

SURVIVORSHIP EDUCATION FOR LATINA BREAST CANCER SURVIVORS: EMPOWERING SURVIVORS THROUGH EDUCATION

EDUCACIÓN DE SUPERVIVENCIA PARA SUPERVIVIENTES DE CÁNCER DE MAMA LATINAS: EMPODERANDO A LAS SUPERVIVIENTES A TRAVÉS DE LA EDUCACION

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Abstract

Objectives: Nueva Luz is an English and Spanish quality of life (QOL) intervention developed to address the educational needs of Latina breast cancer survivors and provide strategies to assist in their transition into survivorship.

Methods: A qualitative approach was used to evaluate the English and Spanish educational intervention (Nueva Luz) content. A purposive sample of eight Latina breast cancer survivors was selected from the group who received the intervention to participate in a digitally recorded interview. Data was analyzed using thematic analysis.

Results: Findings provide evidence that the one-on-one tailored approach is a feasible and acceptable method of providing a bilingual psychosocial intervention. The provision of printed bilingual information along with the verbal instruction from a bilingual and culturally competent health care provider can be effective in helping Latina breast cancer survivor's transition successfully into survivorship, improve QOL and contribute to better patient outcomes.

Conclusions: The study informs our understanding of the cultural context in patient education content and delivery of psychosocial interventions. The findings may also have relevance for other ethnic minority cancer survivors.

"The day to day is a survival...we are surviving" (Participant quote)

INTRODUCTION

Latinos currently are the largest ethnic minority and comprise 15% of the United

States population⁽¹⁾. As the number of Latinos and breast cancer survivors continues to grow, the need to develop education programs that are culturally congruent and linguistically appropriate for non-English speaking and limited English proficient ethnic minorities is increasingly

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vital for this population. Despite the need, remarkably, only a few culturally congruent survivorship intervention programs have been developed, implemented and evaluated to meet the post-treatment needs of Latina breast cancer survivors⁽²⁻⁶⁾.

The transition from active treatment to survivorship can be overwhelming and is critical to long term health care. As the result of cancer and cancer related treatment, many breast cancer survivors are at risk for chronic illnesses and side effects. Latina breast cancer survivors have worse overall quality of life (physical, psychological, social and spiritual) outcomes relative to non-White Latina, African-American and Asian survivors⁽⁷⁻¹⁰⁾. Contextual factors contributing to cancer-related health disparities and poor cancer outcomes include low socioeconomic status, lack of health insurance, low education attainment, legal status, linguistic barriers, insufficient information, immigration status, and discrimination⁽¹¹⁻¹³⁾. Latina breast cancer survivors are vulnerable to poor quality of life (QOL) and survivorship outcomes in comparison to Non-Latina whites. Latina breast cancer survivors report greater concerns over employment, sexuality, higher levels of emotional distress, partner infidelity, higher rates of depression, significant lack of social support and poorer psychological and emotional well-being in comparison to other ethnic groups^(8,14-17). Their specific health care needs are the result of the cancer experience, the adverse effects of cancer treatment, culture and contextual factors.

Breast cancer survivors have ongoing support needs related to the physical, psychological, social and spiritual concerns that may arise after completing primary breast cancer treatment. *Nueva Luz* (New Light English translation) a bilingual (English/Spanish) breast cancer educational intervention was developed to address

the unmet survivorship and informational needs and to improve the QOL of Latina breast cancer survivors after completing primary treatment for breast cancer. The purpose of this pilot study was to evaluate the effectiveness of an English and Spanish survivorship education intervention to assist Latina breast cancer survivors' transition into survivorship. The outcome evaluation involved measures of QOL, uncertainty, distress and acculturation at baseline (pre-intervention) and 3 and 6 months post intervention. The outcome evaluation results of this study are elsewhere and summarized here⁽¹⁸⁾.

This paper presents findings from the qualitative evaluation process completed by a sample of participants who received the bilingual breast cancer education intervention. The program evaluation focused on content, format, cultural and linguistic appropriateness. In addition, insights into the aspects of the program that were most helpful were identified from the participant's perspective.

