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A QUALITATIVE INVESTIGATION OF CANCER SURVIVORSHIP EXPERIENCES AMONG RURAL HISPANICS

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Abstract

Cancer survivorship experiences were explored among Hispanic men and women with cancer and family members of cancer survivors, recruited from two rural Washington communities in the Lower Yakima Valley. Five focus groups were conducted from February 2006–October 2007 with 31 women and 10 men. Disbelief, fear, sadness, strength, courage, faith, and hope were common reactions to diagnosis. Concerns about family/children, losing medical coupons, and feelings of depression/isolation were identified as challenges faced after diagnosis. Participants identified smoking and environmental exposures as causes of cancer, but many believed operating on tumors caused cancer to spread. Participants used conventional treatments, but identified herbal/natural remedies as cures. Most participants reported negative experiences with physicians, and believed their community would benefit from language-appropriate information regarding prevention and treatment. The importance of linking survivors through support groups was emphasized and information elicited from sessions has been used to organize survivor support groups in these two communities.

Keywords

cancer; survivorship; rural Hispanics

INTRODUCTION

Hispanics in the U.S. are diagnosed with later stage cancers and experience poorer cancer-related survival than non-Hispanic Whites (Howe, et al., 2006). This disparity may be explained in part by less frequent receipt of cancer-related screening, inadequate access to preventive services, and lack of knowledge or awareness about cancer risk among Hispanic individuals (Coronado, Thompson, Koepsell, Schwartz, & McLerran, 2004; Rodriguez, Ward, & Perez-Stable, 2005; Thompson, Coronado, Neuhaus, & Chen, 2005; Zhang, Tao, & Irwin, 2000). Qualitative research with Hispanic breast and cervical cancer survivors has revealed that Hispanic women living with cancer also experience poor communication with their physicians due to limited health literacy or language barriers, and may hold inaccurate beliefs about their disease that can have direct effects on treatment and survival (Ashing-Giwa, Kagawa-Singer, et al., 2004; Ashing-Giwa, Padilla, et al., 2004; Ashing-Giwa, Padilla, Bohorquez, Tejero, & Garcia, 2006; Ashing-Giwa, Padilla, Bohorquez, Tejero,

Garcia, et al., 2006). Lack of insurance resulting in the receipt of unsatisfactory care is also associated with poorer survival (Ward, et al., 2008).

Similarly, compared to individuals living in urban populations, those living in rural populations face unique barriers to accessing cancer-related health care, and subsequently, experience poorer cancer-related outcomes (Crowell, Goetz, Wiggins, & Magana, 2007; Palacio-Mejia, Rangel-Gomez, Hernandez-Avila, & Lazcano-Ponce, 2003). Lack of health care coverage is particularly acute in rural areas, where more than half of rural Hispanics under age 65 are estimated to have gone through a period of having no insurance during the past year (AHRQ, 2005). Relatively few U.S. physicians practice in rural areas and rural residents have further distances to travel to reach health care sites (AHRQ, 2005). As a consequence, rural residents are less likely than their urban counterparts to receive preventive health care services (Casey, Thiede Call, & Klingner, 2001), and may experience difficulties complying with recommended treatments.

Psychological distress often accompanies the financial and logistical difficulties faced after cancer diagnosis (Ashing-Giwa, Padilla, et al., 2004; Burgess, et al., 2005; Spencer, et al., 1999). Clinical research has indicated that receipt of psychosocial support after diagnosis can improve quality of life and may improve survival (Spiegel, 2002; Spiegel, et al., 2007). Unfortunately, Hispanics may be reluctant to seek traditional mental health services (Ashing-Giwa, Padilla, et al., 2004) or may lack the financial means to do so (Aziz & Rowland, 2002), which is likely exacerbated in rural areas which face shortages in mental health care providers.

Limited qualitative research has been conducted to explore the experiences of Hispanic cancer survivors, and few previous studies have included male survivors. To supplement some of the gaps in this literature, the current research was conducted to explore the experiences of Hispanic men and women living with cancer, and of family members or friends of cancer survivors from two rural Washington communities. It was also of interest to identify cancer-related information and resources deemed by participants to be useful for other cancer survivors and community members at large. The study took place within two rural communities in the Lower Yakima Valley of Washington State, an ideal setting to conduct this exploratory research given that the region is largely Hispanic and predominantly rural (Census, 2005).

