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13. ABSTRACT (Maximum 200 Words) <p>Purpose. To understand the influence of Latino culture in breast cancer treatment, by developing a conceptual model of the informal support system utilized by 60 triads consisting of Latina cancer patients, their spouses/significant others and family/friends. Participants are drawn from the Breast Cancer Treatment fund, which provides payment for services for uninsured women.</p> <p>Findings. The project has allowed a view into the role and function of the psycho-social support system. Not only does the support "team" assist with the diagnosis, treatment and consequences of breast cancer, it also helps the patient "connect the dots" of a disjointed system by negotiating, supplementing and extending services. Another key area of finding is that the supporting the spouse/partners has been neglected by the medical world. The loss of a breast does not seem to be as significant as the potential loss of a person key in creating a family.</p> <p>Significance. A better understanding of how the psychosocial team functions to assist the patient in "connecting the dots" allows an understanding of where and how the services system does not reach into this population. Programs and policy at the individual and system level can emanate from the emerging conceptual model.</p>				
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(4) INTRODUCTION

(Responses to the comments of Technical Editor Judy Pawlus (March 13, 2001) have been incorporated into this document.)

The purpose of this research project is to understand the influence of Latino culture in uninsured Latinas in breast cancer treatment, by developing a conceptual model of the informal support system utilized by 60 triads consisting of Latina cancer patients, their spouses/significant others and family/friends. Participants are recruited from the Breast Cancer Treatment Fund program, which covers the cost of treatment for uninsured women with breast cancer.

The initial research plan was to interview four types of triads: 15 rural immigrant; 15 US born rural; 15 urban immigrant; 15 US born urban. However, subsequent to interview initiation, the project became aware of the fact that very few US born live in rural areas. Sampling has been modified following suggestions from Technical Editor Judy Pawlus, detailed in Task #4. Open-ended interviews with an interview guide, rather than a standardized closed-ended questionnaire, are used in order to allow the triads to describe their social interaction in the face of a diagnosis of breast cancer. Topics probed in the interview guide include: familial responsibilities; information obtained regarding breast cancer detection and treatment; patterns of discussion and conversation regarding the diagnosis; experiences with control or lack of control; experiences with fear or lack of fear; experiences with health care providers. The interviews are conducted bilingually to preserve the code-switching that naturally occurs. Interviews are being analyzed via a Grounded theory process, which provides for identification and conceptualization of patterns in the responses of participants. The Ethnograph©n software package is being used to assist in the development of conceptual categories. These will lead to a conceptual model of the Latina breast cancer experience, and can serve as a basis for program development in education and formal support group development appropriate for a Latino population base.

(5) BODY: Research Accomplishments for Each Task

Task 1: Finalize recruitment plan. Months 0-4

As required by human subjects regulations, and as a result of identifying legal barriers presented by the Breast Cancer Treatment Fund, the recruitment plan and protocol for outside staff (UCLA) recruitment were finalized prior to project start date. Staff roles within the Breast Cancer Treatment Fund were restructured to allow their staff to make the first contact with subjects. Only when a woman granted verbal permission for contact with a UCLA nurse did that contact occur.

This Task was finalized in the first year, September 2000.

Task 2: Finalize initial interview guide. Months 4-6

The initial interview guide was finalized prior to project start date as a requirement of human subject compliance regulations.

This task was finalized in the first year, September 2000.

Task 3: Identify and recruit sixty (60) Latina women diagnosed with breast cancer, their male partner and a friend and/or other supportive relative. Months 6-28

Recruitment Of Study Participants

In the early months of the project, each step of the research process was discussed with the staff of the Breast Cancer Treatment Fund. It was felt that time spent in such discussion would help create an effective research team.

Staff followed the protocol for identifying, recruiting and interviewing Latina women described in the approved Human Subjects application to UCLA's Office for the Protection of Subjects and described in the approved IRB application to the Dept. of Army's IIRB committee. The UCLA research nurse (interviewer) would act upon the referral from the Breast Cancer Treatment fund quickly—within two weeks—to build on the interest created in the subject by the Breast Cancer Treatment Fund research team of nurse Lisa Gordon and health educator Guillermina Garcia.

However, recruitment of study participants got off to a slow start. The first woman was identified and interviewed in November; in December, a change of staffing and the holidays interrupted the research process, delaying the process until January.

Recruitment continued from January to December 2000. Recruiting was suspended from January to April of 2001 pending resolution of confusion in the consent forms. The confusion resulted in from the following train of events.

In June, 1999, this office submitted consent forms to the UCLA Human Subjects Committee. Between August, 1999 and September, 1999, The US Army suggested changes in the consent forms to the UCLA Human Subjects Committee. In October, 1999, the UCLA Human Subjects committee approved the consent form, but apparently the final version was not received in the offices of the US Army. We recruited from October 1999 to December 2000. In February, 2001, Dr. Howard of the US Army informed us that she did not have a copy of the final, approved consent form in her files. We sent the final, approved version to Dr. Howard, and suspended recruiting. Between February and April, 2001, the version approved by the UCLA Human Subjects Committee was reviewed by Drs. Howard and Moore, and forwarded to Pat McAllister and Karen Stotler. The forms were approved on April 26, 2001, and recruiting was resumed.

Technical Editor Pawlus requested copies of the recruitment plan and/or initial interview guide. These are attached as Appendices.

-Appendix A: Human Subjects Protocol. This contains (pp. 3-6) the recruitment process as approved by the UCLA Human Subjects.

-Appendix B: Consent Form. Three consent forms (for patient, spouse and significant other) each contain initial interview guide as approved by UCLA Human Subjects.

Task 4: Interview sixty (60) Latina women diagnosed with breast cancer, their male partner and a friend and/or other supportive relative. Months 6-30

As of July 30, 2001, thirty two triads have been completed. One member of one additional triad has been interviewed, for a total of 97 completed interviews.

Technical Editor Pawlus noted some confusion in counting the number of triads completed for last year's report. The confusion was on our part, and arose because one triad was not finished: one team member counted 27 triads completed, and another one counted 28 triads as begun. We have eliminated the confusion by specifying a completed triad or an incomplete triad.

Among them there were sixteen rural immigrant triads, ten urban immigrant triads, three rural US- born triads and three completed urban US-born triads and one-third of another US born urban triad.

Technical Issues. Technical Editor Judy Pawlus raised some technical issues in her letter of March 13, 2001. "Inasmuch as the interviewed triads are restricted to those associated with uninsured Latinas, it is recommended that the PI either provide a rationale for believing that the restriction does not inherently bias the resulting view of 'Latino culture,' or revise the statement of study goals to reflect the restriction."

In the light of the concern, I would like to respond to both suggestions: 1.) restate the study goals to more accurately reflect the nature of the universe available for study, and 2.) discuss the strengths and limitations of using uninsured Latinas to study the influence of Latino culture.

Restatement of Study Goals. "The aim of the study is to understand the structure and function of the informal support system used by *uninsured* Latina breast cancer patients."

Demographic representation of Uninsured Latinas. Editor Pawlus raised an "apparent discrepancy between the PI's goal of 'understanding the influence of Latino culture in breast cancer treatment' and the recruitment of triads for interview solely from uninsured Latinas. The PI has offered no support for the implied position that the uninsured are demographically representative of US (or even Los Angeles-area) Latinos as a whole."

The lack of discussion on the topic of representativeness is an oversight that is addressed herein.

The ideal research project would have been to sample all Latinas in the state diagnosed with breast cancer, insured and uninsured alike. The California Cancer Registry contains information about the entire universe of Latinas diagnosed with breast cancer. However, the Registry did not allow the PI access to its universe, either for the purpose of developing an overall profile without individual identifiers, or for individual contact for interviews.

The Breast Cancer Treatment Fund, which provides care for uninsured women diagnosed with breast cancer, did allow the PI access to its universe of uninsured women, 42% of whom were Latina. The question then was this: does limiting the sample to the uninsured hopelessly bias the findings about the influence of Latino culture in breast cancer treatment? The answer is: no, but limiting the sample to the *uninsured only* does introduce an unavoidable emphasis on the immigrant portion of the universe. As immigrants are less assimilated and acculturated than the US born, the influence of Latino culture is likely to be more readily seen in a sample predominantly of immigrants.

-Middle-age Latino adults in the 40-59 years age group in California are predominantly (65.2%) immigrant : a minority (34.8%) are US born. (1999 Current Population Survey).

-In the under-65 age group, nearly half of immigrant adult Latinos (42.8%) do not have health insurance, while a small minority of US born Latino adults (16.6%) are uninsured (1999 Current Population Survey).

-In the 65+ population, Latinos without insurance were more recent arrivals (16 years average in US) compared to those with Medicare coverage (41 years average in the US) (Hayes-Bautista et al 2001)

-Immigrant Latinos are more likely to be Spanish dominant (86%) while US born Latinos are less likely to use Spanish (33%) (Hayes-Bautista et al, 2001)

-More recently arrived Immigrant Latinos are less likely to speak English at all (25.4%), while immigrants who have been in the US for more than 30 years are far more likely to speak English (73.1%) (1990 Census Public Use Microdata Samples).

The general profile is that Immigrant Latinas are more likely to be uninsured, and less likely to be acculturated/assimilated than US born Latinas. The more recently arrived are even more likely to be uninsured and less acculturated than long-term immigrant residents. The Latinas in the Breast Cancer Treatment Fund are predominantly immigrants who are fairly recently arrived compared to the US born.

The influence of Latino culture will be seen more readily in the Breast Cancer Treatment Fund group, as this group is less acculturated than US born or long term residents.

The limitation of this uninsured demographic is that the push-and-pull of two cultures seen in the more assimilated will be less apparent. Given that we were not allowed access into the pool that contained the insured, the uninsured give a more detailed picture of Latino cultural influence than would have a sample limited to the largely US born insured.

- Given that the vast majority of Latinas age 40 and above are immigrant, this bias is less misleading than if the sample had been restricted to US born insured.

The ideal would have been to use the entire universe, but that simply was not made available to this project. As the purpose of the project was to see the influence of Latino culture on the breast cancer experience, this sample of uninsured, largely immigrant women provides as good a window as any.

Revision of Sampling Strategy. The original sampling strategy was to have the sample evenly divided between rural and urban (15 triads each) and US born and Immigrant (15 triads each).

After the project was begun, and we finally had access to the complete BCTF data files, we discovered that the only a small minority of Latinas in the universe were in rural counties: 116 of the total of 1,169 women (9.9%) lived in the rural counties of Fresno, Kern, Kings, Madera, Merced, Stanislaus, Tulare and Ventura. We have interviewed a total of 19 rural triads (16 immigrant, 3 US born), and have nearly exhausted the rural population. It is not likely we will find many more rural Latinas.

By contrast, the vast majority of the Latinas---817 or 69.9% of the total--- lived in the four urban counties of Los Angeles, Orange, Riverside and San Bernardino. We have completed 13 urban triads, and have begun, but not yet finished, one additional urban triad.

As the composition of Latinas in the age 40-59 age group is 65% immigrant and 35% US born, a similar balance will be sought in the final total. This composition (2/3 immigrant and 1/3 US born) is virtually identical to the suggestion of Technical Editor Pawlus for the remaining interviews: "A final option is not to control for rural or urban domicile and simply enroll the first 43 immigrant and 17 US born subjects that qualify". We will adopt Technical Editor Pawlus' suggestion, and complete the interviews in the following way:

	US Born	Immigrant
Target number	17	43
Completed	6	26
To be completed	1	0
New Interviews	10	17

We will enroll 10 new US born urban and 17 Immigrant urban triads, and complete one US born urban triad, for a total of 60 triads. This urban recruitment, scheduling, and interviewing will be much more rapid than the rural ones, which required a tremendous amount of searching, scheduling and travel time for a very rare population.

Technical Editor Pawlus raised the issue of statistical reliability in the sample. The purpose of this research project is to generate conceptual categories. A second, subsequent research project would be to see how these categories are distributed over a population based sample. For the purposes of this project, statistical reliability is probably not possible, given the small numbers. Now that we have adjusted this small sample per Technical Editor Pawlus' suggestion to mirror the US born and Immigrant, we are not consciously introducing a major bias. Test of significance would be better suited to a second project, which would be a quantitative, population-based survey.

Scheduling the interview

At times, it was difficult to honor scheduling requests made by rural participants. Not only do participants have to find an interview time they consider workable given doctor appointments, work and family commitments, but they seem to need time to reflect upon the request and "mull" it over.

