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Ethnic differences in the caregiver's attitudes and preferences about the treatment and care of advanced lung cancer patients

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Abstract

Objective—This study examined differences in attitudes and preferences between African American and White caregivers about cancer treatment and care.

Methods—There were 173 White and 26 African American caregivers of advanced lung cancer patients who were recruited as a convenience sample. A telephone interview was conducted to collect information using a semi-structured questionnaire. Using logistic regression, we examined differences between racial groups concerning therapeutic and caregiving issues controlling for socioeconomic and demographic variables.

Results—The regression analyses showed that African American caregivers had higher expectations for treatment outcomes ($p = 0.05$) but poorer understanding of hospice and a stronger preference for hospice care outside the home ($p = 0.05$). They were more likely to believe that the patient communicates with the family about cancer treatment to meet the family's expectations rather than seek emotional support ($p = 0.01$). They were also more reluctant to endorse children's responsibility to make a treatment decision and are less likely to be fully satisfied with the decision-making process ($p = 0.05$).

Conclusions—The findings suggest some differences in beliefs and cultural values between African American and White caregivers. African American caregivers appear to believe more in the possibility of curative care for advanced lung cancer and eschew hospice care. The findings inform possible challenges regarding communication about end-of-life treatment and care with African American caregivers and a need for the provision of adequate information and education.

Keywords

African American; cancer; oncology; decision making; health disparity

Introduction

African Americans have the highest cancer death rates and shortest survival times among all racial and ethnic groups in the USA. The disparity in cancer outcomes has been attributed to

diagnosis at later stages and treatment disparities such as lack of timely and appropriate treatment [1]. African Americans' attitudes and preferences about cancer treatment and care play an important role in health-seeking behaviors that affect treatment choices and outcomes. Emerging evidence suggests that African American cancer patients prefer more aggressive treatments than White cancer patients [2,3] and are more likely to follow their physician's treatment recommendations [4,5]. In addition, greater numbers of African American cancer patients compared with other patients are less satisfied with the quality of communication between themselves and their physicians and are more likely to express concerns about the lack of sufficiency and clarity of information received [6]. In one study of actual doctor–patient communications, it was demonstrated that oncologists provided less information to their African American breast cancer patients during breast cancer adjuvant therapy consultations [7].

Cancer caregivers' attitudes and preferences about treatment and care options can influence the cancer patients' choices and their subsequent quality of life. Our previous study indicated that although lung cancer patients and their caregivers agreed on many issues concerning cancer treatment and care, their disagreements ranged from treatment goals, how to balance treatment toxicity and quality of life, to when to initiate hospice care [8]. In another study, less than half of caregivers who cared for patients with incurable cancer understood that treatment was non-curative, and 39% of patient–caregiver pairs had non-congruent opinions about cancer treatment [9,10]. It was also demonstrated that patient–caregiver disagreement explains 8% of the variance of depression in both cancer patients and caregivers [8].

Despite the potential impact of caregivers' attitudes and preferences on patient quality of life and treatment decision making, studies of African American cancer caregivers are scarce. Results of two existing studies indicated that African American caregivers were less likely to be involved in breast cancer patients' treatment than White caregivers [11] or develop a plan for end-of-life care [12]. To gain more knowledge in this area, we conducted a study of lung cancer caregivers to assess racial differences in the attitudes and preferences about cancer treatment and care between African American and White caregivers after controlling for demographic and socioeconomic factors.

Methods

This study was conducted between 2001 and 2004 at several large cancer facilities in Cleveland, OH and was approved by all relevant Institutional Review Boards. It was sponsored by the National Institutes of Health and did not involve any conflict of interest. The study was originally designed to assess patient and caregiver communication about cancer treatment and care decisions. Trained research staff reviewed medical charts to identify all potentially eligible patients who received a diagnosis of stage III or IV non-small cell lung cancer. Most patients had received surgery and/or radiation and at least one course of chemotherapy, and most were faced with further decisions. Based on the Institutional Review Board approved procedure, patients gave consent and identified an individual that they relied on most for caregiving. The identified caregivers were then sought for giving consent. The total patient–caregiver recruitment rate was 76%. An honorarium of \$30 was provided for study participation.

A semi-structured questionnaire consisting of both structured and open-ended questions was constructed based on the information that was collected from a previous focus group study [13]. It was used to collect information on the attitudes and preferences about treatment and care and on the choices made in three main areas: (i) trade-offs between treatment aggressiveness and quality of life; (ii) decision making and communication about treatment

and care; and (iii) use of hospice services. The semi-structured interview and questionnaires took approximately 30–45 min to complete. All interviews were conducted by telephone, were audiotaped, and were transcribed.

Descriptive statistics were used to describe the sample demographics. Bivariate statistical tests (Fisher's exact test) were computed initially to compare African American and White caregivers' responses on dichotomous (yes/no) attitudinal variables in the three main areas of interest described in the preceding paragraph. Candidate variables for the logistic regression analyses were chosen from among those attitudinal variables that were found to be significantly different between racial groups and hence served as the dependent variables, with race as the main independent variable and socioeconomic and demographic variables as the covariates. One socioeconomic variable, the insurance variable, was not included in the regression analyses because of substantial missing data. The regression analyses aimed to assess racial differences in attitudes and preferences regarding cancer treatment and care after accounting for socioeconomic influences.

