

# Design, development, and feasibility of a spanish-language cancer survivor support group

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## Abstract

**Purpose** Latino cancer survivors experience lower psychosocial well-being compared to non-Latino Whites. This study describes the development of a culturally appropriate support group and reports on feasibility of implementation and preliminary outcomes.

**Methods** *Promotores* (lay health workers) conducted all aspects of data collection and program implementation. Participants were 29 Spanish-speaking Latino cancer survivors ( $n=12$  men, 17 women) who took part in one of three study phases. Phase 1 included one-on-one interviews and focus groups ( $n=14$ ) to investigate psychosocial needs of survivors. During phase 2, a 10-week program was developed that integrated data from phase 1 and culturally relevant concepts. Session topics included stress, nutrition, physical activity, body image, sexuality, medical advocacy, and social support. In phase 3, the program was implemented within gender-specific groups ( $n=15$ ). Within-group pre-post comparisons of distress (distress thermometer, salivary cortisol) and quality of life (FACIT) were conducted. Follow-up focus groups assessed participant experience

**Results** Phase 1 activities identified survivor needs and interests (e.g., isolation, family and spirituality, supporting other Latinos with cancer). Evidence of program feasibility was

demonstrated (e.g., 90–100 % attendance, 100 % data completion). While interpretation of significance is limited due to sample size, improvements in quality of life [functional ( $p=0.05$ ), social ( $p=0.02$ ), and meaning/purpose ( $p=0.05$ )] were observed among women but not men. Qualitative follow-up revealed high satisfaction with group participation, but discomfort with the topic of sexuality in women.

**Conclusions** This project demonstrates development and feasibility outcomes for providing culturally appropriate psychosocial support to Latino cancer survivors. Limitations, including lack of control group, and future directions are discussed.

**Keywords** Latino · Survivor support group · Distress · Quality of life

## Introduction

Social support resources have emerged as a viable means of alleviating long-term psychosocial burdens of cancer [1, 2] but are limited in availability and uptake among Latino cancer survivors due to linguistic and sociocultural barriers [3]. Latino cancer survivors are known to experience significantly higher levels of distress and lower quality of life compared to non-Latino Whites (NLW) [4–7]. In addition to psychosocial disparities, there is evidence linking chronic distress with physiological dysregulation. The hormone cortisol, a well-established biomarker of distress [8, 9], is linked with cancer-related fatigue [10] and associated with numerous mechanisms of cancer progression [11, 12]. However, the ability to collect and measure cortisol in Latino cancer survivors as a marker of distress has not yet been documented.

Among Latinos, patient-identified contributors to poor psychological well-being include the following: poor patient-physician communication [3, 13], secrecy and shame about cancer [14], concerns about body image and sexuality [3, 15],

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a concern for their family, a desire for health-related education, financial concerns, strong feelings of depression and isolation, and physical limitations due to cancer treatment [16]. Despite these previously identified needs of Latino cancer survivors, a small number of studies have translated these findings into a formalized and culturally competent intervention program [13, 17]. Even fewer studies have explored cancer survivorship in Latino men and the potential need for single-gendered interventions to accommodate cultural norms [18].

Thus, the goals of this study were to formalize a culturally appropriate Spanish-language support group program to be implemented by *promotores* (lay health workers), demonstrate the ability to collect salivary cortisol samples, explore gender-based needs in cancer survivorship, and evaluate the feasibility of the program to impact distress (reduce self-reported distress and concentrations of cortisol awakening response) and improve self-reported quality of life in Latino cancer survivors using a mixed-method approach.

## Materials and methods

### Overview

A mixed-method (qualitative and quantitative methods) approach to address survivor needs occurred in three sequential phases. Use of mixed methods allows for complementary examination of a topic under study [19]. This protocol was approved by the Fred Hutchinson Cancer Research Center's (FHCRC) Institutional Review Board.

### Setting

This study took place in a largely agricultural community where Latinos constitute an estimated 67 % of the total population [20] and primarily identify as Mexican-American (98 %) [21].

### Promotores

*Promotores* are bilingual/bicultural Latinos who often live in the community which they serve providing health-related support, education, and advocacy [22–24]. Through their often long-standing and trusted relationships with communities, *promotores* provide a familiarity often unattainable by researchers, especially among underserved communities. Inclusion of *promotores* contributes to community capacity and potential for program sustainability, if the intervention is successful [25]. Capacity building includes gaining a basic understanding of research methods, community engagement, group facilitation, and education about the topic under study.

