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“Doctor, what do I have?”:

Knowledge of cancer diagnosis among immigrant/migrant minorities

Francesca Gany, MD, MS¹, Lalanthica Yogendran, MD, MPH², Dana Massie², Julia Ramirez, MA², Trevor Lee², Gary Winkel, PhD³, Lisa Diamond, MD, MPH¹, and Jennifer Leng, MD, MPH¹

¹Memorial Sloan-Kettering Cancer Center, Immigrant Health and Cancer Disparities Service, Department of Psychiatry and Behavioral Sciences, Department of Medicine, 300 E. 66th St, 15th floor, New York, NY 10065

²Memorial Sloan-Kettering Cancer Center, Immigrant Health and Cancer Disparities Service, Department of Psychiatry and Behavioral Sciences, 300 E. 66th Street, 15th floor, New York, NY 10065

³Mount Sinai School of Medicine, Department of Oncological Sciences, Icahn Medical Institute, Room 15-70, One Gustave L. Levy Place, Box 1130, New York, NY 10029

Abstract

This study explores patient knowledge of cancer diagnosis among underserved immigrant/migrant minorities. Patients were recruited at a hospital-based cancer clinic in New York City.

Demographic and self-reported diagnosis and treatment information were collected; charts were reviewed to ascertain cancer diagnosis. 434 patients were included. 87% preferred to speak a language other than English in the health care setting. 16% had incorrect knowledge of their cancer diagnosis. Multivariate analysis indicated that both preference for a nonEnglish language and diagnosis of a ‘below the belt’ cancer were jointly predictive of incorrect knowledge (L.R. = 17.01; $p = 0.0002$). ‘Below the belt’ cancers included bladder, colorectal, gynecological, penile, prostate, and testicular cancers. Among this cohort of immigrant/migrant cancer patients, a considerable proportion were unaware of their correct cancer diagnoses. This may have a significant impact on subsequent cancer education, treatment and care. Limited English proficient patients may be at particular risk.

Introduction

The total U.S. population includes 40 million foreign-born individuals, representing 13 percent of the population [30]. Among the foreign-born in the U.S., Hispanics (53%) and Asians (28%) constitute the largest aggregated group [18]. New York City is home to the largest foreign-born population in the U.S [7], with more than one-third (approximately three million) of New York City’s 8.3 million residents being foreign-born [7].

Corresponding Author: Jennifer Leng, MD, MPH | Assistant Attending, Memorial Sloan-Kettering Cancer Center, Immigrant Health and Cancer Disparities Service, Department of Psychiatry & Behavioral Sciences | Department of Medicine, Evelyn Lauder Breast Center, 300 E 66th Street, 15th floor | New York, NY 10065, 646-888-4243 Office | 646-888-4491 Fax | lengi@mskcc.org.

Despite an observed decrease in overall cancer death rates in the U.S., immigrants and minorities continue to experience disproportionately higher cancer incidence and mortality rates for many cancers, as well as decreased access to treatment, end-of-life care, and survivorship services [28, 16]. Immigrant minorities are confronted with considerable barriers to cancer education and care, including language barriers, cultural factors, limited access to health insurance, limited opportunities for education and employment, the high costs of treatment, and other economic, personal, and family health priorities [35, 13].

Language and effective communication are critical in the delivery of quality cancer care, as discussions between providers and patients are frequently complicated and upsetting [41, 38]. The proportion of people in the U.S. who speak a language other than English at home has greatly increased in the last three decades. In 2007, there were more than 55 million speakers of non-English languages in the U.S., approximately half of whom were limited English proficient (LEP) (speak English less than 'very well') [36]. Several authors have shown that language discordance between patients and providers is a considerable barrier in the delivery of effective health care [14, 25, 23, 29, 42, 21, 24, 27, 43]. LEP patients are also less likely to adhere to medical recommendations and follow-up care [24, 27].