METHODS

Study procedures

Cancer survivors and family members or friends of current or former cancer patients were recruited from two rural communities in the Lower Yakima Valley, through flyers, radio, church services, health fairs and other community events. Prospective participants were invited to participate in a 90-minute group discussion about their own cancer experience or their experience with a family member who had been diagnosed with cancer. The focus group sessions were held at the Fred Hutchinson Cancer Research Center's (FHCRC) project office in Sunnyside, or offsite in Toppenish. Focus groups were led by one of two skilled Spanish-speaking facilitators who were trained in focus group techniques and briefed on the discussion topics by the principal investigators who have considerable experience in qualitative data methods. Staff members were trained in listening skills, being flexible when necessary, accepting all ideas and opinions as valid, being non-judgmental, understanding, and being sensitive to individuals who did not want to reveal information, all qualities that are thought to maximize trust of the participants.

Before the discussion, the focus group facilitators explained to the participants that the information gathered would be used for research purposes and that the discussions would be audio-recorded. Participants were assured that their names would not be associated with the tapes. The Institutional Review Board at the FHCRC approved the focus group consent form and the study methods. Written consent was obtained from all participants.

Using an open topic schedule to guide the focus group sessions, the facilitators were given freedom to explore issues that emerged in the discussions. The following topics were addressed: barriers to seeking diagnosis, reactions to and challenges faced after diagnosis, perceived causes of and cures for cancer, experiences with physicians, available sources of cancer-related information and recommendations for information and resources that would be useful for other survivors and family members. Five focus groups were conducted between February 2006 and October 2007, and 41 individuals participated, including 31 women and 10 men. All focus groups were held in Spanish.

Data analysis

Grounded theory was used in the analysis of transcripts, and was based on the audio-tapes and the field notes taken by the note-taker and facilitator. After the focus groups, transcriptions were made of the tapes and the transcripts from all five of the sessions were translated into English. Audio-tapes were shared only with the project staff and were erased after transcription to help maintain confidentiality.

Following principles of qualitative research suggested by Morgan and Krueger (Krueger, 1998; D. L. Morgan, 1998), from each focus group session a matrix of the main topics was created. From the matrix, three staff members independently identified and coded key words and common themes that appeared throughout the sessions. The three staff members then met to review and reach a consensus on all themes and key words. Direct quotes from the focus group sessions were translated and presented in an effort to maintain the richness of the information obtained. Although the specific words may not have been repeated by all participants, the meaning was expressed and affirmed during at least one of the sessions.

RESULTS

Study participants

A total of five focus groups were conducted between February 2006 and October 2007 with 41 participants, 31 women and 10 men (see Table 1). Participants, or family members and friends of participants, had been diagnosed with brain, breast, cervical, colorectal, liver, lung, lymphoma, pancreatic, prostate and uterine cancers.

Overview of themes

Content from the focus group discussions fell into one of three general categories or themes, concerning participants' 1) experience with cancer, 2) experience with physician(s), and 3) information and resources considered useful for other cancer survivors.

Experience with cancer—Barriers to seeking cancer diagnosis included inaccurate risk perception, cultural norms against being examined by a male physician and undergoing mammography or pap smear, embarrassment, denial and fear (Table 2). Participants reported a variety of reactions to their own or their family member's cancer diagnosis, ranging from disbelief and confusion, fear, sadness, helplessness, concerns about family and treatment costs, to more positive reactions including strength, courage, faith in God, and hope. After diagnosis, participants faced challenges including concern for family and finances, and fear of losing medical coupons given a combination of factors such as stricter

immigration laws and potential loss of coupon eligibility due to being out of work after diagnosis. Lack of support from spouse emerged as a challenge uniquely faced by women, particularly for those with breast or reproductive cancers. Accompanying cancer diagnosis were also feelings of depression and isolation, a sense of disconnectedness and a lack of support provided by the community. As the majority of Hispanics in this region of Washington are of Mexican origin, distance from family members living in Mexico was cited as a challenge faced after diagnosis.

Commonly perceived causes of cancer included genetics and heredity, as well as smoking, environmental exposures, pesticides, and sun exposure. However, participants also expressed the belief that physical trauma, the spray of dust from car engines, or proximity to farm animals caused cancer to develop. Several participants with family members who had developed prostate cancer attributed the disease to a history of riding horses. Cancer was also described as an infection, and one commonly held belief was that operating on cancerous tumors could cause the disease to spread to other organs in the body.

Receipt of conventional treatment for cancer was identified, including surgery, radiation, and chemotherapy. However, perceived cures for cancer included a variety of natural and herbal remedies, including *uña de gato* (nail of a cat), bark from campanillo and vanillo trees, and snake meat. Smoking cessation, faith in God and healthy eating were also identified as effective “cures”.