THE NUEVA LUZ INTERVENTION

Nueva Luz, is an individualized multidimensional bilingual (English and Spanish) QOL program developed to address the educational needs of Latina breast cancer survivors and provide strategies to assist in their transition into survivorship. The intervention content was organized using the Quality of Life model^(19,20) conceptualized to include the four domains of physical, psychological, social and spiritual well-being. The intervention provides structured tailored information that is culturally congruent and linguistically appropriate; to address the QOL concerns that women confront after completing primary treatment for breast cancer. The content presented in the intervention sessions is derived from empirical studies, an in-depth review of the

literature, and concepts from the National Comprehensive Cancer Network (NCCN) Guidelines for Breast Cancer and the NCCN Guidelines for Distress Management and the investigators' preliminary studies on QOL and breast cancer.

Cultural core values and linguistic factors were considered in the design and delivery of *Nueva Luz*. This included providing the intervention in the selected language of the participant and allowing family members to be present (*familismo*). In addition, cultural values were included such as *personalismo* which is building a personal relationship characterized by a warm, personal, and empathetic way of relating to others. *Personalismo* is also related to *confianza* (trust). In order to gain trust among Latinos, it is necessary to demonstrate *personalismo* and inspire *confianza* (trust). Similarly, *simpatia* is a relational approach that emphasizes expressions of graciousness and charm. *Respeto* (respect) for individuals reflects feelings of high esteem for a person and willingness to be influenced by that person (Table 1)^(21,22). The education sessions were delivered in a conversational style (*platicas*) to create a comfortable and relaxed atmosphere conducive to teaching and learning⁽²³⁾. Research emphasizes the importance of incorporating and addressing

these cultural values and beliefs when working with Latino populations in a health context. Given the different combinations of monolingual and bilingual language abilities in Latino families, each participant was given an educational binder with the printed teaching materials in Spanish and English.

Nueva Luz was introduced to the participants as *platicas* (conversations) and consisted of weekly face-to-face individual sessions over a four-week period followed by monthly telephone support sessions delivered by the principal investigator (PI) and first author. The English and Spanish educational binder was developed as a teaching resource and used in conjunction with the verbal sessions. The content included educational information on surveillance follow-up, symptom management and healthy lifestyle behaviors. It also included tip sheets with information on how to manage common problems such as fatigue, cognitive issues and fear of recurrence related to breast cancer and treatment.

At the beginning of each session, the patient was presented with a list of common concerns experienced by breast cancer survivors. Then was asked to identify any concerns she wanted to discuss, which ones if any should be omitted and in what

Table 1. **Latino cultural values**

Cultural Values	Definition
Familismo (Familism)	Maintaining a close connection with immediate and extended family members.
Personalismo	Valuing and building a personal relationship rather than institutional relationships
Confianza (trust)	Establishing welcoming and trusting relationships
Simpatia (Kindness)	Pleasant, polite and non-confrontational social interactions even in the face of stress and adversity.
Respeto (Respect)	Demonstrating respect to others based on age, gender, economic status, social position and authority.

order the content should be presented. This provided a tailored approach in delivering the content to the patient's needs and preferences. Session one focused on "Physical Well-Being" and management of physical symptoms and side effects. This session addressed common symptoms such as pain, fatigue, menopausal symptoms, lymphedema, and other symptoms. Exercise and nutrition were also emphasized. During the education session, the PI also discussed any relevant supportive care resources such as the online breast cancer specific websites with patients and made appropriate referrals to social services/social worker, nutrition and rehabilitation as needed.

Session two focused on "Psychological Well-Being" and included a discussion of sources of distress such as fear of recurrence and intrusive thoughts about cancer. Psychological outcomes reported by breast cancer survivors such as mood changes (e.g. frustration, sadness, and worry) were also addressed. Session three concentrated on "Social Well-Being" and emphasized the importance of social support, communication and ways of obtaining needed support. Discussion points also centered on intimacy and sexuality, family needs and employment issues.

