

Differences in psychosocial stressors between black and white cancer patients

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Background Screening patients with cancer for psychosocial distress enables providers to make referrals to resources early in the course of treatment. There is some evidence of differential impact of cancer on mental health between racial/ethnic groups, but the results are not consistent.

Objectives To examine differences in overall distress and individual psychosocial stressors between black and white cancer patients at first visit to the cancer center.

Methods This study included all invasive cancer patients from an urban, academic cancer center in the Midwest who completed the National Comprehensive Cancer Network (NCCN) Distress Thermometer from January 1, 2015 to February 19, 2016. Comparisons were made on overall distress score and for each individual stressor in the instrument. Categorical variables were compared using chi-square or Fisher exact test. Logistic regression was used to predict high distress by race adjusting for sex, age, and cancer type.

Results A total of 933 patients with invasive cancer completed the NCCN distress screening tool. The full sample was 16.9% black, and 32.6% of the sample indicated high distress on their first visit. There was no difference in overall distress score between black and white patients. Black patients more frequently identified housing, ability to have children, and loss of interest as sources of distress, whereas white patients more often identified treatment decisions and nervousness.

Limitations Limitations include limited capacity to explore demographic differences in our sample; some patients did not receive the distress screening tool thus some cancer sites are proportionally more represented in the sample.

Conclusions The findings do not indicate overall distress differences between black and white patients, but they do indicate differences in the source of distress, possibly indicating different resource needs or intervention strategies between black and white cancer patients.

For patients with cancer, acknowledgment of mental and emotional distress is critically important when developing and implementing a treatment plan. The psychosocial distress associated with cancer diagnosis and treatment can have an impact on a patient's quality of life, influence a patient's ability to adhere to treatment regimens, and increase cost of care.¹⁻⁴ Rates of depression have been reported to range from 8%-36%, with a 29% risk of anxiety in cancer patients.^{5,6} Emotional distress is linked to increased hopelessness about their cancer diagnosis, increased issues with chronic pain, and negative treatment outcomes.⁷ Timely screening of psychosocial distress at the first clinical visit enables providers to make appropriate referrals to resources early in their course of treatment; however, referrals to psychosocial interventions remain infrequent nationwide in the United States.⁸

There is some evidence of a differential impact of cancer on mental health diagnoses between

racial/ethnic groups; however, results are not entirely consistent across studies. Using the Kessler Psychological Distress Scale (K6) score, Alcala and colleagues found that cancer was more detrimental to mental health for black patients than for non-Hispanic white patients.⁹ Black breast cancer survivors have also been shown to be more likely to stop working during the early phases of their treatment, indicating that they and their physicians need to take steps to minimize long-term employment consequences.¹⁰ However, in a study of women with breast cancer, black women reported fewer depressive symptoms than did non-Hispanic whites.¹¹

The American College of Surgeons' Commission on Cancer (ACS CoC) developed a set of Continuum of Care standards in 2012, including the implementation of psychosocial distress screening for patients with cancer. Since 2015, all accredited cancer programs are now required to evaluate these patients for signs of distress during at least

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1 pivotal physician visit.¹² The National Comprehensive Cancer Network (NCCN) Clinical Practice Guidelines in Oncology has developed a tool that provides a mechanism for meeting the requirements of the ACS CoC accreditation requirements. The NCCN defines distress in cancer as “a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment.”¹³ The recommendation of the NCCN is to provide a

brief screening for psychosocial distress to identify individuals in need of additional support and to provide referrals for patients at high risk of psychosocial distress. The NCCN Distress Thermometer screening tool has been widely accepted as an effective method of identifying and characterizing distress. The NCCN tool provides a visual analogue scale for patients to rate their current distress on a scale of 1-10, as well as a problem checklist. The problem checklist includes 22 stressors addressing the practical, spiritual/religious, emotional, and physical concerns of patients. Although the NCCN tool is used widely, differences in distress scores between black and white cancer patients have not been previously described. The purpose of the study was to compare the global distress screening scores of black and white patients at an academic comprehensive cancer center in the Midwest. A second objective was to examine the distribution of individual stressors between black and white women.

