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Sociodemographic differences in fears and mistrust contributing to unwillingness to participate in cancer screenings

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Abstract

Effective provider-patient relationships are vital for positive patient health outcomes. This analysis assessed sociodemographic differences in fears and mistrust related to the provider-patient relationship, which may contribute to unwillingness to participate in cancer screenings (CSs). The data are from a stratified, random-digit dial telephone questionnaire of non-institutionalized households in New York, Maryland, and Puerto Rico. Statistically significant results indicate that Hispanics, compared with Whites, were nearly two times more likely to report that fear of being a “guinea pig” and lacking trust in medical people would make them unwilling to participate in CSs. Additionally, those with less education were over two times more likely to indicate a fear of being embarrassed during the screening would make them unwilling to participate in CSs. These results highlight areas where health professionals can improve interactions with their patients and be attentive to their fears and/or mistrusts to promote CSs utilization.

Keywords

Cancer screening; provider-patient relationship; sociodemographic characteristics

Cancer is the second leading cause of death in the United States.¹ Racial/ethnic disparities are apparent in cancer incidence and mortality rates with Blacks possessing the highest rates, followed by Whites and Hispanics.¹ Although many cancers are preventable or highly treatable if detected early, some groups, including racial/ethnic minorities, do not have ready access to quality preventive care, thus decreasing the likelihood of early diagnosis and subsequent survival of cancer.¹ For example, observed disparities in cervical cancer incidence and mortality rates for Hispanics can be partially attributed to lower rates in screening practices.² In order to achieve health equity, increasing participation in and access

to quality preventive health services, such as cancer screenings, is vital and of national importance according to *Healthy People 2020*.³

Currently, cervical, breast, and colorectal cancer screenings are recommended based on evidence that they can reduce both cancer incidence and mortality.^{4,5} Screening tests may begin as early as age 21 and continue through age 75.⁴ Screening frequency varies and can range from annually to every 10 years, depending upon the type of screening conducted. In the United States, through education and awareness, screening rates for colorectal cancer have increased and have remained stable for breast cancer from 2000–2010.⁶ Despite this trend in screening participation, rates fall below *Healthy People 2020* targets.³ Moreover, cervical screening rates have slightly decreased over the past 10 years.⁶ Racial/ethnic disparities are also present regarding screening behaviors, with screening prevalence lower among minorities.^{6,7} For example, in 2010, a greater proportion of Whites (59.8%) had received their recommended colorectal screenings than of Blacks or Hispanics (55.0%, and 46.5% respectively).⁶

In addition to race/ethnicity, factors such as education, socioeconomic status, availability and use of/access to health care services also impact screening rates. Specifically, those with lower educational attainment are less likely to be screened for breast, cervical, or colorectal cancer.^{6–8} Given the complexity of the United States health care system, lack of education may further hinder an individual's ability to navigate the system, thereby preventing them from fully participating in medical encounters.⁹

While cancer screening is critical to all individuals' health, data clearly indicate that minorities and those less educated are among the most vulnerable.^{10,11} Moreover, minority populations, especially Hispanics, have been under-represented in national and community studies.¹² Therefore, the reasons for disparities in screening behavior are less clear among these populations than others. The few studies that have investigated barriers to cancer screenings among Hispanics have uncovered inhibitors such as accessing quality care and poor provider-patient relationships.^{13,14} Psychosocial barriers, such as patient readiness, fear of embarrassment with the screening procedure, fatalistic beliefs, and lack of awareness have also been noted.^{7,11,13–16} Although health insurance has also been identified as a contributor to differences in screening participation, studies indicate that racial/ethnic disparities persist even among universally insured (e.g., Medicare-insured) populations. This finding highlights the existence of factors other than health insurance that may influence screening behaviors.^{17,18}

The provider-patient relationship is vital for positive patient health outcomes.¹⁹ This relationship is multi-faceted, consisting of issues related to communication, trust, asymmetry, knowledge and decision-making. A provider's role in encouraging and increasing preventive health behaviors, such as cancer screening, is undeniable.^{10,20} Unfortunately, minority patients, especially those not proficient in English, are less likely to receive empathy from physicians, establish rapport with physicians, receive adequate information, and be encouraged to participate in medical decision making.²¹ A provider's failure to recommend a screening test serves as a key barrier to early detection and prevention efforts.²² Specifically, research findings indicate that only half of patients referred for colorectal cancer screening tests complete the procedure, primarily because of ineffective provider-patient communication and test concerns.²³

Within the context of the provider-patient relationship are issues of asymmetry and trust. Asymmetry, defined as “the difference in knowledge, experience, or power between provider and patient,”²⁴[pg. 2126] is particularly relevant in relationships where educational and cultural differences—which often characterize minority populations compared with the

majority—exist. Although it may not be possible to completely overcome asymmetry, it can be minimized.²⁴ Trust remains a critical issue in research and practice when working with minority populations, especially African Americans, and has been shown to affect cancer screening rates.^{11,25–27}

