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## Latinos and Cancer Information: Perspectives of Patients, Health Professionals and Telephone Cancer Information Specialists

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### Abstract

Semi-structured interviews were conducted with 16 Latino cancer patients diagnosed in California; 10 health professionals from the San Francisco Bay Area and Fresno, California; and 10 Cancer Information Services (CIS) information specialists from the regional offices handling calls from Spanish-speakers. Interview guides were designed by the investigators to answer three main research questions: 1) How do Latinos obtain information about cancer and what types of information do they access?; 2) What sources of cancer information do they seek out and find credible?; and 3) What are the barriers and facilitators to Latinos obtaining cancer information? Stakeholders generally viewed health professionals as the most credible source of cancer information. All groups regarded family and friends as important sources of information. Patients and health professionals tended to differ on the value of print materials. Although patients found them generally useful, health professionals tended to view them as inadequate for meeting the informational needs of their Latino patients due to the challenge of low health literacy. Health professionals also tended to undervalue Internet resources compared to patients and CIS specialists. All stakeholders viewed language, ethnic discordance and the impact on patients of the initial diagnosis as barriers to effective communication of cancer information. Health professionals and CIS specialists, but not patients, mentioned low literacy as a barrier. Our findings underscore the importance of the physician-patient relationship as a point of intervention to address the unmet informational and psychosocial needs of Latino cancer patients.

## Keywords

Health information; Latinos; Cancer Information Service

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## INTRODUCTION

Patient-centered health care has attracted renewed attention, particularly the provision of patient education and information to facilitate participatory decision-making. Understanding the informational needs of patients is particularly important in the treatment of cancer. Because cancer is a life-threatening disease and treatment options are complex, obtaining accurate and accessible information is critical to informed treatment decision making. Cancer-related information is essential in obtaining better patient-centered outcomes (Arora, 2002; Davison, 1997) and information about treatment is the most cited need of recently diagnosed cancer patients and their families (Rutten, 2005). Arguably, nowhere is this need more critical than in the treatment of cancer where important decisions are made in relatively short periods of time. The National Cancer Institute-sponsored Cancer Information Service (CIS), which was established in 1975, is an important resource for the delivery of cancer health information. Using highly trained bilingual (Spanish-English) information specialists, the CIS provides the most current cancer prevention, diagnostic, and treatment information to the lay public via a toll-free telephone number (1-800-4-CANCER) (Squiers, 2005).

Persons of lower socioeconomic status, especially those with fewer years of formal education, are less likely to proactively seek information about their health problems. When they do make the attempt, they are more likely to encounter barriers (Deering, 1996; Eng, 1998). Latinos, in particular, face socioeconomic and cultural barriers to health care, including cancer screening and treatment (Aziz, 2002; Larkey, 2001; V. Shavers, Brown, ML, 2002). Latinos are more likely to be diagnosed with a more advanced stage of cancer (American Cancer Society, 2009) and they experience disparities in the quality of cancer treatment (V. L. Shavers & Brown, 2002; Wheeler, Reeder-Hayes, & Carey). Therefore, timely and accurate information about their diagnoses and treatment options is essential. These disparities in utilization extend to the use of cancer information services. Despite the informational needs of this population, Latinos make up only 11% of callers to the CIS (Bush, Vanderpool, Cofta-Woerpel, & Wallace, 2010; La Porta, Hagood, Patt, Hodorowski, & Treiman, 2007).

Patients and health professionals are principal stakeholders involved in the delivery and receipt of cancer treatment information. Soliciting their perspectives is important to identify best practices for conveying complex treatment information to cancer patients (Talosig-Garcia, 2005). Especially important is the need to identify effective methods for providing complex cancer diagnostic and treatment information to patients with less education or lower literacy levels, for whom traditional channels may be inadequate.

Most studies regarding the informational sources and needs of Latinos have focused on common misconceptions of cancer among Latino populations (Haras, 2011). However, less is known about where, how, and from whom Latino cancer patients receive their cancer-

related information. Therefore, we examined the information-seeking practices of Latino cancer patients from three perspectives: patients, health professionals, and CIS information specialists. By eliciting information from multiple stakeholders involved in the cancer information exchange, we aimed to identify patient-centered best practices that health professionals can employ to share cancer-related information with Latinos and their families. We looked at how and what types of information related to their disease Latino cancer patients seek and obtain, what sources of cancer information they regard as credible, and what factors influence their ability to obtain cancer information.

