of adherence management.¹⁵ Furthermore, quality of communications with health care providers,¹⁴ a system level factor, was targeted because it has been shown to be associated with higher levels of patient health literacy and better adherence to treatment.

The study's program specialist, who was a clinical psychologist and adherence researcher with expertise in the design of programs to promote adherence to antiretroviral therapy, provided assistance in identifying the scope of content to address HIV health literacy and provider-patient relationships in the context of small groups. This content included didactic information as well as interactive group experiences designed to make learning pleasurable and create behavior change. Content areas included: (1) basic HIV/AIDS information, (2) barriers and facilitators of adherence management, (3) maintaining quality of life and controlling illness-related stress, (4) reducing risks related to transmitting HIV and management of substance use, and (5) communication skills with health care providers and maintaining ef-

fective family and community support systems. Simplified educational instruction, behavior change strategies, and/or social support have been shown in other studies to improve adherence behaviors and were anticipated to work in this instance.¹⁶

Furthermore, concern for the acceptability of the program led to the development of culturally specific strategies for this population. For example, the core cultural values of *familialism* (the significance of the family to the individual) and *simpatia* (the desire to maintain harmony, politeness, and respect in relationships) were discussed in the context of designing the program and the evaluations.

Consideration for the value of *familialism*, or the significance of the family, was addressed in different ways. First, family were encouraged to participate in the first and final sessions of the 5-week program. Additionally, the program's two videotapes (one on coping with HIV/AIDS and treatment and the other on HIV and sexually transmitted diseases [STDs]) included the family perspective, depicted family relationships and were narrated in Spanish by Latinos who were infected or affected by HIV/AIDS. Also, content specific to family roles in helping patients cope with HIV were addressed in the fifth module and included discussions by the parent of an adult HIV-infected patient who is also a spokesperson and advocate in the community.

Simpatia was addressed in desires for good relationships with health care providers. Both advantages and disadvantages of different communication styles were discussed. Assertive options for interacting with providers were framed in ways that would preserve respect and dignity for both the patient and provider.

Because the issue of practicing safer sex was a topic in the program and the program was offered to men and women, it was important to consider the social role of Latinas and the cultural concept of *machismo* (the male role) and *marianismo* (the female role) in discussions of negotiating safer sexual practices. Initial plans included conducting the program in gender-specific groupings to increase opportunities for in-depth discussion and to minimize any inhibitions in discussing safer sexual practices.

However, because of the small number of women in the program and in the absence of resistance from our participants, we combined groups of men and women. What had been anticipated as a potential barrier in discussing safe practices proved not to be problematic.

In summary, we focused on creating an informed, activated patient who could participate in productive interactions with health care providers. The major role of the program was to improve health literacy and promote effective communications with providers. Such a program, it was proposed, would advance high quality disease management in this vulnerable population.

Process of designing the program. The process of designing the program included several initial design and ongoing evaluation feedback loops with the use of client and provider focus groups. Initial feedback and guidance from selected clinic coinvestigators were used in refining the content and interactive experiences. The proposed program and selected component parts were reviewed by the provider focus group consisting of treatment advocates, case managers, health educators, nurse-supervisors, social workers, director of psychosocial services, program and clinical trial coordinators. Feedback from this group was discussed by the design team and suggestions were incorporated. The revised program format was then presented to the patient focus group consisting of 9 male and 2 female patients currently receiving antiretroviral therapy at the designated clinic sites. These focus group members evaluated the clarity of content and delivery methods of the program and made further recommendations that were incorporated.

The final version of the program consisted of a 5-week instructional support modular program with a 6-month follow-up nurse case-management component. The aims of the instructional support modular program, which were conducted in Spanish by our bilingual treatment advocates and nurse practitioner, were to improve knowledge and skills, to build confidence in individuals' abilities to follow their treatment regimen, and teach respectfully assertive communications that might enhance disclosing key information in communications

PROGRAM TO ENHANCE HIV LITERACY

with their physicians and nurses. The program modules were conducted in small groups varying in size from three to seven participants. When participants missed sessions, the session was administered individually by the nurse case manager preliminary to their rejoining their group for the next module in sequence.

The evaluation and research aims of the program included an examination of the acceptability and effectiveness of the program in impacting level of HIV health literacy and treatment adherence.

The following research questions were addressed:

1. What is the level of patient satisfaction with the program?
2. To what extent are patients' health literacy levels and satisfaction with provider-patient communications improved by participation in the program?
3. To what extent are patients' levels of perceived adherence mastery and self-reported medication adherence behaviors improved by the program?