Experience with physician(s)—A sense of trust in one’s physician was expressed by at least one participant, as was the experience of good communication (Table 3). However, the majority of participants expressed negative experiences and interactions with physicians, and believed that they had been neglected in some capacity. Included among these negative experiences were perceptions that the physician was unavailable, rushed for time, insensitive to the feelings of the patient and family members, and/or “negligent.” In several instances, participants reported that they could not understand their physician and others reported that their physician ignored their health concerns and was hesitant to refer them to specialists.

Information and resources recommended for other cancer survivors and community members—Although cancer-related information was reported by some to be available at clinic, hospital and treatment sites, as well as through schools and libraries, others reported that there was a lack of information available locally within the community. Several participants relied on cancer-related information obtained from other cancer survivors.

Participants indicated that information on prevention, disease, treatment and its side effects would have been valuable as they faced their own or their family member’s diagnosis, and suggested that these types of information be made available to other cancer survivors and community members at large (Table 4). The merit of information on early detection, where to go for diagnosis and treatment, and how to find specialists was also cited. In response to feelings of disconnection and isolation, participants identified a need for cancer support groups to be offered in their communities. Support groups were discussed as a means to offer support and hope, as well as practical information, to those newly diagnosed with cancer, and as an important way to connect survivors to one another. The knowledge that others had survived their cancer experiences would have provided comfort for participants after they or their family member had been diagnosed. Although some of the responses elicited were relevant for female cancers only, the reported experiences with cancer diagnosis and treatment, and with physicians, were similar overall between women and men participants. Additionally, recommendations for information and resources to be made

available to other community members and cancer survivors were consistent between women and men participants.

DISCUSSION

A fair amount of the existing literature has discussed issues related to cancer screening among Hispanic men and women in both rural and urban populations, and familiarity with some of these issues can facilitate our understanding of barriers to cancer diagnosis and treatment as well as survivorship challenges. Many of the barriers to seeking diagnosis and treatment identified by participants in our study have also been identified in the literature as barriers related to cancer screening, including cost, fear, embarrassment, and inaccurate risk perceptions (Coronado, et al., 2004; M.E.Fernandez, Palmer, & Leong-Wu, 2005; Strecker, Williams, Bondy, Johnston, & Northrup, 2002). However, much of the survivorship literature to date has focused primarily on issues facing non-Hispanic white women, particularly those living with breast cancer. Few previous reports have explored issues salient for rural Hispanic women and men living with other types of cancer.

A common reaction to cancer diagnosis was fear, and several participants expressed the belief that their cancer was given to them by “God’s will”. This sense of fatalism has frequently been reported in the literature related to attitudes and beliefs among Hispanics regarding cancer (Buki, et al., 2008) and is thought to be linked to delays in diagnosis and treatment. At the same time, having faith in God and taking comfort in one’s spirituality were reported by participants in our study and these sentiments have also been reported in previous studies of female Hispanic cancer survivors (Ashing-Giwa, Padilla, et al., 2004; Ashing-Giwa, Padilla, Bohorquez, Tejero, & Garcia, 2006).

Women participants in our study also reported facing some of the same challenges after cancer diagnosis as reported by Hispanic breast and cervical cancer survivors from prior research (Ashing-Giwa, Padilla, Bohorquez, Tejero, & Garcia, 2006; Ashing-Giwa, Padilla, Bohorquez, Tejero, Garcia, et al., 2006). Feelings of depression, isolation and shame after diagnosis have been reported, as well as fear of abandonment by one’s husband after being treated for cancer (Buki, et al., 2008; Lannin, et al., 1998). Female cancer survivors living in rural areas have also expressed a strong sense of familial responsibility and concern for their children and families which contribute to the challenges faced in accepting their diagnosis and seeking appropriate treatment (Bettencourt, Schlegel, Talley, & Molix, 2007; Buki, et al., 2008). In addition, prior research with non-Hispanic white female cancer survivors living in rural areas has identified concern over losing a part of the female body (i.e. cervix or breast) as a challenge faced after diagnosis (Bettencourt, et al., 2007). This concern has also been identified as a barrier to receiving cancer treatment among Hispanic women in particular (Ashing-Giwa, Padilla, Bohorquez, Tejero, & Garcia, 2006; Ashing-Giwa, Padilla, Bohorquez, Tejero, Garcia, et al., 2006; Buki, et al., 2008), and may be especially salient for this group given the high symbolic value of reproductive organs for women’s identity in Hispanic culture (Buki, et al., 2008). Limited research with Hispanic men has indicated delayed care-seeking behaviors due to shame associated with cancer diagnosis (M. E. Fernandez, et al., 2008), which is also consistent with our findings.

