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Racial differences in information needs during and after cancer treatment: A nationwide, longitudinal survey by the University of Rochester Cancer Center National Cancer Institute Community Oncology Research Program

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Abstract

Purpose—Before treatment, cancer patients need information about side effects and prognosis, while after treatment they need information to transition to survivorship. Research documenting these needs is limited, especially among racial and ethnic minorities. This study evaluated cancer patients' needs according to race both before and after treatment.

Methods—We compared white (n=904) to black (n=52) patients receiving treatment at 17 National Cancer Institute Community Oncology Research Program (NCORP) sites on their cancer-related concerns and need for information before and after cancer treatment. Two-sample t-test and chi-squared analyses were used to assess group differences.

Results—Compared to white patients, black patients reported significantly higher concerns about diet (44.3% vs. 25.4 %,), and exercise (40.4% vs. 19.7 %,) during the course of treatment. Compared to whites, blacks also had significantly higher concern about treatment-related issues (white vs. black mean: 25.52 vs. 31.78), self-image issues (7.03 vs. 8.60), family-related issues (10.44 vs. 12.84), and financial concerns (6.42 vs 8.90, all p<0.05). Blacks, compared to whites, also had significantly greater post-treatment information needs regarding follow-up tests (8.17 vs 9.44), stress management (4.12 vs. 4.89), and handling stigma after cancer treatment (4.21 vs 4.89). [all p < 0.05].

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Conclusion—Pre-treatment concerns and post-treatment information needs differed by race, with black patients reporting greater information needs and concerns. In clinical practice, tailored approaches may work particularly well in addressing the needs and concerns of black patients.

Keywords

Race; cancer survivors; information needs; black and white patients

Introduction

Cancer patients' information needs vary considerably based on sociocultural factors and on their position on the cancer continuum [1]. Before treatment, cancer patients need information about side effects and prognosis, while after treatment they need information to help transition to survivorship and improve their coping and stress management skills [2]. Most patients have multiple sources for obtaining information about cancer treatment and care including: healthcare providers, publications, phone assistance, newspapers, television, radio and internet [3,4]. Preference for source of information is one factor that varies among cancer patients [3]. However, cancer-related information that is developed and tested solely within one sociocultural group may overlook factors associated with the relevance and utilization of that information in other groups of cancer patients. One such underlying factor is the race, ethnicity, or culture of individual patients.

Race, ethnicity, and cultural differences not only moderate individuals' behaviors, responses to treatment, and health [5–7], but also determine how and where cancer patients seek health-related information [8–10]. Kakai et al. [8] argued that while higher educational attainment influences patients' search for information, patients' race/ethnicity overrides their educational level in shaping their choices regarding health information. Studies have found that blacks/African Americans obtain cancer treatment information from media and word of mouth and that they prefer to hear patient testimonials [11]. Accounting for these cultural differences could help health professionals better meet their patients' information needs as well as improve treatment satisfaction [12, 13] and bolster patients' coping and stress management skills [14–16].

We extend earlier research on racial differences in seeking health-related information by assessing cancer patients' concerns, sources of information, and accessibility of information in association with patient race using a longitudinal survey (i.e., pre- and post-treatment). The study was conducted by the University of Rochester Cancer Community Oncology Research Program (URCC-NCORP; formerly University of Rochester Cancer Center Community Clinical Oncology Program, URCC CCOP) at 17 different treatment facilities.

Methods

Survey data were collected to assess the information needs of cancer patients receiving chemotherapy or radiation therapy prior to and following treatment. Eligibility included: no prior history of chemotherapy or radiation therapy; a diagnosis of breast, lung, genitourinary tract, gynecological, hematologic, gastrointestinal, or head and neck cancer; a life expectancy greater than ten months; and being 18 years of age or older. The study was

approved by the Institutional Review Board of the University of Rochester Medical Center. Written informed consent was obtained from each participant.

Measures

Prior to treatment—Patients provided demographic information including age, gender, race, marital status, occupation, educational background and the kind of cancer treatment they had undergone or were going to undergo. Patients were also asked to identify (i.e., yes or no) the sources of information they used from a list of nine medical sources (e.g. cancer care physicians, primary care physicians, nurses, social workers, nutritionists, American Cancer Society etc.) and five community sources (e.g. support groups, family members, religious community, other cancer patients etc.). Media sources such as internet, television, radio, etc., were listed, but as only 20% of patients in the overall sample used those sources, we excluded them from the analyses.