In year 1, we found that after the interviewer made the first telephone contact, participants needed time to discuss the purpose of the research in detail. To find that "best time," the interviewer always makes it a priority to be flexible in her work and personal time. For many participants, "the best time" for the kind of lengthy discussion they needed was either in the evening or on a Saturday. Occasionally, appointments were cancelled, even as little as one hour before the scheduled time of arrival. While these conditions continued during Year 2 and into Year 3, the fact of having a much larger, geographically closer urban pool to choose from makes these conditions far less onerous than in the first year and 1/2

Informed Consent

The approved consent form, available in English and Spanish, is three pages long. Most of the participants have not been comfortable reading documents this size, and have needed anywhere from 20 to 45 minutes to complete the informed consent process.

Many times, the interviewer was asked to read the consent form out loud. Family members also helped read the consent form for the participant. To date, only one participant said she had previously participated in a university-based research project. Participants would frequently ask why the U.S. Army Medical Research and Materiel Command would fund a research project on breast cancer in Latinas; responding to their curiosity stimulated much interest in the project and served to warm up the brief "interviewee-participant" relationship.

The success of this initial interviewee-participant conversation is critical. The research nurse will run into difficulties if the participant does not feel comfortable, feels confused

or suspects that the purpose of the research is other than what has been explained to them. In order to create the greatest possible rapport between the participant and the interviewer, only the UCLA project nurse calls upon the participant to discuss the research and to schedule the interview after the first contact has been made by the Breast Cancer Treatment Fund Research Team. The interviewer takes as much time as necessary to hear concerns, answer questions, and inspire confidence.

So far, all participants have been willing to share their experience and many have requested a follow-up contact to learn what the final analysis revealed.

Travel to Interview

The challenge of interviewing women living in rural areas and of completing each leg of the triad is the time and mileage involved. 9,825 miles have been logged interviewer's car. When it is possible to schedule interviews back to back in the same general location, the interviewer will spend the evening at a low cost hotel. Each interview is emotionally exhausting and beyond the actual time of the interview time is spent building rapport and reading the consent form out loud. While the most productive days has yielded 3 interviews within a 10 mile radio of each other, these days are rare, the usual is 1-2 interview per location day.

Urban interviews present less of a travel problem, and do not require any overnight stays. The remaining interviews will be completed by December 30, 2001.

Place of Interview

In all but two instances, the interviews have occurred in the participant's home. In one of the two exceptions, the interview occurred in the interviewer's car while the participant was on a lunch break from McDonald's. Another participant needed to be interviewed outside her small apartment as family members were sleeping.

Length of the Interview

The average interview lasts 90 minutes, though some have lasted 120 minutes and two were less than 90 minutes long. The length may vary because the interviewer conducts the interview in a manner which allows participants to tell their story.

The process of interviewing

The interviewer actively listens to the story as it unfolds, and probes as necessary. Some participants have said that they "hold" the questions from the informed consent form in their mind as they discuss their experiences. At times, if the interview process feels "too natural" or "emotionally satisfying"; they may suspect that the questions on the consent form have not been covered. Some will even pull out the consent form, point to the numbered paragraph with the questions and check to see that they did in fact answer all the questions in the consent form. All research questions are always covered during the interview.

Bringing Closure to the Interview

After the interview the intimacy created as a result of the interview is respected. Participants feel comfortable asking the interviewer, who is representing not only the study but UCLA and the Dept. of the Army, many questions about higher education, breast cancer treatments, English as a Second Language classes, reconstructive surgery, to read English written letters, advice about husbands, advice about grown children etc. Some participants offer the interviewer crochet articles, others have offered bags of carrots, red onions and recipes. When the interview is done often the interviewer is introduced to the young adult children, neighbors, and extended family members.

- Pace of Interviews. The unforeseen development was that so few of the BCTF patients lived in rural areas, and so many in urban areas. We have exhausted the rural portion of the sample, which took quite a bit of time. The urban interviews will be much faster.

Task 5: Analyze data. Months 10-33

Transcription of taped interviews

Each interview takes about 1 ½ to 2 hours. A 90-minute tape takes approximately 16 hours of staff time to transcribe and produces a document of about 60-120 pages in length. Though very time-consuming, transcription of each taped interview is critical to the analysis. We have had to rely on other sources of funding to hire the staff needed to assist with the transcription of interviews. Transcribers must be fluent in Spanish as well as English and be able to translate easily from English to Spanish and from Spanish to English. Patience is a virtue, many participants speak; softly, with undulating voices, some voices are heavy with regional accents, while others are rapid and very breathy. The transcriber must back up and hear again the conversation until it is familiar enough to capture.

Translation

This analysis is utilizing a linguistic process that we have not seen in the methodological literature. The analysis is being performed using source documents (the transcribed interviews) in both Spanish and English. There are two reasons for using the original language format, at least in the initial analysis effort.

First, as part of the analytic purpose is to generate new categories of concepts used by uninsured Latinas with breast cancer to frame their experience with their informal support group, use of the original language allows us to look for conceptual patterns that might be lost if interviews were a priori translated into English. The interviews in Spanish are not translated to English for the initial analysis.

Second, most participants used some degree of “code switching”, that is, use of both Spanish and English in a single sentence. We are not sure, but the fact of the code switching itself may be part of some pattern, so we will use the original language format.

The use of bilingual source documents means that the analysts must also be bilingual, and able to recognize conceptual patterns in two languages.

When presenting the findings, as we did last year in sharing some of our initial, "open coding" categories, we do translate the quotes for the benefit of those who do not speak Spanish. Technical Editor Pawlus was concerned that the translation "appear[ed] to be word-for-word renderings. Such renderings may not do justice to an interviewee's intent or meaning."

This is a very good point to raise in doing qualitative work in a bilingual population. In being interviewed, many people do not speak in sharp, crisp, coherent sentences, but tend to start and stop, then start again, wander, change subjects, suddenly dart of into another direction, and interject new thoughts as they occur. Both in English and in Spanish, our initial effort is to maintain the emergent quality of the thought, as the very fact of wandering might be part of a pattern. Thus, we try to stay as faithful as possible to the interviewee's mode of expression, realizing that our translation, as any translation, has to be conceptual rather than simply word-for-word. However, in our final versions we present to a professional audience, we do "clean up" the quotes somewhat, to make the interviewee's point easier to understand.

We are constantly faced with the dilemma of reporting a close-to-word-for-word versus presenting a cleaner, more understandable version that still preserves the original intention. If Technical Editor Pawlus has any additional guidance on resolving this issue, we would be pleased to receive that advice.

The software program Ethnograph© is being used to assist in the analysis. The transcriptions are formatted to fit Ethnograph specifications. The software assists in the labeling and recall of labeled events.

The development of conceptual categories is assisted by computerized location of related events.

Pending resolution of the human, and responding to the needs of the Breast Cancer Treatment Fund staff for written materials to use with their Latina enrollees, the 15 rural immigrant respondents were analyzed for the purposes of creating educational materials. Further detail on this treatment of the data is provided in Section 7.

(6) KEY RESEARCH ACCOMPLISHMENTS

Key research accomplishments include:

Development of a plan and protocol for recruitment of uninsured Latinas subjects, approved by UCLA Human Subjects (see attached Appendix A)

Developed and finalized a subject consent form and an initial guide for open-ended interviews of subjects and triads (See Appendix B).

Enrolled and conducted interviews for Immigrant Rural subjects and triads.

Extracted initial themes and "emergent conceptual categories" from first open-ended coding.

(7) REPORTABLE OUTCOMES

Breast Cancer Treatment Fund (BCTF) staff have access to little information in Spanish. At most, the American Cancer Society has translated some of its materials into Spanish, but BCTF staff have shared with us the limitations of such materials. They have been unable to find any materials that would help the family members of the breast cancer patient.

In the interest of maintaining good relations with our key point-of-entrée (i.e. BCTF) to this universe (uninsured Latinas with breast cancer), we agreed to develop a draft of an educational pamphlet for use with rural uninsured Latinas with breast cancer.

The 15 Immigrant rural interviews were analyzed for the purposes of creating educational materials for use by the family members. While these findings may or may not be always applicable to the urban patients, they certainly are useful for rural patients.

I need to stress that the analysis was not for complete theoretical development, but for identifying educational components (Knowledge, Attitudes and Behavior) that families could assist the patients with. The themes in this pamphlet are not necessarily the fully developed themes we are developing for the final analysis, which will be based on the full sample, urban and rural, US born and immigrant, and not just the immigrant rural portion.

Using Ethnograph software, we did a coding for Knowledge, Attitude and Behavior (KAB) issues that were well described by the 15 respondents. To make this educational material user friendly, we did not develop conceptual material, but stayed very close to the families' experiences with the themes they described in the interviews. The KAB themes were:

- The Risk
- The Little Ball
- The Indecisiveness
- The lack of insurance
- Communication
- The word that scares you
- The bad news
- The doctors
- The tangle
- Surgery

Chemo
Radiation
My breast
Doubts
Spiritual strength.

In each of these areas, our task was to describe the experiences of the women and their families. The goal was to let women and their families know that they were not alone in dealing with these issues: these other rural immigrant women had had to manage them as well.

The pamphlet is still in draft stages. It has been reviewed by staff from the BCTF, and their suggestions are being incorporated. The attached copy(Appendix C) is DRAFT ONLY of the educational materials being developed form this project. This is not our final analysis by any means, but it is a way of “repaying” the Breast Cancer Treatment Fund for allowing us access to their patients.

(8) CONCLUSIONS

Following upon suggestion by Technical Editor Pawlus, and after having exhausted the rural portion of the population, the focus will now be on the urban women (Immigrant and US Born), who comprise the vast majority of the uninsured Latina patients assisted by the Breast Cancer Treatment Fund.

(9) REFERENCES

Hayes-Bautista DE, Hsu P, Hayes-Bautista M, Iñiguez D. 2001. *Latino Elderly and Medicare Coverage*. UCLA: Center for the Study of Latino Health & Culture

(10) APPENDICES

Appendix A. Recruitment protocol

Appendix B. Consent form with initial interview questions

Appendix C. DRAFT ONLY version of educational pamphlet.

APENDICES

A Protocol

B Consent forms

C Draft of Educational pamphlet

APPENDIX A

Human Subjects Protocol

5-a. The Basic Protocol

(A detailed research protocol is required for the HSRRB review of your research. All submissions should include the following information:)

1. Project Title. Latina Breast Cancer Patients and their Informal Support System

2. Phase. This research study design does not entail Food, Drug and Cosmetic Act- regulated medical products.

3. Principal Investigator. David E. Hayes-Bautista PhD

4. Location of Study.

California Health Collaborative's Breast Cancer Treatment Fund Program and Breast Cancer Early Detection Program.

1625 E. Shaw Ave Suite 155

Fresno, CA 93710

and

Center For the Study Of Latino Health/UCLA

10911 Weyburn Ave. Suite 333

Los Angeles, Ca 90024-6906

5. Time Required to Complete:

Expected start up data: pending Human Subjects Approval and funding.

Expected completion date: 2 years from approval date.

6. Objectives:

- To develop a detailed description of the informal psychosocial support systems utilized by Latina women who have diagnosed with breast cancer.
- To identify and enroll and interview 60 Latina women who have been recently diagnosed with breast cancer (within 6-18 months), their male partners, a friend or a relative, to participate in this study of informal support systems.
- To audiotape, transcribe and analyze all 180- 60 minute interviews.
- To create a theoretical model from the abstraction of 180 interviews.
- To increase knowledge about Latina Informal Support Networks.

7. Study Population: Latina women diagnosed (within 6-18 months) from four distinct type of backgrounds:

- Immigrant urban resident
- Immigrant rural resident
- US born urban resident
- US born rural resident

	RURAL	URBAN
Immigrant	15 women diagnosed with breast cancer within past 6- 18 months +their male partners +one supportive friend or relative will be identified and asked to participate.	15 women diagnosed with breast cancer within past 6- 18 months +their male partners +one supportive friend or relative will be identified and asked to participate
US born	15 women diagnosed with breast cancer within past 6- 18 months +their male partners +one supportive friend or relative will be identified and asked to participate.	15 women diagnosed with breast cancer within past 6- 18 months +their male partners +one supportive friend or relative will be identified and asked to participate.

Inclusion criteria:

1a. Latina woman, **18 years of age or older** who has been diagnosed with breast cancer within 6-18 months has a male partner and a significant friend or relative that are interested, willing and able to participate in study of informal support system who reside in rural area.

Or

1b. Latina woman, **18 years of age or older** who has been diagnosed with breast cancer within 6-18 months has a male partner and a significant friend or relative that are interested, willing and able to participate in study of informal support systems who reside in urban area.

and

2. Male partner interested and willing to participate in study on informal support systems.
Definition of participation – Male partner willing and able to be interviewed for 60 minutes regarding experience related to female partner’s diagnosis of breast cancer.

and

3. Friend or relative identified by woman participant as supportive, and is interested and willing to participate in study on informal support systems.
Definition of participation – friend or relative identified is willing and able to be interviewed for a total of 60 minutes on his/her experience related to the diagnosis of breast cancer of woman participant.

