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Cancer stage knowledge and desire for information: Mismatch in Latino cancer patients?

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Keywords

Hispanic Americans; Cancer Stage; Knowledge; Patient education; Immigrant Health

Background

Health knowledge has a vital impact on health outcomes. Patients' knowledge influences their ability to actively participate in the decision-making processes for medical care and treatment choices, and their ability to manage their condition to improve medical outcomes [1, 2]. A general understanding of disease and stage is crucial for cancer treatment decision-making and adherence. Further, more knowledge about cancer diagnosis and treatment is a key reason for variation in survival [3].

Immigrants and racial and ethnic minorities often face challenges in accessing medical information and making medical decisions about their disease due to socioeconomic, cultural, and language considerations, in addition to the communication style of health care providers [1]. Studies have found that ethnic minority cancer patients encounter less patient-centered communication [4] and receive less biomedical information during the clinical encounter [5]. Ethnic minorities and the economically disadvantaged are more likely to have less knowledge about their cancer than their counterparts [6–8], and low health literacy skills which may interfere with the ability to access, understand and use health information [9], understand instructions, participate in medical decisions, and maintain healthy lifestyle practices [10].

Immigrants with limited English proficiency face additional barriers. Spanish-speaking Latinas and less educated cancer patients have lower levels of breast cancer treatment knowledge compared to English speaking Latinas and other ethnic groups [11]. Patients who experience language discordance with their health care provider appear to be at elevated risk for receiving limited counseling from their physicians [12]. Janz and colleagues found that

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Spanish-speaking Latinas desire more information about their cancer and treatment and report less satisfaction with their medical decisions for their treatment [13].

Talosig-Garcia and colleagues found that areas of greatest informational need among African-American and Latina breast cancer patients were around diagnosis and prognosis [14]. In their study, only 45% of patients reported being adequately informed about their diagnosis and prognosis at the time of their diagnosis, but 73% did not search for additional cancer-related information after their diagnosis [14]. Cancer patients who need cancer information but who experience difficulties accessing it are at risk of poorer health and well being [15]. Studies have found that the receipt of more medical information and having more health knowledge positively impact adherence to clinical recommendations for cancer screening among Latinas [16].

However, other studies have found cultural differences in the desire for information, expectations of information provision, and role in medical decision-making. Some Latinos prefer to avoid being informed about their diagnoses, especially if it is an advanced diagnosis [17, 18]. Mexican Americans and Mexican immigrants are less likely to believe that a patient should be told the diagnosis of metastatic cancer [18] and more likely to have a preference for a passive role in medical decision-making [19] than European Americans and African Americans. However, as Latinos become more acculturated, they are more likely to share the patient autonomy model with European-American subjects. In other words, more acculturated Latinos tend to request more information, and favor truth telling in diagnosis, prognosis, and medical decision-making [18]. The purpose of this study is to examine the rate of awareness of cancer stage and desire for cancer treatment information; and to determine the demographic and medical correlates of lack of cancer stage knowledge and desire for information among Latino cancer patients. the rate of unawareness of cancer stage and diagnosis and treatment cancer information desires of Latino patients with cancer.

Methods

Design and Participants

This is a nested cohort study of Latino patients enrolled from March 2011 to July 2012 in the “Cancer Portal Project,” which addresses socioeconomic determinants of cancer treatment adherence in patients in ten cancer clinics in New York City. This study was approved by the institutional review boards of all clinics, and all participants provided informed consent prior to the participation. A detailed description of the study methodology and recruitment procedures has been previously published [20].

Measures

A cross-sectional needs assessment survey which is available in English and in Spanish, and which includes sociodemographic data, health-related questions, was administered to all patients as part of the Portal intake process. The needs assessment survey was developed based on published research and on the investigators’ experience with underserved and ethnic minority cancer patients in New York City [20, 21]. Due to the limited literacy of many of the patients, Portal Service Access Facilitators administered the survey.

The survey queries gender, age, marital status, monthly income, educational level, language preference, ethnicity, race, birthplace, years in US, interpretation need, insurance status, and health status: cancer diagnosis, stage, cancer treatments, and comorbidities. The survey also asks about types of assistance that patients want/need, including in the domains of social services, financial support, and information. Unawareness of cancer stage and metastatic status of the tumor were assessed by asking respondents in what stage is their cancer and if their cancer was metastasized or spread; if the participants don’t know the answer, they were categorized as been unaware. Desire for diagnostic and treatment information was assessed with a question asking if patients want or need more information about their cancer diagnosis or treatment.

