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Race-based Concerns over Understanding Cancer Diagnosis and Treatment Plan: A URCC CCOP Study

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Abstract

Background and Rationale—Many studies have reported that socio-demographics influence individuals' illness perceptions, health beliefs and behaviors, and communication with healthcare service providers. However, studies that have examined the roles of socio-demographics on cancer patients' concerns over understanding the diagnosis and treatment plan are few.

Methods—A total of 973 cancer patients completed an information needs assessment questionnaire prior to starting treatment at 20 geographically distinct clinical sites within the University of Rochester Community Clinical Oncology Program (URCC CCOP) network. Written informed consent was obtained from all participants.

Results—The sample was analyzed according to racial group (White, N = 904; Non-White, N = 69). Preliminary analyses showed no differences between these groups in education (some college vs. no college) and occupation (professional vs. non-professional). The results, however, revealed statistically significant differences between Whites and Non-Whites in concerns over understanding the diagnosis and treatment plan for cancer, even after controlling for gender, age, education, and occupation. A higher proportion of Non-Whites, as compared with Whites, also indicated that more information would have been helpful in dealing with these concerns.

Conclusions—Non-White cancer patients have information needs that are not addressed as well as those of White cancer patients. The findings emphasize the need for oncology professionals to consider and integrate information about patients' socio-demographic and racial backgrounds in their communication with multicultural clientele.

Keywords

Cancer diagnosis and treatment; Healthcare disparities; Race; Healthcare Communication; Socio-demographics

Introduction

In spite of significant advances in oncology research and clinical services, cancer remains a serious public health challenge in the United States and throughout the world. Cancer morbidity and mortality affect people of all social classes and all racial and ethno-cultural origins. Incidence and mortality rates of cancer in the United States are estimated at 1,372,910 and 570,280, respectively, for the year 2005 (Jemal et al. 2005).

A diagnosis of cancer affects patients, their families, and their friends on multiple emotional, physical, psychological, and socioeconomic levels (Honda 2004; Houtzager et al. 2004; Patterson, Holm, & Gurney 2004; Pinto et al. 2002; Thorpe & Howard 2003). Problems dealing with cancer, especially contending with socioeconomic barriers to receiving optimal care, are generally greater for individuals from racial and ethno-cultural groups that are traditionally marginalized (e.g., Blacks), as well as ethnic minorities from developing countries, such as the Caribbean, Latin America, and various regions of Africa (Apelberg, Buckley, & White 2005; Fruchter et al. 1986; Rodriguez, Ward, & Perez-Stable 2005; Shavers & Brown 2002; Shirley et al. 2002).

Generally, difficulties associated with cancer prevention, control and treatment for ethnic minorities are attributed to long standing, socio-political problems. These problems include: racism, discrimination, prejudice, racially-based inequitable distribution of resources, lower socioeconomic status, and differences in cultural perspectives and world views (Carlson & Chamberlain 2004; Gornick et al. 1996; Mullins et al. 2005; Pearlman et al. 1996; Shavers & Brown 2002). For example, Schrag et al. 2001 reported that Blacks were considerably less likely than Whites to receive recommended chemotherapy for Stage III colon cancer even after controlling for socio-demographics, clinical, and environmental factors.

Healthcare disparities based on race, ethnicity, culture, and social class constitute a well known social crisis that remains ill-managed and uncontrolled, especially in medical research and clinical service delivery. The disturbing effects of healthcare inequalities are especially noticeable among ethnic minority immigrants with poor English language proficiency, divergent cultural perspectives, inadequate knowledge about available resources, and a lack of healthcare insurance coverage or financial means of accessing appropriate healthcare services (Braun et al. 2002; Jacobs et al. 2005; Parchment 2004; Peek & Han 2004).

In recent years, however, efforts have been undertaken to address the issue of healthcare disparities in research and services based on race, ethnicity, culture, and socioeconomic status. Examples of such reparative endeavors include the National Cancer Institute's (NCI) establishment of a Special Population Network for Cancer Awareness, Research and Training, Minority-Based Community Clinical Oncology Programs, and the Comprehensive Minority Biomedical Program. These programs aim to eliminate healthcare disparities by implementing community interventions and providing support for training of qualified racial and ethnic minority investigators in cancer prevention and control.