This paper focuses on identifying sociodemographic differences in fears and mistrust related to the provider-patient relationship that may contribute to unwillingness to participate in cancer screenings. The results will assist in developing effective strategies for improving the provider-patient relationship to ultimately improve cancer screening participation. Adherence to ethical principles when working with vulnerable populations is particularly important, given the historical maltreatment of minorities in research and the contemporary differentials in treatment within the health care system.²⁸ Better understanding issues of fears and mistrust are essential to the mission of combating health disparities and reversing these long-standing inequities.

Methods

The data were collected from a disproportionally allocated, stratified, random-digit dial telephone survey of non-institutionalized adults (18 years of age and older) living in New York City, New York; Baltimore, Maryland; and San Juan, Puerto Rico. The random-digit dial questionnaire was administered using a computer assisted telephone interviewing (CATI) system. The survey, the Cancer Screening Questionnaire (CSQ), was developed by a multi-disciplinary, multi-university research team within the New York University (NYU) Oral Cancer RAAHP (Research on Adolescent and Adult Health Promotion) Center, a National Institute of Dental and Craniofacial Research/National Institutes of Health Oral Health Disparities Center and was conducted in 2003. The CSQ was adapted from a previously validated questionnaire, the Tuskegee Legacy Project Questionnaire, which was designed to assess willingness to participate in biomedical research.²⁹ English and Spanish versions of the questionnaire were administered per participant preference. The English version of the questionnaire was pilot-tested among people residing in mainland-U.S. recruitment sites (Baltimore and New York). The Spanish version of the questionnaire was validated through pilot-tests in San Juan, Puerto Rico. The CSQ addresses a range of issues related to the beliefs and willingness to participate in cancer screening examinations in an ethnically diverse sample.

Each of the three cities was sampled independently, and with specific racial/ethnic group targets within each city: 300 African Americans (150 in New York City, 150 in Baltimore); 300 Puerto Rican Hispanics (150 in San Juan, 150 in New York City); and 300 Whites (150 in New York City, 150 in Baltimore). Baltimore, New York, and San Juan were selected as recruitment cities to ensure a wide geographic and racial/ethnic representation. The initial sample allocation across strata (within cities) was based on expected yields computed using exchange incidence data. Sampling weights were produced because of the complex design of the CSQ Study. A more detailed explanation of the study design, as well as justifications of methodological decisions, is described elsewhere.^{30,31} A total of 1,148 participants completed the telephone survey. The original targeted enrollment goal of 300 for each racial/ethnic group was met or exceeded within each city: 355 African Americans, 311 Puerto Rican Hispanics, and 482 non-Hispanic Whites. Response rates (the percentage of completions of residential households dialed) for San Juan, Baltimore, and New York were 58%, 51%, and 45%, respectively, with an overall completion rate (percentage of completed interviews once contact was made with the targeted household subject) of 82.6%. The study was approved by the University of Puerto Rico and New York University Institutional Review Boards.

Measures

This analysis assessed four fear/mistrust variables related to the patient-physician relationship. The variables were measured by asking “How much would the following interfere with your taking part in a cancer screening exam...1) fear of being a “guinea pig;” 2) fear that test results are not kept private/confidential; 3) fear of being embarrassed during the exam; and 4) lacking trust in medical people?” Responses were measured on a five-point Likert response scale: Not at all, A little, Some, A great deal, and Totally Interferes. The responses were collapsed into *Interferes* (A little, Some, A great deal, and Totally Interferes) vs. *Not at all* because the degree of interference was not of interest. The sociodemographic variables assessed were race/ethnicity (African American; Hispanic; White), gender; education level (Less than High School; High School Grad; Some College; College Grad; Professional Degree); age group (18–29 years old; 30–59 years old; 60–94 years old), and income level (less than \$20,000; \$20,000 – \$34,999; \$35,000 – \$49,999; \$50,000 – \$74,999; \$75,000 or more per year).

Statistical analysis

Frequency distributions of sociodemographic variables were computed to show the characteristic distribution of the sample. Sample sizes are unweighted and corresponding percentages are weighted. Multivariate logistic regressions with each of the fears/mistrust variables as the dependent variable and the sociodemographic variables as the independent variables were calculated to assess differences in population groups. Odds ratios (ORs) with 95% confidence intervals (CIs) were produced and were adjusted for each of the other sociodemographic variables in the model. A variable for city was also included in the model to account for any differences between Puerto Ricans residing in New York or those residing in San Juan.³² SAS version 9.1 (SAS Institute Inc., Cary, North Carolina) was used for data analyses and a level of $p < .05$ was deemed statistically significant.