MATERIALS AND METHODS

The pilot study was conducted using a quasi-experimental repeated measures design. Eighty-five eligible patients from the study's two administratively linked clinics were randomly assigned using a table of random numbers to receive the intervention program (*Es Por La Vida*) or standard clinic care (standard care only). Evaluation data were collected at baseline and 6-weeks to evaluate changes in health literacy, quality of provider-patient communications, adherence mastery, and medication adherence in the program participants and comparison group patients.

Participants and recruitment procedures

The pilot study was conducted with clients recruited from the study's two HIV community-based not-for-profit clinics in east Los Angeles. According to the clinics' Ryan White Care Act report data, the clinics serve approximately 1000 HIV-infected clients annually.

More than three quarters of the clinics' patients are Latino and male. Additionally, almost all clients report incomes substantially below the Federal poverty level. A little less than half are homeless. The prevalence of active substance abuse and current psychiatric illness is low (4%–5%), yet suspected to be considerably higher. The clinics offer primary care, social services, referrals for psychiatric evaluation, case management, and treatment advocacy.

Inclusion criteria for the recruitment of study participants were the following: Latinos of male or female gender; 18 years or older; monolingual Spanish-speaking or bilingual but prefer to speak Spanish; and self-reported or clinician-assessed problems with medication adherence. All participants had to be enrolled in the clinic for a minimum of 3 months, have detectable viral loads, and be taking combination antiretroviral therapy.

The University's Human Subject's Protection Committee and the Internal Review Committee at the participating clinic granted approval of the study. Furthermore, because sensitive data about illicit drug use were sought, a Certificate of Confidentiality from the National Institute of Health for the study was obtained. Participants enrolled in the pilot study were first screened by the clinic's clinical trial staff and then randomized into one of two groups: the intervention or comparison group. Potential participants were told to call an anonymous hotline number; those who did not have phones were mailed letters of invitation from the medical director of the HIV Division who was a coinvestigator on the study. Potential participants who called the hotline number and expressed interest were then scheduled for an appointment to conduct informed consent and to complete initial baseline surveys. Medical chart abstractions were conducted after securing participant informed consent.

Assessment instruments

Evaluation and research instruments included patient self-report and medical record data on all intervention and comparison group patients. Process evaluation assessment of the acceptability and satisfaction with the instructional modules included week-to-week module

evaluation feedback sheets. These evaluations were completed by all intervention participants at the end of each week of the instructional support program and were anonymous. The evaluations consisted of 14–16 questions (depending on the session) and evaluated both the content and manner of delivery of the program by the program facilitators. They included items such as: "Were the answers given by the facilitators clear?" and "Did you get adequate advice about ways to manage your health?" and open-ended questions that required further explanation such as: "What things did you learn today that you did not know before?" On the closed-ended questions, participants were asked to assign a value of 0 = not at all to 3 = a lot/very much.

Measures evaluating the both intervention and comparison group participants included both survey items and medical chart abstraction data.

Sociodemographic characteristics

Data including age, gender, birthplace, income, primary language, and total years of education as well as proportion of education in the United States were reported by participants on the demographic portion of the survey.

Acculturation

Acculturation, the process by which a person incorporates a new culture,¹⁷ was measured with Marin's five-item acculturation subscale measuring facility with language. Strong support exists for the validity and reliability of the Marin acculturation in Latino populations.¹⁸ Scores on this scale were 1 to 5 with higher scores indicating more use of English and therefore, higher levels of acculturation.¹⁹ In this study, the Cronbach α coefficient for the intervention group was 0.68 and for the comparison group, 0.86.

Health status/disease progression

Health status and disease progression were assessed with data about disease parameters (CD⁺ T-cell count, HIV-RNA viral load [RT-PCR assay]) as indicated in the laboratory reports filed in the patients medical record. Anal-

ysis of viral load was conducted using viral load as a continuous variable.

Time since diagnosis and duration of time on antiretroviral regimen. With the exception of type of antiretroviral regimen, these correlates are believed to reflect duration or level of exposure to features of the disease that may significantly influence patients' familiarity with medical terminology and medication instructions. These factors were measured in the demographic portion of the survey and validated through medical chart abstraction.