Session four was devoted to "Spiritual Well-Being" and included content on finding meaning and purpose after breast cancer treatment, uncertainty and coping strategies. A brief summary and review of the entire 4-week education intervention was integrated into the session. Upon completion of the four sessions, monthly support via telephone follow-up sessions was provided. During these follow-up telephone calls, the PI clarified any questions and content from the previous teaching sessions and addressed any concerns identified by each participant. Interdisciplinary resources were

coordinated as needed. Printed materials in English and Spanish related to each session topic were provided and used as a guide for the implementation of *Nueva Luz*.

METHODS

Sample and Setting

Study participants were recruited from the medical oncology adult ambulatory clinics at a National Cancer Institute (NCI) designated comprehensive cancer center in the United States. Eligibility criteria included 21 years of age or older, diagnosed with stage I, II or III breast cancer, completing primary cancer treatment (those receiving adjuvant hormonal therapy were eligible), self-identify as Latina, and able to read and understand English or Spanish.

Design

This pilot project used a two-group, prospective longitudinal randomized controlled design. A qualitative approach was used to evaluate the educational intervention. After informed consent, patients were randomly assigned to the experimental or to the attention control group. The attention control condition involved usual standard of care, in addition to monthly telephone calls provided to patients for study retention purposes only. Patients assigned to the experimental group received the intervention in their language of preference (English or Spanish). The four weekly teaching sessions were completed at 1 month post accrual. Length of the intervention was tailored to the patient's needs and was approximately between 30- 60 minutes in length. The variation on the length of each education session was dependent upon the complexity of the subject's, needs or concerns. A total of 52 Latina breast cancer survivors were

randomized to either the intervention (N=34) or the attention control group (N=18). A purposive sample of eight Latina breast cancer survivors from the intervention group agreed to participate in a digitally recorded interview.

Procedures

The study was reviewed and approved by the Institutional Review Board of an NCI-designated cancer center. The patient's physician introduced the overall purpose of the study and solicited permission from potential patients to meet with the PI who was responsible for all aspects of study procedures, including subject accrual, intervention implementation and follow-up. The PI approached all individuals meeting the eligibility criteria during a regularly scheduled clinic visit. Once eligibility was determined, the study purpose and procedures were introduced. Written informed consent was obtained in the chosen language of all the subjects prior to enrollment.

A semi-structured interview guide was used to evaluate and elicit information about the *Nueva Luz* education program. Sample questions include: "What did you find most helpful about the education sessions?" and "Is there anything that you did not understand?" The interviews were conducted by the PI in a private room, and in the language of choice of the participant. Six interviews were conducted in Spanish and two in English. After the interview, each participant was given a \$25 gift card for their participation.

Qualitative Analysis

The Spanish interviews were transcribed verbatim from Spanish to English by an experienced accredited American Translators Association English-Spanish/Spanish-English translator. Data

was analyzed using thematic analysis⁽²⁴⁾. The first author who is bilingual listened to each audiotape (both English and Spanish) and checked for congruency of audiotape and transcription. All transcripts were analyzed in their original language to preserve linguistic accuracy and nuances of meaning. Two bilingual researchers analyzed the data by reading the transcripts to become familiar with the data. Independently, the data were analyzed by the researchers line by line, and then codes and themes were developed. Thus, comments mentioned across transcripts were considered indicators of emerging patterns. The final list of themes was reviewed to ensure themes represented the transcripts and were assembled into groups that best represented patients' responses. The interviewer's prior work and familiarity with Latinos helped build rapport, trust, and fostered communication with the study participants⁽²⁵⁾.

Program Evaluation

The program evaluation focused on the content, format, cultural congruence and linguistic appropriateness. The participant's perspective regarding which aspects of the program were most beneficial and which were least beneficial were solicited. A patient centered approach was utilized in obtaining feedback, including the patient's overall experience, satisfaction and program feedback.