Analysis

Data analyses were conducted in two stages. Descriptive (i.e. percentages, means) statistics were employed to examine knowledge about stage, metastatic status, and desire for diagnosis and treatment information. For the purpose of this study, patients were classified as being unaware, if they reported not knowing their stage, or if their tumor was metastatic or not. Binary logistic regression analyses were then run to determine what sociodemographic, clinical, and cultural variables were associated with their patients' cancer stage knowledge and noted needed information assistance. All data were analyzed using the Statistical Package of the Social Sciences (SPSS), version 19 software.

Results

A cohort of 271 Latino cancer patients completed the survey. Characteristics of the patients are displayed in Table 1. As shown, the mean age of patients was 55. Most patients (62%) were single, divorced, separated or widowed, women (60%), unemployed (62%), have a mean age of 56 (SD=12.67) and had completed less than a high school degree (61%). About a third of the sample reported having no income (36%), 14% were uninsured and more than two thirds (69%) had Medicaid for Emergency Care.

The majority (70%) of the sample was monolingual in Spanish or had limited proficiency in English; only 30% reported speaking English well or being fluent in English. The four most common countries/territories of origin were the Dominican Republic (35%), Puerto Rico (24%), Ecuador (10%), and Mexico (10%), and 7% of patients were born in the mainland United States. Forty-five percent of patients had resided in the mainland United States for more than 20 years.

Only 17% had a recurrent tumor and the most common diagnosis was breast cancer (40%). On average, our sample of patients had been diagnosed with cancer for three months (SD= 1.2 years). Thirty seven percent were receiving intravenous chemotherapy at the time of the survey and thirty four percent were receiving radiation therapy. Close to two thirds of the sample (65%) had no knowledge of their stage and 38% were unaware of the metastatic state of their tumor. Only 15% of the patients stated that they would like additional information about their diagnosis and/or treatment.

After controlling for the remaining sociodemographic characteristics (age, gender, marital status, monthly income, education level and insurance status), males were more likely to be unaware of their cancer stage (OR=2.53, CI=1.42–4.48) and metastatic status (OR=2.13, CI=1.24–3.64). After controlling for the other sociodemographic variables, patients with lower levels of education (6th to 11th grade) were more likely to request assistance with information about their cancer diagnosis and treatment, and those who were uninsured were more likely to be unaware of the metastatic state of their tumor (OR=2.66, CI=1.13–6.26).

Patients who reported needing or using interpretation services for their health care were more likely to be unaware of their cancer stage (OR=4.24, CI=5.75–7.98) or tumor metastatic status (OR=3.29, CI=1.71–6.31), and less likely to request additional information about their cancer diagnosis or treatment (OR=0.36, CI=0.14–0.93). Being an immigrant from Mexico (OR=7.64, CI=1.78–32.77) or Ecuador (OR=3.50, CI=1.00–12.71), having limited English proficiency (OR=3.51, CI=1.25–9.85) and being monolingual in Spanish (OR=5.62, CI=1.84–17.15) were associated with lacking knowledge about tumor stage.

Patients who reported not needing assistance with diagnostic and treatment information were more likely to be immigrants from the Dominican Republic (OR=0.19, CI=0.04–0.92) and monolingual in Spanish (OR=0.28, CI=0.08–0.95).

Being unaware of the stage of the tumor was predicted by being diagnosed for less than six months (OR=1.82, CI=1.03–3.22) and having recurrent cancer (OR=2.36, CI=1.09–5.11). Patients who were receiving chemotherapy were more likely to know the metastatic status of their tumor (OR=0.42, CI=0.19–0.95). Wanting more information about the cancer diagnosis and/or treatment did not predict lack of knowledge about cancer stage. However, a higher desire for information showed a non significant trend towards knowing the metastatic status of the tumor (OR=0.42, CI=0.17–1.04).

Discussion

This study shows considerably low levels of stage and metastatic awareness among Latinos diagnosed with cancer. Patients who need linguistic interpretation, males, uninsured and immigrants were more likely to have informational deficits about their stage and progression of their tumor. This lack of knowledge might adversely impact their treatment decisions and disease management.