Hispanic men and women also face significant financial barriers to receiving treatment, particularly those living in rural areas (M. E. Fernandez, et al., 2008). Some individuals may delay or stop treatments due to prohibitive out-of-pocket expenses (Ashing-Giwa, Kagawa-Singer, et al., 2004; Ashing-Giwa, Padilla, et al., 2004; Ashing-Giwa, Padilla, Bohorquez, Tejero, & Garcia, 2006; Ashing-Giwa, Padilla, Bohorquez, Tejero, Garcia, et al., 2006; Wilson, Andersen, & Meischke, 2000). Participants in our focus group sessions echoed

these challenges and emphasized a fear of losing medical coupons due to recent changes in immigration laws and potential loss of eligibility for services after cancer diagnosis.

Some inaccurate perceptions and beliefs about the causes of and spread of cancer have been expressed in prior research with Hispanics (M. E. Fernandez, et al., 2008; C. Morgan, Park, & Cortes, 1995) and other racial/ethnic groups (Margolis, 2004; Margolis, et al., 2003), and are consistent with our findings. Research with Hispanic and African American populations has identified a belief that cancer is spread by the air when the body is opened or operated on in surgery (Lannin, et al., 1998; Margolis, 2004; Margolis, et al., 2003; C. Morgan, et al., 1995). This is consistent with the belief expressed by some of the participants in our focus groups that operating on cancerous tumors would cause the cancer to spread. Our research also highlighted the belief held that traditional folk medicines (i.e. natural/herbal remedies) are true cures for cancer over conventional cancer treatments. This finding is consistent with other reports that have indicated use of home brewed teas (Chou, Horng, Tolmos, & Vargas, 2000) and herbal remedies (Lee, Lin, Wrensch, Adler, & Eisenberg, 2000) among Hispanic women with breast cancer. Reliance on these traditional folk medicines appears to be more common in rural settings given the lack of access to and great distances necessary to travel to receive conventional treatments (M. E. Fernandez, et al., 2008).

Some participants in our study expressed a high level of satisfaction with their physicians citing open communication and trust, although negative experiences were more commonly expressed. Our findings emphasizing survivors' negative experiences with physicians echo findings reported in other work (Ashing-Giwa, Padilla, Bohorquez, Tejero, & Garcia, 2006; Ashing-Giwa, Padilla, Bohorquez, Tejero, Garcia, et al., 2006; M. E. Fernandez, et al., 2008). Ashing-Giwa et al. reported the perception among female Hispanic cancer survivors that their physicians did not listen to them or take their concerns seriously. Survivors believed that they were discriminated against in the health care setting due to limited health care coverage and limited English proficiency (Ashing-Giwa, Padilla, Bohorquez, Tejero, & Garcia, 2006; Ashing-Giwa, Padilla, Bohorquez, Tejero, Garcia, et al., 2006). This is discouraging given the fact that Hispanic cancer survivors perceive communication with physicians as a key factor in the quality of their care (Ashing-Giwa, Padilla, Bohorquez, Tejero, & Garcia, 2006), and have identified medical professionals as being a very important component of their social support network during and after treatment (Buki, et al., 2008).

The lack of information and services available to cancer survivors, particularly in Spanish, is an additional barrier to care faced by men and women living in limited-resource areas. Research with Hispanic and other cancer survivors indicates a need for informational support at all stages of treatment, regarding what to expect from the treatment itself, how to deal with emotional distress, what lifestyle changes to expect as well as how to deal with these changes (Buki, et al., 2008; Cappiello, Cunningham, Knobf, & Erdos, 2007; Thewes, Butow, Girgis, & Pendlebury, 2004). Several of these issues were also identified by participants in our focus groups.

Although prior research has indicated that Latinas are reluctant to participate in traditional one-on-one psychotherapy (Ashing-Giwa, Padilla, et al., 2004), other work with female cancer survivors, particularly those living in rural areas, has indicated that exchanges with other survivors are an important component of support during and after treatment (Buki, et al., 2008; Wilson, et al., 2000). Additionally, some researchers have reported that language-appropriate peer support groups can provide a culturally acceptable alternative for delivering essential psychosocial support to cancer survivors who may be in need of these services as they deal with the challenges of their diagnosis (Napoles-Springer, Ortiz, O'Brien, & Diaz-Mendez, 2008). Participants in the present study expressed a desire for community support

groups to be established and offered in Spanish, suggesting that there would be acceptance of this type of psychosocial support in these rural communities.