### Experience/training

*Promotores* had extensive experience working as lay health workers for the FHCRC—employed full-time to deliver health promotion education, conduct qualitative research, and organize large community health events in collaboration with local organizations. *Promotores* were required to complete and maintain human subjects, information privacy, and confidentiality certifications. An 8-h training led by the primary investigator (PI) included a review of qualitative data collection procedures and an introduction to study goals and the interview/focus group guides. An additional 40 h of training were provided for group facilitation by a licensed clinical social worker and the PI. The training included topics like group dynamics, the role of a facilitator, procedures for urgent emotional distress among participants, should it arise as well as the support group content. Once support groups began, *promotores* and the PI spoke via telephone prior to every session for 30–60 min to ensure the content was well understood and *promotores* were confident in their ability to facilitate the group.

### Monitoring

Focus group, interview, and support group fidelity were achieved through in-person evaluation by field managers, review of focus group and interview audio-recordings, and written post-session summaries of each session by the *promotores*. Bilingual/bicultural field supervisors attended 20 % of the focus groups and support group sessions to evaluate consistency of content presentation and facilitation performance between *promotores*. In the presence of a certified translator who was native to the research setting, the PI reviewed a randomly selected portion (approximately 25 %) of every focus group and interview recording.

### Participants

#### Eligibility

Criteria for phases 1 and 3 were identical with the exception of time since diagnosis (phase 1,  $\leq 10$  years; phase 3,  $\leq 5$  years). Participants needed to self-identify as Latino, be fluent in Spanish, at least 18 years old, a current resident of the region, and, for independence, not enrolled in another study phase. Participants also needed a self-reported diagnosis of any cancer type, except non-melanoma skin cancers (often easily treatable, very rarely associated with metastasis or death and, as such, not reportable to cancer registries [26]), to have completed treatment for their primary cancer (except adjuvant therapy), and not be actively undergoing treatment for a second, metastatic, or recurrent cancer.

## Demographics

Time since diagnosis differed between groups because of phase-related eligibility criteria. Phase 1 participants averaged 5.5 (SD=7.1) years and phase 3 participants averaged 3.2 (SD=1.9) years since diagnosis. Analysis of all other demographic data using chi-square and *t* test comparisons, as appropriate, indicated no statistically significant differences between phases 1 and 3 (data not shown). No significant differences in demographics were present by gender (with exception of cancer types that occur exclusively or more frequently in men or women). Therefore, Table 1 presents demographic data combined for the two phases.

## Recruitment

Trained *promotores* conducted recruitment for all study phases. Independent samples were recruited for each study phase, although procedures were the same. Procedures

included distribution of study information for recruitment purposes via fliers placed in public areas (e.g., grocery stores and salons), advertisements on local Spanish-language radio and television stations, and community partners (local medical and service organizations) advertised through their networks. Interested participants were asked to call the research staff who further described the study purpose and procedures and conducted an initial telephone screening to confirm eligibility.

## Procedures

### Phase 1. Formative data collection

Phase 1 used a concurrent independent method of inquiry with a qualitative priority [26]. Focus groups and one-on-one interviews were conducted and survey data collected to identify needs and topics of interest to participants. After determining eligibility, *promotores* contacted participants via telephone to determine a mutually agreed upon time and location to hold

**Table 1** Demographics and cancer type for the combined sample and by gender. Mean±SD are provided for age, years of education, and years living in the USA (for foreign born participants only). Frequency, *n*, and percent of sample (%) are presented for annual household income, country of birth, and language preference

	Combined ( <i>n</i> =29) M (SD)	Men ( <i>n</i> =12) M (SD)	Women ( <i>n</i> =17) M (SD)
Age	54.31 (10.72)	56.75 (14.01)	52.59 (7.64)
Years of education	6.28 (4.17)	6.58 (4.42)	6.06 (4.10)
Years living in USA	30.2 (16.44)	37.63 (14.87)	25.25 (16.11)
	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)
Income			
<\$15,000	7 (24)	2 (17)	5 (29)
\$15–35,000	18 (62)	9 (75)	9 (53)
>\$35,000	4 (14)	1 (8)	3 (18)
Country of birth			
Born in Mexico	20	8 (67)	12 (71)
Born in USA	9	4 (33)	5 (29)
Language preference			
Spanish-preferring <sup>a</sup>	19 (66)	7 (58)	12 (71)
English-preferring	9 (31)	1 (8)	0 (0)
Bilingual	1 (3)	4 (33)	5 (29)
Cancer type			
Breast	6 (21)	0 (0)	6 (35)
Colorectal	3 (10)	1 (8)	2 (12)
Endometrial/cervical	2 (7)	n/a	2 (12)
Leukemia	1 (3)	1 (8)	0 (0)
Lung	1 (3)	0 (0)	1 (6)
Multiple myeloma	1 (3)	1 (8)	0 (0)
Non-Hodgkin's lymphoma	5 (17)	4 (33)	1 (6)
Osteosarcoma	1 (3)	0 (0)	1 (6)
Ovarian/uterine	4 (14)	n/a	4 (24)
Prostate	2 (7)	2 (17)	n/a
Stomach	2 (7)	2 (17)	0 (0)
Testicular	1 (3)	1 (8)	n/a