Measures of quality of provider communications

Quality of provider communications was assessed with survey items from a measure of satisfaction with communication with health care providers shown to be reliable and sensitive for use in Latino/Spanish speaking and Latino/English speaking populations.²⁰ This measure consists of five items assessing aspects of provider communications to which patients are to rate their providers' communications using a seven-point rating scale. For example, patients were asked to rate how well their provider explains their medications and their medical tests and procedures. The responses range from very poor/poor to excellent/the best. This scale was able to distinguish differences in Latino Spanish language respondents and Latino English language respondents' satisfaction with providers communications in a large medical care practice study of more than 7000 respondents patients. To this five-item measure we added two additional questions from the University of California, San Diego Treatment Center California Collaborative Treatment Group baseline patient questionnaire (Little S. California Collaborative Treatment Group, University of California, San Diego, California, personal communication, October 26, 1999). These questions asked patients to rate their provider with respect to their willingness to respond to their questions and concerns and the extent their providers acted in a warm and friendly manner. The resulting measure consisted of four items assessing the relational component of communication or supportive manner of the provider, while three

items measured the instructional skills of the provider. The Cronbach α reliability for the scale was 0.88 for the intervention group and 0.91 for the comparison group.

Measures of health literacy

In this study, both measures of health literacy and specific measures of functional health literacy were used. For example, the HIV Illness and Treatment Knowledge and Misconceptions measure contained basic HIV information items and therefore assessed general health literacy. The modified REALM and the measure of comprehension of instructions on prescription bottles assessed individuals' command of knowledge to take medications correctly as stated in the prescribed instructions and thus was more a measure of functional health literacy.

HIV Illness and Treatment Knowledge and Misconceptions Survey. We measured HIV/AIDS disease and treatment knowledge and misconceptions using a 17-item survey that included basic knowledge of HIV transmission, treatment, and included common and important misconceptions. Items were derived from previous research assessing HIV-related knowledge among Latino populations.^{19,21} They included selected items from HIV medication information pamphlets to broaden the scope to include potential misconceptions about HIV antiretroviral therapy. Respondents were asked to respond to this list of 17 statements about HIV illness and treatment by stating whether they thought the statement was a Myth or Fact. Examples of statements were: "You can catch HIV from a toilet seat," and "When you are on HIV medications, you cannot transmit the virus to anyone else." "Don't know" responses were coded as incorrect. Correct answers were summed to form a score ranging from 0 (no knowledge) to 17 (high level of knowledge).

Modified REALM. The Rapid Estimate of Adult Literacy in Medicine or REALM in its original form is a short screening instrument that was designed to be used in public health and primary care settings to assess patients with low

reading levels. The REALM is preferred over other literacy measures because it assesses medical knowledge and is easily implemented in a variety of clinic populations. The advantage of the REALM over longer measures that measure functional health literacy such as the Test of Functional Health Literacy in Adults (TOFHLA) is that it can be administered in 1 to 2 minutes by personnel with minimal training and has displayed excellent concurrent validity with standardized reading tests.²² A limitation of the REALM is that it is not illness-specific and has limited direct applicability to assessing specific patients learning needs. To make the instrument applicable for HIV patient populations, HIV terms were added to the original set of medical terms. In keeping with the format of the original REALM, 24 medical terms were chosen because they reflected varying levels of difficulty. For example, terms ranged from HIV, virus, and symptoms (lower level of difficulty) to terms viral replication, protease inhibitors, HIV-resistant strains (higher level difficulty). Individuals were asked first if they had heard these terms (recognition) and second, whether they could explain them (understanding). Cronbach α for the recognition and understanding scales were 0.84 and 0.80 for the intervention group and 0.73 and 0.73 for the comparison group.

Recognition and understanding of instructions on prescription medication bottles. This measure was an investigator designed assessment of the ability of participants to read and comprehend the prescription label on medication bottles. Participants were first presented with a medicine bottle with instructions in Spanish. The second bottle contained instructions in English. Both bottles included cautionary statements, such as: take medications with lots of water and avoid exposure to sunlight; dosage schedule directions, such as: take 1 tablet by mouth every 6 hours as needed or take 1 tablet daily; as well as additional information about when to take the medication, such as: take as needed for nausea and vomiting. These medications were for treatment side effects or prevention of opportunistic infections; neither addressed a prescription for an antiretroviral medication.

Scores ranged from 1 to 4. A score of 1 indicated that they could read or understand the directions on either bottle but not both. A score of 4 indicated that they could read and accurately explain the directions on both bottles.