There are a number of possible explanations for the high percentage of Latinos with informational deficits about their cancer diagnosis. Latinos with low acculturation, immigrants and with low limited English proficiency might not have the same access to their disease information than other cultural/linguistic groups. Furthermore immigrants and ethnic and racial minorities more often have limited health literacy [9]. Medical practices that provide care for Latinos with low acculturation may not have professional interpretation services readily available or trained staff to provide information in a culturally sensitive manner. Janz and colleagues [13] observed that Spanish-speaking Latinas reported needing the most help with understanding information related to their breast cancer. Other studies have indicated that patients whose main spoken language is not English have more difficulty communicating with their physicians, including Latina breast cancer survivors [22, 23]. Therefore, even if information about stage has been provided, due to limited health literacy or lack of English fluency, underserved minorities may encounter problems understanding or processing the meaning of the staging system, or other biomedical concepts such as tumor, organs, tissues, etc.

Health care providers are not uniformly competent in cross-cultural communication, and this, along with a history of covert or overt racial discrimination, may result in less effective provider–patient interactions [10] that may affect the amount and quality of information that patients received. Studies have found that medical health providers communicate differently with cancer patients of different ethnicities [4, 5], they offer less medical information to ethnic minorities, less educated, and low-income patients. They are less likely to tailor their medical consultation to the specific needs of minority patients [5]. Furthermore, studies have shown that interpreters engage less in “interpretative divergences”, interpretations that do not convey the content and meaning of the original source message, when the source messages are patient-oriented instead of technical or medically-oriented [24].

We hypothesized that the diagnostic informational deficits might lead to more information need and desire, as has been shown in previous studies [13]. However, we found the opposite. Immigrant patients and patients that reported needing language interpretation were less likely to request more information about their diagnosis and treatment. This discordance between the lack of information about cancer staging and the lack of patients’ perceived need for information might result from a variety of factors: Low health literacy, informational avoidance, different coping styles, and deference to the medical professionals. Patients’ health literacy may affect that individual's ability and desire to seek out health information [25]. Patients with low health literacy are faced with foreign or technical terms, complex ideas, multiple options, which can be overwhelming. In order to cope, patients may reduce their decision burden using potentially maladaptive strategies such as information avoidance or maintaining a passive approach. Further, patients with low literacy levels might not be aware of their informational deficits or the need to receive more information to make decisions about their medical care, resulting in a lack of interest or desire to receive more information.

Informational avoidance, as a coping style, may be more prevalent for Latinos with low literacy due to lack of comprehension of the information presented, fatalistic beliefs, or a way to maintain control over their cancer experience. Studies have provided evidence regarding the relationship between patient satisfaction and information-seeking. Steptoe and colleagues [26] found in their sample of patients with metastatic cancer that “blunters” (those who avoid or prefer minimal information) had a higher level of satisfaction with cancer-related information they received, even though “monitors” (those who actively seek information) had a higher level of factual knowledge. In a study with Mexican immigrants, a common theme was the lack of control over the cancer, instead of control in receiving or not receiving information [27]. Some participants reported avoidance of information about cancer as a means of control and as a demonstration in the power of God [27]. A fatalistic attitude may contribute to higher information avoidance [30].

Latinos might have lower desire for disease information due to a higher preference for a passive decision-making approach, being less autonomic in regards to decisions of medical care and preferring more family-centered care. Within a family-centered model is the sole responsibility of the family to hear the bad news of the diagnosis and prognosis and to make difficult decisions about life support [18]. It is possible that Latinos in this sample lacked the appropriate family support during clinical encounters, since family members can serve as facilitators of clinical information acquisition. Also, among Latinos, the view of physicians as authority figures and an unquestioned deference to authoritative figures [31] may maintain a passive role in relation to their physicians and their health information.

Clinical Recommendations

The present study does not imply that information should not be provided to Latino patients, nor that efforts to enhance communication will be ineffective. Patients might not request additional provision of information, even when they have knowledge gaps. During the clinical encounter, clinical practitioners should assess the individual educational needs and tailor the education accordingly. Practitioners should appraise if written materials (even if the materials are in the patient’s primary language) are the effective way to provide information given the general literacy and health literacy of the patient and/or family. Health care providers should continue assessing the informational needs of a patient during different stages of the treatment, realizing at the beginning patients’ and families can be overwhelmed by the information provided. This can lead to miss or misunderstanding the information and new questions may emerge along the treatment process.

Monolingual English-speaking medical staff should work closely with interpreters to identify knowledge gaps and provide information in a culturally-sensitive manner. The key to culturally responsive care is to provide patient-centered care and communication, built on respect, sensitivity, composure, partnership, honesty, astuteness, curiosity, and tolerance [30]. Specifically with Latinos areas that need to be incorporated to enhance the health communication are inclusion of the family, cultural traditions and collectivism, while attending to acculturation, language, generation status and national origin [29].