<sup>a</sup> Participants indicated they spoke Spanish only or Spanish better than English

each session (focus groups and interviews). All sessions were gender-specific and led by a gender-matched *promotor/a*. All groups and interviews were held at the FHCRC satellite office. *Promotores* reviewed the informed consent with each group or individual to ensure comprehension. Then, the baseline survey (demographics, health history, and list of topics of interest) was completed. Surveys were completed with the assistance of the *promotores* if a participant had limited literacy. Focus groups and interviews ranged from 60–90 min in duration. All sessions were audio-recorded and participants received \$20 compensation for their time.

Focus groups rely on the interaction of participants to promote discussion and generate consensus of ideas [27]. Focus groups were the primary method of assessment; however, two one-on-one interviews were conducted to accommodate unexpected changes in participant schedules. One-on-one interviews ensure that no undue pressure is placed on the individual to respond in a socially desirable way [27]. In both formats, the interview guides were semi-structured and sought information about current psychosocial and physical sequelae of cancer, social and informational support resources, and type of information they would seek now, looking back.

Upon completion of each session, 100 % of the audio-recordings were transcribed and translated into English by certified Spanish-language translators. To verify accuracy of the translations prior to beginning analyses, the research supervisors performed intermittent checks of the focus group and interview transcriptions and translations.

### *Phase 2. Development of cancer support group protocol*

Materials and content for the support group were developed and the protocol formalized by the research staff (including *promotores*). Since phase 2 program development relied, in part, on findings identified during the phase 1 analysis, the process of program development is presented in phase 2 results and includes identifying content, a description of the support group format and means of integrating cultural features into the program's protocol.

### *Phase 3. Support group implementation*

Phase 3 used a sequential independent method of inquiry with an equal qualitative and quantitative priority [26]. Evaluation included pre-post quantitative examination of the intervention followed by qualitative assessment of the support group experience to collect participant feedback about the program and gain explanatory insights for quantitative outcomes. Similar to phase 1, *promotores* contacted participants prior to the start of the intervention group to arrange a mutually agreed upon time and day to hold sessions. All sessions took place at the

FHCRC satellite office. Three to 4 days prior to the start of each support group series, *promotores* arranged for in-person meetings either at the participant's home or at the FHCRC satellite office (as chosen by the participant) to complete the informed consent and a baseline survey. This allowed the *promotores* to carefully review the informed consent with each participant to enhance comprehension and allowed the *promotor/a* to assist participants with limited literacy to complete baseline and follow-up surveys. *Promotores* explained the salivary sample collection device (salivettes). The post-intervention assessment was completed 3–4 days after completion of each support group series.

The support group itself took place over a series of 10 weekly meetings. A gender-specific closed group format (including gender-matched *promotor/a*) was selected to enhance stability and group cohesion. Individual sessions were approximately 90 min. Each session consisted of three segments: (1) a didactic introduction to the session topic by the *promotor/a*, (2) a dynamic group discussion exploring the topic, and (3) an activity that explored behavioral strategy related to the session topic (see Table 2). Participants in the support group received a \$10 gift card upon completion of each survey and \$10 for providing two salivary samples at each pre- and post-intervention time point for a total of \$40.

Feasibility of completing a support group for Latino cancer survivors was assessed using measures of attendance, questionnaire completion rate, and salivary sample collection, as well as data from the follow-up focus groups and *promotores* reports. Follow-up focus groups were conducted upon completion of the 10-week session to gain insights to the successes and limitations of the program, appropriateness of the cultural factors, and ideas for future sessions. Each focus group was about 1 h and participants received a \$10 gift card for participating in a follow-up focus group.

### Measures

All surveys were translated into Spanish by certified translators on the research team or were linguistically validated by the referenced developer of the questionnaire.

### *Demographic and general interest survey*

All participants, regardless of phase, completed a demographic survey and provided cancer-specific and general health information. Additionally, phase 1 focus group participants were asked to select potential topics of interest from a list of options garnered largely from the scientific literature discussing survivor needs.