## **METHODS**

### **Participants**

As part of a larger study focusing on the CIS, semi-structured interviews were conducted with 16 Latino cancer patients diagnosed in California; 10 health professionals from the San Francisco Bay Area and Fresno, California; and 10 staff members (information specialists) from the CIS regional offices handling calls from Spanish-speakers. CIS information specialists are trained to answer phone calls and provide state-of-the-art information on cancer and its treatment and community resources.

### **Latino cancer patients**

In 2006, we sampled 102 Latino men and women diagnosed with breast, prostate, or colorectal cancer identified through the California Cancer Registry (CCR), whose physicians did not object to their participation. Of the original sample, 22 patients declined to participate and 41 were unreachable, leaving a total of 39 eligible participants. We conducted interviews with willing participants until data saturation (no new themes emerged from the data) was achieved (n=16). A bilingual, experienced interviewer obtained written consent and interviews were audio recorded. Participants received \$40 for completing the interview.

### **Health professionals**

A convenience sample of health professionals was recruited from San Francisco General Hospital and Fresno Community Hospital. Additionally, physicians of CCR patients identified by the registry as the physician of record were mailed a study invitation letter along with a reply postcard to indicate their willingness to participate in a face-to face semi-structured interview. Interviews with 10 health professionals were completed. Each health professional received \$100 for participation.

### **CIS information specialists**

Were recruited from the CIS national Spanish-language call center and from another CIS regional office that handled all Spanish-language calls received after business hours. Ten information specialists were selected by CIS administrators as having experience with Spanish-language calls from California patients. Semi-structured telephone interviews were conducted with information specialists and were audio taped and transcribed verbatim.

## Interviews

Semi-structured interview guides for patients, health professionals and CIS information specialists were developed based on the literature pertaining to cancer information services and the medical encounters of cancer patients. The guides were designed to answer three research questions: 1) How and what types of cancer information do Latinos seek and obtain; 2) What sources of cancer information do they find credible?; and 3) What are the barriers and facilitators to Latinos obtaining cancer information?

Patient interview guides consisted of 49 questions that addressed the following: 1) sources of cancer information; 2) barriers to and facilitators of information seeking about cancer; 3) barriers to and actual use of telephone information services such as the CIS; and 4) opinions about the acceptability of CIS-initiated (out-going) calls to cancer patients. One interview guide was developed for both health professionals and CIS information specialists. The guide consisted of 33 items assessing their perceptions of Latino cancer patients': 1) cancer information-seeking practices and 2) barriers to and facilitators of seeking cancer information.

Semi-structured interviews with Latino cancer patients, health professionals, and CIS information specialists were digitally audio-recorded and transcribed verbatim. Spanish-language interviews with patients were transcribed in Spanish and translated into English. All study procedures were approved by the University of California, San Francisco Committee on Human Research and informed consent was obtained from all participants.

## Data Analysis

We used both deductive and inductive coding schemes (Strauss & Corbin, 1998) in which transcripts were coded and analyzed for salient themes, which were then contrasted and compared across stakeholder groups. As codes emerged, they were categorized into our three main research questions. Each of the three stakeholder groups was asked parallel questions in order to triangulate findings and compare similarities and differences across groups. Data were coded independently by two Spanish-English bilingual-bicultural researchers. All authors met, reviewed and discussed the coding results until consensus was reached.

## RESULTS

### Participant characteristics

**Latino cancer patients**—In person semi-structured interviews were completed with 16 Latino cancer patients. The average age of the cancer patients was 57 years. Fifty percent of patients were men, 63% had completed high school and 31% were employed at least part-time. Less than half of participants were married (44%), and the majority reported having health insurance (69%). Fifty percent of patients reported that their health was at least “very good”. Most of the study interviews were conducted in Spanish (81%), and the majority of participants were foreign born (88%), although the average time spent in the U.S. was 31 years.