Although our study sample represents a group of self-selected participants who were willing to discuss their own or their family members' cancer experiences and may have been more vocal or likely to participate in a cancer support group in the future, their responses have highlighted important areas that deserve further attention in improving the survivorship experiences of Hispanic women and men in these rural communities. Culturally- and language-appropriate cancer-related information and resources are needed, and communication between patients and physicians needs substantial improvement. In response to feelings of disconnection and isolation, the desire on the part of cancer survivor and family member participants in the Lower Yakima Valley to be involved in community peer support groups was widely affirmed. Although a limited number of support groups were available for cancer survivors in the larger city of Yakima prior to our research, the support groups were not offered in Spanish and the distance from both Sunnyside and Toppenish to the city of Yakima was prohibitive.

CONCLUSIONS

A need for cancer support groups was identified by participants in response to feelings of disconnection and isolation after diagnosis. Cultural and knowledge barriers to obtaining cancer diagnosis exist within this population of rural Hispanics as do misconceptions about the causes of and cures for cancer. The presence of support groups in these communities can serve as a means to combat these misconceptions, and to provide accurate and practical information for survivors, family members and community members at large. In light of the largely negative experiences and interactions with physicians reported by participants, the support groups may also be used as a venue for providing health information in a non-clinical setting. They may also serve as an outlet to teach individuals ways to assert themselves with their healthcare providers. In response to the findings from the focus groups, cancer support groups in Spanish have now been organized in the communities of Sunnyside and Toppenish. In an effort to sustain the support groups in the future, facilitators are training community member participants in leadership and group facilitation.

Implications for Clinical Practice

Findings may also have important implications for clinical practice. Potential gaps in knowledge and understanding of cancer diagnosis among Hispanic cancer patients should be called to the attention of physicians who care for these individuals. Physicians must be sensitive to the possibility that their Hispanic cancer patients may hold misconceptions about the causes of and cures for cancer, and these misconceptions should be addressed with a thorough explanation of the diagnosis and treatment options. Physicians should also be aware that health literacy and/or language barriers may prohibit full comprehension of cancer diagnosis and treatment options, and should ensure that translators are available to assist with doctor-patient communication during each visit. Developing an understanding of cultural norms within the Hispanic community that may hinder health-care seeking behaviors, including embarrassment and norms against touching oneself, will also be necessary for physicians to direct patients in current cancer treatment and future preventive care, and to facilitate more supportive and positive interactions with patients. To the extent possible, physicians should also work to connect their patients with cancer support groups available in the community, which can help them to address the fear, anxiety, depression, isolation and other psychosocial concerns commonly faced after diagnosis.

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Table 1

Focus group participants

Focus Group #	Date	Women	Men	Total
1	Feb-06	3	2	5
2	Feb-06	6	2	8
3	Mar-06	7	1	8
4	Sep-07	8	4	12
5	Oct-07	7	1	8
		31	10	41