RESULTS

Sample Demographics

Eight women who completed the intervention program consented to be interviewed. The average age of these participants was 52 years (range 41-66 years). Five were born in Mexico, two in El Salvador and one in Costa Rica. Six

Table 2. **Socio-demographic characteristic (N=8)**

Characteristics	Years
Age	
Mean	52.3
Range	41-66
Number of years living in United States	
Mean	23.1
Range	4-40
Characteristics	N
Country of birth	
Mexico	5
El Salvador	2
Costa Rica	1
Preferred language	
Spanish	6
English	2
Education	
High school or less	6
College	2
Marital status	
Married	3
Not married	5
Employment status	
Working (part-time)	1
Housewife	3
Unemployed	4
Religion	
Catholic	7
Protestant	1
Stage of cancer when diagnosed	
Stage 1	6
Stage 3	2

had a high school education and 2 were college graduates. Only one participant was employed (part-time), four reported being unemployed and three were homemakers. The women interviewed were predominantly Spanish-speaking (Table 2)

Interview Data

The comments from the individual interviews are organized by the following categories: (1) program content and format, (2) benefits of the program, (3) education and support, (4) empowerment/engagement, (5) spirituality/faith and (6) suggestions for improvement.

Relevance of program content and format

In general, the participants endorsed the *Nueva Luz program* bilingual content and format and the program's relevance for Latina breast cancer survivors. Table 3 presents representative comments about the program. The participants expressed the importance of having tailored one on one education sessions because this provides the opportunity to ask questions and dispel any doubts or discuss any concerns. Equally noteworthy was having English and Spanish printed materials with information that was relevant and easy to understand, as demonstrated by these quotes:

"You have to have the conversations (*platicas*) and the educational binder... Because that way you can understand you need the help from somebody who talks to you. Because if somebody just gives you a...book or something. The book you just leave it on the night table and you forget. On the other hand talking about... conversations, you learn more everyday and you like to share with others. So talking helps you to read the educational binder."

"Sometimes you don't understand certain things, and for example with you I could ask questions. Of what I didn't understand from the educational binder, from the pages I read. Yes, it is important to talk to somebody...like you."

Table 3. **Participants comments on the relevance of the program content and format**

"It's well explained in words I can understand, which is what I like."

"The educational binder helps because in my situation sometimes I forget certain things. I'm forgetful. I read the educational binder again and that way I remember the conversations."

"The materials were very useful, all the materials you gave me to read and they were easy to read, I can understand."

"The tip sheets helped because it shows you what you need to do...and how you need to do it, the care you need to have."

"It's adequate for me; it gives me the information that I need."

"I was interested in everything; everything that had to do with my problem."

"It's very important to talk to somebody, who knows about this subject."

"Everything helped, because some of the things I had doubts about, you would confirm that they were because of the treatment, or any other question. Oh, yes it was very useful."

"It has to be complementary; the writing and the spoken. More written information in Spanish."

"The information is better both ways, in writing and have the support of you to help us understand better. Even if the language is not that difficult, there's always questions that you need to have a follow up."

"The four conversation sessions helped me a lot."

"The bilingual educational binder was a lot, a lot of help. Because there are people like me who don't speak enough English as to understand everything."

Benefits of the program

The women (100%) indicated that the program had been beneficial in helping them confront their concerns in a practical and thoughtful way with tips from the nurse and the printed materials. These are examples of the how the program helped:

"...With the emotional part, that was very helpful because that encouraged me to do the rest and you helped my feelings

to be positive. And my state of mind to be focused on what I needed or wanted to do."

"All those subjects that we spoke about, they're very important because, there were ideas that you gave me, on how to cope with the fatigue, or what to do with the way I was feeling, or even eating."

"The conversations helped me...Because that helped me to fight the tiredness, how do they call it, the anxiety I felt...It lifted my spirits."

"I was afraid even to ask, because I said, ok if I ask, maybe I'm not going to like what I'm hearing... so, but you know, that's not the case, you know you need to get yourself educated, informed. And leave on the side the scary part."