Methods

Study sample

The study included all cancer patients from a cancer center in the Midwest who completed the NCCN distress thermometer during January 1, 2015-February 19, 2016. The patient population for this cancer center was primarily non-Hispanic white and non-Hispanic black, therefore, only patients identifying as non-Hispanic white and non-Hispanic black are included in this analysis. As part of routine clinical care, patients are asked to complete the NCCN distress thermometer at their first visit to the center. All patients in this analytic sample were newly diagnosed patients. Some patients also completed the NCCN screening tool at additional appointments; therefore, for patients with more than 1 completed tool, only the first dis-

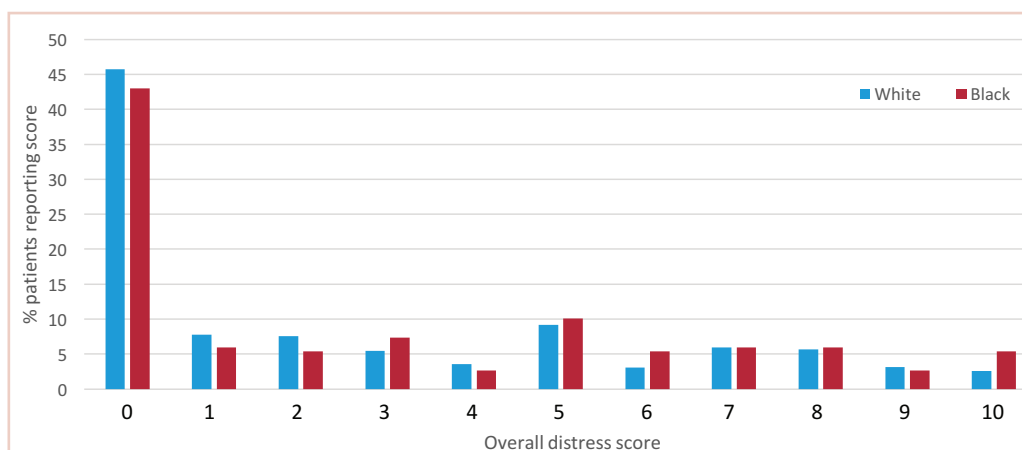


FIGURE Distribution of overall distress scores for black and white cancer patients. Distress levels were assessed using the National Comprehensive cancer networkd distress thermometer (range, 0 [no distress] to 10 [extreme distress]). The overall distress score was categorized into low distress (<4) and high distress (\geq 4) for analysis.

tress screening was used in this analysis. Overall scores and individual stressor scores were entered into the electronic medical record by clinic staff at the time the patients were roomed for their visit. Patient demographics were collected through a reporting mechanism within the electronic medical record that allows for monitoring of the psychosocial screening process.

Variables

Race was assessed through self-report and classified as non-Hispanic white and non-Hispanic black. There were not enough patients of any other racial/ethnic group to be included in this analysis. Age was categorized as 18-40 years, 41-60 years, 61-84 years, and 85 years and older. Cancer type was grouped as follows: head and neck cancer, gastrointestinal cancer (esophagus, stomach, small intestine, colon, rectum, anus), hepatobiliary (liver, gallbladder, pancreas), sarcoma (bone and soft tissue), melanoma, non-melanoma skin cancer, breast cancer, genitourinary (prostate, kidney, bladder), hematologic, and brain.

Two primary outcomes were assessed: overall distress, and each individual problem indicator. Overall distress was assessed using the thermometer visual analog rating (the thermometer rating of the NCCN screening tool) where possible values range from 0 (no distress) to 10 (extreme distress). The overall distress score was categorized into low distress (<4) and high distress (\geq 4) for analysis. The response options for individual stressors on the problem list are Yes or No for each of 17 discrete stressors: child care, housing, insurance/financial, transportation, work/school, treatment decisions, dealing with children, dealing with partner, ability to have children, family health issues, depression, fears, nervousness, sadness, worry, loss of interest, and spiritual/religious concerns. Physical complaints were not assessed

TABLE 1 Demographics for the participants by race

Demographic	Race		Chi-square	P-value
	White (n = 775)	Black (n = 158)		
Sex			3.02	.08
Female	291 (37.6)	71 (44.9)		
Male	484 (62.4)	87 (55.1)		
Age, y			3.27	.35
18-40	68 (8.8)	20 (12.7)		
41-60	306 (39.5)	66 (41.8)		
61-84	380 (49.0)	68 (43.0)		
85+	21 (2.7)	4 (2.5)		
Type of cancer			51.1	<.0001
Head & neck	271 (35.0)	53 (33.5)		
Gastrointestinal	63 (8.1)	16 (10.1)		
Hepatobiliary	41 (5.3)	16 (10.1)		
Sarcoma	46 (5.9)	18 (11.4)		
Melanoma	108 (13.9)	0 (0)		
Nonmelanoma skin	42 (5.4)	2 (1.3)		
Breast	31 (4.0)	14 (8.9)		
Genitourinary	79 (10.2)	26 (16.5)		
Hematologic	89 (11.5)	12 (7.6)		
Brain	5 (0.6)	1 (0.6)		

in this study. Comparisons were made between white and black patients on overall distress score as well as for each individual psychosocial stressor.