**Health professionals**—Interviews were completed with 10 health professionals. Seven of 10 health professionals were women. Six self-identified as White or Caucasian, two as Latino, and the remaining two as Asian American or Pacific Islander. The majority of health professionals identified a public hospital as their primary practice setting (n=8). Four were physicians, three were nurses, one was a clinical psychologist and two were allied health personnel.

**CIS information specialists**—Interviews were completed with 10 information specialists identified by CIS leadership. Information specialists ranged in experience from three months to 23 years. Nine self-identified as Latino and one as non-Latino White. The majority of CIS specialists were women (n=7).

## Themes

We have grouped the findings into two major categories that emerged from the data: sources of cancer information and factors influencing the ability to seek and obtain cancer information (Table 1). The subcategories of sources of cancer information that were discussed by participants were physicians, family and friends, print materials, and Internet sources. The salient factors that affected Latino cancer patients' ability to seek and access cancer information included the initial impact of the diagnosis, existential concerns (fear of death), concern for family members, lack of language concordance of information, literacy issues and the complexity of cancer information, and cultural differences in preferences regarding interpersonal communication styles.

## Sources of cancer information

Of the four sources of cancer information that emerged in the interviews, patients viewed physicians as the most credible source of cancer information. In fact, because of physicians' expertise, patients preferred to receive their cancer information from their physicians rather than other types of health professionals (e.g., nurses). For some patients, their physician was the *only* source of information they relied upon. Despite this reliance on physicians for information, patients expressed discomfort in the clinical setting due to feeling rushed through the visit. This discomfort manifested itself in several ways, from patients feeling uncomfortable about asking questions, to simply feeling nervous when speaking to their physicians.

Physicians and nurses also recognized themselves as a source of health information for Latinos. However, they felt that patients, especially Latino patients, become overwhelmed at times with the amount of information so that they often spread out the information over repeated visits. Also, it was evident that providing information to Latinos was often more time- and resource-consuming than giving the information to non-Latino patients. It is likely that the language barriers added difficulties to the interaction.

CIS specialists also identified physicians as a source of information for patients, although from their perspective, physicians were not the only source of information that patients accessed. Specialists felt that patients had to rely on other sources because physicians often

did a poor job of providing information given competing obligations, used medical jargon and complex language, or did not speak Spanish or use professional language interpreters.

Family and friends were identified by all three stakeholder groups as an important source of cancer information. However, health professionals valued this source less than patients, and some suggested family and friends were a source of incorrect information. Although, patients viewed friends and family as important sources of information, they tended to view them more as a source of support. Often, the experiences of friends helped contextualize and confirm the information provided by physicians. Family members and friends who had experienced a cancer diagnosis were particularly supportive and instrumental in helping patients seek the information necessary to make treatment decisions, especially immediately after the diagnosis.

Patients reported relying on print materials, including informational pamphlets provided by their physicians, to learn more about their disease as their treatment progressed. Written information was easily accessible, useful, and essential for patients unable to access other sources. For some patients, the printed information they received from health care providers was extremely helpful, especially when treatment side-effects became an issue.

However, health professionals, particularly physicians, questioned the utility of printed cancer information. One issue identified was the lack of availability of informational materials in Spanish. Another issue was that they felt Latino patients required more detailed guidance from their physicians and clinics in language that was simple and easy to comprehend. Thus, they felt that much of the written information was inadequate for Spanish-speaking Latinos or patients with low literacy levels.

Internet resources were also mentioned by both Latino patients and CIS specialists, but not recognized as an important information source by health professionals. Latino patients reported using Internet resources, including websites, to learn about cancer. For some patients, the Internet was a medium that allowed them to ask the questions they could not ask their physicians. It was also seen as a complimentary source of information about cancer treatment options or prevention. For patients seeking to learn more detailed information regarding specific treatments, the web-based resources provided a wealth of information presented in a way that some patients found engaging and could easily be shared with friends. This information was available in Spanish, which made it easier for patients to understand. CIS specialists, however, felt that Latinos were not avid Internet users. According to one CIS specialist, older, less acculturated Latinos were less likely to use the Internet for information than younger more acculturated Latinos.