"Thank God, I had help, because I remember there were those times, when I was very depressed."

Education and Support

Breast cancer survivors need tailored verbal and printed education. Also support to understand and deal with the consequences of cancer and cancer treatment as evidenced by the following comments. One hundred percent of the participants agreed that this tailored approach was vital during their transition process.

"Yes, it (*Nueva Luz*) helped me because I did not feel alone...Because when you were talking to me, I would say. Oh, she understands me. I would say. What she's saying is true, it is. I felt identified with the information you gave me..."

"I like to participate in the conversations because most of all they give me information to help me. I lose my memory and I grab the educational binder again and I start reading it, and that's the way I keep remembering the conversation."

"I did not have the tools, you gave me the tools"

"You were the only one that I was able to talk to you about everything"

Engagement & Empowerment

The one-on-one tailored approach kept the women engaged. The education and information taught empowered participants to share what they learned. The educational binder was shared not only with female relatives and friends who were diagnosed with breast cancer

but with healthy family members and friends. The women stated:

"I put it into practice what I learned with my daughter and now with my sister."

"I have shared it (educational binder) with women who I know who are going through treatment and they say that my help has been very helpful...and they thank me."

"I'm thankful to God because with the conversation sessions, with everything I've been able, to help other people."

"But all those ideas that you gave me about what to do when I was tired, you know when I was dizzy, you know... Nutrition, exercise, and all that helps. Because that brought up my feelings, my expectations higher, my state of mind, was like oh, yes I can do this!"

The education intervention empowered these women not only to take care of themselves but to share the information with other women.

Spirituality/Faith

Although the participants were not directly asked about spirituality, some participants talked about how God and their faith were a source of strength and comfort in dealing with cancer and the consequences of cancer related treatment as illustrated by the following quotes.

"Because of my faith I'm healthy. The faith I have for my God who in each step has saved me to continue. Because life is a battle."

"At the beginning I got very depressed with the chemo but I knew I was going to heal and what you have to have is faith and know that is what God wants, not what we want. It's up to God to help us keep going and to survive an illness like this, you have to be thankful to God and to the people (health care providers) who help us. He (God) gives them understanding and wisdom to help us."

"Thank God I am healed and in God I trust that maybe with time, I'll be a little stronger now. I'm alive thanks to my doctors and to God..."

Suggestions for improvement

Participants indicated the need for further emphasis on nutrition and age-related concerns about sexuality and body image (ways of looking good and feeling better) as exemplified in these comments;

"I want to learn how to cook more healthy and what to eat to feel better"

"..What worries me is the sexual relationship"

"...I don't have a breast, it makes me feel like...inhibited"

In addition to the participants who were interviewed, a group of women who were randomly assigned to receive the intervention also made written and verbal comments about the Spanish translations and the program content and format. Based on these comments the Spanish and English versions were revised.

The cultural values and beliefs *personalismo*, *familismo*, *simpatia*, *confianza* (i.e., trust), *respeto* (i.e., respect), were reflected in the findings of this research. It was vital for participants not only to have education in their preferred language but also to have a female providing the intervention, education and support. One English speaking participant who was born in Mexico but had been living in the US for over 40 years said:

"You make me feel comfortable and, is good to have a, a female. You know, you feel more comfortable talking to a female than to a male and because you know you're a women and you know. I mean even though you don't have cancer, but you're a woman. So I think that's important to me."

DISCUSSION

Participants evaluated *Nueva Luz* and provided feedback regarding the intervention content, feasibility of implementation, acceptability, practicality, and the cultural and linguistic appropriateness. The comments from the interviews were useful in determining content modifications. The participants had specific suggestions on the intervention content to be revised, added or omitted. They also indicated that the bilingual intervention had been beneficial in helping them confront their survivorship concerns in a positive and thoughtful way with guidance from the nurse, the opportunity to ask questions and the bilingual printed materials helped reinforce what was taught. Research suggests that the combination of one-on-one education with a bilingual and culturally competent health care provider and printed education materials can be an effective teaching approach to engage and to empower Latina breast cancer survivors^(6,26).