Table 2

Experience with cancer

<i>Barriers to seeking cancer diagnosis or treatment</i>	
Norms against touching oneself	Even though they recommend when you go to your annual check up to get checked, she didn't. There are people ... with other mindsets, that believe that it is not good, or I don't know, their minds are still very... that's their custom...not to touch themselves ...
Inaccurate risk perception	She thought that since she never had a husband she would not get cancer...and when they went it was too late ... it started in the uterus and spread to all the internal organs. I think that she didn't even last four months after that.
Embarrassment	Because of embarrassment ...they don't go
Fear	Many people don't go to the doctor as well because they think that if they go, they will find... they'll take out even what's not there
Denial	they think that they do have [cancer] but they don't want to know
<i>Reaction to diagnosis (of self or family member)</i>	
Disbelief	...when they told me, the first thing that came to my mind was, why me? Because I was diagnosed with lung cancer, but I don't smoke... That is why the first thing that came to me was that, why me?
Fear	Well, death. That you are going to die or the person that has cancer is going to die.
Sadness	...it is a feeling of sadness; overall, you never know who will be diagnosed with cancer, that is the first thing. After they diagnose someone, well either way, the feeling is bad because very few survive. The only chance is if they detect it in time.
Strength	What do you get out of screaming, running ... If you have it, oh well...you have to be strong.
Courage	I just saw my son, and I gave myself courage, and he gave me courage, and I said, I have to go on for him, for myself, and I will do it.
Faith	...I'm very scared, very scared, but at the same time I have a lot of faith in God. I will move forward...I think that you have to be brave...
Hope	First, you don't believe, you think that it is not true, the things that they are telling you... that the doctors failed... Those are things that come to mind. And second is that hopefully there is a cure and that ... it's not so bad and that you will be cured.
<i>Challenges faced after diagnosis</i>	
Family concerns	But [my son], I know, I don't think he or my other girl took it well. They just heard that I had cancer, and because of my mom, because of what she went through, they thought "My mom is going to die." I said, "No, don't say that." But it had a bad impact on them. Of course they [the kids] have to be impacted. The mother is the most loved...what brought one to this world. How are they not going to? ... they have to worry, partly because it's a part of their body that is parting. Because you know that one is a piece of flesh of the mother or the father, right? So when the mother parts it would be like if they are losing an arm. ... my son was only six years of age and I thought, since he was so small... that there is going to be no future for him.
Financial concerns	We didn't have money, we didn't have work here, and my mom ... they didn't tend to her because we owed the hospital... Like... right now she is still in treatment, the injections are very expensive and there isn't any help for her injections. It's a lot of money and they've already insisted that they give her [the treatment] ... about three months ago she told us that she was going to leave us because it was, well, it was too much money and her husband did not make much... It's too expensive. ... both of [my friends] are farm workers. What resources are available for them? I know that one of them already told me that it's hard for them to find help because the medical coupon will not cover certain things. What are they going to do later on? Both of them do not have documents.
Fear of losing medical coupons	She says... "OK, right now they give me the medical coupon, but the way the immigration laws are right now, there are no reforms, there is nothing." That's what she is worried about... "Up to now it's good." She says, "But what is going to happen in the future?"
Lack of support from spouse	... on many occasions the husbands don't support the wives well. Sometimes the machismo doesn't allow them to, doesn't let them support them... There was a lady in physical treatment with me, and they took out one of her breasts, and... she was young, she was my age. We were around the same age in years, and they took out her breast and she had no support from her husband and the lady let herself die, because her husband instead of supporting her or helping her out in the house, that man would tell her that she was no longer good because she wasn't a complete woman

because they had removed her breasts. And she would go to chemo and she began to withdraw from the treatment... and the woman died very young, leaving a child...
 [She] didn't get operated for cervical cancer; supposedly because the husband told her that he wasn't going to be an idiot anymore. "If you're going to get your uterus taken out, you're no good to me anymore." And they'd rather let themselves die.

- Depression** Well I felt bad. I felt like...well that all doors closed for me. I felt like in a cell I wanted to get out through a door, but they all closed on me, and well, I felt very sad and depressed.
 Since I am alone here and do not have family, I would get more depressed. And well, I also got... depression...And like right now, I am still taking medication for depression.
- Isolation** ... that is why one gets depressed more, because you don't get to talk to other cancer survivors in order to get advice... And... when you go through chemotherapy, you feel really bad ...
- Separation from family** When, the case of which I'm referring to is with one of my husband's sister and she was in Mexico and my husband is here...His challenge was that he could not see her. She was the older sister and she was very attached to him and him to her. It was, I felt my husband's pain...and handling the situation of talking on the phone with each other and for her to say that she was fine, she felt fine, but, but not my husband, he couldn't handle the situation.

Beliefs about causes of cancer

- Genetics** I also believe that it's...part genetic, right? If my mom...that's why I want to learn. I am telling you that my older sister was diagnosed.
- Environmental exposures** ... I also believe that the environment has a lot to do with it. Nowadays there are a lot of chemicals. Some are registered. There are others that they throw away without thinking about it...
 I say that it depends on this part of here of Hanford [nuclear plant], all this. The water is contaminated, the rivers are contaminated. They can't...they say on television, on the radio that you can't...eat fish from the Yakima River. Sunnyside and everything is contaminated... All of that is part of the radiation that Hanford has here.
 Would it be because of all the pesticides that are being used right now? All the food is exposed, they are not natural, the tree does not grow fruit, but they use fertilizers, chemicals and other things.
- Sun** Because of the sun, because one is always working in the rays of the sun.
- Physical trauma** ... if one hits himself and a bruise forms and the blood remains, the cells are dead. That little blow on that area does not vanish because the bruise is going away. Something stays inside ... it continues to grow, feeding off of the same thing, like if the dead cells pass once again in our organism, I think that they feed themselves there with ...
- Riding horses** ... two uncles of mine passed away from prostate cancer, and in Mexico, ... since they were very young ... well they transported the horse dressings. And well, they say, but I don't know, that that is what affected them. And that is why... they got [prostate] cancer...they were always on horses.
- Spray of dust from car engines** I was a mechanic all of my life...and the dust from the brakes...that is very bad for cancer, that's why you never wash them, let's say, you never blow air on them ... And if you are not careful then the air takes it, and the air takes it and spreads it somewhere else, but that gives cancer, I don't know what kind of cancer, but cancer comes from there, from that material.
- Proximity to farm animals** ... And they were saying that a lot of women had cancer... a lot of them from being so close to the feed they were giving the animals... in that town, where they had the chicken farms there were already like ten or something like that [had cancer].... In that town, a large number of people died of cancer. It is called el Palo Verde in Jalisco...they fought so they could remove the chicken farms out of that town.
- Operations on cancerous tumors** There is cancer...and if they operate you they don't stop it, it scatters. But its like she said, the cancer, you need to know where the cancer is. If they operate and they don't know where it is at, like in my sister's case, they operated her and it scattered...
- Infections** Cancer is like infections, right? ...I think that they are infections...