Results

The weighted frequency distributions of the sociodemographic variables are listed in Table 1. The sample included slightly more minorities (African Americans and Hispanics) than Whites. A majority of the sample was between the ages of 30–59 years old, and with lower income levels. Table 2 shows the statistically significant logistic regression results. Hispanics, compared to Whites, were nearly two times more likely to report that fear of being a “guinea pig” (OR=1.94; 95% CI: 1.10 – 3.43) and lacking trust in medical people (OR=1.72; 95% CI: 1.01 – 2.94) would make them unwilling to participate in cancer screenings. Individuals indicating a household income of \$35,000 – \$49,999, compared with \$75,000 or more were less likely to report that a fear of test results not being kept private/confidential (OR=0.42; 95% CI: 0.20 – 0.89) would make them unwilling to participate in cancer screenings. Those with a professional degree were less likely than those with only a college degree to report that fear of being a “guinea pig” would make them unwilling to participate in a cancer screening (OR=0.48; 95% CI: 0.26 – 0.92). Individuals with less than a high school degree (OR=2.74; 95% CI: 1.36 – 5.56) and high school graduates (OR=2.36; 95% CI: 1.32 – 4.22), compared with college graduates, were both over two times more likely to indicate fear of being embarrassed during the screening would make them unwilling to participate in cancer screenings.

Discussion

Cancer screening currently offers opportunities for early detection, diagnosis, and treatment of multiple cancers. Given the disparities in cancer screening utilization and adverse health implications of such disparities, it is critical to understand the factors contributing to the

problem. The physician influences a patient's cancer screening utilization and decision-making.^{20,33} Therefore, the purpose of this analysis was to assess sociodemographic differences between fears and mistrust as related to the provider-patient relationship that may contribute to unwillingness to participate in cancer screenings.

The results indicate that racial/ethnic and educational discrepancies exist regarding fears and mistrust and highlight areas where health professionals can improve in the way they interact with their patients, particularly with Hispanics and those with lower educational attainment. Hispanics lacked trust in medical professionals and feared being a "guinea pig," whereas those less educated cited a fear of being embarrassed during conduct of the cancer screening. This is consistent with studies that illuminate racial/ethnic and educational divides regarding provider-patient relationships and communication. Trust has been a long-standing issue between minorities and the medical establishment.²⁵ The majority of research investigating trust among minorities has focused on African Americans.^{25,34} The results of this study indicate that additional studies or interventions that examine the relationship between trust and medical engagement and asymmetry among the Hispanic population are needed. Based on the definition of the ideal provider-patient encounter provided earlier in this article, it may be that Hispanics do not believe that the medical personnel will act in their best interests. However, according to a study by Chan *et al.*, Hispanic males consider themselves "*machos*" and prefer that cancer screening information come from the doctor rather than from printed materials.¹⁵ Medical providers must understand such preferences and become equipped to provide screening information in a manner that is culturally sensitive so that each person will have a reasonable understanding of the other's beliefs, expectations, and goals.²⁴ Hispanics' fear of being used as a "guinea pig" is similar to findings in breast cancer research with African American women. Results revealed concerns about being used as a "guinea pig,"³³ while other studies identify a broader fear that physicians exposed African American patients to unnecessary risks.²⁵ Additional research should investigate this sentiment among Hispanics. Providers must work to dispel patients' fears and be respectful of the context for their concerns. Given the demographic shift in the United States, which has now labeled Hispanics as the largest minority group,³⁵ significant efforts must be directed towards increasing trust, as well as understanding additional impediments to and promoters of cancer screenings among Hispanics.

The fear of embarrassment expressed by those with less education is not unusual. Fear of embarrassment has been associated with lower levels of adherence to cancer screening recommendations previously.¹⁵ Additionally, less educated people often have lower health literacy, thus making it more difficult to process and act upon prescribed health information. In a recent study by Zapka *et al.*, differences in screening recommendation were noted based on the physicians' perception of patients' ability to comprehend.¹⁰ Specifically, primary care providers who reported that patients usually/sometimes had difficulty understanding colorectal cancer information were less likely to recommend fecal occult blood tests and colonoscopy or colonoscopy only.¹⁰ Moreover, literacy rates are predicted to decline over the next decade, creating additional issues for provider-patient communication.³⁶ Education seems to be increasing in relevance concerning health care and health behaviors. Researchers advocate introducing new models, such as integrating health literacy into adult literacy programs, to equip those with lower literacy to adequately communicate during clinical encounters.³⁶