### **Factors influencing the ability to seek and obtain cancer information**

The impact of the initial diagnosis was viewed by all stakeholders as a barrier to seeking and obtaining cancer information among Latinos. Patients, health professionals and CIS information specialists each recognized Latino patients' distress at the time of diagnosis, the fear of dying and the impact on children. For Latino patients, this involved fear for themselves, concerns for the impact of the diagnosis on family members, and the need for emotional support from health professionals. Health professionals as well as CIS specialists

felt that often, at the time of diagnosis, it was difficult for patients to fully comprehend or retain cancer-related information provided by health professionals, due to the overwhelming nature of the diagnosis. All three stakeholder groups stressed that language discordance between Spanish-speaking patients and their non-Spanish speaking clinicians was a barrier to delivering cancer information. Patients noted their frustration in communicating with clinicians who did not understand their language and could not provide them with health information in Spanish. In turn, health professionals reported having limited Spanish language resources available for their patients and noted the additional effort required to communicate complex cancer information to these patients. Although medical information was often translated for their patients in a variety of ways, the three stakeholder groups were in agreement that the informational needs of Spanish-speaking patients were not fully met.

Literacy and the complexity of cancer information were identified by both health professionals and CIS information specialists as a barrier to providing Latinos with cancer information. According to one physician, low levels of health literacy prevented Latino patients from taking advantage of the health information presented to them, even when this information was provided to them in Spanish. Both health professionals and CIS personnel found different strategies to assist their patients, including breaking down the information and providing it throughout their treatment, rather than all at once.

Interpersonal communication style preferences and cultural differences in these preferences were raised by all three stakeholder groups. Two interpersonal style issues emerged: issues of trust and disclosure and direct versus gentler or more measured approaches to sharing of cancer information. Health professionals felt that Latino patients needed to time to open up to their providers and that they were more likely to discuss cancer with their family and friends. Trust or *confianza* was identified by health professionals as especially critical to Latino cancer patients. Having ethnic concordant providers, e.g., patient navigators, was also seen as facilitating information sharing between Latinos and providers and served to enhance trust. As one physician noted, having Latina navigators made information more accessible for patients. Latinas could relate to each other, and patients could feel comfortable asking questions and sharing personal experiences. Both health professionals and CIS specialists described clear cultural differences between less acculturated Latinos and Anglos in terms of preferred communication styles. They felt that Latino English speakers generally preferred more direct communication styles than Spanish speakers.

## DISCUSSION

The aim of this study was to identify sources of cancer information for Latino cancer patients and barriers and facilitators to effective communication of cancer information in this population. We interviewed the principal stakeholders in the delivery and receipt of cancer treatment information: Latino cancer patients, health professionals, and CIS information specialists. By triangulating their responses we obtained a comprehensive view of the health information-seeking behaviors of Latinos, as well as the barriers to and facilitators of delivering this information. With few exceptions, we found that the three sources shared common views regarding the value of health professionals as important and credible conveyers of cancer information. However, language and ethnic discordance of Latino

patients and their health professionals and the need to provide complex cancer information in lower literacy formats were identified by health professionals and telephone specialists as current challenges limiting the effectiveness of cancer information exchange.

Our data is consistent with the literature documenting fear and anxiety as major barriers that prevent Latino cancer patients from seeking information (Davis, 2009). The distress caused by a cancer diagnosis often prevents patients from retaining cancer-related information or asking questions at the time of diagnosis (Davis, 2009). Although fear may be considered a universal reaction to a cancer diagnosis, it can be mitigated by understanding the course of the disease and obtaining appropriate support for treatment decision-making (Hack, Degner, Watson, & Sinha, 2006). There is substantial evidence that Latinos tend to suffer disproportionately higher levels of psychological distress due to a cancer diagnosis, compared to their non-Latino counterparts (Ashing-Giwa & Lim, 2011; Clauser et al., 2008; Yanez, Thompson, & Stanton, 2011). Our results suggest that this is due in large part to discordance between patients and sources of cancer information related to language, literacy, and interpersonal communication styles.