Beliefs about cures for cancer

- Natural remedies or herbs** I know of a man that took a medicine from Mexico. Well this has been years that he took it, and it cured his cancer. The *uña de gato*...
 And he knew about a lot of remedies, that I remember. He did get better for a long time. The peelings from a tree named, Campanillo...Cook and drink them. And others from one called, Vanillo...I don't remember any others.
 They say the Cancerina...But it has not been proven to have helped anybody. And I don't know if ... leaves of cancerina...It is an herb...Cooked like in a tea.
 They told me that dialvaca tea is good... Daily, daily, drink all you can...
 I am taking a remedy with aloe, honey, and salda wine.
 I remember, they gave my grandmother snake...Because is was like fresh meatright now I have heard that they process it, dry it, and sell it as capsules. In addition, they would even give my grandmother crab.
 Like I tell you, at that time you would not hear much about chemotherapy and radiology. They would mash [the crabs]. With like rice and serve it like a beverage.
 I've heard that this homeopathic medicine or acupuncture could possibly, I don't know.

Smoking cessation	Stop smoking
Faith	Faith...in God
Eating healthy	I tried to... to eat healthier. I don't eat any fats, I hardly eat any pork or cattle meats. Very little beef, pork I never eat. And try to eat more fruit, more vegetables more...healthier.

Table 3

Experience with physician

Level of comfort and trust with doctor/satisfaction with care	
Trust	Well the doctor that I'm seeing... the doctor that I worked with referred me to him, and I have a lot of faith in him, and I also have a lot of trust in him. So ...I feel safe...I feel good with him, because he doesn't give up. When something doesn't work out, he uses something else, but he is always doing something. He doesn't give up.
Communication difficulty	But it's just that one doesn't understand the doctor because he speaks, like, in other words there are words that are too... that one doesn't understand.
Lack of availability	In my case the physician was not around ... every time we would make appointments to talk to her a she was always busy and on emergencies. She was never there. So we... well, we waited until we went to see the physician in Seattle and with him we were able to talk. He would explain a lot to us.
Lack of time	They want to send us out as soon as possible from where we're at Everything is hurried up...
Insensitivity	Now, another thing. When there is a case like that... what would it be called? ...lack of thought That a person comes, or that they send a person from the clinic where a person is hospitalized and at the moment they say to him, that the tumor was cancerous. What do you believe they should tell him? Tell him little by little, being that she [his daughter] was pregnant and seeing how he was there lying down. Don't you think that they could go about telling us little by little?
Negligence	...my mother-in-law... her physician ... he never wanted to tell us anything. He would get mad, yell, and tell us that she was going to be released. But that is not the response we were looking for and after...he said he has going to go on vacation and was going to pass the case on to a female physician and that is when she said, the physician, that the operation was not necessary...but they had already operated her, all she needed was chemotherapy and whatever she had would have gone away. Because what she had was a small tumor and she said that supposedly with radiation she would be cured. But I think that they left something in her because she would cry a lot, a lot from the pain. She was skinny, and becoming slimmer and slimmer and she would go to the clinic in Grandview. They would tell her that it was gastritis... She went to Toppenish on emergency because she didn't feel good and ... they... did that thing and use that camera, colonoscopy... And that is when they detected that it was a tumor and they tested it and it was cancerous.... And we were very upset with the doctor because...for one year and it was ...that is only gastritis and gastritis and all the medication was for gastritis ... if they would have done the exams she might have been able to fight. ...we never knew, because we were here and my mom was in Mexico. But they took her to Mexico... and in reality, like they say; they didn't tend to her right. They hurt her a lot, after; she said they just left her. She wanted to be at home and calm. ...the doctor that I had ... she ignored me completely. She did not want to run tests on me, did not want to do anything to me. Finally I switched doctors. What I am hearing, is that the majority have to go through one or two doctors in the, here in the clinic before they are able to find out that they have something. I was dying; the pain was so intense that I could not bear it. Then I returned, in February I returned and I said, "Doctor" I said, "I cannot do this anymore. Please give me a pass to go with another doctor." I said, "People have told me that there are tests that can show what is wrong with me. Where there are machines that can, those tests can do it, they can detect it." He said, "I am going to order an MRI for you." But we begin with the problem of the insurance; it did not want to cover. They did not want to give me medical coupons.
Hesitant to refer to specialists	And they don't want to send you out of the clinic because they will lose money because I spoke with other private doctors, the first thing they would say to me was, "do you have medical coupon?" No, "do you have insurance?" No. "We cannot help you. You need a reference from your family doctor in order for us to help you." So it is very difficult