Other interventions have already garnered success by working with providers and patients.^{16,37} Many consider developing positive provider-patient relationships to be the responsibility of the provider,²² however some would argue that there is mutual responsibility. Therefore, interventions have focused on better equipping physicians for the clinical encounter as well as improving patients' communication skills.³⁷ For example, a

health literacy intervention aimed at improving providers' communication resulted in an increase in colorectal cancer screening recommendations.¹⁶ Moreover, a tailored education-coaching intervention by Street *et al.* in 2010 resulted in cancer patients being more participatory in the encounter and better able to communicate pain.³⁷ Studies have also emphasized the importance of the feedback loop and "closing the loop" (i.e., the patient is able to restate what they have learned during the encounter) to ensure that information transmitted during the clinical encounter is understood by the patient.^{16,22,38} Given the complexities of screening recommendations and that individuals with low educational attainment often have low health literacy, closing the loop is particularly vital. Additionally, communication could be especially difficult when there is a language barrier present (such as with non-English speakers). To further reinforce and encourage adherence to screening recommendations received during the clinical encounter, incorporation of programs such as non-physician patient navigation systems have also been suggested.¹² Such interventions may assist in reaching the *Healthy People 2020* health communication objective of increasing the proportion of people reporting that their providers have satisfactory communication skills, which includes patients being involved in decision making to their satisfaction and providers listening carefully to them, explaining things in a way that they can understand, and perhaps most importantly, showing them respect.³

Improving provider-patient communication holds tremendous promise because it offers one of the more readily changeable contributors to cancer screening adherence. Evidence clearly suggests that there is an urgent need to improve provider-patient communication. However, according to Zapka *et al.* in a colon cancer study, "What to discuss [in the clinical encounter] is both a practical and an ethical question."¹⁰[pg. 518] The guidelines recommend describing the full menu for ethical reasons, perhaps both to stress their equivalence for preventing and detecting colon cancer and to give patients the chance to match their preferences and values to the test options. Will providers make the ethical or practical decision and how can patients be empowered to assist providers in making the ethical decision? The answer to these questions have far-reaching implications for reducing fears and anxieties, thereby increasing cancer screening adherence and eliminating existing disparities.

Limitations

As the Cancer Screening Questionnaire does not obtain data on the respondent's health insurance nor on the race/ethnicity of the respondent's provider, exploration of the influence of those factors on the findings was not possible. Literature demonstrates the race/ethnicity of a provider affects the provider-patient relationship and therefore would have been of more value to our study. Additionally, individuals without health insurance may have limited opportunities to see a provider. Provider-patient communication is an important indicator of a strong provider-patient relationship; however, this factor was also not specifically measured and thus, could not be assessed. These limitations present opportunities for future investigations.

Conclusion

Given that the provider-patient relationship is an important factor in adhering to cancer screening recommendations, this article explores the differences between sociodemographic groups in fears and mistrust, as related to the provider-patient relationship. It is vital that providers treat their patients in an ethical manner to reduce disparities in cancer screening participation. The results highlight areas where health professionals can improve interactions with their patients, particularly with Hispanics and those with lower educational attainment. Health professionals should be aware of and sensitive to patient's fears and mistrusts to promote cancer screening utilization for all.

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Table 1

Weighted frequency distributions of sociodemographic variables (N=1148)

Variables	N	%
Gender		
Male	401	45.5
Female	747	54.5
Race/Ethnicity		
African American	355	31.1
Hispanic	311	22.4
White	482	46.5
Age Group		
18–29 years old	216	22.9
30–59 years old	679	53.4
60–94 years old	253	23.7
Education Level		
Less than High School	182	12.1
High School Grad	312	27.1
Some College	241	22.8
College Grad	252	23.9
Professional Degree	153	14.1
Income Level		
<\$20,000	327	24.2
\$20,000 – \$34,999	246	24.5
\$35,000 – \$49,999	155	16.0
\$50,000 – \$74,999	149	16.7
\$75,000	146	18.6

Table 2

Statistically significant logistic regression * results between sociodemographic characteristics and reporting unwillingness to participate in cancer screenings

Variables	Odds Ratio	95% Confidence Interval	p-value
Fear of being a guinea pig			
Hispanic vs. White	1.94	1.10 – 3.43	0.023
Professional Degree vs. College Grad	0.48	0.26 – 0.92	0.026
Fear that test results are not kept private/confidential			
\$35,000 – \$49,999 vs. \$75,000	0.42	0.20 – 0.89	0.024
Lack of trust in medical people			
Hispanic vs. White	1.72	1.01 – 2.94	0.047
Fear of being embarrassed during the cancer screening			
High School Grad vs. College Grad	2.36	1.32 – 4.22	0.004
Less than High School vs. College Grad	2.74	1.36 – 5.56	0.005

* Adjusted for race/ethnicity, age, gender, educational level, income level, and city