There are limited data among the general population on knowledge of cancer diagnosis. Santoso et al., in a study of 284 cancer patients in Tennessee (55% African American, 41% Caucasian), found that 91% of patients correctly identified the primary site of their cancer [33]. Among immigrant minorities, similar studies have not been conducted, although several related studies have been published [40, 32, 34]. Tchen et al. explored understanding of disease status among Chinese, Spanish, Portuguese, Italian, and English-speaking cancer patients and found that estimates of probability of cure by English speakers were closer to physicians' estimates compared to non-primary English speakers [40]. In a study of Vietnamese immigrants with no personal history of cancer, Nguyen et al. explored patient experiences of cancer communication, and found that individuals described problems with communicating with physicians about cancer, they did not often engage in cancer-related discussions with their doctors and they described a poor understanding of tests they had received [32]. Further, participants described language and translation difficulties during encounters with physicians and the health care system [32]. Factors related to culture and socioeconomic status may also contribute to problematic cancer communication. Scarinci et al. explored sociocultural factors associated with cervical cancer screening among Latina immigrants, and found that participants believed fate played a role in the development of cervical cancer and preferred not to know if they had the disease [34].

This study explores patient knowledge of cancer diagnosis among underserved immigrant and migrant minorities.

Methods

The Cancer Portal Project enrolls patients at ten hospital-based cancer clinics in New York City with large numbers of immigrant patients, assesses their needs for socioeconomic and psychosocial support services, and then facilitates access to corresponding resources. As part of the Portal intake, patients are asked a series of demographic and health questions,

including their diagnosis. Intakes are conducted in the patients' preferred languages. Most patients at Portal service sites prefer to communicate in languages other than English, most often Spanish and Chinese. This is a nested cohort study of Portal patients and knowledge of their cancer diagnoses at one of the cancer clinics participating in Portal. The study was approved by the NYU Institutional Review Board (the authors' affiliation at the time this study was conducted).

Portal patients were recruited between September 2008 and December 2010. Eligible patients included all adults with a cancer diagnosis who were undergoing treatment at the time of recruitment. Bilingual staff approached all patients in the waiting areas of cancer clinics to ask them if they wished to participate in Portal. Staff administered the Portal intake and a needs assessment survey in patients' preferred languages. To elicit patient knowledge of their diagnosis, as part of this intake, the following question was asked about cancer diagnosis, "What is your most recent primary cancer diagnosis?" Patients were not prompted if they did not know their diagnosis nor were they further probed about understanding of their diagnosis. A review of the electronic medical record was conducted to ascertain patients' cancer diagnoses. Cancer diagnosis was retrieved from oncologists' notes where the diagnosis was documented for the first time. Notes did not include description of the conversation held with the patient and/or family members when the news of the diagnosis was given. Patients were considered to have incorrect knowledge of their cancer diagnosis if: 1) for a solid tumor, they reported a cancer site that was different from that documented in their chart (ie esophageal instead of gastric); 2) for a liquid tumor, they reported the wrong type of cancer (ie leukemia instead of multiple myeloma); 3) they reported a solid tumor when they had a diagnosis of a liquid tumor, or vice versa; 4) they reported that they did not know what type of cancer they had; 5) they correctly described one of the sites the cancer had metastasized to, but did not report the primary diagnosis or reported the wrong primary (ie patient stated "lung", chart indicated primary uterine cancer with metastases to the liver and lung); or 6) they reported one correct cancer site but had 2 primary cancers.

This study assesses patients' self-reported cancer diagnoses compared with physician documented diagnoses in the patients' electronic medical records. As this study was a retrospective comparison, study staff did not intervene if patients were unaware of their correct cancer diagnosis at the time the medical record review was conducted, as the chart review staff did not have contact with the patients.

Descriptive analysis was performed to examine sociodemographic characteristics, self-reported cancer diagnosis, and cancer diagnosis ascertained by chart review. Univariate and multivariate logistic regression was used to evaluate variables that predicted correct knowledge of diagnosis. The conventional p value < 0.05 was considered statistically significant. Statistical analysis was performed using SAS Version 9.2 (SAS Institute Inc., Cary, NC).

Results

Sociodemographic and Cancer Characteristics

434 patients were included in the study. Fifty-eight percent were born in Latin America/Puerto Rico, 31% in Asia, and 5% in the Caribbean. Sixty-eight percent were female, as breast was the most common type of cancer diagnosis. Fifty-eight percent were between the ages of 50 and 69, 61% had lived in the U.S. for 15 years or fewer, and 60% had not completed high school. The majority (87%), preferred to speak a language other than English in the health care setting. The most commonly spoken languages were Spanish (55%) and Chinese (Mandarin/Cantonese) (28%). Twenty-five percent were uninsured. Among those who were insured, 42% had Medicaid for emergency services, and 47% had fee for service Medicaid. Sixty-one percent reported that they did not currently have a primary care physician, and 84% had not been working with a social worker. (Table 1)

The most common cancer diagnoses were breast (29%), cervical (8%), colorectal (7%), and lung (6%). 65% of patients had been diagnosed at least 4 months prior to study recruitment. Sixteen percent of participants had incorrect knowledge of their cancer diagnosis.