Exclusion criteria:

1. Latina woman has not been diagnosed with breast cancer, or
2. Latina woman has been diagnosed with breast cancer less than 6 months ago, or
3. Latina woman has been diagnosed with breast cancer more than 18 months ago, or
4. Latina woman cannot identify a male partner or supportive friend or relative, or
5. Latina woman's male partner and/or supportive friend or relative is not interested or able to participate in study of informal support systems.

8. Protocol Design

(Outline the proposed methodology in enough detail to show a clear course of action. Technological reliability and validity of procedures should be indicated. Minimum guidance for the plan includes:)

8a. Subjects identification

How will Latina women diagnosed with breast cancer with 6- 18 months ago be identified?

- Subjects will be identified through patient enrolled in, or contacted through, the California Health Collaborative's Breast Cancer Treatment Fund Program and /or the Central California Partnership of the Breast Cancer Early Detection Program

Who will approach Latina woman to participate?

- One of any of the following staff member from the Center For The Study of Latino Health and/or California Health Collaborative will approach potential subjects via telephone or in-person:

Carolyn Lane RN OCN California Health Collaborative/ BCEDP
Robin Wood Program Manager-California Health Collaborative/ BCEDP
Carolina Soto Community Outreach, California Health Collaborative
Guillermina Garcia California Health Collaborative/ BCEDP
Maria Hayes-Bautista RN, PHN, MPH Center For The Study of Latino Health/UCLA

How will Latina women be approached what will be said?

How will they be invited to participate?

What will be explained?

When contacting subjects staff will take all necessary steps to protect patient confidentiality. Project staff will only communicate with the breast cancer patient initially, prior to contacting triad subjects. If patient's is unavailable, when staff attempts contact, no attempts to leave messages will be made that in anyway links the patient to her condition.

“ My name is _____ and I work with the Center For The Study of Latino Health at UCLA and The California Health Collaborative. We received your name from: (The Breast Cancer Treatment Fund Program, The Breast Cancer Early Detection Program, or Name of Provider within network) We are asking woman who have been recently diagnosed with breast cancer to help us understand their experience and the experience of their partner and friend or relative.”

We believe that we will learn from you and your partner and friend or relatives and what needs to be done in a clinic, a doctor's office or in the community to help all woman. You will be compensated \$20.00 for your time.

Would you allow us to interview you?

Yes / No If yes

Do you believe your male partner will allow us to interview him?

Yes / No If yes

Do you believe a friend and or relative you feel has been supportive will allow us to interview him or her?

Yes / No If yes -

*Would you allow us to contact and interview your
Male partner, and your friend or relative?*

What is the best way to contact you?

What is the best way to contact him (male partner)?

What is the best way to contact your friend or relative?

Spanish Version

"Hola, mi nombre es _____ y trabajo para El Centro de Estudios para la Salud Latina de la Universidad de California de Los Angeles y/o en el The California Health Collaborative. Y estamos preguntando a mujeres que recientemente han sido diagnosticadas con cancer en el seno que nos ayuden a entender las experiencias por las que estan viviendo por esta situacion, como tambien las experiencias de su esposo/pareja, amigos, y/o parientes.

Nosotros creemos que podemos aprender mucho de usted y de su esposo/companero, amigos y parientes, de que es lo que se debe hacer en la clinica, oficina de doctor, o en la comunidad para ayudar a toda mujer que han sido diagnosticadas con cancer en el seno. Por su tiempo se le compensara \$20.00.

Nos permitiria Ud. Entrevistarla?

Si / No if yes.

Ud. Cree que su esposo/pareja nos permitiria entrevistarlo?

Si / No if yes.

Us. Cree que una amiga o pariente que le ha brindado su apoyo durante esta etapa, nos permitiria entrevistarla?

Si / No if yes.

Cual seria la mejor forma de comunicarnos con Ud.?

Cual seria la mejor forma de comunicarnos con su esposo/pareja?

Cual seria la mejor forma de comunicarnos con su amiga/pariente?

- A signed written consent from the patients will be secured prior to contacting subjects' partners and friends or relative.

b. Subject assignments

Who will approach the subjects?

California Health Collaborative and UCLA Center For The Study of Latino Health staff members will be responsible for making initial contact with identified interested, eligible women:

Carolyn Lane RN OCN-BCEDP

Robing Wood – Program Manager – BCEDP

Carolina Soto – BCEDP

Maria Hayes-Bautista RN PHN MPH, Center for the Study of Latino Health

Who will approach the subjects male partner?

California Health Collaborative and UCLA Center For The Study of Latino Health staff members will be responsible for making initial contact with male partner:

Carolyn Lane RN OCN-BCEDP

Robing Wood – Program Manager – BCEDP

Carolina Soto – BCEDP

Maria Hayes-Bautista RN PHN MPH

Who will interview the subject – Latina women

Who will interview the subject's male partner?

Who will interview the subjects friend and/or relative?

One of the following California Health Collaborative and UCLA Center For The Study of Latino Health, staff members will be responsible for interviewing initial subject, subject's male partner, and subject's friend and/or relative.

Carolina Soto, Breast Cancer Early Detection Program, C.H.C.

Guillermina Garcia, Breast Cancer Early Detection Program, C.H.C.

Maria Hayes-Bautista RN, PHN, MPH Center For The Study of Latino Health/UCLA

Where will interviews take place?

Interviews will take place at one of the following site(s)- at most convenient time agreed upon by the interviewee and interviewer.

1. The California Health Collaborative site.
2. The office of one of the Network Providers in the Partnership of the Breast Cancer Early Detection Program.
3. When suggested by the interviewee and agreed upon by the interviewer, the interviewers' parked car in public place.
4. The interviewees' home if and when appropriate.
5. When suggested by the Interviewee, an appropriate and available and available room in a religious institution or community organization.

c. Evaluations prior to entry

Subjects, male partner and friend or relative will be approached individually and invited to participate.

A signed, written consent from the patients will be secured prior to contacting subjects' partner and friend or relatives.

If male partner and/or friend do not feel they are interested in participating subject will be assisted with any referral and/or information she requests and/or needs and will be dropped from the study of informal support systems.

A numeric tally of refusals will be included, with no further identifying information included.

d. Evaluations to be made during the conduct of the study.

This study entails 60 minutes open-ended interviews that will be audiotaped, transcribed and then analyzed.

Each participant, their partner and friend or relative will be assigned a twenty-one digit code.

The 21 digit alphanumeric code will be utilized to code for: Urban Rural participant, male partner, friend or relative, date of diagnosis, Interview date will be coded.

U _ /M _ /FR _ /DX _ / _ /I _ / _
R _ /M _ /FR _ /DX _ / _ /I _ / _

Code: One of the following alphabets will be circled and the appropriate number will complete the coding.

U-urban two-digit ID number 01-60

or

R-rural and two digit ID number 01-60

and

M-male and two digit ID number 01-60

FR-friend or relative and two digit ID number 01-60

DX-diagnosis month and year

I-interview month and year

A file will be recreated for each Latina woman participating in this study. Included in this file will be a confidential face sheet that will identify male partner and friend or relative to be contacted to complete triad interviews.

1. Once a subject agrees to participate, the telephone number and address of the male partner and friend or relative will be recorded on the face sheet. Face4 sheets will be handled carefully and confidentially.

2. A telephone call will be made to the male partner and friend or relative within 24-48 hours of the initial contact with Latina woman to invite male partner and friend or relative to participate in study of informal support systems.

This study does not entail laboratory evaluations or specimens to be collected.

9. Risks/benefits Assessment (*Detail benefits of the research to the subject, precautions to be taken to minimize and/or eliminate risks, and specific medical or nursing care that will be needed.*)

Risks. The only foreseeable risk to the subject is if during the interview a health, mental health and/or social need arises or is assessed by the interviewer and this need cannot be easily met or a resource found to which the interviewee may be referred to.

All interviewers will be trained and supervised by Carolyn Lane RN OCN and Maria Hayes-Bautista RN, PHN, MPH both are registered nurses and trained either in public health nursing or home health nurse. All interviewers will have available to them a list of health, mental health and social services resources in the area. All interviewers will carry a mobile cellular and will be accompanied by when possible by another research team member.

Benefits. The benefits of this research far outweigh the risks. To understand how Latina women immigrant and US born cope with breast cancer will allow the medical world, its providers and its institutions to better understand the of culturally appropriate and supportive networks desired and needed by Latina women.

10. Reporting of Serious and Unexpected Adverse Events.

Serious and unexpected events will be reported to the U.S. Army Medical Research and Materiel Command Deputy Chief of Staff for Regulatory Compliance and Quality (301-619-2165 or non-duty hours, 301-619-2165 and send information by facsimile to 301-619-7803). A written report will follow the initial telephone call within 3 working days. Address the written report to the U.S. Army Medical Research and Materiel Command, ATTN: MCMR-RCQ, 504 Scott Street, Fort Detrick, Maryland, 21702-5012

If a situation arises that suggests a person is at risk of harm, the necessary steps will taken to seek help and report such a suspicion or adverse event as required by the ethics of medical practice and by law.

11. Description of Protocol Drug(s) or Device(s).

This research study does not entail the use of drug(s) or device(s).

12. Disposition of Data. *Where will the data be stored and for how long?*

Participant files will be kept in a locked file cabinet housed in the offices of the Center For The Study of Latino Health/UCLA. A copy of the file will also be kept in a locked file cabinet in the office of the California Health Collaborative. All files will be shredded at the end of the study period.

Audiotape interviews will be labeled within the twenty-one digit code and will be stored in the office(s) of the California Health Collaborative and/or Center For The Study of Latino Health/UCLA. **In addition, they will be labeled "For Official Use Only".**

The audio taped interviews will be transcribed by Center For The Study of Latino Health staff members. No identifying information will be indicated. Interviews will be conducted on a first name only basis.

The audio will be destroyed after the transcribed data has been verified.

Transcribed audiotapes will be coded and stored in the Principal Investigator's personal file cabinets.

Analysis of transcribed tapes will be done by the Principal Investigator.

13. Modification of the protocol. *Describe the procedure to be followed if the protocol is modified.*

This protocol has been established with input from key staff of the California Health Collaborative and the Center For The Study of Latino Health, however, if a team member sees a need in the future, to make a change in the protocol, a decision will be made by the Principal Investigator.

This protocol and a copy of the Informed Consent Form will also be submitted to the UCLA office for the Protection of Research Subjects. Any changes suggested by the UCLA office for the Protection of Research Subjects will be forwarded to the Dept. Of United States Army Medical Research and Materiel Command.

If and when a change in protocol is decided, the P.I. will inform appropriate individuals at the UCLA office for the Protection of Research Subjects, P.O. Box 951694, LA CA 90095-1695 and to the Dept. Of United States Army Medical Research and Materiel Command.

14. Roles and Responsibilities of Study Personnel. *Briefly describe the duties of the study personnel.*

Carolyn Lane RN OCN and Robin Wood Program Manager (Breast Cancer Early Detection Program)

- a. will be responsible for informing providers in the Network "Partnership of the Breast Cancer Early Detection Program" of this project's funding.
 - b. For referring identified subjects to the team members of this study.
 - c. For making initial contact –when subjects' male partner and friend or relative's preferred language in English, and
 - d. For interviewing subjects who prefer English
- Responsibility for interviewing will be given after appropriate training in qualitative data gathering and an introduction to grounded theory methodology is provided.

Carolina Soto and Guillermina Garcia BCEDP (fluent Spanish speakers)

- a. will be responsible for making initial contact with subject and subject's male partner and friend and/or relative.
 - b. Will assist as needed with interviews in Spanish.
- Responsibility for interviewing will be given after appropriate training in qualitative data gathering and an introduction to grounded theory methodology is provided.

Maria Hayes-Bautista RN PPHN MPH (Center For The Study of Latino Health/UCLA)

- a. will be responsible for the overall coordination of this project.
- b. for interviewing in Spanish and/or English, and
- c. for conducting training in qualitative data gathering.

15. Signature of the Principal Investigator.

“ I have read the foregoing protocol and agree to conduct the study as outlined herein.”

Signature of
Principal Investigator

Date

APPENDIX B

CONSENT FORM
Latina Breast Cancer Patients and Their Informal Support Systems
Woman Diagnosed with Breast Cancer

We are asking you to authorize David E. Hayes-Bautista Ph.D., Director of the Center for the Study of Latino Health at the University of California, Los Angeles to include you in his research to explore and better understand the structure and function of the informal support systems used by Latina breast cancer patients. You have been asked to participate in this research because you have been recently diagnosed with breast cancer, and you have indicated an interested in participating in this study.