Patients were asked to describe their level of concern regarding their current illness and upcoming treatment. Four scales were used and each scale has a list of items from which the patients chose. Each item assessed degree of concern using a five point Likert-type scale ranging from “1, no concern” to “5, a great deal of concern.” The scales were: (a) treatment concerns, which consisted of seven items including “eating right,” “exercising,” “knowing if treatment will work,” and “understanding the diagnosis;” (b) self-image concerns, which consisted of three items including “being disfigured or scarred,” “being a burden to family and friends,” and “becoming isolated;” (c) family issues, which consisted of three items including “being able to have children,” “caring for my family,” and “easing my family’s stress,” and (d) financial issues, which consisted of three items including “maintaining my job,” “paying for care not covered by insurance” and “finding community services.” The internal consistency of each of the concern scales was evaluated by Cronbach’s alphas; all four scales had internal consistency above .80 and were thus acceptably consistent.

Following treatment—Within two weeks following the completion of treatments, participants were asked to describe their current need for information in four domains. Items in each domain assessed information needs on a three-point scale with response options of “1, I do not need information,” “2, I need more information,” and “3, I need much more information.” The scales were: (a) follow-ups, which had five items including “What tests or other follow-up should I have?” “What symptoms should prompt me to call my doctor?” (b) healthy lifestyle, which had six items including “How do I get information about exercising after cancer?” “How do I get information about nutrition after cancer?” (c) Stigma and self-image, which had three items including “how do I learn to deal with people who may avoid me?” “How do I become sexually comfortable with myself after cancer and cancer treatment,” and (e) stress management, which had two items including “how can I manage my anxiety about recurrence?” “How should I talk to my family and friends about my cancer?” The Cronbach’s alphas for three of the information domain items were above .70 thus acceptably consistent. However, the Cronbach’s alpha for stress management items was .53, possibly due to the fact that this scale included only two items.

Statistical Analyses

Patients were dichotomized as either white or black/African American on the basis of self-identification. Descriptive statistics were used to describe the demographic characteristics. Two-sample t-test and chi-squared analyses were done to compare white and black patients on study measures. Analysis of covariance was used to examine differences between whites and blacks in concerns and information needs controlling for other demographic factors. We executed multiple analyses without adjusting for the p-values because this is an exploratory study. All data were analyzed using the IBM SPSS Statistics 22 for Windows.

Results

Demographics

A total of 985 cancer patients (928 whites, 57 blacks) consented to participate in the study and provided demographic information. However, because of loss to follow-up and missing data we included data collected from 956 patients (904 whites and 52 blacks) in our pre-treatment analyses and 740 (704 whites and 36 blacks) in our post-treatment analyses. The mean age at pre-treatment was 61 years (SD =13, range = 20 -92). There were no statistically significant differences at pre-treatment between whites and blacks in age, occupation, and marital status, but the educational attainment of whites was significantly greater than blacks (10.1 vs. 5.3, respectively; $p < 0.05$). There were no statistically significant differences between those who did and those who did not complete the post-treatment assessment in occupation, marital status, and education. The medical and demographic characteristics of the patients are presented in Table 1.

Pre-Treatment Sources of Information—Chi-squared analyses of the 14 sources of information regarding cancer concerns and care revealed significant differences between white and blacks on only two sources, i.e., from their religious community and from other cancer patients. More blacks (55%) than whites (39%) reported accessing cancer information from their religious community ($p < 0.05$). However, more whites (66%) than blacks (42%) reported accessing cancer information from other cancer patients ($p < 0.01$). Very few whites (11%) and blacks (10%) used cancer support groups as their sources of cancer information in large numbers (See Table 1).

Pre-Treatment Concerns—Three separate analyses were executed to assess patients' pre-treatment concerns. First, the four pre-treatment concerns subscales were summed and analyzed using two-sample t-tests. This analysis showed that whites had significantly lower concern than blacks on all four subscales, i.e., treatment-related issues (white vs. black mean: 25.52 vs. 31.78), self-image issues (7.03 vs. 8.60), family-related issues (10.44 vs. 12.84), and financial concerns (6.42 vs 8.90, all $p < 0.05$). Second, analyses of covariance (ANCOVA) were employed to further explore the difference between white and black patients' pre-treatment concerns. The ANCOVA results showed that after controlling for education, age and gender, there remained significant differences between white and black patients on all the pre-treatment concern variables. Finally, analyses of individual items were conducted by chi-squared tests, which showed that blacks had greater concerns about each item than Whites. For instance, black patients reported significantly higher concerns than

whites about diet (44.3% vs. 25.4 %,) and exercise (40.4% vs. 19.7 %,) during the course of treatment (all items $p < 0.05$). See Table 2 for details.