Predictors of Correct Knowledge of Diagnosis

Preferred language was dichotomized into those whose preferred language was English compared to those who preferred a non-English language. This variable was a marginally (Wald Chi-Square = 3.3958; $p = 0.0654$) significant predictor of correct knowledge of diagnosis. Those who preferred to speak a non-English language were 2.69 times more likely to give an incorrect diagnosis compared to English speakers (95% C.I. = 0.94, 7.69). (Table 1)

Preliminary univariate analysis suggested that patients diagnosed with cancers ‘below the belt’ were differentially associated with correct knowledge of diagnosis. This was explored and cancer site was found to be a significant predictor of correct knowledge of diagnosis (Wald Chi-Square = 13.715; $p < 0.001$). Patients diagnosed with cancers ‘below the belt’ were 2.78 times more likely to give an incorrect diagnosis compared to those whose cancer involved another site (95% C.I. = 1.62, 4.78). ‘Below the belt’ cancers included bladder, colorectal, gynecological, penile, prostate, and testicular cancers. (Table 1)

Multivariate analysis indicated that both preferred language and cancer site were jointly predictive of correct knowledge of diagnosis (L.R. = 17.01; $p = 0.0002$). Those with cancers ‘below the belt’ were 2.75 times more likely to give an incorrect diagnosis compared to those whose cancer involved another site (95% C.I. = 1.60, 4.74). Those who preferred a non-English language were 2.54 times more likely to give an incorrect diagnosis compared to English speakers (95% C.I. = 0.87, 7.35). To provide more granular detail on cancer site as a predictor of correct knowledge of diagnosis, cancer site was re-categorized into four groups: colorectal (1), male reproductive (penile/prostate/testicular) (2), and gynecological (3) (all ‘below the belt’ cancers); and all other cancer diagnoses (4). Bladder cancer was excluded from the analysis to keep cell sizes reasonably large (there were only 4 patients with bladder cancer). Follow-up contrast statements indicated that patients with colorectal cancers (category 1) were significantly (Wald Chi-Square = 12.23; $p = 0.0005$; O.R. = 3.96;

95% C.I. = 1.83, 8.56) more likely to give an incorrect diagnosis compared to those having all other cancers (category 4). Patients having male reproductive cancers (category 2) were marginally significantly (Wald Chi-Square = 2.88; $p = 0.0897$; O.R. = 3.33; 95% C.I. = 0.80, 13.80) more likely to give an incorrect diagnosis compared to those having all other cancers (category 4). Patients with gynecological cancers (category 3) were marginally significantly (Wald Chi-Square = 2.75; $p = 0.0973$; O.R. = 1.80; 95% C.I. = 0.91, 3.55) more likely to give an incorrect diagnosis compared to those having all other cancers (category 4).

Discussion

In this exploratory study among largely immigrant cancer patients, we found that 16% of patients had incorrect knowledge regarding their cancer diagnosis. While preference to speak a non-English language and a diagnosis of cancer 'below the belt' were predictive, there are potentially a number of other factors also linked to incorrect knowledge. Social, cultural and religious beliefs [34, 10], health literacy [9] and unmet communication [20, 12] needs (separate from the issue of language barriers) may all play a role. Hack et al. conducted a review of the literature related to the communication needs and goals of cancer patients [20]. Several areas of unmet need were described, most of which were related to needs for information related to disease and treatment, including the extent of disease prognosis, and treatment intent, alternatives, and side effects [20]. A multitude of variables have an impact on cancer communication. Miscommunication about terminology can result in poor patient understanding, patients' informational needs may require elicitation by the physician, patients' non-verbal cues should also be attended to, highlighting the importance of patient satisfaction with the relationship with the physician, and a more tailored patient-centered approach responding to the specific needs, skills, beliefs, and emotions of the patient, as well as external and environmental factors may contribute to more successful communication [20, 2, 45]. The review largely discussed the concerns of English-speaking patients, noting that studies among minorities were lacking, although Maly et al. found that older and Latina patients with breast cancer received less information from their physicians compared to those who were younger and non-Latina [20, 26].