We will also will be interviewing your spouse/partner and family members or friends, to understand how their role of interaction with you.

PROCEDURES

If you volunteer to participate in the research, you will be asked to be interviewed for approximately 60 minutes. The questions that will be asked are:

1. Please describe your family responsibilities.
2. Please describe your recall of your reaction to the diagnosis of breast cancer.
3. What were your initial feelings?
4. Please describe your recall of your family's reaction to the news of the breast cancer diagnosis.
5. Please share to the extent you feel comfortable, an important conversation regarding the breast cancer diagnosis, you may have had with a friend or relative.
6. Please share to the extent you feel comfortable, an important conversation regarding the breast cancer diagnosis, you may have had with your spouse/relative and/or friend.
7. How would you describe your relationship with your health care provider(s)?
8. Before your diagnosis, what had you heard about breast cancer?
9. What are your feelings now?

The interviews can be held at one of any of the following locations depending on your preference:

1. Your home if and when appropriate.
2. The California Health Collaborative site located at 1625 Shaw Suite 155.
3. The office of your doctor a member of the Network Providers in the Partnership of the Breast Cancer Early Detection Program.
4. In the interviewers car parked in a public place.
5. An appropriate and available room in a religious institution or community organization.

The interview will be audio taped. You have the right to review the tapes and to edit or erase any information that identifies you. The tapes will be used only for research purposes. The tapes will be transcribed and no names will be used. Once the transcriptions are done, the tapes will be destroyed.

INITIALS: _____
 Subject Witness

APPROVED

MAY 18 2001

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POTENTIAL RISKS AND DISCOMFORTS

There are minimal potential risks and discomfort. Similar studies have found that respondents welcome the opportunity to talk about their feelings however, if there is any discomfort experienced by recall of painful incidents, the interviewer will not probe further. Also if you feel you would like information regarding resources that provide emotional and psychological support, the interviewer and/or the BCEDP staff will assist you.

ANTICIPATED BENEFITS TO SUBJECTS

Others who have studied the affects of breast cancer e.g. Drs. Rose Maly and Feher S. Frank "Coping with breast cancer in later life" have found that respondents find it helpful to talk with others about breast cancer. This research project will provide you with an opportunity to speak with others about your health concerns.

ANTICIPATED BENEFITS TO SOCIETY

Your participation can help us better understand how breast cancer affects Latinas, their spouse and/or male partners and their family (relatives) This understanding can help health administrators and providers develop and provide more culturally competent care to Latinas diagnosed with breast cancer and their families.

PAYMENT FOR PARTICIPATION

A payment of \$20.00 (twenty dollars) will be awarded to you for your participation, by signing this document you are acknowledging that you received said amount in cash. Other than payment specifically stated in the consent form, there is no other compensation available for your participation in this research.

PRIVACY AND CONFIDENTIALITY

Any information that you share will be confidential and that no information that identifies you will be shared by the researcher without your written permission, except: If necessary to protect your rights or welfare (for example, if you are injured and need emergency care); or if required by law. In addition, representatives of the U.S. Army Medical Research and Materiel Command are eligible to review records as a part of their responsibility to protect human subjects in research.

PARTICIPATION AND WITHDRAWAL

Your participation in this research is voluntary and there are no additional costs to you that may result from your participation in the research. If you choose not to participate, that will not affect your relationship with UCLA or any other medical institution, or your right to health care or other services to which you are otherwise entitled. If you decide to participate, you are free to withdraw your consent and discontinue participation at any time without prejudice to your future care at any medical center

INITIALS:

 Subject

 Witness

If you have further questions, comments or concerns about the study, you may call David E. Hayes-Bautista, Ph.D. at (310) 794-0663 or Carolyn Lane RN OCN (559) 244-4554. You are not waiving any legal claims, rights or remedies because of my participation in this research study. If you have any questions or concerns about the informed consent process or the rights of subjects, you may write or call the Office for Protection of Research Subjects, UCLA, Box 951694, Los Angeles, CA 90095-1694, and (310) 825-8714.

You have read (or someone has read to you) and understand the information provided above. You have been given an opportunity to ask questions and all of your questions have been answered to your satisfaction. You have been given a copy of this form, as well as a copy of the Subjects' Bill of Rights.

UCLA IRB#: G99-03-084-03
Expiration Date: May 17, 2002

APPROVED

MAY 18 2001

UCLA GENERAL CAMPUS
INSTITUTIONAL REVIEW BOARD

BY SIGNING THIS FORM, YOU WILLINGLY AGREE TO PARTICIPATE IN THE RESEARCH IT DESCRIBES.

I understand that I will be given a copy of this form.

Name of Subject

Signature of Subject

Date

Address

I have explained the research to the subject of his/her legal representative, and answered all of her/his questions. I believe that she/he understands the information described in this document and freely consents to participate.

Investigator's Name and Signature

Date

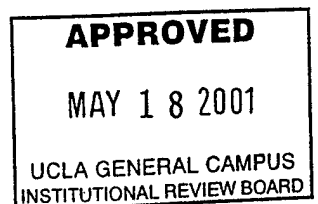
My signature as witness certified that the subject or her/his legal representative signed this consent form in my presence as her/his voluntary act and deed.

Witness Name

Witness Signature

Date

UCLA IRB#: G99-03-084-03
Expiration Date: May 17, 2002



CONSENT FORM

Latina Breast Cancer Patients and Their Informal Support Systems Spouse or Partner of a Woman Diagnosed with Breast Cancer

We are asking you to authorize David E. Hayes-Bautista Ph.D., Director of the Center for the Study of Latino Health at the University of California, Los Angeles to include you in his research to explore and better understand the structure and function of the informal support systems used by Latina breast cancer patients. You have been asked to participate in this research because you are the spouse/partner of a woman diagnosed with cancer, and you have indicated an interest in participating in this study.

PROCEDURES

If you volunteer to participate in the research, you will be asked to be interviewed for approximately 60 minutes. The questions that will be asked are:

1. Please describe your family responsibilities.
2. Please describe your recall of your reaction to the diagnosis of breast cancer.
3. What were your initial feelings?
4. Please describe your recall of your family's reaction to the news of the breast cancer diagnosis.
5. Please share to the extent you feel comfortable, any fears you may have had or have regarding body changes in appearance as a result of the diagnosis of breast cancer.
6. Please share to the extent you feel comfortable, an important conversation regarding the breast cancer diagnosis, you may have had with your spouse/relative and/or friend.
7. How would you describe your relationship with your spouse's or female partner's health provider(s)?
8. Before your partner's diagnosis, what had you heard about breast cancer?
9. What are your feelings now?

The interviews can be held at one of any of the following locations depending on your preference:

1. Your home if and when appropriate.
2. The California Health Collaborative site located at 1625 Shaw Suite 155.
3. The office of your doctor a member of the Network Providers in the Partnership of the Breast Cancer Early Detection Program.
4. In the interviewers car parked in a public place.
5. An appropriate and available room in a religious institution or community organization.

The interview will be audio taped. You have the right to review the tapes and to edit or erase any information that identifies you. The tapes will be used only for research purposes. The tapes will be transcribed and no names will be used. Once the transcriptions are done, the tapes will be destroyed.

INITIALS:

Subject

Witness

APPROVED

MAY 18 2001

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PROTENTIAL RISKS AND DISCOMFORTS

There are minimal potential risks and discomfort. Similar studies have found that respondents welcome the opportunity to talk about their feelings however, if there is any discomfort experienced by recall of painful incidents, the interviewer will not probe further. Also if you feel you would like information regarding resources that provide emotional and psychological support, the interviewer and/or the BCEDP staff will assist you.

ANTICIPATED BENEFITS TO SUBJECTS

Others who have studied the affects of breast cancer e.g. Drs. Rose Maly and Feher S. Frank "Coping with breast cancer in later life" have found that respondents find it helpful to talk with others about breast cancer. This research project will provide you with an opportunity to speak with others about your health concerns.

ANTICIPATED BENEFITS TO SOCIETY

Your participation can help us better understand how breast cancer affects Latinas, their spouse and/or male partners and their family (relatives) This understanding can help health administrators and providers develop and provide more culturally competent care to Latinas diagnosed with breast cancer and their families.

PAYMENT FOR PARTICIPATION

A payment of \$20.00 (twenty dollars) will be awarded to you for your participation, by signing this document you are acknowledging that you received said amount in cash. Other than payment specifically stated in the consent form, there is no other compensation available for your participation in this research.

PRIVACY AND CONFIDENTIALITY

Any information that you share will be confidential and that no information that identifies you will be shared by the researcher without your written permission, except: If necessary to protect your rights or welfare (for example, if you are injured and need emergency care); or if required by law. In addition, representatives of the U.S. Army Medical Research and Materiel Command are eligible to review records as a part of their responsibility to protect human subjects in research.

INITIALS:

_____ **Subject**

_____ **Witness**

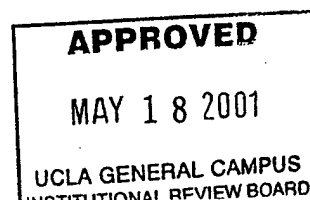
PARTICIPATION AND WITHDRAWAL

Your participation in this research is voluntary there are no additional costs to you that may result from your participation in the research. If you choose not to participate, that will not affect your relationship with UCLA or any other medical institution, or your right to health care or other services to which you are otherwise entitled. If you decide to participate, you are free to withdraw your consent and discontinue participation at any time without prejudice to your future care at any medical center

If you have further questions, comments or concerns about the study, you may call David E. Hayes-Bautista, Ph.D. at (310) 794-0663 or Carolyn Lane RN OCN (559) 244-4554. You are not waiving any legal claims, rights or remedies because of my participation in this research study. If you have any questions or concerns about the informed consent process or the rights of subjects, you may write or call the Office for Protection of Research Subjects, UCLA, Box 951694, Los Angeles, CA 90095-1694 (310) 825-8714.

You have read (or someone has read to you) and understand the information provided above. You have been given an opportunity to ask questions and all of your questions have been answered to your satisfaction. You have been given a copy of this form, as well as a copy of the Subjects' Bill of Rights.

UCLA IRB#: G99-03-084-03
Expiration Date: May 17, 2002



BY SIGNING THIS FORM, YOU WILLINGLY AGREE TO PARTICIPATE IN THE RESEARCH IT DESCRIBES.

I understand that I will be given a copy of this form.

Name of Subject

Signature of Subject

Date

Address

I have explained the research to the subject of his/her legal representative, and answered all of her/his questions. I believe that she/he understands the information described in this document and freely consents to participate.

Investigator's Name and Signature

Date

My signature as witness certified that the subject or her/his legal representative signed this consent form in my presence as her/his voluntary act and deed.

Witness Name

Witness Signature

Date

UCLA IRB#: G99-03-084-03
Expiration Date: May 17, 2002

APPROVED
MAY 18 2001
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CONSENT FORM

Latina Breast Cancer Patients and Their Informal Support Systems Family and/or Friend of a Woman Diagnosed with Breast Cancer

We are asking you to authorize David E. Hayes-Bautista Ph.D., Director of the Center for the Study of Latino Health at the University of California, Los Angeles to include you in his research to explore and better understand the structure and function of the informal support systems used by Latina breast cancer patients. You have been asked to participate in this research because you are a family member/friend of a woman diagnosed with cancer, and you have indicated an interest in participating in this study.

PROCEDURES

If you volunteer to participate in the research, you will be asked to be interviewed for approximately 60 minutes. The questions that will be asked are:

1. Please describe your family responsibilities.
2. Please describe your recall of your reaction to the diagnosis of breast cancer.
3. What were your initial feelings?
4. Please describe your recall of your family's reaction to the news of the breast cancer diagnosis.
5. Please share to the extent you feel comfortable, any fears you may have had or have regarding body changes in appearance as a result of the diagnosis of breast cancer.
6. Please share to the extent you feel comfortable, an important conversation regarding the breast cancer diagnosis, you may have had with your relative/friend diagnosed with cancer.
7. How would you describe your relationship with your relative/friend's health provider(s)?
8. Before your relative's/friend's diagnosis, what had you heard about breast cancer?
9. What are your feelings now?

The interviews can be held at one of any of the following locations depending on your preference:

1. Your home if and when appropriate.
2. The California Health Collaborative site located at 1625 Shaw Suite 155.
3. The office of your doctor a member of the Network Providers in the Partnership of the Breast Cancer Early Detection Program.
4. In the interviewers car parked in a public place.
5. An appropriate and available room in a religious institution or community organization.