**Table 2** Support group session topic and activities outline

Session no.	Topic	Activity
1	Opening and welcome	Yarn spiderweb (demonstrating the interconnectedness of group members)
2	Stress management	Relaxation (progressive muscle relaxation and deep breathing)
3	Stress management II	Relaxation (guided meditation and deep breathing)
4	Nutrition	Recipe exchange (making favorite recipes healthier)
5	Physical activity	Chair-robics video (Nez Perce Nimiipuu Health Program)
6	Medical advocacy	Role Playing (list and rehearse questions for next visit to doctor)
7	Body image	Expressive Art (create something that represents how you feel about your body or what you feel most strongly)
8	Sexuality and intimacy	Look Good Feel Better© program (American Cancer Society)
9	Social support	Planning social support for the future
10	Closing	Discuss experience in group, process the closure of the group

### Quality of life

Quality of life was measured using the Functional Assessment of Cancer Therapy-General (FACT-G) [28]. The FACT-G is a 27-item compilation of general questions divided into four primary QOL domains: Physical (PWB), Social (SWB), Emotional (EWB), and Functional Well-Being (FWB). An additional 12 questions assessed spiritual well-being (FACIT-Sp). Response options ranged from 0 to 4 (0=not at all, 4=very much).

### Distress

Distress was assessed using the National Comprehensive Cancer Network Distress Thermometer [29] and salivary cortisol measurements. *Distress Thermometer*. The distress thermometer was selected because it is extremely accessible to the low-literacy population present in this community and is a common tool used by clinicians to assess patients' distress and make support referrals. Participants rated their level of distress from 0 to 10 (0=no distress, 10=extreme distress) and indicated causes of their distress from a predefined list in the areas of practical, physical, family, and emotional problems or spiritual/religious concerns. *Cortisol*. Cortisol awakening response (CAR) is the change between first waking and 30 min after waking [30]. Under natural conditions in healthy adults, increases in CAR vary but have been found to average 50 % (equivalent to a mean CAR of 0.28 µg/dL) with a minimum CAR of 0.09 µg/dL for identification as a CAR [31]. However, substantially larger increases in CAR have been positively associated with levels of daily stress [32]. CAR was calculated using samples collected 1 day immediately prior to the start and after completion of the support group series. Proper

packaging for room temperature storage was provided for delivery to the *promotor/a*. Samples were stored in a −20 °C freezer at the satellite office until time of assay. Cortisol was measured by ELISA at Salimetrics LLC (State College, PA, USA).

### Data analysis

#### Qualitative data

Transcripts were reviewed by two coders using a thematic approach and constant comparative method by which central concepts emerge through open coding and relating codes to each other [33, 34]. Using Atlas.ti® software, the transcripts were coded using a codebook of key constructs developed with keywords and ideas identified during the initial transcript reviews. Codes were used to discern broad themes and patterns. Many of the themes that emerged in this study were previously identified in a robust study conducted, independently, in a similar target population and geographic region [16] offering an opportunity for replication and showing saturation had been reached for those themes. Therefore, although described below, percentages or frequencies are not reported for these themes [35, 36]. Quotes representing themes different from Livaudais et al. were selected from participant transcripts and are presented in the results section along with their frequencies (code occurrence, CO).

#### Quantitative pre-post measures

Data were entered into SPSS® statistical software. All analyses were exploratory in nature and do not represent the power needed to properly interpret statistical significance. Pre-post analyses were conducted using paired sample *t* tests. Statistical significance was held at  $p \leq 0.05$ .



## Results

### Phase 1: qualitative assessment

Themes that emerged included concern about the impact of cancer on family, depression and isolation, spirituality in coping, patient-physician communication barriers, and a sense among some women that female cancer equates to a loss in femininity and self-worth. Further, both men and women identified fear of recurrence (16 CO), difficulty with memory (14 CO), and fatigue (12 CO) as part of their survivorship experience.

Participants also described ways they worked to improve health and cope with long-term consequences of cancer. Among these, diet/nutrition (19 CO) and physical activity (11 CO) were the most common strategies discussed by both men and women. One woman reported, “Now I am more conscious of what I eat...before I used to eat whatever I pleased. Now, I pay attention to what I’m going to cook or...buy.” Another theme was the desire to help other cancer survivors. Both men and women noted the importance of social support and the benefits of group programs. Specifically, the importance of emotional, instrumental, and informational support was described. The most commonly reported way to help other survivors was emotional support. A male survivor indicated they would help other cancer survivors as, “I could talk to them....Tell them not to lose hope and encourage them...look forward to the future...think about better life up ahead.” Instrumental support, most often appeared in a financial and informational context. A male participant stated, he would “help them economically, a little bit, but a few dollars.” They also saw themselves as important informational resources for the newly diagnosed. One woman described, “I would like to help someone...to learn more about cancer. I think that would be most important...to get educated in how to survive it.”

In addition to qualitative data, frequencies of patient-reported interests selected from a list of options resulted in identification of multiple topics of interest. Topics selected as an area of interest for at least 50 % of both men and women included fear of recurrence, fatigue, emotions, coping, stress, memory, screening, medical care, pain, spirituality, nutrition, body image, exercise, social support, heart disease concern for family, sleep, communication, talking to the doctor, and sexuality (see Table 3).