Our study supports the importance of the physician-patient relationship as a source of medical information for minority patients (Buki et al., 2008; Livingston, Minushkin, & Cohn, 2008; Talosig-Garcia, 2005). However, it also points to the challenging aspects of patient-physician informational exchanges determined by health care system constraints such as length of visit, availability of professional medical interpretation services, and cultural competency. Health professionals may not provide all of the necessary information and patients often seek additional explanations of diagnosis and treatments (Fagerlin et al., 2006). While written information was noted by all three stakeholder groups in our study as an important supplemental source of information, it may not be readily available at the clinic sites or, when available, the language or literacy level of the materials may be inappropriate. Web-based information was also identified as a useful source for patients in our study. While studies have shown low use of the Internet for cancer-related information among Latinos (Davis, 2009; Talosig-Garcia, 2005), most recent surveys support the increasing use of the Internet among this population (Pew Research Center, 2013). However, research still indicates that Latinos who feel less comfortable speaking English seek health information less frequently than those who speak English (Survey, 2012).

Informational support from family and friends was mentioned primarily by cancer patients, suggesting the need for increased awareness among health professionals of the emotional and informational benefits of this type of support. The literature has shown the benefits of support groups in Latinos (Buki, et al., 2008; Napoles-Springer, Ortiz, O'Brien, & Diaz-Mendez, 2009) and prior work with Latino cancer survivors indicates that exchanges with other survivors are an important component of support during and after treatment (Buki, et al., 2008; Napoles-Springer, et al., 2009; Yanez, et al., 2011). Additionally, language-appropriate peer support groups can provide a culturally acceptable and complementary resource for delivering essential psychosocial and informational support to cancer survivors who may be in need of these services as they deal with the challenges of their diagnosis (Napoles-Springer, et al., 2009).



Although family and friends were also identified as an important source of information for patients by physicians and CIS specialists, findings were mixed as to the usefulness of the information received from these sources. In particular, health professionals were doubtful about the accuracy of information provided.

Latinos faced multiple barriers to accessing cancer information. All stakeholders noted barriers to communication, particularly between patients and their physicians. Language and literacy were particularly problematic and severely limited the informational exchanges between patients and physicians. The quality of medical interpretation services and the cultural competence of the provider, interpreter, or specialist must also be taken into consideration. Medical information, even when accurately interpreted, may be difficult to understand for Spanish-speaking Latino cancer patients with low literacy levels (Wong et al., 2012). Other studies have also noted language barriers between providers and patients for other health conditions (Bush, et al., 2010) and for languages other than Spanish (Nguyen, Barg, Armstrong, Holmes, & Hornik, 2008).

There are several limitations to our study. Since this study was based on formative analysis completed as part of a larger study, only 16 cancer patients were included in the study. However, this is a hard to reach and important study population. In conducting this research, we focused on being able to reach saturation in responses (no new themes emerged). However, these opinions may not reflect those of all Latino cancer patients, health professionals, and CIS specialists. Another possible limitation is inaccurate recall. Because interviews were conducted up to two years after the patient's initial diagnosis, respondents may not have accurately recalled the cancer-related information received at that time or their initial reactions. In addition, these data were collected in 2006 and since that time there has been a large expansion of computer and smart phone use. However, there is little online information available in Spanish at low literacy levels. One study found that Hispanics indicated lower Internet health information-seeking than non-Hispanic whites (Pena-Purcell, 2008). Other studies have shown that online health information-seeking is significantly associated with higher education and being younger (Lee, Boden-Albala, Larson, Wilcox, & Bakken, 2014), while cancer patients typically are older, and as indicated above, those with low literacy levels are most in need of additional information.

## CONCLUSION

Our findings underscore the importance of the physician-patient relationship as a point of intervention to address the unmet informational and psychosocial needs of Latino cancer patients. These results provide meaningful insights into Latino cancer patients' informational needs from three different perspectives, including patients, health professionals, and CIS specialists serving Latino patients. Our findings suggest that best practices for cancer information exchange with Latino patients should: 1) use an empathic approach; 2) use medical interpreters when needed; 3) involve family members when desired by the patient; 4) occur over a period that gives patients time to move from their initial reactions to the diagnosis to a state in which they can absorb complex cancer information; and 5) be offered in varying formats and literacy levels to accommodate differences in learning styles and interpersonal communication preferences of patients. Health

professionals can help overcome some of the barriers identified in the study by providing additional Spanish-language resources and more opportunities for discussing cancer-related questions after the initial diagnostic visit. Because Latino cancer patients may initially ask few questions and health professionals' time may be limited, referral to linguistically and culturally appropriate psychosocial and informational support services, such as the CIS assumes greater importance. Providing Latinos and their families with accurate cancer-related information, which they can access readily is consistent with providing high quality cancer care for all patients and may help address informational and psychosocial health disparities experienced by Latinos with cancer.