The interview will be audio taped. You have the right to review the tapes and to edit or erase any information that identifies you. The tapes will be used only for research purposes. The tapes will be transcribed and no names will be used. Once the transcriptions are done, the tapes will be destroyed.

INITIALS:

Subject

Witness

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PROTENTIAL RISKS AND DISCOMFORTS

There are minimal potential risks and discomfort. Similar studies have found that respondents welcome the opportunity to talk about their feelings however, if there is any discomfort experienced by recall of painful incidents, the interviewer will not probe further. Also if you feel you would like information regarding resources that provide emotional and psychological support, the interviewer and/or the BCEDP staff will assist you.

ANTICIPATED BENEFITS TO SUBJECTS

Others who have studied the affects of breast cancer e.g. Drs. Rose Maly and Feher S. Frank "Coping with breast cancer in later life" have found that respondents find it helpful to talk with others about breast cancer. This research project will provide you with an opportunity to speak with others about your health concerns.

ANTICIPATED BENEFITS TO SOCIETY

Your participation can help us better understand how breast cancer affects Latinas, their spouse and/or male partners and their family (relatives) This understanding can help health administrators and providers develop and provide more culturally competent care to Latinas diagnosed with breast cancer and their families.

PAYMENT FOR PARTICIPATION

A payment of \$20.00 (twenty dollars) will be awarded to you for your participation, by signing this document you are acknowledging that you received said amount in cash. Other than payment specifically stated in the consent form, there is no other compensation available for your participation in this research.

PRIVACY AND CONFIDENTIALITY

Any information that you share will be confidential and that no information that identifies you will be shared by the researcher without your written permission, except: If necessary to protect your rights or welfare (for example, if you are injured and need emergency care); or if required by law. In addition, representatives of the U.S. Army Medical Research and Materiel Command are eligible to review records as a part of their responsibility to protect human subjects in research.

INITIALS:

_____ **Subject**

_____ **Witness**

PARTICIPATION AND WITHDRAWAL

Your participation in this research is voluntary there are no additional costs to you that may result from your participation in the research. If you choose not to participate, that will not affect your relationship with UCLA or any other medical institution, or your right to health care or other services to which you are otherwise entitled. If you decide to participate, you are free to withdraw your consent and discontinue participation at any time without prejudice to your future care at any medical center.

If you have further questions, comments or concerns about the study, you may call David E. Hayes-Bautista, Ph.D. at (310) 794-0663 or Carolyn Lane RN OCN (559) 244-4554. You are not waiving any legal claims, rights or remedies because of my participation in this research study. If you have any questions or concerns about the informed consent process or the rights of subjects, you may write or call the Office for Protection of Research Subjects, UCLA, Box 951694, Los Angeles, CA 90095-1694, and (310) 825-8714.

You have read (or someone has read to you) and understand the information provided above. You have been given an opportunity to ask questions and all of your questions have been answered to your satisfaction. You have been given a copy of this form, as well as a copy of the Subjects' Bill of Rights.

UCLA IRB#: G99-03-084-03
Expiration Date: May 17, 2002

APPROVED

MAY 18 2001

UCLA GENERAL CAMPUS

BY SIGNING THIS FORM, YOU WILLINGLY AGREE TO PARTICIPATE IN THE RESEARCH IT DESCRIBES.

I understand that I will be given a copy of this form.

Name of Subject

Signature of Subject or Legal Representative

Date

Address

I have explained the research to the subject of his/her legal representative, and answered all of her/his questions. I believe that she/he understands the information described in this document and freely consents to participate.

Investigator's Name and Signature

Date

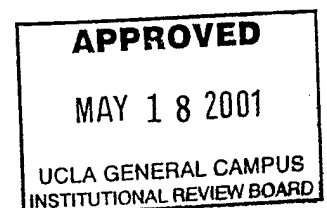
My signature as witness certified that the subject or her/his legal representative signed this consent form in my presence as her/his voluntary act and deed.

Witness Name

Witness Signature

Date

UCLA IRB#: G99-03-084-03
Expiration Date: May 17, 2002



FORMA DE CONSENTIMIENTO
PACIENTES LATINAS CON CANCER EN EL SENO Y SU SISTEMA DE APOYO
Mujeres diagnosticadas con cáncer en el seno

Por medio de este documento le estamos pidiendo su autorización para que David E. Hayes-Bautista, Ph.D., Director del Centro de Estudios de la Salud Latina, de la Universidad de California en Los Angeles, que la incluya en el estudio para explorar y mejorar el conocimiento acerca del apoyo que reciben o necesitan las mujeres diagnosticadas con cáncer en el seno. Se le ha invitado a participar en este estudio por que es una mujer que ha sido diagnosticada con cáncer en el seno.

También entrevistaremos a su esposo/pareja, algún miembro de su familia o a una amiga/o, esto nos ayudaría a entender como es la relación de ellos hacia Ud.

PROCEDIMIENTO

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- 1.) Por favor describa sus responsabilidades familiares?
- 2.) Por favor describa cuál fue su reacción cuando se le diagnosticó el cáncer (Ud. , su esposa/pareja, amiga/pariente?
- 3.) Cómo se sintió cuando lo supo?
- 4.) Recuerda cuál fue la reacción de su familia cuando se enteraron del diagnóstico del cáncer?
- 5.) Hasta donde Ud. se sienta comfortable, por favor recuerde algunas de las conversaciones que haya tenido sobre la diagnosis de cáncer?
- 6.) Por favor describa, hasta donde Ud. se sienta comfortable, alguna conversación importante que haya tenido con su esposo, algún amigo o pariente sobre la diagnosis de cáncer?
- 7.) Cómo describiría usted la relación que mantiene usted con su doctor/proveedor de salud?
- 8.) Antes del diagnóstico, que es lo que había escuchado sobre el cáncer del pecho?
- 9.) Que es lo que siente ahora?

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 Participante **Testigo**

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FORMA DE CONSENTIMIENTO
PACIENTES LATINAS CON CANCER EN EL SENO Y SU SISTEMA DE APOYO
Esposo o pareja

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- 1.) Por favor describa sus responsabilidades familiares?
- 2.) Por favor describa cuál fue su reacción cuando se le diagnostico el cáncer a su esposa/pareja,
- 3.) Que fue lo primero que sintió?
- 4.) Por favor describa la reacción de su familia cuando se enteraron del diagnostico del cáncer?
- 5.) Hasta donde Ud.. se sienta comfortable, por favor recuerde algunas de las conversaciones que haya tenido sobre la diagnosis de cáncer?
- 6.) Por favor describa, hasta donde Ud. se sienta comfortable, algunos temores que haya tenido tenga respecto a los cambios en la apariencia del cuerpo como resultado del diagnostico del cáncer en el pecho?
- 7.) Cómo describiría usted la relación que mantiene usted con el doctor/proveedor de salud de su esposa/pareja?
- 8.) Antes del diagnostico de su esposa/pareja, que es lo que había escuchado sobre el cáncer del pecho?
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FORMA DE CONSENTIMIENTO
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Familiar o amigo de una mujer diagnosticada con cáncer en el seno

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6.) Por favor describa, hasta donde Ud. se sienta comfortable, algunos temores que haya tenido o tenga respecto a los cambios en la apariencia del cuerpo como resultado del diagnostico del cáncer en el pecho?
7.) Como describiría usted la relación que mantiene usted con el doctor/proveedor de salud de su pariente/amiga la cual ha sido diagnosticada con cáncer en el seno?
- 8.) Antes del diagnostico de su pariente/amiga, que es lo que había escuchado sobre el cáncer del pecho?
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APPENDIX C

Quince Mujeres y Sus Familias

Nos Ayudan A Comprender
El Cáncer del Seno.

Fifteen Women and Their Families
Help Us Understand Breast Cáncer.



The Center for the Study of Latino Health and
Culture, School of Medicine, UCLA

DRAFT

“Ella es el alma del hogar, ella es la familia, ella es el cerebro, ella es alguien muy importante para todos aquellos que la rodean... ¿por qué le pasa esto a una gran mujer?”

“She is the soul of our home, she is the family, she is the brain, she is someone very important for everyone around her...why does this happen to such a great woman?”

El Riesgo

Algunas de nuestras participantes no creían que estaban en riesgo de contraer cáncer del seno, porque ellas habían tomado precauciones. En algunos casos, no había historial de cáncer del seno en la familia. Otras creían que no estaban en riesgo porque no tenían la edad de alto riesgo. Mientras que otras utilizaban el método de alimentar a los hijos con el pecho como medida de prevención para no contraer el cáncer.

“...Yo había oído en las noticias ‘que cuando uno cría a sus hijos con sus pechos, no le pegaba el cáncer.’ Que por eso era mejor dar pecho porque el cáncer no da. Y dije ‘ya no me va a dar cáncer porque yo crío a todos mis hijos con pecho’”

DRAFT

The Risk

Some of our participants did not believe they were at risk because they thought that they had already taken precautions. In some cases, there was no known history of breast cancer in their family. Others believed that they did not fall within the age range of high risk. While others felt that by breast-feeding they lowered their chances of getting cancer.

"...I heard it in the news 'when you breast-feed your children 'you do not get cancer.' This was a good method to prevent cancer. Then I told myself 'I will never get cancer because I breast-fed my children'"

BC 05-01-01 (woman)

La Bolita

La primera señal era un cambio, generalmente descrito por nuestras participantes como una bolita que se les desarrolla en el seno. Algunas de nuestras participantes no sabían lo que esto significaba. Ellas creían que esto era algo pasajero y que pronto se les iba a quitar. Para nuestras participantes la señal de dolor era algo que indicaba preocupación, algo que requería acción. En alguno de los casos no hubo acción, porque no les dolía.

“Tenía pues, no sé que tanto tiempo tendría, que yo me bañaba y me tallaba y decía, ‘¿Por qué tengo sumido el pezón, por que tengo sumida la bolita? ¿Por qué la tengo sumida y ésta no?’ A nadie le consultaba pues no me dolía nada.”

“Y ese día fui, ya tenía tiempo de que me sentía algo, como cuando a uno le pegan, se siente algo duro, larguito aquí. Me tentaba, pero no me dolía.”

“No se sentía mal, no mas se le estaba sumiendo y sumiendo el pezón. Pero no sentía dolor.”

La persistencia del dolor fue la señal, por la cual algunas de nuestras participantes tomaron acción y fueron al doctor. Es de suma importancia estar claros acerca de la seriedad que esto puede causar en un futuro.

“Y yo le decía, ¿Sabe que doctora? A mí me sigue doliendo mi bolita, le digo, Me lavo, y cuando me baño se me mueve ésta, como carnecita.”

Algunas de nuestras participantes atribuyeron el dolor a los cambios físicos del cuerpo como cuando una mujer menstrua o a la fuerza física utilizada cuando una desempeñaba sus trabajos.

“Me siento algo aquí, pero como a veces cuando me va a bajar mi menstruación se me hinchaba. Y cuando me bajaba, se me quitaba. Y esa vez, no.”

DRAFT

*“Luego como estuve trabajando donde hacían ventanas, y era pura fuerza, dije
‘¿Sería de tanto ejercicio que hacía?, y pensé que se me habían hecho los
nervios bola ahí’ ... y pues como me dolía el brazo, pensé que era eso.”*

THE LITTLE BALL

The first symptom is a change in the breast, usually described as a “little ball” that develops. Some of our participants did not know what this symptom meant. They believed that it was temporary and it would go away soon. For our participants, pain was a sign to worry, and something that needed action. In some cases they took no action because this symptom caused them no pain.

“ I don’t know for how long, when I took a shower and scrubbed myself I wondered, ‘Why do I have my nipple sunken in; why do I have the little ball sunken in? Why do I have this one sunken in and not the other?’ I did not consult with anyone, as nothing was hurting.”

“On the day I went, I had been feeling something for a while, like when someone hits you. It felt hard and long, right here. I used to touch it, but it did not hurt.”

“She didn’t feel sick; the only thing was that her nipple was sinking and sinking. But she didn’t feel any pain.”

The persistence of pain was the sign that made some of our participants take action and go to the doctor. It is very important to understand the serious effect that this can have in the future.

“And I said to her, ‘You know what, doctor? My little ball continues to hurt.’ I told her, ‘I wash, and when I am bathing, this moves, like a little piece of meat’.”

Some of our participants attributed the pain to changes in their bodies—for example, menstruation—or to the result of physical effort used when a woman was doing her work.

“ I felt something here, but sometimes, right before I started menstruating, it would get swollen. Then, when I started menstruating, it would go away. But that time it didn’t.”