### Phase 2: Development of the cancer support group program

Using the data collected during phase 1 of the study, the following were identified as important components to include in the support group: addressing physical and emotional needs, providing health education (including information about achieving nutritional and physical goals), assisting in

**Table 3** Frequency (%) with which participants selected topics of interest

Topic	Combined ( <i>n</i> =14) <i>N</i> (%)	Men ( <i>n</i> =6) <i>N</i> (%)	Women ( <i>n</i> =8) <i>N</i> (%)
Fear of recurrence	14 (100)	6 (100)	8 (100)
Fatigue	13 (93)	6 (100)	7 (88)
Emotions	13 (93)	5 (83)	8 (100)
Coping	13 (93)	5 (83)	8 (100)
Stress	13 (93)	5 (83)	8 (100)
Memory	13 (93)	5 (83)	8 (100)
Screening	13 (93)	5 (83)	8 (100)
Medical care	13 (93)	5 (83)	8 (100)
Pain	12 (86)	5 (83)	7 (88)
Spirituality	12 (86)	4 (67)	8 (100)
Nutrition	12 (86)	4 (67)	8 (100)
Body image	11 (79)	3 (50)	8 (100)
Exercise	11 (79)	3 (50)	8 (100)
Support	11 (79)	3 (50)	8 (100)
Heart disease	11 (79)	4 (67)	7 (88)
Concern for family	10 (71)	4 (67)	6 (75)
Sleep	10 (71)	4 (67)	6 (75)
Communication	10 (71)	4 (67)	6 (75)
Talking to the doctor	10 (71)	3 (50)	7 (88)
Sexuality	9 (64)	3 (50)	6 (75)
Disability	8 (57)	2 (33)	6 (75)
Diabetes	7 (50)	2 (33)	5 (63)
Will planning	7 (50)	2 (33)	5 (63)
Smoking	5 (36)	1 (17)	4 (50)
Other	2 (14)	1 (17)	1 (13)

communication with physicians, and providing opportunity for the aspiration to help others diagnosed with cancer.

Topics selected from a list of options provided on the survey were considered for inclusion when selected by over 60 % of the sample and at least 50 % of men and women (see Table 3). As some topics that appeared in 60 % of the sample were inherently more concrete, they offered a natural framework for group discussion, e.g., talking to your doctor and nutrition. These topics served as lead topic for a single session in the support group. The list of topics selected for each session is presented in Table 2. Other topics of interest to participants and relevant to cultural competency were more transcendent and were not exclusive to a single session, therefore, were discussed in all or multiple sessions, often introduced by participants themselves. These topics included spirituality, the role of emotions, coping with fear, impact of cancer, and long-term effects of cancer on family and friends.

Topics of interest to men and women were similar in many respects. Although, for some topics (e.g., body image, exercise, spirituality, and social support) the frequency of selection differed between men and women, the fact some of these

topics were discussed during the qualitative assessment and there were some men who demonstrated an interest in these topics, the research team determined that topics meeting the above inclusion criteria should be incorporated into the program in an effort to evaluate the acceptability of the topics to both men and women, as well as the potential willingness of each gender to discuss the topics that had previously been identified by both Latino men and women (from the same geographic region) as important to cancer survivorship [16].

To accommodate potential differences between men and women, groups were single-gendered, led by a gender-matched *promotor/a*, and differed slightly in how the topics were discussed within the group rather than involving tremendously different content. For instance, the sexuality and intimacy session included presentation of potential sexual side effects, the relationship of sexuality/intimacy/body image, how to talk to your partner about changes/challenges, self-exploration, emotional intimacy, and was developed to be the most brief of the didactic segments in the series. The only specific content presented that differed was the description of sexual side effects of cancer treatment for men and women, as appropriate. Rather, the main difference lay in the presentation of the material and balance between discussion and activities. Documented differences in the perceived appropriateness of discussion about sexuality among Latino men and women have identified cultural norms in which sexuality may be more freely discussed among men but is considered inappropriate among women, especially in the case of a conversation between a man and woman [18]. As a result, open discussion about the material presented in the didactic portion was limited for the women's group. Instead, the large majority of the session in the women's group involved an activity provided by the American Cancer Society, the Look Good Feel Better© program. As part of this ACS program, a certified beautician provides a gift bag of supplies and provides individual assistance with the application of make-up and hairstyling for the women. In contrast, the men's session considered the material presented in the didactic portion of the session and largely involved open discussion. Men discussed current relationships and the impact of cancer on sexual activity and drive. Men did receive a care package provided that included skin lotion, shaving cream, a comb, a FHCRC water bottle, and hat which was accompanied by a brief discussion of care of the physical body as it relates to sexuality and intimacy. In most other sessions, however, the content and presentation were similar for men and women with flexibility during the open discussion for each group to explore an area of their choice with more depth (see phase 3 results, "Promotores Reports" for example).