Our finding that patients with cancer 'below the belt' were more likely to have incorrect knowledge of their cancer diagnosis warrants further exploration. There is a paucity of research on how diagnosis of a 'below the belt' cancer might influence patient knowledge, although several groups, including the Canadian Cancer Society and the Alberta Cancer Foundation, have developed campaigns and educational and support programs to raise funds and awareness, provide education and support, and provide screening to 'fight cancer below the belt' [3, 11, 19, 39, 37, 15]. Explanatory models of cancer in different cultures may potentially provide some understanding of factors that may impact patient knowledge. In a diverse population of women requiring follow-up for abnormal pap smears, Nelson et al. described Spanish-speaking Latinas and Asian women as being more likely to endorse fatalistic beliefs and misconceptions about cancer, and women who delayed care were more fatalistic and had more misconceptions about cancer [31]. Although further work is needed to assess whether factors such as fatalism and cancer misconceptions specifically impact knowledge of cancer diagnosis, Nelson et al. provide evidence that these factors play a role in behavior related to diagnostic testing for cancer, and therefore may potentially also have a

role in knowledge of diagnosis [31]. In a study in California by Chavez et al., Latina immigrants were more likely than U.S. born Latinas or Caucasian women to have fatalistic beliefs; Latinas who believed fate was a risk for cervical cancer, who would prefer not to know if they had the disease, and believed that there is nothing to prevent it, were less likely to have completed a Pap smear [8]. Among Latinas, fear, fatalism and embarrassment affecting cervical cancer screening behavior [34, 8, 6] may potentially contribute to incorrect knowledge of a cervical cancer diagnosis. Barriers to screening for colorectal cancer among Hispanics include embarrassment, machismo, stigma, and the shame of being seen as sick [1, 17]. These factors may also play a role in incorrect knowledge of a colorectal cancer diagnosis. Among the Chinese population, Yeo et al. used an ethnographic approach to explore the cultural meaning of cancer and illness explanatory models of cancer in Chinese-Australians [44]. The authors found that informants described terms that were consistent with Western biomedical concepts as well as a wide range of traditional Chinese beliefs about illness and cancer, including supernatural explanations derived from Buddhist, Tao, and Confucian philosophies ([44]). These findings may have relevance in the delivery of cancer care for this population, and particularly on how a diagnosis of cancer is understood [44]. Further in depth, qualitative research exploring explanatory models in the understanding of a cancer diagnosis is needed.

This study has limitations. Patients were asked to self-report their cancer diagnosis on one occasion, in a quantitative survey. The survey tool did not allow for a more in depth assessment of patient understanding, which limits interpretation of the findings. Further, it is possible that they had an incorrect knowledge of diagnosis at the time the survey was administered, but later in the course of their disease they may have gained a clear understanding of their diagnosis. However, of note, 65% of patients had received their diagnosis at least four months earlier. Education levels were not shown to be significantly different between patients with correct and incorrect knowledge of their cancer diagnoses, although we did not collect data on health literacy, which could have played a role.

Improving health care practitioners' knowledge of and sensitivity to diverse patients' cultural backgrounds, unique preferences, and their social, economic, and linguistic barriers in interfacing with the health care system should also be addressed. Cultural responsiveness training could help to improve patient-provider communication. In oncology, cultural responsiveness includes the detailed knowledge, awareness, attitudes, and clinical capacities essential for optimal cross-cultural communication in the medical setting [38]. Cultural responsiveness is critical in the oncological context, where cultural factors related to patient health beliefs and values, behaviors, and priorities can affect the decision to seek care, the recognition and reporting of suspicious symptoms, and accurate understanding of diagnostic and treatment information [38, 4, 5, 22]. From the patient perspective, community and clinic/hospital-based programs should be developed to educate and improve patients' self-efficacy in actively participating in their care, including teaching patients how to find information and resources in their preferred languages, how to ask questions, and communicate their needs and concerns in the cross cultural, interpreted medical encounter.

Qualitative studies would be useful in achieving a more nuanced and detailed picture of patient knowledge of their disease. Incorrect knowledge of diagnosis may have a significant

impact on subsequent cancer education, treatment and care, with long-term implications in survivorship and cancer outcomes. Limited English proficient patients may be at particular risk for suboptimal cancer care. Further research addressing the literature gap on cancer communication in the language discordant encounter among immigrant minorities and limited-English proficient populations is needed to inform the development of interventions to effectively address errors in communication.