Delivering the intervention in a conversational style to create a comfortable and informal setting helped to establish *confianza* (trust) and *personalismo*. Equally important was delivering the education in a culturally congruent manner. This was done by speaking Spanish or English at an appropriate level, recommending feasible physical activities, integrating the family into relevant interactions, using culturally meaningful illustrations to engage participants and encouraging them to ask questions. This quote exemplifies the importance of addressing and incorporating these core cultural values and beliefs when providing psychosocial interventions. "Because you knew how to talk to me and you would explain everything to me. And yes you were patient with me, because I also asked you questions."

Through the education intervention, a relationship (*personalismo, trust and respect*) was established between the PI and the participants. The PI inquired about the participant's family members and some participants shared personal stories, family pictures and cooking recipes with the PI. The follow-up telephone calls allowed the participants to ask questions, and the PI to convey individual, personalized caring and support for each participant. It is necessary to develop mutual *respeto* (respect), *confianza* (trust) and to build a warm personal relationship (*personalismo*) to keep the participants engaged. The participants reported feeling empowered by the knowledge gained, and to share what they learned with others (patients, sisters, daughters). Empowering patients through education may motivate them to take a more active role in their health care^(27,28). Providing a culturally congruent tailored intervention in the selected language of the participant and incorporating Latino core cultural values in all patient interactions is vital when working with Latinos in a health context. Cultural respect promotes trust which increases the patient's confidence and compliance as evidence by this comment, *"Thank you for all your help and the information, you made me feel important like. I was a member of your family. God bless you."*

The pilot findings provide evidence that the one-on-one tailored approach is a feasible and acceptable method of providing a bilingual psychosocial intervention for this underserved population. The provision of printed bilingual information along with the verbal instruction from a bilingual and culturally competent health care provider can be effective in helping Latina breast cancer survivors transition successfully into survivorship, improve QOL and contribute to better patient outcomes^(6,29,30).

Patients need the information to more fully understand their post-treatment

survivorship issues and concerns, and ways to respond to these. It is well documented in the literature that education interventions must be developed within a socio-cultural context and tailored to fit the patient's culture, educational needs, language preference, lifestyle, education level and socioeconomic status⁽⁵⁾. Cancer education interventions should be culturally congruent and the methods used in delivering the education should consider the contextual factors, as well. The content included was valued by the participants, but additional information on healthy living, intimacy/sexuality, and body image issues should be included.

STUDY LIMITATIONS

A few limitations should be noted. The PI was responsible for all aspects of the research study which might have influenced participants to report more positive outcomes. Most of the participants were of Mexican ancestry and receiving care at a national cancer institute designated comprehensive cancer center; therefore results may not generalize to other Latina breast cancer survivor subgroups. Despite limitations, this study provides valuable findings into the educational needs of Latina breast cancer survivors and addresses some significant gaps in the literature. These pilot results provide beginning evidence of the value of a culturally congruent English/Spanish intervention. Future studies should focus on larger randomized ethnic populations. Overall, the participants were enthusiastic, grateful and provided positive feedback to the *Nueva Luz* intervention. One participant expressed *"What I want to add is that I'm pleased and I'm grateful with you for the information and for the time you took to give us this information. God bless you today, tomorrow and always."*

CONCLUSIONS

Findings inform the understanding of the cultural context in patient education, content and delivery of psychosocial interventions and the impact of a tailored English and Spanish education on the QOL of Latinas following primary breast cancer treatment. However, more intervention research is needed with Latina breast cancer survivors that consider contextual factors affecting survivorship outcomes and QOL. The findings may also have relevance for other ethnic minority cancer survivors and provides evidence that may inform additional development and testing for future research.

Acknowledgments: *The project described was supported by Grant Number K07CA106551-01A2 from the National Cancer Institute. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the National Cancer Institute or NIH.*

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