With regard to accessibility of the program, as part of the research team, *promotores* provided feedback during the development of the formalized program to ensure that the materials were accessible to the community and contained

culturally appropriate content (Table 4 provides examples of how cultural content was integrated into the program). Aspects of the support group that helped create a culturally competent environment included both extrinsic and intrinsic features [37, 38]. Extrinsic features included holding all group sessions in Spanish, using *promotores* as group facilitators, and providing all written and audio/visual content in Spanish. More intrinsic features included *personalismo* (the desire to build a personal connection with others), *respeto* (deference to authority), *simpatía* (importance of being polite), *familismo* (importance of family), *marianismo/machismo* (beliefs about gender roles and caring for the family), *vergüenza* (embarrassment/shame), and spirituality (religious values/beliefs/the sacred) [39]. These cultural features were present in every session. Other culturally relevant features that were addressed were the need to present content in simple terms as up to 70 % of the region's population had less than an eighth grade education (40 % less than fourth grade education) [16].

### Phase 3: Support group evaluation

#### *Feasibility*

Feasibility of the formalized support group protocol was demonstrated through regular participant attendance (90–100 %) in all groups, 100 % survey data collected, and all but one salivary sample collected. Summary reports from *promotores* suggested a supportive and collaborative atmosphere at all sessions and that the formalized content made implementation of the program more accessible to them and offered a way in which to support one another as facilitators.

#### *Quantitative assessments*

Comparisons of pre-/post-distress thermometer scores showed modest improvements overall. Most participants had a baseline distress score above the clinically relevant cut-off of 4 [40]. Participants with high distress scores (above 7) showed the greatest decline in stress. Women tended to have higher distress scores compared to men and showed the greatest change in distress (see Table 5). However, both men and women with distress scores above 7 showed decline in distress compared to those with scores lower than 6 at baseline. Causes of distress were due to emotional (worry, sadness, depression) and physical symptoms (pain, nausea). Overall, the frequency of emotional effects decreased from baseline to follow-up in both men and women. The frequency of most physical symptoms remained about the same or increased between baseline and follow-up, although fatigue appeared to decline in both men and women. Changes in CAR were not statistically significant [ $t=1.08$  (12),  $p=0.30$ ] (see Table 5). Interestingly, at baseline, CAR values were minimal and

**Table 4** Examples demonstrating how deep features were integrated into the support group curriculum

Cultural concept	Features of concept relevant to the intervention	Resolution
<i>Personalismo</i>	Meaningful personal connections need to first be sharing of personal information	<ul style="list-style-type: none"> <li>In-person group setting provided opportunity for <i>personalismo</i> to occur (i.e., sharing of cancer stories and other personal information)</li> <li>Session topics progressed toward more emotionally intimate topics</li> </ul>
	Patient-doctor interactions in the U.S. tend to refrain from personal exchanges (e.g. communication with physicians).	<ul style="list-style-type: none"> <li>Medical advocacy session discussed patient-physician dynamics</li> <li>Role-playing exercises allowed participants to rehearse conversations</li> <li>Participants helped each other develop questions for their next medical visit</li> </ul>
<i>Respeto and Simpatía</i>	Latinos may not ask questions or offer information for fear of appearing disrespectful	<ul style="list-style-type: none"> <li>The idea that asking questions and offering information could be helpful for the medical staff's goal of providing adequate and well-informed patient care</li> </ul>
<i>Familismo</i>	Family is often central to participant concerns and, in most cases, social support	<ul style="list-style-type: none"> <li>Participants encouraged to discuss support group content with family and friends</li> <li>Participants often discussed how the support group content related to their families as barriers and/or facilitators</li> </ul>
<i>Marianismo/Machismo</i>	Traditional gender roles may hinder disclosure during group discussions (e.g., sexuality and body image)	<ul style="list-style-type: none"> <li>All groups were single-gendered and facilitated by a same-sex <i>promotor/a</i></li> <li>Topics such as sexuality and body image were placed near the end of the series to allow time for group cohesion</li> </ul>
	Desire to care for the family before self and importance of supporting the family	<ul style="list-style-type: none"> <li>Discussions included the idea that taking care of themselves may allow them to take better care of their families</li> </ul>
<i>Vergüenza</i>	Sexuality is viewed as a very private matter between intimate partners.	<ul style="list-style-type: none"> <li>The didactic portion of the session was limited with the activity taking most of the session and focusing on the participant's comfort/relationship with their own body</li> </ul>
	Concern about having low education and low literacy	<ul style="list-style-type: none"> <li>All written material provided were read aloud by <i>promotores</i> and activities were used to reinforce the session's educational content</li> </ul>
Want to help others in the community	A desire to help others was highlighted in Phase 1 and throughout the sessions	<ul style="list-style-type: none"> <li>A leadership brochure was developed and distributed to help participants</li> <li>2 participants asked to advocate for the support group during a regularly scheduled health education radio spots</li> </ul>
Spirituality	Spirituality is often central to daily lives and beliefs regarding disease and recovery	<ul style="list-style-type: none"> <li>Ground rules included respect for all perspectives and beliefs; discussion of spirituality or religion was free-flowing throughout the sessions.</li> <li>Each group established rules regarding opening and closing of each session (opportunity for spiritual expression)</li> </ul>