Data analysis

Descriptive statistics (counts and proportions or means and standard deviations) were calculated stratified by race. Categorical variables were compared by race using chi-square or Fisher exact test. Logistic regression was used to predict high distress by race adjusting for sex, age, and cancer type. All analyses were conducted using SAS 9.4 (Cary, NJ).

This study was reviewed and approved by the Saint Louis University Institutional Review Board (protocol number 26269).

Results

A total of 933 patients with cancer completed the NCCN distress screening tool. Of that total, 45 patients did not complete the overall distress score thermometer, but did complete the checklist of individual stressors. Those 45 patients were excluded from the logistic regression analysis for overall distress score, but included on comparisons of individual stressors. The distribution of overall distress

scores by race can be seen in the Figure. Briefly, the full sample was 16.9% black and 38.8% female. In all, 32.6% of the sample indicated high distress on the distress thermometer at their first visit. Demographics for the participants stratified by race are reported in Table 1. There was no statistically significant difference in the gender or age distribution between black and white patients. Cancer distribution did vary by race. Black patients were proportionally more represented in gastrointestinal cancers, hepatobiliary cancers, sarcomas, breast cancer, and genitourinary cancers. White patients were proportionally more represented in melanoma, nonmelanoma skin cancers, and hematologic cancers.

Table 2 presents bivariate comparisons on overall distress and individual stressors between black and white patients. There was no difference in the high distress between black and white patients in bivariate analysis (31.9% and 36.1%, respectively, $P = .30$). However, there were differences in the individual stressors identified for each racial group (Table 2). White patients, compared with black patients, more frequently identified treatment decisions (17.6% vs 10.1%, $P = .02$) and nervousness (26.8% vs 18.4%, $P = .02$) as sources of distress. Black patients, compared with white patients, more frequently identified housing (5.1% vs 1.7%, $P = .009$), the ability to have children (2.5% vs 0.4%, $P = .02$), and loss of interest (15.2% vs 8.9%, $P = .02$) as sources of distress. Distress scores did not differ between black and white patients for child care, insurance or financial issues, transportation, work or school, dealing with children, dealing with partners, family health issues, depression, fears, sadness, worry, or spiritual or religious concerns.

Table 3 presents the results from the logistic analysis predicting high distress. In adjusted analysis, black race did not predict high distress (OR, 0.94; 95% confidence interval [CI], 0.62-1.44). High distress was associated with sex, age, and some cancer categories. Women had 77% higher odds of high distress compared with men (OR, 1.77; 95% CI, 1.25-2.51). Compared with patients aged 18-44 years, patients aged 61-84 had 43% lower odds of high distress (OR, 0.57; 95% CI, 0.33-0.98), and patients aged 85 and older had 74% lower odds of high distress (OR, 0.26; 95% CI, 0.07-0.98). There was no statistically significant difference between patients aged 18-40 and those aged 41-60 for high distress (OR, 1.01; 95% CI, 0.59-1.73).

TABLE 2 Chi-square analysis comparing scores for individual stressor categories between black and white cancer patients

Stressors	Race, n (%)		Chi-square	P-value
	White (n = 775)	Black (n = 158)		
Overall distress				
High	247 (31.9)	57 (36.1)	1.05	.30
Low	528 (68.1)	101 (63.9)		
Practical problems				
Child care	7 (0.9)	3 (1.9)	1.2	.27
Housing	13 (1.7)	8 (5.1)	6.8	.009
Insurance/financial	66 (8.5)	19 (12.0)	2.0	.16
Transportation	31 (4.0)	9 (5.7)	0.9	.34
Work/school	31 (4.0)	8 (5.1)	0.4	.54
Treatment decisions	136 (17.6)	16 (10.1)	5.3	.02
Family problems				
Dealing with children	18 (2.3)	5 (3.2)	0.4	.53
Dealing with partner	27 (3.5)	8 (5.1)	0.9	.34
Ability to have children	3 (0.4)	4 (2.5)	Not applicable	.02*
Family health issues	65 (8.4)	12 (7.6)	0.1	.74
Emotional problems				
Depression	103 (13.3)	27 (17.1)	1.6	.21
Fears	147 (19.0)	28 (17.7)	0.1	.71
Nervousness	208 (26.8)	29 (18.4)	5.0	.02
Sadness	103 (13.3)	23 (14.6)	0.2	.67
Worry	229 (29.6)	43 (27.2)	0.3	.56
Loss of interest	69 (8.9)	24 (15.2)	5.8	.02
Spiritual/religious concerns	8 (1.0)	3 (1.9)	Not applicable	.41*