Measures of adherence mastery and self-reported medication adherence

Assessment of adherence to one's antiretroviral medication regimen was measured with questions from the Adult AIDS Clinical Trials Group (ACTG) Adherence Baseline Questionnaire²³ modified for use in this study. Participants were first asked to list each of their medications by name with the help of a picture depicting the color, shape, and size of antiretroviral medications. Then they were asked about their adherence to each of these medications for four points in time: yesterday, the day before yesterday (2 days ago), 3 days ago, and 4 days ago. For the purpose of this study, medication dosage was the unit of analysis; and, total number of doses missed was considered the measure of level of adherence. Although self-report of adherence is an indirect method of actual medication taking, it has predicted important virologic and immunologic outcomes.²⁴ One further measure of medication adherence also included items from the ACTG baseline questionnaire and included a question about participants level of certainty that they had mastered their medication regimen requirements. They were asked to identify how certain they were that they would be able to take all or most of their medications correctly where 0 = not at all sure and 3 = extremely sure.

Data analysis

The data from the evaluation of the acceptability and effectiveness of the program were analyzed using descriptive and comparative statistics. Initially, baseline descriptions of the intervention and comparison group participants were analyzed using univariate statistics (means, standard deviations, and percentages). Then differences between the two research conditions (program and comparison groups) were examined for equivalency using χ^2 analyses and analysis of variance (ANOVA). To examine the relative effectiveness of the program, significant differences in the intervention and comparison

groups at baseline and 6-weeks on the study variables were examined. Change scores were calculated by subtracting baseline from 6-week follow up assessments so that a positive result indicates a positive change. Change scores were entered into a bivariate linear regression analyses. McNemar tests²⁵ were used to test the significance of the changes in the intervention group with the intervention as the sole independent variable and HIV treatment-related knowledge and misconceptions, the dependent variable.

RESULTS

The results of the evaluation of the acceptability and effectiveness of the program are based on the initial pilot testing of the program with intervention and comparison group study participants. While 43 intervention and 42 comparison group participants were initially recruited, 2 participants in each group were lost to follow-up at 6-weeks. Comparisons in Table 1 reflect the number at 6 weeks follow-up. Reasons for being lost to follow-up were: 1, suspended antiretroviral therapy; 2, unable to locate, and 1, unable to participate because of being held in an immigration detention center. Baseline and 6-week follow-up data were available for 41 intervention and 40 comparison group patients.

Acceptability of the program

To evaluate the acceptability of the program we conducted assessments of expressed satisfaction with the intervention program. The program consisted of five once per week instructional support modular sessions. We conducted evaluations of each of the sessions. On average, intervention participants' evaluations of the program were very good to excellent. On a rating scale of 1 = poor and 4 = excellent. Mean scores were 3.96 (0.22) for how much the sessions were helpful to participants and 3.98 (1.4) overall satisfaction with the sessions (not in table). Furthermore, at the end of the modular program, intervention group participants were asked to give their suggestions for improvement of the overall program. Only two did not respond. Fifteen (34.9%), said they had no suggestions indicating that they were satis-

fied with the program as is. Eleven (25.6%) made suggestions about the structure of the program: classes to be held on weekends ($n = 3$); more women in the classes; extend hours; more time for questions ($n = 2$); meet on the weekends; more meetings; more people in the groups; programs should be longer ($n = 2$); and keep same presenters from one group to the next. Three participants made suggestions about the process of instruction: Instead of speaking up in the group, have members write down ideas ($n = 2$) and provide time for more discussion. The remainder of the participants (4) made suggestions about the content of the program: more presentations; more on anxiety and sexuality; more advanced content; and more guest speakers (not tabled).

Differences among intervention and comparison groups at baseline

Differences in intervention and comparison groups were not anticipated but were found.

In order to assess these differences, we compared both groups on selected subject characteristics and health status and treatment indicators at baseline. These comparisons are summarized in Table 1.

There were no significant differences between groups with respect to age, gender, proportion born outside the United States, education, income, language spoken at home, or level of acculturation at baseline. The majority of participants in the intervention and comparison groups were male, born outside the United States, had less than 12 years of education, and spoke Spanish at home. The average age of the intervention group was older and more participants in the intervention group reported average monthly incomes less than \$500, but these differences were not significant. There were no significant differences in level of acculturation, both groups were less than moderately acculturated with scores of less than 2 on the acculturation scale measuring language use (potential range, 1–5 with 5 representing

TABLE 1. SOCIODEMOGRAPHIC AND BASELINE HEALTH STATUS INDICATORS FOR INTERVENTION (GROUP 1) ($n = 41$) AND COMPARISON (GROUP 2) ($n = 40$) PARTICIPANTS