The information the providers deliver needs to be as specific as possible to the individual patient and family situation and sensitive to the preferences of the patients in accessing and receiving their biomedical information. This is especially important because communication studies have found that physicians' talk with cancer patients seems to be "scripted" and is not especially tailored to the individual patient from different races or educational levels [5].

Study Limitations

This study has several limitations. First, although we controlled for sociodemographic variables, the cross-sectional nature of our analyses limits inferences on causality. A longitudinal design could shed light on the changes of information acquisition and needed information assistance as patients cope with the disease in different phases (early stage, advanced or remission).

Second, we recognize that our needs assessment was developed for the Portal Project, which was designed to help and support immigrants and people from other underserved communities to access cancer treatment and cope with the condition. The language and format of the clinical questions and needs assessment included brief and simple statements that were based on common language and the type of needs presumed to be more salient in underserved cancer populations. We only included two questions that measured informational needs (information about diagnosis and treatment) and both questions measured the presence rather than level of need. We also defined informational deficits as lacking information about stage and metastatic status of the tumor. Future studies should measure other areas of informational needs (survivorship, side effects, etc), level of need (including ordinal scale questions), desire of assistance and preferred sources of assistance. Furthermore, health knowledge and informational deficits about the disease should be measured in a more comprehensive way, including basic information about staging system, treatment and side effects. In addition, given that information desire/need was measured with only two questions, patients might interpreted these question in different ways, or their response could be influenced by previous experiences, such as dissatisfaction with information previously received.

A third limitation is the imbalance of cancer types. Breast cancer patients comprised a large percentage of the sample; consequently, cases were too few for focused analyses with different types of cancer, which is the reason why we include all self-reported cancer types. Future studies can benefit from comparing self-reported clinical information with information from patients' medical records, limiting the analyses to a specific diagnosis and stage. Finally, this sample was collected in New York City, from patients who were enrolled in ongoing health care, and may not be representative of a national sample of Latino cancer patients.

Conclusion

Patients with cancer, who belong to ethno-cultural minority subgroups with low levels of literacy or education, face a number of obstacles to learning about their illness. They sometimes receive complex information in a manner that is not culturally sensitive or tailored for their needs and literacy levels. Studies have reported that there is a need to provide culturally appropriate cancer-related information and failure to account for culture and linguistic issues can result in less satisfaction with information provided [13, 30] and incomplete knowledge [29]. Further studies, with quantitative and qualitative approaches, should focus on identifying barriers of acquisition of disease information and other disease-specific informational deficits. Patients may benefit from culturally tailored psycho-educational interventions that aim to empower patients to take a more active role and request more information about their disease.

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Table 1

Description of demographic, cultural and medical characteristics (N=271)

	n (%)
Age [*]	55.50 (12.67)
Gender	
Female	188 (59.5)
Marital Status	
Single/separated/widowed	192 (61.5)
Educational Level	
< 6th grade	56 (18.9)
6th –11th grade	124 (41.8)
High School Diploma or more	117 (39.4)
Employment Status	
Unemployed	193 (61.9)
Employed	82 (26.3)
Retired	37 (11.9)
Current Monthly Income	
$0	113 (36.3)
$1 – $900	146 (46.9)
>$900	52 (16.7)
Insurance Status	
Uninsured	44 (14.2)
Emergency Medicaid	53 (17.1)
Medicaid, Medicare or other insurance	213 (68.7)
Language	
Spanish	232 (73.4)
Bilingual	16 (5.1)
English	66 (20.9)
English Proficiency	
None	90 (29.1)
Limited	127 (41.4)
Well/Fluent	92 (29.8)
Birth Place	
Dominican Republic	111 (35.1)
Puerto Rico	77 (24.4)
Ecuador	32 (10.1)
Mexico	31 (9.8)
USA	23 (7.3)
Years in Mainland	
< 5 years	54 (17.1)
6–20 years	88 (27.8)
> 20 years	143 (45.3)

	n (%)
Type of Cancer	
Breast	126 (39.9)
Gastrointestinal	55 (17.4)
Gynecological	44 (13.9)
Time since Diagnosis [*]	.75 (1.20)
Cancer Recurrence	52 (16.5)
Stage of Cancer	
I	27 (25.7)
II	28 (26.7)
III	29 (27.6)
IV	21 (20.0)
Stage Unawareness	195 (64.8)
Metastasis	42 (13.3)
Metastatic state Unawareness	114 (38.0)
Informational need/desire	38 (15.0)
Current treatment	
IV Chemotherapy	117 (37.0)
Radiation	108 (34.2)

Note.