*Fisher exact test

Discussion

Management of patients with cancer continues to evolve. Although a tremendous amount of importance is still placed on the pathophysiology of cancer and its prescribed treatments, more emphasis is being assigned to the physical and psychosocial effects of cancer on these patients. In 2008, the Institute of Medicine published a report that examined the psychosocial health of patients with cancer.¹⁴ The report recommended that all cancer care should ensure the provision of appropriate psychosocial health services by facilitating effective communication between patients and care providers, identifying each patient's psychosocial health needs, coordinating referrals for psychosocial services and monitoring efficacy of psychosocial interventions. The inclusion of psychosocial distress screening in all cancer programs accredited by the ACS CoC helped to prioritize the identification and treatment of psychosocial issues for all cancer patients.

The present study is the first of its kind to compare the individual stressors identified through psychosocial distress screening between black and white cancer patients. In our sample, 304 of 933 patients (32%) reported high distress, with a total score of ≥ 4 . Previous research on overall distress difference across race/ethnicity is mixed. VanHoose and colleagues found no difference in overall distress between racial groups,¹⁵ Alcalá and colleagues found higher overall distress in black patients with cancer compared with white patients with cancer,⁹ and Culver and colleagues found black women with breast cancer had lower overall distress compared with white women.¹¹ We found no difference in the presence of high distress between black and white patients at our cancer center in either crude or adjusted analysis. Differences in overall distress across studies may be owing to the timing of screening. Given that overall distress may vary across time^{16,17} and there is no current infor-

TABLE 3 Adjusted multivariate logistic regression predicting high distress^a

Variable	Odds ratio (95% CI)
Race	
Black	0.94 (0.62-1.44)
White	Reference
Sex	
Female	1.77 (1.25-2.51)
Male	Reference
Age, y	
18-40	Reference
41-60	1.01 (0.59-1.73)
61-84	0.57 (0.33-0.98)
85+	0.26 (0.07-0.98)
Cancer	
Head and neck	0.12 (0.06-0.25)
Gastrointestinal	1.35 (0.63-2.89)
Hepatobiliary	2.16 (0.94-4.94)
Sarcoma	0.77 (0.35-1.70)
Melanoma	0.73 (0.34-1.55)
Nonmelanoma skin	0.31 (0.11-0.84)
Genitourinary	1.11 (0.50-2.43)
Hematologic	1.02 (0.48-2.13)
Brain	1.02 (0.18-5.88)
Breast	Reference

CI, confidence interval; OR, odds ratio

^aAll variables included in the adjusted model are included in this table.

mation on whether temporal variations in distress differ by race, it is possible that the time of distress assessment may influence demonstrated differences between racial groups. For example, if different stressors affect black and white women differentially, and those stressors are associated with different points across the cancer continuum, then we might see that the magnitude of racial differences in overall

stress are time dependent. Alcala and colleagues examined any cancer diagnosis across the lifespan, whereas Culver and colleagues examined multiple time points across treatment for a small group of breast cancer patients. Badr and colleagues, in a sample of head and neck cancer patients, found that distress increased across the course of treatment;¹⁸ however they did not examine variations in type of stressors related to overall distress, nor did they examine racial differences in distress. Differences in results may also be the result of differences in measurement of distress. Culver and colleagues did not examine distress using the NCCN distress thermometer, rather psychological distress was measured by a scale rating a series of “mood-descriptive adjectives” (p. 497).¹¹ Alcala used the K-6 as a measure of psychological distress;⁹ therefore, demonstrated differences in overall distress between white and black women may vary across studies because of differences in measurement of the underlying distress variable. The lack of racial differences in overall distress in our study is consistent with the findings of VanHoose and colleagues,¹⁵ who also examined distress near the start of treatment and also used the NCCN distress thermometer as the measure of psychosocial distress.