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Table 1

Themes from qualitative interviews with patients, health professionals and Cancer Information Specialists about cancer information seeking and access among Latino cancer patients.

	Patients	Health professionals	CIS Information Specialists
<b>Sources of cancer information</b>			
<b>Physicians</b>	<p><i>The doctor [is where I get my information], a doctor knows more information than a nurse. (female breast cancer patient)</i></p> <p><i>No [I do not ask anyone else for information], I go directly to the doctor. Because others cannot, because the cancer treatment is serious. (female breast cancer patient)</i></p> <p><i>Yes, he devotes time to me, but I also see him rushing to get to the next patient, so I hate to hold him up a little longer, so then I feel neglected. Furthermore, I get a little nervous because if I ask him something or if they are going to give me some diagnosis. (female colorectal cancer patient).</i></p>	<p><i>I think most Latinos are like, tell me as much as I want to hear and then that is enough, just tell me what to do. (female nurse)</i></p> <p><i>From me... and they seem to be pretty happy, but we make a real effort, 'cause we have like a large Latino population, to provide them the information. (male physician)</i></p>	<p><i>The patients that I've talked to, usually they don't have a lot of information. The information they do have seems to be from doctors. (female CIS Information Specialist)</i></p> <p><i>Doctors do a very poor job of actually giving patients information. They usually rely on someone else to do that for them. (female CIS Information Specialist)</i></p> <p><i>But they have very little information from the doctors. Either the doctors are too busy, or explain it in a way that is very difficult to really grasp. (female CIS information specialist)</i></p>
<b>Family and Friends</b>	<p><i>....the doctors and everyone, had the same opinion that I had, have the surgery, and [there was] a friend who had cancer, too, and [she] told me exactly what the doctors had told me. (female breast cancer patient)</i></p> <p><i>My partner, she went through breast cancer ten years ago....So it was really good having her there, because she asked a lot of the questions that I didn't know. (male prostate cancer patient)</i></p>	<p><i>Friends and family, I would probably say, [are] where Latino cancer patients get their cancer information], yeah, and that is why a lot of them get wrong information. (female Latina nurse)</i></p>	<p><i>[Patients] call saying my friend or my family told me this, but they're not really understanding what's going on. (female CIS Information Specialist)</i></p> <p><i>Based on the experience that I have, I think that there is a variety of sources, such as word of mouth- I mean friends, family members. (female CIS Information Specialist)</i></p> <p><i>In my experience, it's from friends. Friends and family members, Especially elderly family members. (male CIS Information Specialist)</i></p>
<b>Print materials</b>	<p><i>After my diagnosis, they sent me some papers explaining the type of cancer. The doctors gave you another paper, and they explain everything to you. There they explain all the things and all the risks and all the things that one has to do. (male prostate cancer patient)</i></p> <p><i>I had difficult times. Then I went and looked at the papers they gave me and realized that it was a normal thing. Then that relieved me; it totally reassured me. (male prostate cancer patient)</i></p>	<p><i>I usually take them the state required pamphlet and I review it with them. And I also ask about literacy, you know, if they need help understanding, if they need help reading things, because a lot of our patients have low literacy levels or can't read or write at all. (female Latina psychologist)</i></p>	<p><i>Perhaps the local newspaper- small newspaper in their community. (female CIS Information Specialist)</i></p> <p><i>Many times it may be health professionals or educational pamphlet. (female CIS Information Specialist)</i></p>
<b>Internet</b>	<p><i>After my diagnosis, [my search for information] was through the Internet. They show the types of cancer, the processes, show options if you are going to have a lumpectomy, or if it's going to be a mastectomy. (female breast cancer patient)</i></p>	<p>Not observed.</p>	<p><i>The younger ones...yeah, the younger ones go on the Internet, and they try to do it themselves. (female CIS information specialist)</i></p>