[*] Mean and standard deviation for age and time since diagnosis Owing to rounding and missing data, percentages may not add up to 100

Table 2

Odds ratios (OR) and 95% confidence intervals (CI) of sociodemographic characteristics predicting stage unawareness, metastasis unawareness and information desire after controlling for the remaining demographic characteristics

	Stage Unawareness		**Metastasis Unawareness**		**Information Desire**	
	OR	**(95%CI)**	**OR**	**(95%CI)**	**OR**	**(95%CI)**
Age	1.01		1.01		0.99	
Single Status						
Partnered/Married	1.00		1.00		1.00	
Single	1.38		1.40		0.88	
Gender						
Female	1.00		1.00		1.00	
Male	2.53	(1.42–4.48)**	2.13	(1.24–3.64)**	1.42	
Education						
High School graduate	1.00		1.00		1.00	
None to 5h grade	1.07		1.73		0.24	
6th–12th grade	1.07		1.53		3.20	(1.32–7.80)**
Employment Status						
Employed	1.00		1.00		1.00	
Unemployed	0.61		0.68		1.21	
Retired	1.53		1.00		0.53	
Monthly Income						
>$900	1.00		1.00		1.00	
$0	1.97		1.75		0.36	
$1–900	1.43		1.46		0.98	
Insurance Status						
Insured	1.00		1.00		1.00	
Uninsured	1.91		2.66	(1.13–6.26)*	1.06	
Insured with Emergency Medicaid	1.01		2.12		0.39	

Note.

[*] p<.05,

[**] p<.01

Table 3

Odds ratios (OR) and 95% confidence intervals (CI) of language and immigrant characteristics predicting stage unawareness, metastasis unawareness and information desire after controlling for the remaining demographic characteristics

	Stage Unawareness	**Metastasis Unawareness**	**Information Desire**
	OR (95%CI)	**OR (95%CI)**	**OR (95%CI)**
Acculturation			
English proficient US born	1.00	1.00	1.00
None English proficient immigrants	5.62(1.84–17.15) **	1.96	0.28(.08–.95) *
Limited English proficient immigrants	3.51(1.25–9.85) *	1.70	0.59
English proficient immigrants	1.10	0.65	0.51
Interpretation Need			
No	1.00	1.00	1.00
Yes	4.24(5.75–7.98) ***	3.29(1.71–6.31) ***	0.36(.14–.93) *
Birth Place			
United States	1.00	1.00	1.00
Dominican Republic	2.68	1.52	0.19(.04–.92) *
Puerto Rico	2.18	0.86	0.73
Mexico	7.64(1.78–32.77) **	2.75	0.81
Ecuador	3.50(1–12.71) *	2.33	0.36
Years in US			
More than 20 years	1.00	1.00	1.00
0–5 years	2.40	1.18	0.61
6–20 years	1.26	0.91	0.31

Note.

*p<.05,

**p<.01,

***p<.001

Table 4

Odds ratios (OR) and 95% confidence intervals (CI) of medical characteristics predicting stage unawareness, metastasis unawareness and information desire after controlling for demographic characteristics

	Stage Unawareness		**Metastasis Unawareness**		**Information Desire**	
	OR	**(95%CI)**	**OR**	**(95%CI)**	**OR**	**(95%CI)**
Time since Diagnosis						
More than 6 months	1.00		1.00		1.00	
Less than 6 months	1.82(1.03–3.22)*		1.16		0.54	
Cancer Recurrence						
First cancer	1.00		1.00		1.00	
Recurrence	2.36(1.09–5.11)*		0.75		0.95	
IV Chemotherapy						
Off	1.00		1.00		1.00	
On	1.08		0.42(.19–.95)*		0.64	
Radiation						
Off	1.00		1.00		1.00	
On	1.69		1.30		1.40	
Physical Comorbidities						
0	1.00		1.00		1.00	
1	1.11		1.16		0.87	
≥ 2	0.52		0.63		1.40	
Psychological Comorbidities						
0	1.00		1.00		1.00	
1	0.93		0.67		0.65	
≥ 2	0.79		0.75		2.01	
Information Desire	1.11		0.42			

Note.

[*] $p<.05$