Post-Treatment Information Needs—Two-sample t-test analyses for patients' post-treatment information needs revealed a significant difference between whites' and blacks' information needs for follow-ups and tests (8.18 vs. 9.44), information about stress management (4.11 vs 4.89), and information to handle stigma (4.22 vs 4.89; all $p < 0.05$). There was no significant difference between whites and blacks on need for information about leading a healthy lifestyle. After controlling for education, occupation, age and gender, ANCOVA results showed that there were significant differences between white and black patients on all the post treatment information need variables. Exploratory analyses of individual items for post-treatment information needs were conducted by chi-square analyses. A significantly higher proportion of blacks than whites needed more information about follow-up tests (72% vs. 58%), side effects (69% vs. 59%), frequency of follow-ups (61.1% vs. 46.8%), and management of anxiety about reoccurrence (64% vs. 53%; all $p < 0.05$). Similarly, 30% of black patients compared to 13% of whites reported that they needed more information about healthy living after their cancer treatments ended ($p < 0.05$). See Table 2 for details.

Discussion

The current study found significant differences between white patients and black patients about their illness and treatment concerns. At baseline, as expected, both groups were very concerned about cancer treatment, as well as about financial, family and self-image issues. However, the black/African American minority group were more likely to express concern about cancer treatment issues such as being able to engage in exercise, choosing a healthy diet, and understanding the diagnosis and treatment plan. This finding dovetails with previous research [17] showing that minority patients, especially black cancer patients, may be more likely to lead sedentary lifestyles than their white counterparts. Minority cancer patients might therefore be concerned about being able to exercise due to physical inactivity prior to their diagnosis, compounded by fatigue or physical function difficulties due to cancer. Black patients' concerns about financial issues and being able to care for their family members during cancer treatment could similarly be attributed to environmental factors, other socioeconomic factors, and lack of support systems. Previous studies have indicated that minorities are disproportionately affected by cancer because of socio-economic variables [18, 19]. Further research is needed to disentangle the mechanistic underpinnings of treatment, financial, and family concerns among black patients.

In terms of post-treatment information needs, black patients in this study were more likely to report that they needed information about treatment follow-up and tests. This finding is consistent with a study by Royak-Schaler et al. [20], who concluded that there was difference in information needs between black/African American cancer patients and their physicians. The demand for more information among black patients could mean that the information received by minority patients did not directly address their needs. Black/African American patients were more likely to express concern about the efficacy of treatment. This concern could stem from the lack of trust some minorities have in the healthcare system in

general. This finding echoes previous research showing that minority patients distrust their physicians and the healthcare system [21–23].

The findings of the study show that the majority of the white patients were more likely to use primary care physicians' information sources than black patients. This could reflect another finding of the study, that white patients were more likely to follow-up with their primary care physicians than black patients. Surprisingly, few non-Hispanic Whites and black/African American patients used professional cancer organizations such as the American Cancer Society or National Cancer Institute as sources of information. Though the American Cancer Society and National Cancer Institute may have credible cancer treatment and prevention information that can be of great value to cancer patients, the results of this study show that both white and black patients may not be utilizing the resources of these institutions. This may be due to a lack of access to the resources of these institutions or because they find it difficult to navigate through their websites.

The study also shows that black patients were more likely to obtain information from their religious community. A previous study found that racial/ethnic minority patients rely on their religion for information and support [24], and this study replicates the finding that black cancer patients may be more likely to depend on their religious community for their informational needs. By contrast, whites were more inclined to access information from other cancer patients. This finding contradicts Muñoz-Antonia et al (11), who asserted that black patients rely on testimonies of other cancer patients. Further research is necessary to assess whether this small but nationwide sample of patients is representative of larger communities of black patients in the United States. Surprisingly, neither white nor black patients utilized cancer support groups as a common source of cancer information. It may be that neither white nor black patients had easy access to support groups. It may also mean that patients did not want to tell others about their cancer situation or that they simply did not trust those support systems.

Limitations

Findings of this study must be interpreted in the light of several limitations. One limitation is that the study used self-report questionnaires, which could introduce biases including social desirability bias. Specifically, it is possible that the respondents reported what they believed the researcher was expecting to see. Another possible bias in this study is sampling bias, since random selection was not used in recruiting participants to the study. The parent study also did not assess cultural differences that may have influenced the responses of black and white participants; as such, we treated black and white participants as two dichotomous and distinct groups. The classification of the patients into white and black groups is consistent with previous research in this area [25].

Furthermore, racial differences were noted even when we controlled for demographic factors such as education, occupation, age, and gender, indicating that the dichotomized race still explains some variance in information needs and concerns when accounting for potential confounders. The final major limitation of the study is the small sample size of the black patients, as this precluded further subgroup analysis among black patients. Results of this study should be viewed as preliminary and should be replicated in a larger and more diverse

sample of black and white patients. Notwithstanding with the limitations, this study offers a unique first look at information needs and concerns among black vs. white patients, contributes to the body of knowledge about information needs, and could inform future research in this area.