We did find differences in the individual stressors between racial groups, indicating that the source of distress does vary between black and white cancer patients. Black patients more frequently reported distress secondary to housing, loss of interest and their ability to have children than did white patients. By comparison, white patients more frequently reported distress secondary to nervousness and treatment decisions than black patients. Identified differences in individual stressors may be attributable to sociocultural differences or differences in external support. It is also possible that black patients are more likely to willingly report distress related to nonpsychological factors, whereas white patients are more willing to report factors, such as nervousness, that are related to psychological disorders. Although it has been suggested that black cancer patients have more concerns about finances and work than do white cancer patients,¹⁹ we did not identify a statistically significant difference in child care, insurance or financial issues, transportation, work, or school between these 2 cohorts. This may be because the psychosocial distress screening score included in this study was performed at the time of initial diagnosis, and not further into their prescribed treatment at which point the financial worries may be more realized. Psychosocial screening scores obtained at subsequent visits were not included in the analysis because they are not routinely collected as part of clinical care in the center where this study took place. Furthermore, it is impossible to identify where a specific patient is in their treatment regimen based on their demographic data or subsequent distress scores in our data extraction tool. Further investigation into the sources of distress at different time

points along the continuum of care may shed more light on this topic.

Limitations

There are several limitations to this study. First, the method of data extraction from an electronic medical record report limited the capacity to explore possible differences between the patients in our sample, such as insurance status, level of education, available social support, current employment status, stage of disease, overall prognosis and prescribed treatment regimen.

Second, there were likely patients who either did not complete a psychosocial distress screening tool or whose data were not entered into the electronic medical record for inclusion in the analysis. The present study period took place during the implementation of the NCCN tool at the center. Although the policy was to screen all new patients as part of routine care; not all patients seen at the center received the NCCN screening tool at their first visit. Owing to the mechanisms for data entry and abstraction, only information from the patients who had a completed form was able to be accessed for this study, thus a statistical comparison between those who did and did not receive the NCCN tool cannot be made. During the timeframe for this study, the head and neck, breast, genitourinary, and hematologic services completed proportionally more NCCN screening of new patients than other services in the center. This is reflected in the distributional breakdown of cancer in the overall sample of this study. It is possible that the results are more representative of differences between black and white cancer patients in the services that were more likely to properly implement NCCN screening.

Third, our patient population was derived from an urban, academic medical center and the results may not be generalizable to other patient populations.

Fourth, the NCCN distress thermometer is a single-item rating of overall global distress that is not intended to be a diagnostic indicator of psychological comorbidity and, therefore, does not distinguish between common psychological diagnoses such as depression or anxiety. However, the usefulness of the tool is to provide an impetus for referral to services that may then encompass the evaluation and

diagnosis of particular psychological conditions. Further, the distress thermometer tool is designed to identify stress relating to the social aspects of cancer diagnosis and treatment and is not limited to psychological distress alone.

Strengths

Despite the limitations, there are also significant strengths to this study. The NCCN tool is a widely accepted measure for the assessment of psychosocial distress in patients with cancer. The measure is a common and routine clinical instrument,²⁰ and has also been used widely in research.^{18,21-24} Given the urban, academic environment of our clinical practice, our population is more racially diverse than other settings, allowing for initial examination of disparities between white and black cancer patients.

Clinical implications

Understanding differences in common psychosocial stressor between black and white cancer patients may allow for clinicians to strategically look for different types of stressors in order to facilitate faster referrals to appropriate services. It has been established in the literature that distress is correlated to cancer-related outcomes and distress screening is now considered standard of care when treating cancer patients. Identifying differences in psychosocial stressors among black and white cancer patients is paramount to ensuring that the appropriate resources are available to assist them through their cancer journey. The differences in type of stressor, may indicate fundamental differences in the way patients perceive their disease or the social and cultural implication of a cancer diagnosis. In this study, white patients were more likely to find distress in the psychological realm (nervousness, decision-making), whereas black patients were more likely to be distressed about social issues (housing, ability to have children, and loss of interest). The referral needs of patients may be quite different, even with similar levels of overall distress. More research is necessary to further characterize sources of distress for cancer patients, how this distress impacts a patient's physical and emotional well-being and how health care providers can better identify these issues and make the necessary referrals to support the whole patient.

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