“And when I was working making windows, and I had to lift heavy things, I said to myself, ‘Would it be because of all the physical effort I was making?’ And I thought that my nerves had bunched up there...because my arm hurt, I thought it was that.”

La Desidia

Aún cuando descubrieron la primera señal, fue difícil para nuestras participantes hacer algo. Ellas no se atendieron, y no fue porque no hayan querido, si no porque desafortunadamente ellas no disponían de seguro médico o recursos económicos con que pagar la consulta. Nuestras participantes sí se preocuparon por su salud.

“Cuando ella me dijo que sentía algo en su pecho, yo le dije que no lo dejara a la desidia, que fuera al doctor. Y ella me dijo que no tenía dinero, que se sentía mal porque no tenía dinero, que ¿Cómo le iba a hacer?”

Otras veces, lo dejaron a la desidia porque no les dolió, creyeron que era una cosa pasajera, algo que no tenía mucha importancia. Y cuando acudieron al doctor fue cuando se dieron cuenta que era demasiado tarde, y se lamentaron el no haber ido antes.

“Yo pienso... ¡Como todas! Me duele esto, hoy no me duele ¿Pa’ que voy a ir al doctor? me duele 2, 3 días, mañana voy. Y lo deja uno a la desidia, y va cuando es demasiado tarde. Pero ella nunca pensó que tenía algo grave.”

THE INDECISIVENESS

Even after they found the first sign, it was difficult for our participants to do something about it. They did not seek medical attention, not because they did not want to but because, unfortunately, they did not have medical insurance or the ability to pay for a visit to the doctor. Our participants did worry about their health.

“When she told me that she felt something in her breast, I told her not to put it off, to go to the doctor. She told me that she had no money, that she felt bad because she didn’t have any money, and what was she going to do?”

At other times, they put it off because they were not in pain; they believed it was a temporary thing, something that was not very important. When they did seek medical attention, they realized that it was too late, and they regretted not having sought medical attention earlier.

“I think...she thought—like everybody else!—‘This hurts. It doesn’t hurt today, so why should I go to the doctor? It’s been hurting for two or three days now; I’ll go tomorrow.’ So the woman puts off doing anything, and she goes when it’s too late. She never thought she had anything serious, though.”

Con Dinero o Sin Dinero: La Falta de Seguro

Los trabajos como los que nuestras participantes y esposos tenían no eran bien pagados, así que muchas mujeres campesinas se sintieron impotentes de no poder hacer algo. Se detuvieron porque no les alcanzó y les fue difícil ir a chequearse la bolita.

“Yo pago seiscientos dólares de mi casa. Pago trescientos dólares de mi carro. ¿Que me queda? Mas los biles. A veces no sé ni cómo ajustamos, porque él gana mil cuatrocientos al mes. Casi nomás el carro y la casa. Eso es todo.”

La falta de recursos económicos, fue una de las principales razones por la cuál muchas de nuestras participantes no buscaron atención medica de inmediato. Pero esto no quiere decir que ellas no estuvieron conscientes de la bolita.

“Sí, pensaba ir en esa semana, pero que en eso se me llega la renta, y ya menos fui, por que pues sin dinero...”

Los trabajos del campo rara vez ofrecieron seguro médico. La falta del seguro médico hizo más difícil obtener atención médica.

“Ese doctor, de primero cuando fuimos me cayó bien. Buena gente y todo. Pero cuando supo que no tenía aseguranza, me pregunto que ‘¿Quién iba a pagar la operación?’, Le contesté que no tenía aseguranza y fue cuando ya no quería [verme] Me preguntó ‘¿qué quién iba a pagar?’”

En la mayoría de nuestros casos, no se les brindó atención médica por falta de seguro médico.

“En el hospital no me chequearon. No me atendieron, porque no tenía Medi-Cal ni aseguranza ni nada. Lo que me dijeron fue, ‘¿Tienes para pagar la operación? Esto cuesta mucho dinero’, Dije ‘No tengo’. Entonces se quedó así.”

Para nuestras participantes la ayuda del gobierno era la única alternativa para poder atenderse cuando se enferman, porque carecían de recursos económicos.

“Cuando uno se enferma, si no agarra ayuda del gobierno, no puede pagar uno un doctor. Esa es la realidad.”

Para muchas de nuestras participantes la lucha en el sistema médico fue difícil. La tenacidad de muchas de ellas y el apoyo de sus familiares y amigos venció esas barreras, y así fue como conocieron que existían otras opciones de ayuda médica.

“No iba al doctor hasta que una amiga mía me dijo donde podría ir, a una agencia donde ayudan. ... ella me llevó y si no es por su ayuda pues yo pienso que no hubiera ido yo al doctor.”

Una de las cosas que nuestras participantes aprendieron durante esta difícil etapa de su vida fue la importancia de recibir un tratamiento a tiempo, antes de que sea demasiado tarde.

“Tiene bajos recursos, no tiene uno con que pagar una operación de esas. Por esa razón la llevé tarde al hospital. Esperé a que se le pusiera rojo, se le inflamó bastante, ya estaba grave.”

WITH MONEY OR WITHOUT MONEY—THE LACK OF INSURANCE

The jobs that our participants or their husbands had, do not pay well, so some rural women feel powerless to do anything. They delay because it hasn't hit them yet, and because it is difficult to go have the "little ball" checked out.

"I pay \$600 for my house. I pay \$300 for my car. What does that leave me? Plus the bills. Sometimes we don't know how we have enough because he only gets paid \$1,400 a month. That just barely covers the car and the house. That's it."

The inability to pay was one of the principal reasons many of our participants did not seek immediate medical attention. But this does not mean that they were not aware of the "little ball."

"Yes, I was planning on going that week, but then the rent came due, so it lessened the possibility of my going, because without money...."

Agricultural jobs rarely provide medical insurance. This lack of insurance complicates the decision to seek medical care.

"This doctor, I liked him in the beginning. He was a good man and all. But when he found out that I did not have insurance, he began to ask, 'Who is going to pay for the surgery?' I told him that I had no insurance, and that was when did not want to see me anymore. He asked, 'Who is going to pay?'"

In most of our participants' cases, they did not receive medical attention because they did not have medical insurance.

"They did not examine me at the hospital. They did not take care of me because I did not have Medi-Cal or insurance or anything. What they told me was, 'Do you have the money to pay for the surgery? This costs a lot of money.' I said, 'No, I don't have it.' Then things were left at that."

For our participants, help from the government is the only option for getting medical attention when they are ill because they lack economic resources.

"When you get sick, if you don't get help from the government, you cannot pay the doctor. That is just reality."

For many of our participants, fighting the medical system was hard. The tenacity that many of them had, and the support of their families and friends, overcame these barriers; and it was in that way that they learned that other options for getting medical help existed.

"I was not seeing a doctor until my friend told me where to go, to an agency that helps people. She took me there. If it weren't for her help, I think I would not have gone to the doctor."

One thing our participants learned during this difficult stage in their lives was the importance of receiving timely treatment, before it is too late.

"Anyone who has a low income doesn't have the money to pay for that type of surgery. Because of that, I delayed taking her to the hospital. I waited until it had gotten red. It got really swollen, and her condition was already serious."

La Comunicación

Para nuestras participantes, la comunicación era de suma importancia, pero desafortunadamente la mayor parte del tiempo el idioma era un obstáculo para que ellas se comunicaran con el doctor.

“Pues yo, como no le entendí ¿verdad? Dije ‘Ay Dios Mío ¿Qué me diría?’”

En algunos casos, un familiar ó una amiga podía servir de intérprete, pero para que la comunicación fuera exitosa se requería más que hablar el mismo idioma. Se requería saber como interpretar el mensaje. Para nuestras participantes la ayuda de un desconocido para comunicar una noticia tan importante fue vista como algo brusco y frío.

“Yo no hablaba [ingles], y el no hablaba español. Me puso una señora y [me] dijo ‘El doctor dice que tienes cáncer’.”

Sin embargo, nuestras participantes entendieron que utilizar todos los recursos disponibles era muy importante. Ellas buscaron la manera entre familia y amistades, para formar una red de apoyo y así facilitar la comunicación y lograr entendimiento.

“Armábamos como un rompecabezas de todo lo que oíamos. Yo entiendo el Ingles mas bien que hablarlo. Entiendo mas, pero entre mi cuñada y yo juntábamos las cosas, problemas para hablarlo.”

Sobre todo, la red de apoyo ayudó a estas mujeres entender mejor al doctor, y a sentirse apoyadas durante esta situación tan difícil: la diagnosis de cáncer.

“Me ponía tan nerviosa y el miedo era tan grande, [que] escuchaba pero mi mente no captaba lo que decía. Mis orejas estaban, las tenía, pero mis oídos no escuchaban.”

En fin, la red de apoyo sirvió para comunicarse y mejorar el entendimiento.

“Vamos a prepararnos bien. Vamos a ir todos, porque a mí se me va a pasar algo. Mas oídos, mas todo. Yo hacía la pregunta, mi cuñada hacía la pregunta... This was our team. We were together.”

COMMUNICATION

For our participants, communication was of extreme importance. Unfortunately, most of the time, language was a barrier to communication between them and the doctor.

"Well, because I didn't understand him, right? I said, 'Oh, my God, what did he just tell me?'"

In some cases, a family member or female friend was able to serve as an interpreter; but it takes more than just speaking the same language for communication to be successful. It takes knowing how to interpret a message. For our participants, the use of an unknown person to communicate such important news was seen as something cold and impersonal.

"I didn't speak [English], and he didn't speak Spanish. He brought a lady in, and she told me, 'The doctor says you have cancer'."

Nonetheless, our participants realized it was very important that they use all available resources. They tried to form a supportive team among their family and friends, to facilitate communication and arrive at understanding.

"We would put everything we heard together like a jigsaw puzzle. I understand English better than I can speak it. I understand a lot, so between me and my sister-in-law, we would gather everything together, the problems, to talk it over."

Above all else, a support team helped these women to understand the doctor better, and to feel supported in this extremely difficult situation: a diagnosis of cancer.

"I was very nervous. The fear was so great. I would hear things, but my mind could not grasp what he was saying. My ears were there, I had ears, but they were not listening."

The point is that a support team helps a woman communicate and improves her understanding of the situation.

"We are going to prepare ourselves well. We are all going together, in case anything is going to slip by me. The more ears, the better. I asked my questions, my sister-in-law asked her questions. This was our team. We were together."

La Palabra Que Asusta

Uno de los mayores problemas que nuestras participantes vivieron fue el temor de hablar sobre el cáncer, como si el cáncer pudiera regresar solamente con nombrarlo. Este temor fue manifestado de diferentes maneras. El cáncer fue visto para unas como una vergüenza.

“En nuestra cultura todavía existe esa idea de que como tener cáncer era como una vergüenza para la familia.”

Para otras fue casi como un juicio moral, o sea, como algo el cual no es aceptado por nuestra sociedad.

“El cáncer, para mi hermana, sigue siendo como una anatema, una cosa que no podía suceder en la familia, ¡Es algo maldito! ¡No esta bien visto dentro de la sociedad! Y parece como que si fuera una peste, es una forma que entienden el proceso del cáncer todavía.”

Y sorprendentemente, algunas de nuestras participantes y sus familias creyeron que una diagnosis de cáncer es equivalente a la muerte.

“Cuando me dijeron que tenía cáncer, yo casi me desmayé allí. Porque yo pensaba que cáncer es como que está uno al borde de morirse.”

Para la mayoría de nuestras participantes, el “cáncer” solamente se hablaba en voz baja.

“Hablando [del cáncer] en voz baja, no era una conversación abierta, no era un tema.”

Para otras simplemente.

“No mas al oír la palabra cáncer [se] horrorizaban.”

Al final nuestras participantes aprendieron que, aunque la palabra “cáncer” nos asuste, tenemos que hablarlo e informarnos sobre lo que en realidad es el cáncer.

THE WORD THAT SCARES YOU

One of the greatest problems that our participants went through was the fear of talking about cancer, as if saying the word would make the cancer recur. This fear was manifested in different ways. For some people, cancer was seen as a shameful thing.

"There still exists in our culture the idea that having cancer is like something shameful in the family."

For other women, it was almost a moral judgment, or perhaps something that is not accepted by polite society.

"For my sister, cancer continues to be like a curse, something that could not happen in our family. It's something damned! It is not looked upon well in society! And it seems like a plague. That's one way that they still think about the process of cancer."

Surprisingly, some of our participants and their families believed that a diagnosis of cancer was equivalent to a death sentence.

"When they told me that she had cancer, I almost fainted right then and there. Because I thought that someone who has cancer is a person on the point of dying."

For the majority of our participants, the word 'cancer' only was mentioned in hushed tones.