Implications for practice

The findings of this study highlight the unique importance of race in influencing cancer patients' information needs. After adjusting for demographic characteristics of the participants, there remained significant differences between white and black patients' concerns about cancer illness and treatment. Therefore, health officials who are caring for cancer patients, especially different ethnic groups, should integrate the socio-cultural differences of patients into their planning and implementation processes. Second, it is also clear that race influences patients' utilization of sources of information. This means specific information sources should be targeted in order to meet the information needs of diverse groups of patients. Finally, black patients desire additional information about tests and follow-ups, healthy living, stress management, and how to handle stigmas, but informational materials may not be tailored or targeted to this community. Health professionals should make conscious efforts to build trust among black cancer patients and provide more information about healthy living and stress management. Future research should consider interventions that train staff to build trust and consider using interventions delivered by peers using Community Based Participatory Research (CBPR) models to deliver the information delivered to patients and survivors.

In conclusion, the array of cancer patients' concerns, informational needs and sources, and their reliability vary by race. The findings show that health professionals need to understand the socio-demographic and racial backgrounds of their clientele in order to provide services to meet the needs of their patients.

Acknowledgments

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Table 1

Demographic characteristics, clinical and sources of information by racial group

	White (n = 928) n (%)	Black (n = 57) n (%)
Age		
Mean (SD) years	60.75 (12.74)	58.61 (13.02)
Range years	20 – 92	33 – 80
Gender		
Male	329 (35.5)	24 (42.1)
Female	599 (64.5)	33 (57.9)
Married		
Yes	665 (71.7)	28 (49.1)
NO	263 (28.4)	29 (50.8)
Education		
Graduate Degree	94 (10.1)	3 (5.3) *
Bachelor Degree	196 (21.1)	10 (17.5)
Associate Degree	215 (23.2)	17 (29.8)
High School degree	342 (36.9)	15(26.3)
Less than High School	81 (8.7)	12 (21.1)
Diagnosis		
Hematologic	67 (7.2)	4 (7.0)
Lung cancer	124 (13.4)	9 (15.8)
Genitourinary track cancer	161 (174)	12 (21.1)
Breast Cancer Other	438 (47.2)	26 (45.6)
	Information source (n = 904)	Information Source (n = 52)
Medical		
Cancer Care Physician	856 (97)	47 (95.9)
Information sheet from Doctor	738 (84.4)	39 (79.6)
Nurse	717 (82)	41 (83.7)
Primary Care Physicians	628 (72)	31 (63.3)
Waiting Room materials	435 (49.8)	29 (59.2)
American Cancer Society	370 (42)	16 (32.7)
National Cancer Institute	266 (30.5)	10 (20.8)
Nutritionists	112 (12.8)	10 (20.8)
Social Workers	79 (9)	9 (18.4) *
Community		
Family members	727 (83.2)	39 (79.6)
Friends	723 (82.7)	41 (83.7)
Other cancer patients	578 (66.1)	24 (42.10) *
Religious Community	343 (39.2)	27 (55.1) *
Support group	93 (10.6)	5 (10.2)

* Significantly different from whites ($p < 0.05$)

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Table 2

Pre-treatment concerns and post information need by White and Black patients

	White (n = 904)	Black (n = 52)
	mean (SD)	mean (SD)
Concern variables	Degree of concern [†]	Degree of concern
Treatment-related	25.52 (9.48)	31.78 (9.16) *
Self-image-related	7.03 (3.35)	8.60 (3.80) *
Family-related	10.44 (4.15)	12.84 (5.51) *
Financial Concerns	6.42 (3.30)	8.90 (4.07) *
Information need variables	Degree of info need (n=704) ^{††}	Degree of info need (n=36)
Treatment follow-up information	8.18 (2.64)	9.44 (3.52) *
Healthy lifestyle information	10.04 (3.14)	11.03 (4.03)
Stress management information	4.11(1.34)	4.89 (1.98) *
Stigma and Self-image information	4.22 (1.36)	4.89 (1.89) *

* Significantly different from whites (p<0.05)

[†] Degree of concerns for scales were assessed on different scales: treatment-related scale 7–35; self-image and family scales 3–15; and financial scale 2–10 in which higher numbers denote greater concern

^{††} Degree of information need scales were assessed on: Treatment follow-up scale 3 – 15; healthy lifestyle scale 3 – 18; stress management scale 3 – 6 and stigma and self-image information scale 3 – 15 in which higher numbers denote greater information need