<i>Individual characteristics</i>	% or Mean (SD) and Range	
	<i>Group 1</i>	<i>Group 2</i>
<i>Sociodemographic characteristics</i>		
Age (mean)	41.90 (8.47) [31–65]	39.55 (9.32) [21–78]
Gender (% male)	87.8%	92.50%
Born outside U.S. (%)	97.56%	92.50%
Education (% < 12 years)	78.05%	87.18%
Income (% ≤ \$500/month)	47.50%	33.33%
Language at home (Spanish)	78.05%	72.50%
Level of acculturation (mean score) ^a	1.67 (0.59) [1–3]	1.84 (0.85) [1–4.8]
<i>Baseline health status and treatment indicators</i>		
CD4 count	213.68 (203.16) [4–1084]	353.28 (312.57)* [24–1193]
Viral load	68,788.32 (128,581.64) [25–708,576]	32,791.43 (90,459.52) [25–471,935]
Time since diagnosis (years)	7.73 (4.92) [0–18]	4.77 (3.88)** [0–17]
Time on ART (months)	62.04 (39.88) [0–144]	44.53 (33.82)* [0–120]

Demographic results based on Time 2 (6-week) sample sizes; those finishing the program.

^aPotential range, 1–5; higher score indicates higher level of acculturation.

^bMedian = 174 and 205.5, respectively.

^cMedian = 18,434 and 400.

* $p \leq 0.05$.

** $p \leq 0.01$.

*** $p \leq 0.001$.

greater acculturation). Despite lack of significant differences in sociodemographic characteristics, there were significant differences between the intervention and comparison groups at baseline with respect to health status and treatment indicators. The intervention group had been diagnosed for a longer duration (7.7 versus 4.8 years, $p \leq 0.004$) and had been on antiretroviral medications for a longer period of time (62.0 versus 44.5 months, $p \leq 0.04$). Intervention group participants differed from comparison group participants with respect to CD4 count ($p \leq 0.02$) but not viral load ($p \leq 0.15$).

Preassessment (baseline) and Postassessment (6 weeks) of groups on health literacy, quality of provider-patient communications, and self-reported adherence

Table 2 shows how the intervention and comparison groups differed at both time periods

(baseline and 6-week follow-up). The comparison group reported significantly greater quality of patient-provider communications than the intervention group, at baseline, $F(1,81) = 14.64$, $p \leq 0.00$. At 6-week follow up the intervention group reported significantly greater knowledge with respect to HIV/AIDS treatment, $F(1,80) = 7.49$, $p \leq 0.01$. The intervention group also had greater levels of recognition, $F(1,80) = 3.62$, $p \leq 0.06$, and understanding of HIV terms, $F(1,81) = 11.50$, $p \leq 0.00$. There were no significant differences between groups on the measure of understanding instructions on medication prescriptions. The comparison group continued to report higher quality of patient-provider communications.

There were no significant differences between groups on measures of adherence mastery and adherence behaviors (number of doses missed, last 24 hours and last 4 days) at both time periods (Table 2).

TABLE 2. COMPARISON OF HEALTH LITERACY AND ADHERENCE MASTERY AND BEHAVIORS FOR INTERVENTION AND CONTROL GROUPS, BASELINE AND SIX WEEKS

	Baseline		6 weeks	
	Group 1	Group 2	Group 1	Group 2
I. Level of health literacy				
HIV Knowledge/misconceptions (scale score)	12.83 (2.65)	13.54 (1.98)	15.15 (1.72)	14.50 (1.57) ⁺
HIV/AIDS disease-related knowledge/misconceptions	8.29 (1.72)	9.27 (1.16)**	9.28 (1.32)	9.35 (1.14)
HIV/AIDS treatment-related knowledge/misconceptions	4.54 (1.60)	4.27 (1.53)	5.88 (1.16)	5.15 (1.21)**
HIV terms:				
Global recognition (scale score)	17.07 (4.38)	18.64 (3.04) ⁺	21.20 (3.20)	19.73 (3.71) ⁺
Global understanding (scale score)	12.49 (4.88)	13.62 (3.48)	17.95 (4.41)	14.88 (3.66)***
Level understanding of prescription instructions (scale score)	2.80 (.93)	2.88 (.97)	2.93 (1.01)	2.70 (1.07)
Quality of communications with health care provider	21.13 (4.27)	25.23 (4.77)***	23.24 (3.97)	26.00 (5.24)**
II. Perceived adherence mastery and adherence behaviors				
Adherence mastery	1.76 (1.93)	2.00 (0.55)	2.02 (1.93)	5.93 (.62)
Self-reported medication adherence:				
Doses missed, last 4 days	2.38 (4.55)	1.82 (4.86)	1.26 (3.02)	2.16 (3.23)
Doses missed, last 24 hours	.56 (1.45)	.29 (1.21)	.29 (0.96)	.32 (0.96)

⁺ $p \leq 0.10$.