**Table 5** Distress thermometer and quality of life mean (SD) scores and *p* values overall, for men and women at baseline and follow-up

	Overall ( <i>n</i> =15)			Men ( <i>n</i> =6)			Women ( <i>n</i> =9)		
	Baseline	Follow-up	<i>p</i>	Baseline	Follow-up	<i>p</i>	Baseline	Follow-up	<i>p</i>
Distress thermometer	5.6±3.5	3.3±3.6	0.11	5.3±3.2	4.0±3.7	0.57	5.8±3.8	2.9±3.7	0.14
Cortisol awaking response (µg/dL)	0.10±0.26	0.01±0.17	0.30	0.12±0.32	0.04±0.18	0.67	0.08±0.32	-0.02±0.16	0.17
Physical well-being	22.6±5.4	23.3±3.8	0.35	19.0±6.4	21.5±1.8	0.10	25.0±3.0	24.6±3.0	0.58
Emotional well-being	19.3±2.9	18.2±3.7	0.19	18.0±3.7	17.0±3.5	0.33	20.1±2.1	19.0±3.8	0.37
Functional well-being	17.7±5.4	19.7±4.9	0.05*	15.3±6.9	16.7±4.8	0.50	19.2±3.8	21.8±4.0	0.05*
Social well-being	17.0±6.7	20.6±4.7	0.01*	18.5±6.8	20.2±4.2	0.34	16.0±7.3	20.8±5.3	0.02*
Spiritual well-being	36.6±8.1	39.7±5.5	0.06	35.3±9.6	37.0±6.7	0.58	37.4±7.4	41.6±3.8	0.05*

Norms for the FACIT are PWB 21.2 (6.2), EWB 18.1 (4.5), FWB 18.8 (6.4), SWB 22.3 (4.8). Norms for meaning/purpose are not available

\**p*≤0.05 (however, given the small sample size interpretation of these values is limited and should be considered preliminary)



diminished even further at follow-up for both men and women [31].

When examining quality of life, FWB and SWB improved in both statistical and clinically meaningful ways (at or above 0.5 standard deviations) [41]. However, overall differences were due primarily to changes present in women (see Table 5). Although some QOL scores increased, they remained lower than population norms published by the FACIT developers [42]. For instance, SWB in women improved from 16.0 (SD=7.3) to 20.8 (SD=5.3) and men from 18.5 (SD=6.8) to 20.2 (SD=4.2) compared to the published norm of 22.3 (SD=4.8) (see Table 5). Changes in PWB among men were slightly lower than the norm at pre- and post-intervention, but women scored substantially higher at both pre- and post-intervention (see Table 5). EWB scores were approximately equivalent to norms at both pre- and post-intervention. Finally, although norms for SWB are not available, men and women scored high on the spirituality scale.

### Qualitative assessments

*Follow-up participant focus groups* During follow-up focus groups, participants reported that the group setting provided a safe environment in which men and women felt comfort and relief from emotional isolation related to cancer. Second, nutrition and physical activity were identified as the most helpful because these topics were on the forefront of participants' minds when they entered the group and the role of these factors in long-term health was well understood, but information about these subjects was lacking. Third, participants appreciated the education segments of the program and opportunity to challenge their normal patterns of thinking, such as implementing stress management techniques. One man stated, "it's something I never imagined we would have, these kinds of lessons. So I felt very good, I felt relaxed."

Comments regarding their overall experience, session topics, format, and environment were overwhelmingly positive. One woman described the group by saying, "for me, this wasn't a coincidence. For me this was something sent from heaven." However, some female participants expressed discomfort discussing issues of sexuality. Suggestions for future groups included involvement of family and friends, and more time on nutrition and physical activity. Participants also stated a willingness to speak on behalf of the program and encourage others to attend. Finally, when asked about the importance of having a Latino-centered group, participants commented on the benefit of an environment that supports an unspoken cultural understanding. One participant stated, "being here as Latinas...in feeling and listening to your music, your environment, and eating something [traditional]— even if they are modified recipes...this lifts up our souls, encourages us, your spirit is elevated, and, it makes it easier for us to carry our illness."