Table 4

Information and resources useful for other cancer survivors

<i>Useful information</i>	
Prevention	I went to an instruction that they gave in Mexico about smoking and they showed us the organs, how... One of my brothers, I accompanied, for support, a brother, he smoked a lot, ...and we went, and they show you there how they have the organs. I said, "Wow," since that day my brother quit smoking. So I think that it is something very harmful. I have another brother here in Sunnyside. On the 8 th there was a program here in "Nuestra Casa," cancer prevention, but I was in Olympia that day that's why I didn't go with him. But it is very good to have information here ...
Disease and treatment	To receive more information...like... how cancer starts, where it comes from, and why. ... not all cancers are deadly. There is... cancer salvation. It's just that the people need to be strong. I know that it is difficult to say don't be scared but one has to be strong and move forward. And ... people should know more, be more educated. Once they did the biopsy they saw that I didn't have [cancer] in the body, only on the lung. They decided that they were going to remove my lung later. And they didn't explain to me why and I asked, various times, but they didn't explain it to me...That's all they told me. "Your operation will be intense, from the operations that people can get on their bodies, yours is the biggest one." "But," he said, "if you, if your blood, and if your body respond well, you won't have any problems, you will be fine." And I told them, "but can you explain to me, what are the risks for me or anything else?" and he told me, "no" he said "after the operation we will see what's going to happen and there we'll explain things to you."
Side effects of treatment	When they give us the medications it is the same thing, they only tell you "you are going to take this pill for this amount of time, one daily, and that," but they do not tell one the consequences. I took Tamoxifen for five years and now after five years that I have taken Tamoxifen I have osteoporosis. Something the doctor did not warn me about, did not even say to me "you are going to suffer from this ..." I think that when a person is diagnosed with cancer, I think that they should be told everything. Everything that's there, and the side effects that the medications could have. Because if they tell the person what they have, so dryly or abruptly, yes, as they do...they also have to inform them of everything...provide good information for everything that's there and from there it's up to the person to do what they want to do and to go wherever they want to go with it.
Importance of early diagnosis	To look for it, to look for it as fast as you can.
Where to go for treatment	I think that also, it would be good to know where to go when you don't have the resources. Because there are people who have cancer...and are not working. It is not enough... to pay a specialist. As I understand they are expensive and not all people have the means to go to that specialist. Or not all people receive medical coupon, they can only get certain services. In the hospitals there are charity programs. In all those places ...if they deny them a coupon the hospitals are obligated to cure people. Toppenish hospital has a lot of help for people that don't have resources, because they don't have medical coupon or they don't have... sufficient money to pay.
How to find specialists	I would like to know... to what doctors, what doctors, what type of doctors to go to when something suspicious is... because I don't know...what doctors and not all...are specialists ... Find the best specialist, and not believe that we will be cured with a tea that doesn't work... We have to find specialists who know what cancer is, not just go off of what a random person says.
<i>Useful resources</i>	
Support	well, what I want to learn is what is available for [my friends]. What resources are available, what help is available...I just want to find help... something like support, like therapy for them. I think... the support; give them as much support as you can. Because So they won't be so down. If they relapse it will be worse. ... if nobody is sick with cancer in the family...it takes them like by surprise, right?... [Support programs] are very nice because ...it is good to know ...what steps to take...one is more prepared. Even the people who do not have it and who do not suffer from it, it is good to be informed.
Hope	The possibilities that they are going to heal... That...that there are people dedicated to the study of cancer, that there are new methods... ...to give it all they got, to be patient and not fear or be frightened and keep calm because fear is the last thing that they should feel, it's the last thing one should feel.
Empowerment	Information, information and for one to know how to act when things happen to us in the clinic ... so if we are not comfortable with the situation there, that is also why we are in these classes...so one can be informed on one's own account. Or everything that can be done.