^{*} $p \leq 0.05$.

^{**} $p \leq 0.01$.

^{***} $p \leq 0.001$.

Figure 1 displays the differences between the intervention and comparison groups with respect to the amount of change that occurred over time. The intervention group showed greater change over time than did the comparison group with these outcomes: HIV/AIDS global knowledge and misconceptions, global recognition and global understanding of HIV terms. The intervention group increased in knowledge one point greater than the comparison group (HIV/AIDS global knowledge and misconceptions), $t(80) = 2.32$, $p = 0.03$, and showed the most change in recognition of HIV terms, $t(81) = 2.97$, $p = 0.00$, and understanding of HIV terms $t(81) = 3.52$, $p = 0.00$. Again, no differences were found between the groups, over the 6-week time period, for understand-

ing of prescription terms, adherence mastery or adherence behaviors (data not tabled).

Table 3 presents changes in scores on the HIV/AIDS treatment-related knowledge and misconceptions scale for the intervention group from baseline to 6-week follow-up. As illustrated in this table, there were four items on which significant improvement occurred. Compared to baseline, significantly more intervention participants could correctly identify that these items were myths or facts: "When you are on HIV medications, you can't transmit the virus to anyone else," McNemar (1,36) = 16.67, $p = 0.00$; "Many antiretroviral medications are poisonous and that is why they have side effects," McNemar (1,36) = 5.40, $p = 0.02$; "Skipping a dose of antiretroviral medication is ok, you can catch up at your next dose," McNemar (1,36) = 4.26, $p = 0.04$; and, "If you feel good, you don't really need to take antiretroviral medicine," McNemar (1,36) = 4.57, $p = 0.03$.

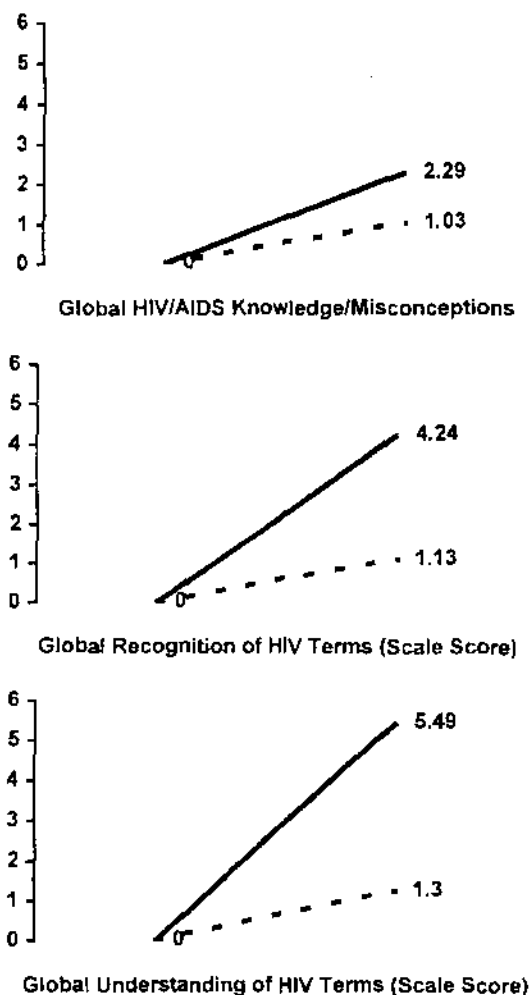


FIG. 1. Changes in health literacy, baseline and 6 weeks, for intervention and control groups. —, intervention group; - - -, control group.

DISCUSSION

The findings of this initial pilot study evaluating the acceptability and effectiveness of the *Es Por La Vida* program are tentative. Interpretation of these results must be tempered by the fact that the sample size was small, follow up was of short duration (6 weeks), and there was substantial reliance on subjective outcome measures. A more comprehensive evaluation of the program is forthcoming when the results of the evaluation of the participants for baseline, 6 weeks, and 6 months are available. However, the description of the program and preliminary analysis of study results provide important directions for future evaluation and for understanding the impact of the instructional support aspect of the program.