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Table 1 Sociodemographic Characteristics, Cancer Site, and Knowledge of Cancer Diagnosis, n(%)^a

	All Cancer Patients n=434	Correct Knowledge of Diagnosis n=364(84)	Incorrect Knowledge of Diagnosis n=70(16)	P value ^b
Gender				
Male	137(32)	253(70)	44(63)	0.274
Female	297(68)	111(30)	26(37)	
Age				
20–39	60(14)	50(14)	10(14)	0.522
40–49	78(18)	68(19)	10(14)	
50–59	145(34)	123(34)	22(31)	
60–69	106(24)	89(25)	17(24)	
70–99	44(10)	33(9)	11(16)	
Missing	1	1	0	
Country/territory of birth				
Latin America/Puerto Rico ^c	252(58)	205(56)	47(68)	0.315
Caribbean ^d	22(5)	20(5)	2(3)	
Asia ^e	132(31)	116(32)	16(23)	
Other Countries ^f	27(6)	23(6)	4(6)	
Missing	1	0	1	
Years in the U.S.				
Less than 1 year	20(5)	17(5)	3(5)	0.471
1–5 years	75(18)	59(16)	16(24)	
6–9 years	80(19)	65(18)	15(23)	
10–15 years	85(20)	74(21)	11(17)	
16–20 years	70(16)	63(18)	7(11)	
>20 years	95(22)	81(23)	14(21)	
Missing	9	5	4	
Preferred language				
English	55(13)	51(14)	4(6)	0.065
Non-English languages	378(87)	313(86)	65(94)	
Missing	1	0	1	
Education				
Kindergarten – 5th Grade	73(17)	58(16)	15(23)	0.233
6th – 8th Grade	129(31)	105(30)	24(36)	
Some High School (9th – 11th Grade)	48(11)	40(11)	8(12)	
12th Grade/HS Graduate	101(24)	91(26)	10(15)	
Some college	28(7)	24(7)	4(6)	
College graduate (16 or more years)	26(6)	22(6)	4(6)	
None	15(4)	14(4)	1(2)	
Missing	14	10	4	

	All Cancer Patients n=434	Correct Knowledge of Diagnosis n=364(84)	Incorrect Knowledge of Diagnosis n=70(16)	P value ^b
Health insurance status				
Insured	320(74)	271(75)	49(71)	0.503
Uninsured	111(26)	91(25)	20(29)	
Missing	3	2	1	
Type of health insurance	n=320	n=271	n=49	
Medicaid	152(48)	122(45)	30(61)	0.310
Emergency Medicaid	136(43)	119(44)	17(35)	
Medicare	14(4)	13(5)	1(2)	
Medicaid and Medicare	5(2)	4(1)	1(2)	
Private	8(3)	8(3)	0(0)	
Insured – Not Otherwise Specified	5(2)	5(2)	0(0)	
Do you currently have a primary care provider?				
Yes	163(39)	140(40)	23(33)	0.333
No	260(61)	214(60)	46(67)	
Missing	11	10	1	
Social worker				
Yes	67(16)	53(15)	14(20)	0.259
No	365(84)	309(85)	56(80)	
Don't Know	2	2	0	
Cancer 'below the belt'				
Yes ^g	121(28)	89(24)	32(46)	<0.001
No	313(72)	275(76)	38(54)	

^aPercentages calculated excluding Missing and 'Don't Know' values.

^bP values calculated excluding Missing and 'Don't Know' values.

^cLatin America/Puerto Rico includes Belize, Bolivia, Brazil, Chile, Colombia, Costa Rica, Cuba, Dominican Republic, Ecuador, El Salvador, Guatemala, Honduras, Mexico, Nicaragua, Panama, Peru, Puerto Rico, and Venezuela.

^dThe Caribbean includes Antigua, the Bahamas, Barbados, the Common Wealth of Dominica, Grenada, Guyana, Haiti, Jamaica, St. Lucia, St. Vincent, Trinidad, and the Virgin Islands.

^eAsia includes China, Malaysia, Taiwan, Tibet, Thailand, and the Philippines.

^fOther countries include Algeria, Bangladesh, Egypt, England, Gambia, Ghana, Guinea, Hungary, India, Israel, the Ivory Coast, Morocco, Nepal, Nigeria, Poland, Senegal, Tanzania, and West Africa.

^gIncludes bladder, colorectal, gynecological, penile, prostate, and testicular cancers.