"They were talking [about cancer] in hushed tones. It wasn't an open conversation. It was not a subject to talk about."

For others, simply,

"Just hearing the word 'cancer' horrified them."

In the end, our participants learned that, even though the word 'cancer' frightens us, we have to talk about it and inform ourselves about what cancer really is.

La Mala Noticia

Aun sospechando que la existencia de la bolita no sea nada buena, la diagnosis cuando es confirmada “cáncer del seno,” es una noticia muy difícil

“Cuando le dieron los resultados que tenía cáncer, nos asustamos bastante, porque todo el tiempo pensamos lo peor. Pensamos que lo tuviera desparramado y que no tuviera remedio, que así la iban a dejar o, que ya estuviera toda llena de cáncer”

Un problema descrito muchas veces por nuestras participantes fue la forma en la cual se les comunicó la diagnosis de cáncer.

“Pero nunca en mi vida pensé que iba ser cáncer. El doctor entró, se sentó y dijo ‘Pues, es cáncer’ y yo ‘Caramba.’ Y él como si no fuera nada.”

La forma en como se comunicó la noticia es de suma importancia para nuestras participantes. En Estados Unidos, los doctores solían ser mas “parcos” o mejor dicho más directos y menos sensibles en su comunicación. Daban la noticia de golpe.

“El doctor aquí no tiene tacto. Le dice a uno directamente que tiene el cáncer, y eso es, para muchos latinos, chocante.”

Para nuestras participantes él haber contado con una red de apoyo fue vital, ya que esto les ayudó a asimilar mejor el impacto de la noticia.

“Él [doctor] me sorprendió a mí. De repente [dijo], ‘Sabes que, tu abuelita tiene cáncer. Le podemos cortar el pecho ó le podemos hacer radiación así con su pecho o ¿qué quieres que le hagamos? Dile a ella ahorita’.”

THE BAD NEWS

Even when the women suspected that the “little ball” was not a good sign, the diagnosis of “breast cancer,” when confirmed, was very bad news.

“When they gave her the results, that she had cancer, we got really frightened because we always think the worst. We thought that it might have spread, and that there was no remedy—they would leave her like that, or that she already was full of cancer.”

A problem often described by our participants was the way in which a diagnosis of cancer was announced to them.

“But it never crossed my mind that it was going to be cancer. The doctor came in, sat down, and said, “Well, it’s cancer.” And I said, “Holy smoke!” And he was acting as if it were nothing.”

The way in which the news is announced is extremely important for our participants. In the United States, physicians usually were more laconic—or, better said, more direct and less emotional—in their announcement. They gave the news all at once.

“The doctors here have no tact. He tells a person outright that she has cancer, and for many Latinos that is jarring.”

For our participants, depending on a support team was vital, especially because this helped them to assimilate the impact of the news more easily.

“The [doctor] surprised me. All of a sudden he said, “You know what? Your grandmother has cancer. We can cut off her breast or we can give her radiation for her breast, or what do you want us to do? Tell her this right now.”

Los Doctores

Formar un equipo fue de vital importancia para nuestras participantes. Ellas simplemente querían asegurarse que su doctor fuera miembro activo de ese equipo, un equipo que junto con la red de apoyo les ayudara a combatir el cáncer. Pero desafortunadamente no siempre fue así.

“Está bien, él es mi doctor. El y yo vamos a ser compañeros por mucho tiempo. Yo le pregunté ‘¿Sabes como me llamo?’ Y él me mira y responde ‘Sí.’ Me le queda viendo y le dije ‘Bien, no mas quería saber.’”

Como en cualquier equipo, se tenía que dar la comunicación y el entendimiento, para que este fuera exitoso. Mientras que los doctores la mayor parte del tiempo si hablaban, muchas de nuestras participantes se cohibieron de hablar, y no hicieron preguntas.

“Cuando ella se sienta con el doctor, se cierra. Tiene miedo de lo que va a decir. Le tiene temor al doctor. Tiene el temor de decirle que tiene dolor porque piensa que va a ser algo peor.”

En alguno de los casos, como en cualquier equipo, los miembros del equipo no se llevaban bien.

“Me tocó también un doctor muy rude I didn't like him at all because he was always in a bad mood for me, you know. I would like, yo quería preguntarle algo y no pude por que he was always in a bad mood.”

DEPT

THE DOCTORS

Forming a team was of vital importance for our participants. They merely wanted to be sure that their doctors were active members of the team, a team that joined with their support team to help the women battle the cancer. Unfortunately, this was not always the case.

"He's okay, he's my doctor. He and I are going to be partners for a long time. I asked him, 'Do you know my name?' He looks at me and says, 'Yes'. I keep looking at him, and I said, 'Good, that's all I wanted to know'."

As on any team, it is necessary for there to be communication and understanding for the team to be successful. While physicians usually did most of the talking, many of our participants felt reticent about talking and did not ask questions.

"When she sits down with the doctor, she clams up. She is afraid of what he is going to tell her. She is scared of the doctor. She is frightened to tell him that she feels pain because she thinks that it's going to be something worse."

In some cases, as with any team, the team members did not get along.

"The doctor struck me as being very rude. I didn't like him at all because he was always in a bad mood for me, you know. I would like—I wanted to ask him something, and I couldn't because he was always in a bad mood."

When this happened, a new team member was sought who would be supportive in these very important moments.

El Enredo

Para las mujeres que no gozaban de seguro médico, hubo varios programas que les podían ayudar a obtener atención médica. El más conocido era el Medi-Cal. Puede parecer un enredo calificar, pero valía la pena hacer la lucha. Nuestras participantes aprendieron que saber las opciones disponibles hizo mas claro el enredo.

“Para que uno califique, tiene que uno no estar trabajando, no estar ganando nada. Pero se imagina, ¿Quién no va a estar sin trabajar para calificar?”

El ser elegible para recibir Medi-Cal podía ser difícil. Esto implicaba ir a las oficinas muchas veces, responder a muchas preguntas, y en ocasiones hasta sentirse perdidos.

“Pues, yo ahí firmé un montón de papeles ¡Pero yo no sé de qué! Y con eso que yo no sé leer.

En muchas ocasiones nuestras participantes dependieron de miembros de la familia para aclarar el enredo y solicitar cobertura de asistencia medica.

“Me ayudó el gobierno, pero ella [mi nieta buscaba] las aseguranzas y todo. Ella hablaba por una parte y por otra. Me consiguieron una aseguranza. Y esa aseguranza me pago todo.”

Aunque algunas de nuestras participantes no fueron elegibles para recibir ayuda de unos programas del gobierno se dieron cuenta que hubo programas que les pudieron brindar ayuda. No les fue fácil, pero dicen que hay que hacer el esfuerzo de buscarlos, porque muchas veces los trabajadores del hospital no saben de ellos.

“La persona que te atendió, no te informó que había un programa que podía ayudar a las personas con cáncer. Entonces es causante que tu pecho lo perdiste.”

THE TANGLE

For women who did not enjoy health insurance, there were many programs that could help them get medical attention. The best known was Medi-Cal. Qualifying can seem a tangle, but it was worth fighting for. Our participants learned that knowing about their available options helped to clear up the tangle.

“For a person to qualify, she has to be unemployed, not earning any money. But imagine it. Who is going to not work just in order to qualify?”

Becoming eligible to receive Medi-Cal could be difficult. It implied going to the Medi-Cal offices many times, answering lots of questions, and at times feeling lost.

“Well, I signed a whole pile of papers there. But I don’t know what they were for! On top of that, I don’t know how to read.”

Our participants frequently depended on family members to clear up the tangle and to apply for coverage from a medical-assistance program.

“The government helped me, but she [my granddaughter, looked for] the insurance and everything. She did all the talking. They got me insurance. And that insurance paid for everything.”

Even though some of our participants were not eligible to receive aid from certain government programs, they learned that there were private programs that could offer them help. It was not easy for them, but they say that one has to make the effort to look for these programs, for sometimes hospital personnel do not know about them.

“The person who took care of you, did not inform you that there was a program that could help people with cancer. That was the reason you lost your breast.”

La Cirugía

El tratamiento de cáncer del seno generalmente comenzaba con una cirugía para extirpar el cáncer del cuerpo.

“¡[Hagan] lo que quieran! Pero ¡Que no me vayan a dejar eso ahí! Yo pues siempre pensando en esta otra señora que nomás duró 6 meses.”

Para muchas de nuestras participantes el conocimiento acerca de los hospitales fue mínimo, lo cual las llevó a tener temor a ciertos procedimientos.

“Y como yo nunca había visitado una sala de operación, por que cuando me operaron yo le dije al doctor que no quería entrar con los ojos abiertos, que yo ya quería entrar durmiendo.”

El no conocer el procedimiento de la cirugía creó temor entre nuestras participantes. Muchos de estos temores eran solamente un mito que se manifiesta comúnmente entre algunas comunidades Latinas.

“Le decían que era como una mata, que si la podaban, crecía mas. Y le decían que no dejara que se cortara [el pecho]”

SURGERY

Treatment for breast cancer usually begins with a surgery, to remove the cancerous growth from the body.

“Let them do whatever they want! But they’re not going to leave that thing in there! See, I’m always thinking about this other lady, who lasted no more than six months.”

The knowledge that many of our participants had about hospitals was minimal, which caused them to be afraid of certain procedures.

“And because I had never visited an operating room, when they operated on me, I told the doctor that I didn’t want to go in with my eyes open, that I wanted to go in already asleep.”

Not knowing about the surgical procedure created fear in our participants. Many of these fears were based solely on a myth that commonly appears in some Latino communities.

“They told her that [cancer] was like a bush: that if they pruned it, it grew back even more. And they told her not to let them cut off [her breast].”

La Quimo

El tratamiento también podía incluir la quimioterapia. La “Quimo” era como un suero que mata células cancerosas. Para poder servir así, era bastante fuerte. Se inyectaba cada dos o tres semanas.

“Así como le dijo el doctor, si aguantaba la quimioterapia, con el tiempo iba a regresar a su normalidad. Pero ella no creía, decía que no, tenía miedo.”

Por ser tan fuerte, podía provocar por un tiempo efectos secundarios, los cuales pueden ser, pérdida de cabello, sed, calenturas, boca amarga, y mareos entre muchos otros.

“Luego ella me decía, ‘Pero es que se me va a caer el pelo.’ Ella pensaba que se iba a hacer mas viejita, porque si le dijeron, que todo su cuerpo iba a cambiar.”

“Era un calor que yo tenía, yo hubiera querido que me cayera agua helada, porque era un calor que me venía de los pies, yo sentía fuego por todo el cuerpo. ¡No explicaron eso!”

“Tenía una sed tremenda.”

“Uno se tiene que estar cepillando cada momento los dientes, porque es el sabor a quimo, que usted lo siente aquí, en la boca del estomago.”

“Yo me quedaba tiesa así. Yo no quería ni moverme porque tengo miedo de ir a vomitar.”

Para la mayoría de nuestras participantes que recibieron la “Quimo” estos efectos fueron muy dolorosos.

“Era tanto el dolor que cada vez que venía mi fecha para ir a la semana de quimo, me ponía tan nerviosa porque sabía que iba a volver el dolor otra vez.”

CHEMO

Treatment also could include chemotherapy. "Chemo" was like a saline solution that killed cancerous cells. In order to be effective, it was quite strong. It was injected every two or three weeks.

"Just as the doctor told her, if she put up with the chemotherapy, in time she would return to normal. But she did not believe it; she kept saying no. She was scared."

As it is so strong, it can cause side effects for a while, which can include hair loss, thirst, fevers, a bitter taste in the mouth, and nausea, among many others.

"Back then she used to tell me, 'But my hair is going to fall out'. She thought that she was going to get even older because they told her that her whole body was going to change."

"It was a fever I had. I would have wanted ice water to pour down on me because it was a heat that came all the way up from my feet. I felt fire all over my body. They didn't explain that!"

"I was tremendously thirsty."

"A person has to be brushing her teeth all the time because the taste is like chemo. You feel it here, at the top of your stomach."

"It left me stiff, like this. I didn't want to move because I was afraid that I was going to throw up."

For most of our participants who received "chemo," these side effects were very painful.

"The pain was so bad that every time my appointment to go for chemo for the week came around, I would get very nervous because I knew I that the pain was going to come back again."

Sometimes these side effects were so strong that some women did not want to continue treatment, even though it was the last step in their therapy. The support team encouraged them to continue treatment.

"There were times when she felt really bad. She used to lose hope, and she told me the same thing over and over: 'I'm not going to the doctor anymore. I'm not going to do this anymore'. And I used to make her push forward again, and her spirits would lift once more."