The purpose of the evaluation was twofold: to determine the acceptability of the program and to evaluate the effectiveness of the program in changing levels of knowledge and adherence outcomes. The results of the study indicated that the instructional modules were very well received and are acceptable to the participants. Both participant mean scores and

TABLE 3. CHANGES IN INTERVENTION GROUP PARTICIPANTS, BASELINE, AND SIX-WEEKS, ON MEASURES OF HIV/AIDS TREATMENT-RELATED KNOWLEDGE AND MISCONCEPTIONS

HIV/AIDS Treatment-related knowledge/misconceptions	Baseline	6 weeks
When you are on HIV medications, you cannot transmit the virus to anyone else.	37.50%	92.11%***
Many antiretroviral medicines are poisonous and that is why they have side effects.	57.89%	85.00%*
Skipping a dose of antiretroviral medication is fine, you can catch up at your next dose.	56.41%	79.49%*
If you feel good, you do not really need to take antiretroviral medicine.	65.00%	87.18%*
Taking a "drug holiday" is good. It gives your body a chance to recover from all those medications and their side effect	64.10%	76.92%
People who are Latino have worse side effects from antiretroviral medicines than other people.	87.50%	87.50%
When it comes to HIV, alternative therapies/medicines like herbs and vitamins are better than antiretroviral medications that the doctor prescribes.	92.11%	92.31%

* $p \leq 0.05$.

** $p \leq 0.01$.

*** $p \leq 0.001$.

narrative comments revealed high levels of satisfaction with the program.

A critical dimension of the *Es Por La Vida* program was this simplified instructional support aspect of the program. Low levels of HIV health literacy were shown to be significant and associated with lower education, lower income, and poorer quality of provider-patient communications in this sample of HIV-infected Latino men and women.²⁷ The piloted intervention successfully addressed major knowledge deficits and corrected important misconceptions that could potentially impact adherence behaviors. These results are supported by other studies that report the interrelationships of a number of factors that make this population more vulnerable to poor access and utilization of health care services. For example, those with less education and less command of English have been shown to have lower literacy levels and also tend to be less knowledgeable about health-related issues. They also access health care services less than those who are more acculturated.²⁷ As indicated in these preliminary analyses of data from the pilot study, although HIV health literacy increased for both groups, significant changes occurred for intervention participants, relative to comparison group participants, at 6-week assessment. Some of the knowledge

gained on the part of the intervention group, such as about skipping doses and transmitting HIV while on antiretroviral therapy might be crucial to their becoming more adherent.

CONCLUSIONS

Despite relative gains on some measures of health literacy, there were no significant changes with respect to reported medication adherence or adherence mastery for either the intervention or the comparison group at the 6-week interval. However, lack of demonstrative change in adherence mastery and behaviors might be expected in the short term. Additionally, the analysis was confined to commonly used self-report approaches. Electronic monitoring or pill counts were not available for analyses. Furthermore, viral load as a potential indicator of adherence behaviors is most meaningful when analyzed over time, commonly every 1- to 3-month intervals.

The significance of the program seems to be in its ability to enable and empower participants to more fully participate in their care. This initial analysis of preliminary data allows for scrutiny of both the strengths and weaknesses of the program in meeting its goals and begin to guide changes in the content and pro-

cess of the program. Furthermore, the sustainability of the program in the management of clinic patients is currently being evaluated. This evaluation will entail examining project design factors, the organization of service delivery to integrate the program successfully, and factors in the community that will influence how it will be implemented. Readyng patients to participate actively in their care is an important step in the direction of creating informed activated patients. This program achieved its goals in correcting misconceptions and enhancing disease- and treatment-related knowledge, which in turn have the potential for influencing adherence.

ACKNOWLEDGMENTS

This paper was completed with the support of the Universitywide AIDS Research Program and the State Office of AIDS grant #R00-LA-112.