Researchers and funding institutions are recognizing the need to develop culturally sensitive intervention models that are applicable across divergent racial, ethno-cultural, and socioeconomic groups. Many studies have examined the issues of healthcare disparities based on race and socioeconomic status (Ayanian et al. 2005; Baquet et al. 2005; Lillie-Blanton et al. 2000; Rodriguez, Ward, & Perez-Stable 2005; Triverdi et al. 2005). Few studies, however, have examined the roles of specific ethno-cultural variables in healthcare disparities. This gap in the literature is surprising, because previous studies have shown that ethnic and cultural backgrounds influence attributions about illness etiology, help-seeking attitudes, health beliefs and behaviors, and description of symptoms (Baider & Sarell 1983;

Chiu 1996). Many studies have reported significant relationships between culturally-related health beliefs and behaviors. For example, many researchers reported that have reported that many Latina women attribute their breast cancer to unrelated causal factors, such as the ingestion of sugar substitutes, spicy foods and antibiotics; bruises from physical abuse, breast-feeding, fondling, and sexual activity during menstruation (Hubbell 1995; Hubbell 1996; Perez 1992). Other researchers examining explanations of illness among Chinese have reported that members of this group often attributed their cancers to external factors such as bad luck or divine punishment (Ho, Chan, & et al. 2003; Wong-Kim 2003).

Patients' socio-demographic and cultural heritage undoubtedly influences their communications with healthcare providers, as well as the treatment process and outcome (Bottorff et al. 1998; Bretkopf, Pearson, & and Bretkopf 2005; Bruera et al. 2000; Chavez et al. 1997; Gregg & Curry 1994; Perez 1992). Understanding the influence of patients' socio-demographic backgrounds on illness perception, communications in the clinical dyad, and treatment adherence could result in significant improvements in oncology research and clinical service delivery. Such understanding could help increase success rates in cancer prevention and control, as well as reduce or eliminate healthcare disparities based on race, ethnicity, and culture.

Confusion and lack of a clear understanding of the cancer diagnosis and treatment plan could have damaging physical and psychological consequences for patients. A clear comprehension of the diagnosis and treatment plan is critical to cancer patients' decision making and could influence symptom remission and survival rates. Poor communication could lead to inaccuracies in assessment, diagnosis, and intervention, especially in cross-cultural patient-clinician dyads.

The present study examines the role of cancer patients' socio-demographics (i.e., age, race, gender, education, and occupation) in their concerns over understanding the diagnosis and treatment plan. It was hypothesized that concerns over understanding the diagnosis and treatment plan would vary as a function of patients' racial group. Race was also expected to independently predict patients' perceptions of the availability of information, reported use of additional information, and beliefs that more information would have been helpful in dealing with their concerns over understanding the diagnosis and treatment plan.

Method

The present study includes data from 973 (630 females and 343 males) cancer patients, following diagnosis and referral for treatment at 20 geographically separate treatment facilities. These data were collected as part of a longitudinal study, conducted by the University of Rochester Cancer Center Community Clinical Oncology Program, to assess the information needs of cancer patients scheduled to begin their first chemotherapy or radiation therapy regimens. Criteria for inclusion were as follows: a) no previous history of chemotherapy or radiation therapy; b) a diagnosis of breast, lung, genitourinary tract, gynecological, hemotologic, gastrointestinal, or head and neck cancer; c) a life expectancy greater than ten months; and d) age of 18 years of age or older. The Institutional Review Boards of the University of Rochester Medical Center and each participating site approved the protocol. Written informed consent was obtained from each participant.

Participants

Participants ranged in age from 20 to 92 years (mean = 60.5). Of the total sample, approximately 93% (n = 904) indicated that they were White, and 7% (n = 69) indicated that they were Non-White (including Blacks, Latinos, and others). Participants also reported divergent educational achievements that include less than High School (9.6%, n = 93),

completed high school (35.6%, $n = 346$), some college experience (24%, $n = 234$), completed 4-years of college (20.6%, $n = 200$), and completed graduate training (10.3%, $n = 100$). Occupations included managerial and professional (36.3%, $n = 353$), technical and clerical (16.3%, $n = 159$), homemaker (13.1%, $n = 127$), trade and service (12%, $n = 117$), and labor (8.1%, $n = 79$). Approximately 0.5% ($n = 5$) of the participants reported their occupation as “student,” and 13.7% ($n = 133$) did not respond to this item. Preliminary chi-squared analyses on the sample showed no statistically significant differences between Whites and Non-Whites in education (coded as some college vs. no college) and occupation (coded as professional vs. nonprofessional) (both, $ps > 0.05$). (See Table 1.)