A veces, eran tan fuertes estos efectos que algunas mujeres no querían seguir con el tratamiento, aunque fuera la última etapa. La red de apoyo les animaba para que continuaran con el tratamiento.

“Había veces que se sentía muy mal, que se desesperaba y me volvía a decir lo mismo, ‘Ya no voy a ir al doctor. Ya no voy a hacer esto’, y la volvía a empujar yo, y otra vez pa’riba.”

DRAFT

RADIATION

Treatment also can include radiation to kill cancerous cells. It consists of therapy with high-powered X-rays. Not being familiar with the process of radiation treatment lent itself to confusion and fear among our participants.

"I did not know where the radiation was going to shoot out, from below, from above, from the sides—they didn't prepare me. Beforehand, they put little tattoos on me, they took measurements, they took photographs, but they did not tell me where the rays were coming from."

"I seized by a fear of the radiation. But it wasn't really the radiation, but rather the room, the bed. I thought they were going to leave me in there."

La Radiación

El tratamiento también puede incluir la radiación, para matar células cancerosas. Consiste en una terapia con rayos X de alta intensidad. El no conocer el proceso de la radiación se prestó a confusión y miedo entre nuestras participantes.

“Yo no sabía de dónde iba a disparar la radiación, de abajo, de arriba, de los lados, no me prepararon. Antes, me pusieron tatuajes chiquitos, me tomaron medida, me tomaron fotografía, pero no me dijeron de donde venían los rayos.”

“Le agarré un miedo a la radiación. Y no era a la radiación, sino al cuarto, la cama, pensaba que me iban a dejar allí.”

Mi Seno

Perder un seno fue traumático para nuestras participantes, pero en ocasiones no había otra opción.

“Eso es bastante deprimente, se deprime uno mucho. Nomás decir que se lo van a quitar [el pecho] con eso se deprime. Y luego cuando se mira uno, más. Porque el doctor de las radiaciones me dice que si me hubieran operado cuando la bola estaba chiquita no me hubiera pasado nada. No hubiera perdido mi pecho.”

Irónicamente, para algunas mujeres preferible perder la vida, antes de que les cortaran un seno.

“Yo les digo que se cuiden, que vayan a chequearse siempre. Otras me dicen ¡No, yo prefiero mejor morirme antes que me vayan a cortar un pecho! Pero si no quieren entender, pos’ ¡allá ellas!”

DRAFT

MY BREAST

Losing a breast was traumatic for our participants, but at times there was no other choice.

"It's pretty depressing. A person gets very depressed. Simply their saying that they are going to take off [a breast] is enough to depress someone. And then, when a person looks at herself, she gets even more depressed. The radiation doctor tells me that if they had operated on me when the ball was little, nothing more would have happened to me. I would not have lost my breast."

Ironically, for some women it is preferable to lose their lives than to have a breast cut off.

"I tell them to take care of themselves, that they should go get check-ups all the time. Some women tell me, 'No, I'd rather die before I'd let them cut my breast off!' But if they don't want to understand, well, tough luck for them!"

Las Dudas

Aún después del tratamiento, muchas de nuestras participantes se quedaron con la duda de que era “cáncer”. Ellas buscaron saber de dónde proviene el cáncer y porque les llegó a ellas.

“Quisiera saber de donde viene el cáncer. Quisiera saber que es cáncer. Porque a mí cuando... me operaron esto... era un liquido verde. Era verde puro. Que es como lama del arroyo.”

Con frecuencia muchas de nuestras participantes se quedaron con la duda porque se cohibieron de hacer preguntas. En nuestra cultura Latina, el doctor es visto como una persona de respeto y autoridad, alguien que sabe lo que esta haciendo.

“Si, me quedaron unas preguntas que hacer y no sé porque no las hice. No sé qué es el cáncer. Se me olvidó decirle que yo quería saber que es cáncer.”

Las redes de apoyo sin duda alguna ayudaron a hacer las preguntas que muchas de nuestras participantes no pudieron hacer por sí mismas.

“No pregunté tampoco, no, no, no pregunté. Yo estaba muy nerviosa.”

DOUBTS

Even after treatment, many of our participants were left with doubts about what cancer was. They sought to learn where cancer comes from, and why it struck them.

"I would like to know where cancer comes from. I would like to know what cancer is. Because to me, when...they operated on me for it...it was a green liquid. It was a green like this one, pure green. It's like slime from a stream."

Many of our participants frequently were left with doubts because they felt constrained from asking questions. In our Latino culture, a doctor is seen as a person who commands respect and has authority, someone who knows what is going on.

"Yes, I had a few questions left to ask, and I don't know why I didn't ask them. I don't know what cancer is. I forgot to tell him that I wanted to know what cancer is."

Without question, support teams helped with asking the questions that many of our participants could not ask for themselves.

"I didn't ask, either. No, no, I didn't ask. I was very nervous."

La Fuerza Moral

Seguir con los pasos del tratamiento para el cáncer del seno es difícil. Pero la red de apoyo es, tal vez, el elemento más importante en su cumplimiento. En varios casos, los esposos apoyaban a nuestras participantes, acompañándolas a las citas médicas.

“Cuándo vi la cosa sería ¡Dejé todo! ¡Dejé todo! Y me dediqué solamente a ella. ¡En sus momentos mas duro nunca la dejé! Yo estuve en todas sus citas, cuando la operaron estuve ahí. Estuve 3 días en el hospital, y se portaron a una altura muy grande. Por que a mí me dieron un camita y estuve a un lado de ella.”

El apoyo moral de la pareja era fundamental para una mujer diagnosticada con cáncer.

“No por que le habían quitado un pecho le voy a despreciar. Al contrario, le doy mas apoyo. Ella me dice ‘A lo mejor no me vas a querer’ le digo ‘No, estás muy equivocada, por eso soy tu pareja, para vivir las buenas y las malas’.”

“ ‘Ya sabemos que se te va a caer el pelo, we know that, pero te va a salir pa’ tras’. Le digo, ‘Mírame a mí, se me cayó, y no me va a salir pa’ tras. Además cuando se te empiece a caer el pelo yo me voy a cortar el mío. Porque de perdida estoy igual’. Y así fue.”

El sentirse parte integral de la vida cotidiana, fue algo muy importante para nuestras participantes.

“Los fines de semana que no trabajamos nos vamos a dar la vuelta a un restaurante, a bailar a los salones. ‘Nos vamos’, le digo ‘Arréglate. Ponte ¡bien!’ Le digo ‘Eres bella’.”

Desafortunadamente, aunque algunos de los esposos quisieran, ellos no pudieron dar el apoyo personal debido al trabajo.

“Cuando me operaron no pudo él [mi esposo] faltar al trabajo.”

También hubo algunos casos donde el esposo por diferentes razones no les brindó al apoyo que nuestras participantes necesitaban.

“Mi esposo nunca fue conmigo. Él ni en cuenta. Sí supo, cuando vine yo le dije ‘Me dijo el doctor que sí tengo cáncer’. No me contesto nada. Ni nunca vi que me preguntara, ‘¿Cómo te sientes?’ Nunca me preguntó que sentía yo, ni yo tampoco me animaba a decirle. Nunca platicamos de esto. Seguro el se preocupaba, pero yo no lo notaba.”

Familiares y amigos podían brindar el apoyo para buscar, y terminar el tratamiento.

“Cuando me atreví a decirles mi situación, pues ellas [mis hermanas] luego, luego me apoyaron. A lo lejos, para que no me sintiera sola. Que ellas estaban conmigo.”

Además de familiares y amigos, también hubo grupos de apoyo, que sirven para compartir experiencias.

“Ella acostumbraba solo entre nosotros, y nunca buscamos esos grupos de apoyo. ¡Era mi opinión! Yo pensaba que no servían. Y tal vez me equivoqué.”

La fe también dio un gran apoyo a la mujer recibiendo tratamiento para el cáncer del seno.

“Lo mejor que puede hacer es pedirle a Dios, pedirle con fe que todo salga bien.”

Juntos en la fe, la red de apoyo agarraba aun más fuerzas.

“La velita esa con el santo mi esposo la puso desde que el doctor me pronosticó el cáncer. Desde esa fecha del año pasado hasta ahora toda la semana cuando ya va la velita caminando ya trae la próxima.”

“Nosotros le damos ánimo, y le decimos que no pierda esperanza. Ella se va a aliviar. Primeramente Dios, ella se va a aliviar. Ella y yo hicimos una promesa a la Virgen de allá de Guadalajara.”

Siempre habrá gentes mal habladas que se aprovechan de la situación para mofarse de lo que no hayan tenido que sufrir, pero la red de apoyo ayudó a la mujer a salir adelante.

“Hay comentarios como con mala intención de lo que ya estaba pasando. En una reunión estábamos reunidos y entro una persona y dijo ‘¡hay, yo pensaba que era la pelona!’ Por que ella había perdido su pelo.”

Pero lo más importante era hacerle saber que vive, y sigue siendo parte de la vida.

“Pero nunca perdimos el buen humor y amor, nunca lo perdimos. Por ejemplo, cuando a ella la operaron no tenía ni fuerzas ni para ir al baño. Me llamaba al baño para que yo le subiera la ropa interior. Entonces yo bromeaba con ella, diciéndole yo practico bajándolos y no subiéndolos.”

SPIRITUAL STRENGTH

Completing a course of treatment for breast cancer is hard. But a support team is perhaps the most important element in finishing it. In many cases, husbands supported our participants, accompanying them to their doctor's appointments.

"When I saw that it was serious, I dropped everything. I dropped everything! I dedicated myself to her alone. I never left her, even in her hardest moments! I was at all her doctor's appointments. When they operated on her, I was there. I was at the hospital for three days, and they treated me very well; for they gave me a cot, and I stayed at her side."

Moral support between a married couple was fundamental for a woman diagnosed with cancer.

"I told her that I was not going to value her less because they had removed a breast. On the contrary, I am supporting her even more. She tells me, 'Maybe you're not going to want me anymore'. I tell her, 'No, you're very wrong. It's for things like this that I'm your partner, to live through the good and the bad'."

"We already know that your hair is going to fall out, we know that, but it's going to grow back later. I tell her, 'Look at me. My hair has fallen out, and it's not going to grow back later. When your hair starts falling out, I'm going to cut mine. That way, I'll have suffered a loss, too'. And that's how it was."

Feeling themselves an integral part of everyday life was something very important to our participants.

"On the weekends, when we're not working, we go out, to a restaurant, to go dancing at dance halls. 'Let's go,' I tell her. 'Get prettied up. Make yourself look nice'. I tell her, 'You're beautiful'."

Unfortunately, even though some husbands wanted to, they were not able to give support in person, as they had to work.

"When they operated on me, he couldn't miss work."

There also were some cases in which a husband, for various reasons, did not offer the support that our participants needed.

"My husband never went with me. He never was in the picture. Yes, he knew about it. When I came [home], I told him, 'The doctor told me that, yes, I have cancer'. He didn't respond at all. I never even saw him ask me 'How are you feeling?' He never asked me what I was feeling, and I never had the courage to tell him. We never discussed it. Sure, he was worried, but I never saw it."

Family members and friends were able to offer support in seeking, and completing, treatment.

"When I finally dared to tell them about my situation, then, then [my sisters] supported me. Even from a distance, so that I wouldn't feel alone. Because they were with me."

In addition to family and friends, there also were support groups, who provided an opportunity to share experiences.

"She was used to being only with us, and we never looked for those support groups. It was [due to] my opinion! I thought they weren't any use. Maybe I was wrong."

Faith also gave great support to a woman receiving treatment for breast cancer.

"The best thing that anyone can do is to pray to God, pray to Him with faith that everything will turn out well."

Joined together in faith, the support team gathered even more strength.

"The candle that my husband lit to my name-saint, back when the doctor diagnosed me with cancer—from that day last year until now, all week long, while the candle is burning, the next one is already ready."

"We encourage her and tell her not to lose hope. She's going to get better. God willing, she's going to get better. She and I made a promise to the Virgin down there in Guadalajara."

There always will be tactless people who take advantage of the situation to make fun of what they have not had to suffer, but the support team helped the woman to get through that.

"There were comments made, with hurtful intent, about what she had been going through. At a party, we were all together, and a certain person came in and said, 'Hey, I thought it was Baldy!' Because she had lost her hair."

But the most important thing was to let the woman know that she was still alive and that she continued being part of life.

"We never lost our sense of humor, though, and we never lost our love. For example, when they operated on her, she didn't even have the strength to go to the bathroom by herself. She used to call me into the bathroom so that I could pull up her underwear for her. So I used to joke around with her, telling her, 'I have plenty of practice pulling them down but not pulling them up!'"