*Promotor/a reports* Written summary reports were provided by the *promotor/a* after each session. In each report, their own observations and insights were expressed regarding the effectiveness and participant experience during each session. Interestingly, all of the session summaries reflected positive experiences for participants. Both the men's and women's group members were always fully involved and engaged. For example, during the body image session, the material presented during the didactic portion of the support group was identical and focused on exploration of the cognitive and emotional impact of physical changes associated with their cancer. More specifically, how each participant's own relationship with their bodies changed as a result of their cancer was examined. The *promotor* and *promotora's* reports for the body image session described positive experiences and deep connection between group members for both groups:

"Session 7 was a great platform to get the men talking and searching a little deeper. Since the connections within the group have already been established up to this point, the men were willing to engage in the topic of Body Self Image freely. They related and conversed about several negative and positive feelings they have in regards to how they view their body and they enjoyed talking about positive self-affirmations. For the activity, the men bounced ideas off each other...their creations were great and all 3 chose to do something different." - Nathan, men's group *promotor*

"These ladies had so much to share. As they talked about body image they expressed how they physically and mentally changed after their treatment. One lady shared how she would isolate herself after having her breast removed. She said she felt as if everyone noticed. She mentioned how she didn't feel the same and she felt as if everyone would stare at her. Another lady mentioned her weight gain and how it affected her self-esteem. The ladies were all very engaged in this topic. By listening to their stories I could hear in their voices how these physical changes affected them. As we did the art activity there were tears of emotion. They shared how cancer affected their relationship with their families... It was an Amazing group today with a lot of emotion." -Monica, women's group *promotora*

### Discussion

This multi-phase study demonstrates the use of a mixed-method approach to identify survivor needs, develop, and conduct preliminary evaluation of a support group program for Latino cancer survivors in a culturally appropriate manner.

In the initial (formative) phase of the study, many qualitative themes emerged that were consistent with previous research [3, 16, 43], but new themes also emerged and included ideas such as a desire to help other cancer survivors and a strong interest in receiving nutrition and physical activity education. Other topics of interest were identified from survey data and both were used to inform development of the support group program.

Quantitative assessment of the support group suggested clinical and statistically significant effects on psychosocial measures; however, those changes were primarily observed in women. Although data from the formative research (quantitative and qualitative) suggested the selected content for both men and women were similar, the lack of observable change in scores among men may have been due to small sample size or indicate a need for differential content, presentation, or measures (in particular, more robust measures of fatigue and pain). However, these findings should be interpreted with caution as statistical power was low given the sample size and inability to adjust for multiple comparisons or potential covariate factors. Cortisol data, similarly limited by sample size, showed no significant change over time but was notably low compared to values observed among healthy adults [31]. This may reflect chronic dysregulation of cortisol and be more strongly tied to fatigue. Appropriately powered future studies should examine the relationship of CAR with fatigue in Latino cancer survivors. Further, it is known that CAR is sensitive toward state (as opposed to trait) distress and, as a result, can be highly variable on a daily basis. Thus, it has been suggested that 6 days of CAR sample collection may be required to gain a more accurate view of CAR patterns in a given group [44]. Highlighting the importance of a mixed-method approach, qualitative feedback from group participants was generally positive regarding the support group experience. Participants expressed enthusiasm and appreciation for group content. However, it should be noted that the cultural concepts of *respeto* or *simpatía* (desire for harmony) may have biased some responses limiting critical feedback to *promotores* who also conducted the support group. Also, the generalizability to the larger Latino population may be limited as participants in this study were Mexican-American and residents of a rural community.

Based on group attendance, survey completion, salivary sample collection, and *promotores* summary reports, it was determined that implementation of a 10-week social support group was feasible. The high rates of attendance were due, in part, to several known incidences that reflect group cohesion. Specifically, as reported by the *promotores*, on two to three occasions, participants offered to reschedule sessions if one member was unable to attend and a couple of participants, that did not know each other prior to the group, offered assistance with transportation to at least two sessions. Summary reports of *promotores* noted quick group cohesion based on participant's willingness to share personal information and verbal gestures of

support to other members of both men's and women's groups the groups. Further, the role of the *promotores'* skill to present the materials, facilitate group cohesion, and implement the intervention in a culturally competent manner should not be underestimated when considering the quantitative, qualitative, and observational data presented.

## Conclusion

In conclusion, several studies have qualitatively examined the emotional and physical effects of cancer on Latinos, but studies that translate such data into actionable programs that are quantitatively assessed are scarce. This study is another step toward providing psychosocial support to Latino cancer survivors and demonstrated the importance of mixed-method approach. Although interpretation of the quantitative findings is limited by sample size, the observations about strengths and weaknesses of developing and implementing a formalized program for Latino cancer will hopefully contribute to additional progress. Based on the current findings, future studies should delve more deeply into identifying how best to address and measure the needs of Latino men.

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