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	Patients	Health professionals	CIS Information Specialists
	<i>It is good stuff. It is good reading. It tells you about the different procedures that are out there and new stuff that is coming out. That's the only real time that I can listen to other men that have gone through it, to tell me their experiences, that you're just talking. I just set up to help my best friend. (male prostate cancer patient)</i>		
<b>Factors influencing the ability to seek and obtain cancer information</b>			
<b>Initial impact of diagnosis</b>	<i>I thought about my son who is young and that is what worried me the most—my son. At that time, I wished that someone, from the Hospital had told me more. They did say it was not so bad, but I felt very scared at first. I felt very scared, very sad, as I repeat, for my son. (female breast cancer patient) ...If you tell someone "You have cancer," their world collapses. So, I think that there should be a bit of psychology in the way that the patient is told and then in how to help so that the patient can find ways to overcome the situation, to not die before it is time. (female breast cancer patient)</i>	<i>I think the very real notion that, oh I have got this I am going to die, is a major barrier to overcome for people for whom I have some form of therapy. (Caucasian oncologist) Cancer is a very personal problem. They're scared and they've never had to deal with their own mortality. So, for them, I think, there's a great deal of comfort sitting there and talking to somebody. And so, trust is a big part of cancer treatment anyway. (Caucasian urologist)</i>	<i>Well, sometimes they're scared. A lot of time they're scared, because they don't really understand it too well, or maybe they, for whatever reason, they didn't get a lot of information from their doctor about that particular situation. A lot of them are pretty afraid. (female CIS Information Specialist)</i>
<b>Language discordance</b>	<i>I would have liked to have information. They gave me information, but in English, but since I don't speak English, don't know how to read in English, what was I going to do with that? They told me, of course, that they didn't have them [written information] in Spanish and so the only thing they were able to do was have a nurse explain it to me... I did not understand much of the information that she gave me because for me the information was too brief. (female breast cancer patient).</i>	<i>First of all, there is a language barrier. We do use translation services by telephone or we use a family member sometimes. I'm not really sure exactly how. The patients – I'm not sure how much the families tell the patients when they are translating or even translation services, so they are getting like a second hand story. I don't think they really get that full understanding, so they are a little more frightened and unsure of what is going to be happening. (Caucasian oncology nurse)</i>	<i>And the clinics they go to. They try to get as much information. However, I would have to say that if the health professional that takes care of that visit does not speak Spanish, their information is very limited. (female CIS information specialist)</i>
<b>Literacy and complexity of cancer information</b>	<i>Not observed.</i>	<i>Unfortunately a lot of the stuff that gets translated to Spanish is transferred at just as high a literacy level as the English stuff, and it is nuts. (White oncologist) What I try to do is break it down, give them a little bit at the beginning, and then when they are going to go to radiation and so forth. I think it is just really mind boggling for them to just take this, so books I don't think work that well. (Latina nurse)</i>	<i>I think that the majority of the people that actually contact our service are probably on a high school level, or basic college level...So I think the communication style you have to have that in mind that you may have to sometimes put it in perspective for them and in layman's terms for them. (female CIS information specialist)</i>
<b>Interpersonal communication style preferences</b>	<i>I have been trusting him pretty good. My doctor that I have in Kaiser has been straight forward in telling me the problems. He is not beating around the bush. He is just telling me straight like it is</i>	<i>I think they will go to the person they know to get the information... I think it's difficult for Latinos to really open up about their personal stuff with someone they don't know. And for us, it even takes a little while to build that 'confianza'</i>	<i>They would appreciate us giving the information a little bit gentler. And it's part of the culture, I think. But the English-speaking caller that we get usually calls for information and that means the cold facts. This is this, this or that. Not that we don't do that with the</i>

	<b>Patients</b>	<b>Health professionals</b>	<b>CIS Information Specialists</b>
	<i>what are the results and what can happen. The good part and the bad part. (male colorectal cancer patient)</i>	<i>before we actually hear all the details about what's going on with them. (Asian/Pacific Islander physician) I think that culturally, Latino women like to talk to other Latinos, [with whom they tend to be] less secretive about cancer and stuff. They like to share information with one another, so the clinics have a pretty good system where they have what are trained women from the community, many of whom are cancer survivors, who actually help to do little group sessions where they can talk. (surgeon)</i>	<i>Spanish-speaking, but it's – you know, it's a way of providing the information that makes it different. (female CIS Information Specialist)</i>

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