Measures

All participants completed an Information Needs Assessment questionnaire (INA), which included items that assessed patients' personal and demographic backgrounds, perception of current health condition, as well as potential concerns related to treatment, self-image, family, and financial issues. The INA also included items about medical, community, and media resources for information about cancer. Patients' concerns over understanding the diagnosis and treatment plan for cancer were assessed on separate 5-point Likert scales that ranged from “1 = no concern” to “5 = a great deal of concern”. In addition, patients' reports of a) whether or not information was available to them, b) if yes, did they use it or not, and c) would more information have been helpful, were also assessed.

Results

Independent sample T-tests were conducted to examine race differences in concerns over understanding the diagnosis and treatment plan. The results showed statistically significant differences between Whites and Non-Whites in concerns over understanding the diagnosis (Mean 2.7 whites, 3.4 Non-Whites; $p = 0.001$) and the treatment plan (Mean 2.7 Whites, 3.4 Non-Whites; $p = 0.001$) for cancer. Two analyses of covariance (ANCOVAs) were conducted to further explore the relationships between race (White and Non-Whites) and cancer patients' concerns over understanding the diagnosis and the treatment plan. The independent variable for both ANCOVAs was race (White and Non-White) and the covariates were education, occupation, age, and gender. The results showed that after controlling for education, occupation, age, and gender, Whites and Non-Whites remained significantly different in their concerns over understanding the diagnosis ($p = 0.003$) and treatment plan ($p = 0.01$) for cancer. Estimated marginal means were 2.7 whites and 3.3 Non-whites for concerns over understanding the diagnosis; and 2.8 white and 3.3 Non-Whites for concerns over understanding the treatment plan.

In addition, Chi-square analyses were conducted to examine race-based differences in cancer patients' perceptions of availability of information, reported use of available information, and indication that additional information would have been helpful in dealing with concerns over understanding the diagnosis and treatment plan. The results showed no significant differences between Whites and Non-Whites in perception of availability of information and reported use of available information (all $ps > .05$). The results, however, showed that Whites and Non-Whites significantly differed in their indications that more information would have been helpful in dealing with their concerns over understanding the diagnosis and treatment ($p < .05$ for both). A higher proportion of Non-Whites (70.3%) than Whites (53.1%) reported that more information would have been helpful in dealing with their concerns over understanding the diagnosis. Similarly, a higher proportion of Non-whites (69.4%) than Whites (53.4%) reported that more information would have been helpful in dealing with their concerns over understanding the treatment plan.

Two logistic regressions (LR) were conducted to further examine the role of race, controlling for the other variables (education, occupation, age, and gender), as a predictor that patients would indicate that additional information would have been helpful. The results showed that race significantly predicted the belief that additional information to deal with concerns over understanding the diagnosis (OR = 1.96, 95% CI = 1.12, 3.42) and the treatment plan (OR = 1.84, 95% CI = 1.05, 3.22). Non-Whites were significantly more likely than Whites to indicate that more information would have been helpful to them in both analyses.

Discussion

The primary goal of the present report was to examine the influence of cancer patients' socio-demographic characteristics on concerns over understanding the diagnosis and treatment plan. We also examined the role of race in patients' perception of availability of information, reported use of available information, and beliefs that additional information would have been helpful to understanding the diagnosis and treatment plan. Overall, the results supported the hypotheses that concerns over understanding the diagnosis and treatment plan for cancer would vary based on race. The findings also confirmed previous findings that socio-demographic backgrounds significantly influence individuals' experiences with various aspects of the healthcare system (Braun, Mokuau, Hunt, Kaanoi, & Gotay 2002; Mullins, Blatt, Barayor, Hui-Wen, & Baquet 2005; Pearlman, Rakowski, Ehrich, & Clark 1996; Shavers & Brown 2002).

Generally, education and occupation are cited as important underlying factors inherent in race-based differences in patients' experiences with the healthcare system. For instance, race comparative studies typically show that Blacks, as compared with Whites, are less educated, more likely to have non-professional jobs, and have lower socioeconomic status. These commonly reported socio-demographic characteristics of Blacks and other ethnic minorities have also been shown to highly correlate with receiving suboptimal healthcare services (Carlson & Chamberlain 2004; Mullins, Blatt, Barayor, Hui-Wen, & Baquet 2005; Triverdi, Zaslavsky, Schneider, & Ayanian 2005).

Interestingly, results of the present study revealed no statistically significant difference between Whites and Non-Whites in education and occupation. This finding of invariance between the groups was surprising, especially because national statistics generally report marked differences in educational and occupational levels between White and Non-White populations in the United States (Bauman & and Graf 2003; Fronczek & and Johnson 2003). The observed comparable levels of education and occupation between the groups could be due to several factors: Non-Whites in the present sample may not be representative of their respective larger racial and ethnic groups.