REFERENCES

- Andersen RM, Bozzette SA, Shapiro MF. Access of vulnerable groups to antiretroviral therapy among persons in care for HIV disease in the U.S. *Health Serv Res* 2000;35:389-416.
- Cunningham WE, Mosen DM, Morales LS, Andersen RM, Shapiro MF, Hays RD. Ethnic and racial differences in long-term survival from hospitalization for HIV infection. *J Health Care Poor Underserved* 2000;11:163-178.
- Centers for Disease Control and Prevention. HIV/AIDS Surveillance report. United States Department of Health and Human Services, March 1999, 1-39.
- Centers for Disease Control and Prevention. HIV/AIDS Surveillance Report 2000;12:1-44.
- HIV Epidemiology Program, Los Angeles County Department of Health Services. Epidemiological profile of HIV/AIDS in Los Angeles County 2000.
- HIV Epidemiology Program, Los Angeles County Department of Health Services. Advanced HIV (AIDS) surveillance summary, July 15, 2002.
- Bozzette SA, Berry SH, Duan N, et al. The care of HIV-infected adults in the United States: Results from the HIV cost and services utilization study. *N Engl J Med* 1998;339:1897-1904.
- Russell LD, Alexander MK, Corbo KF. Developing culture-specific interventions for Latinas to reduce HIV high-risk behaviors. *J Assoc Nurs AIDS Care* 2000;11:70-76.
- Diaz RM. *Latino Gay Men and HIV: Culture, Sexuality, and Risk Behavior*. New York: Routledge, 1998.
- Katz MH, Cunningham WE, Mor V, et al. Prevalence and predictors of unmet need for supportive services among HIV-infected persons: Impact of case management. *Med Care* 2000;38:58-69.
- Fogarty L, Roter D, Larson S, Burke J, Gillespie J, Levy R. Patient adherence to HIV medication regimens: A review of published and abstract reports. *Pat Educ Counsel* 2002;46:93-108.
- Kalichman SC, Ramachandran B, Catz S. Adherence to combination antiretroviral therapies in HIV patients of low health literacy. *J Gen Intern Med* 1999;14:267-273.
- Morse EV, Simon PM, Walker J. Issues of recruitment, retention, and compliance in community-based clinical trials with traditionally under-served populations. *Appl Nurs Res* 1995;8:8-14.
- Mostashari F, Riley E, Selwyn PA, Altie FL. Acceptance and adherence with antiretroviral therapy among HIV-infected women in a correctional facility. *J Acquir Immune Defic Syndr Hum Retrov* 1998;18:341-348.
- Muma RD, Ross MW, Parcel GS, Pollard RB. Zidovudine adherence among individuals with HIV infection. *AIDS Care* 1995;7:439-447.
- Murphy DA, Lu MC, Martin D, Hoffman D, Marelich WD. Results of a pilot intervention trial to improve antiretroviral adherence among HIV-positive patients. *J Assoc Nurs AIDS Care* 2002;13:57-69.
- Marin G, Sabogal R, Marin B, Osteros-Sabogal R, Perez-Stable E. Development of a short acculturation scale for Hispanics. *Hispanic J Behav Sci* 1987;9:183-205.
- Marin G, Marin B. *Research with Hispanic Populations*. Newbury Park, Ca.: Sage Publications, 1991.
- Gomez CA, Marin BV. Gender, culture, and power barriers to HIV prevention strategies for women. *J Sex Res* 1996;33:355-362.
- Morales LS, Cunningham WE, Brown JA, Liu H, Hays R. Are Latinos less satisfied with communication from health care providers? *J Gen Intern Med* 1999;14:409-417.
- Flaskerud JH, Uman G. Directions for AIDS education for Hispanic women based on analyses of survey findings. *Public Health Rep* 1993;108:298-304.
- Davis TC, Long SW, Jackson RH, et al. Rapid estimate of adult literacy in medicine: A shortened screening instrument. *Fam Med* 1993;23:391-395.
- Chesney MA, Ickovics JR, Chambers DB, et al. Self-reported adherence to antiretroviral medications among participants in HIV clinical trials: The AACTG adherence instruments. Patient Care Committee & Adherence Working Group of the Outcomes Committee of the Adult AIDS Clinical Trials Group (AACTG). *AIDS Care* 2000;12:255-266.
- Haubrich R, Little S, Currier J, et al. The value of patient-reported adherence to antiretroviral therapy in predicting virologic and immunologic response during unrestricted therapy. *AIDS* 1999;13:1099-1107.

25. Stokes ME, Davies CS, Koch GC. Categorical Data Analysis Using SAS System, 2nd ed. Cary, NC: SAS Institute Inc., 2000.
26. van Servellen G, Brown J, Lombardi E, Herrera G. Health literacy in low income Latino men and women receiving antiretroviral therapy in community-based clinics. *AIDS Patient Care STDs* 2003; 17:283-298.
27. Zambrana RE, Breen N, Fox SA, Gutierrez-Mohamed ML. Use of cancer screening practices by Hispanic women: Analysis by subgroup. *Prev Med* 1999;29: 466-477.

Address reprint requests to:
Gwen van Servellen, R.N., Ph.D., FAAN
Professor, Acute Care Section, School of Nursing
3-246 Factor Building
School of Nursing
700 Tiverton Avenue
Box 956917
Los Angeles, CA 90095-6917

E-mail: Gservell@sonnet.ucla.edu

Copyright of AIDS Patient Care & STDs is the property of Mary Ann Liebert, Inc. and its content may not be copied or emailed to multiple sites or posted to a listserv without the copyright holder's express written permission. However, users may print, download, or email articles for individual use.