Given these similarities between Whites and Non-Whites in the present sample, one would logically anticipate parallel findings in other important aspects of individuals' healthcare experiences, such as understanding of the diagnosis and treatment plan. Such anticipation would be based on a notion that individuals would belong to equivalent social milieus and experience comparable levels of exposure to healthcare information, based on similarities in socioeconomic status. In spite of parallel socioeconomic status, as indicated by the educational and occupational levels of participants, the results showed that Non-Whites had significantly greater concerns than Whites over understanding the diagnosis and treatment plan. These observed race-based differences in patients' concerns remained consistent even after adjusting for other socio-demographic variables.

Variations between Whites and Non-Whites in concerns over understanding the diagnosis and treatment plan underscore the importance of race in communication between patients and healthcare service providers. Our findings suggest that concerns of Non-Whites or ethnic minorities are not addressed as well as those of Whites. If this conjecture is accurate, it is a serious social problem, because inconsistency in dealing with cancer patients based on race will result in a widening of the already burdensome and detrimental healthcare disparities confronting ethnic and racial minorities in the United States.

It is also possible that other factors, including personal characteristics of patients and their healthcare providers, communication style, interpersonal and relational attributes, cultural perspectives, and world views are influencing the results. Perhaps the findings are influenced by underlying societal problems, such as racial biases and stereotypical attitudes of healthcare professionals' vis-à-vis patients from traditionally marginalized and disadvantaged social groups. On a more pragmatic level, the differences in concerns over understanding the diagnosis and treatment plan could indicate that cancer prevention and control programs, developed for the general public, are not reaching Non-Whites as effectively as Whites. This supposition is supported by several factors, including the noticeably smaller proportion of racial and ethnic minorities in almost all oncology studies compared to their overall population proportions. In addition, it is also possible that Non-White cancer patients are experiencing more difficulties navigating through the web of available cancer-related information because of socio-cultural differences in health beliefs, attitudes, behaviors, and socially imposed gender roles and expectations.

The cancer diagnosis and treatment processes often result in increased levels of psychosocial apprehension, anger, fear, and confusion for patients and their families. This state of psychological disequilibrium could be aggravated by hurried interactions between patients and oncology professionals brought about by the demands of the clinical setting. Many researchers have reported that personal, situational, and relational factors influence communications among cancer patients, their families, and their oncology service providers, and have proposed training models to improve communication skills in clinical oncology settings (Maguire et al. 1996; National Cancer Institute 2005; Parle, Maguire, & Heaven 1997; Roter et al. 1995). It is possible that personal and situational factors that influence communication in clinical settings are contributing to the present findings. If this assumption is correct, then the development of effective strategies to help improve communication in culturally diverse clinical settings could lead to significant reductions of stress and worries among patients, their families, and their friends. This approach could subsequently result in significant improvements in patients' quality of life (Brown et al. 1999; Fallowfield & Jenkins 1999; Maguire, Faulkner, Booth, Elliott, & Hillier 1996). Studies that examine the influence of a patient's race, ethnicity, and other relevant socio-cultural factors on the treatment process are needed. These studies could facilitate the development of culturally sensitive treatment models that are applicable across divergent racial and ethno-cultural groups.

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Table 1

Clinical and socio-demographic characteristics by racial groups.

Characteristic	Whites N = 904	Non-Whites N = 69
Age		
Mean (SD), years	60.7 (12.8) ^a	56.6 (14.6) ^a
Range, years	20–92	23–90
Sex		
Male	316 (35.0%)	27 (39.1%)
Female	588 (65.0%)	42 (61.9%)
Race		
White	904 (100%)	
Black		52 (75.4%)
Hispanic		5 (7.2%)
Other		12 (17.4%)
Education		
Some College	494 (54.6%)	40 (58.0%)
High School or less	410 (45.4%)	29 (42.0%)
Occupation		
Professional/managerial	330 (36.5%)	23 (33.3%)
Other	574 (63.5%)	46 (66.6%)
Primary cancer site		
Alimentary Tract	78 (8.6%)	5 (7.2%)
Breast	428 (47.3%)	29 (42.0%)
Genitourinary Tract	148 (16.4%)	11 (15.9%)
Gynecologic	46 (5.1%)	6 (8.7%)
Hematologic	67 (7.4%)	7 (10.1%)
Lung	124 (13.7%)	10 (14.5%)
Other	13 (1.4%)	1 (1.4%)

^aThere was a significant difference between these groups ($P < 0.05$)