Results

One hundred and seventy-three White and 26 African American caregivers (13% of the caregiver sample) made up the sample. African American caregivers were younger (mean age 49 vs. 57 years; $p = 0.01$) and were less likely to be a spouse or partner (60% vs. 30%; $p = 0.05$). They were less likely to be married compared with White caregivers (68% vs. 86%; $p = 0.05$) and were twice as likely to earn less than \$25,000 a year (38% vs. 18%; $p = 0.05$). Both racial groups were similar in gender and education. Fewer African American caregivers had private insurance (Health Maintenance Organization, Preferred Provider Organization/ Point of Service, and fee for services) (36% vs. 72%), and more had governmental insurance (e.g., Medicaid: 41% vs. 5%) than White caregivers. Racial differences in type of insurance were significant at $p < 0.001$ by an exact statistical test (see Table 1).

Logistic regression analyses revealed significant associations between caregivers' race and their attitudes and preferences about the treatment and care after accounting for socioeconomic and demographic factors. Table 2 presents the significant associations between race and caregiver attitudes towards cancer treatment and care adjusted for age, gender, marital status, education, household income, and caregiver's relation to the patient. African American caregivers were significantly more likely to report that the goal of treatment was to cure cancer ($p = 0.03$), that hospice is a place where people die in peace ($p = 0.01$), that hospice equates to hopelessness, death, and dying ($p = 0.01$), and that hospice care is preferred outside the home ($p = 0.01$) as compared with White caregivers. White caregivers were more likely to think that the patient talked with the family about cancer treatment to obtain emotional support ($p = 0.001$), whereas African American caregivers were more likely to attribute the patient's talking to meeting family's expectations ($p = 0.01$). African American caregivers were also less likely to agree that children have a responsibility to make treatment decisions ($p = 0.03$) and are less likely to report complete satisfaction with their own involvement in the decision-making process ($p = 0.05$).

Discussion

This study found that African American and White caregivers varied significantly in their attitudes and preferences about treatment and care for lung cancer patients. The study indicates that African American caregivers, as compared with White caregivers, continued to believe that treatment was for curative rather than palliative purposes and to be more avoidant around issues of death and dying, as evidenced by their preferences to have hospice

care take place outside the home [14]. Previous studies have indicated that socioeconomic conditions such as concerns about family burden could contribute to this view [13,15]. In this study, we found differences between racial groups even after controlling for socioeconomic variables such as income and education. A lack of understanding of treatment and hospice care may have played a pivotal role in African American caregivers' views or arrangement of cancer treatment and end-of-life care [16]. Therefore, provision of more information and education on health care delivery are imperative to assist African American caregivers to gain a better understanding and make more informed decisions about cancer treatment and end-of-life care.

Study findings shed light on additional racial differences in the attitudes towards communication about cancer treatment and care. Although we did not detect a significant difference between these two racial groups in the number of family members with whom a patient talked, we did find significant differences in the caregiver's perception concerning the meaning of those communications. For example, African American caregivers were more likely to believe, as compared with White caregivers, that the patient's rationale for communication with family members was to meet the family's expectations rather than to seek emotional support. The exact reasons for these beliefs remain unknown, but a possible explanation lies in a long-held value of 'being stoic' [17]. African Americans value 'toughness' in the face of adversity and rely on God and personal perseverance to endure hardship [18,19]. This culturally shared value may have affected caregivers' perceptions of a patient's communication as a mechanism to fulfill familial responsibilities as opposed to seeking emotional solace from family members. Finally, the tendency of African American caregivers to deny responsibility of children to assist in making treatment decisions may be viewed in the same light. These findings may alert health care providers to a particular communication dynamic found in many African American families, the importance of probing information, respectively, from African American patients and caregivers, and the need of additional emotional supports for African American cancer patients. The matter is clinically significant in that if African American patients are less likely to share decision making with caregivers when they are competent, it may make it more difficult for caregivers to act as surrogate decision makers if and when the patient becomes incapacitated.

Overall, African American and White caregivers were in agreement about cancer treatment and care issues for advanced lung cancer patients in most areas that we examined; their differences as presented here mainly concern their approach to end-of-life care and unwillingness to accept that sometimes, treatment intent is not curative. The influence of African American caregivers' attitudes on their own well-being and on making treatment decisions for African American patients has yet to be understood. The extent to which the observed racial differences matter and how much they matter remains to be important questions for future research.

The study has some limitations. The African American sample size was small, and because they represent a sample from a Midwestern region, they may or may not mirror African American caregivers elsewhere. The findings reported here, although preliminary, are an indication to researchers to further research and understand these important issues that may affect treatment course and quality of life outcomes. They also provide clinicians with evidence of a need for greater awareness of culturally shared beliefs and their influences on treatment and care on the part of African American families. Increased medical professionals' involvement with caregivers, better education and knowledge, and improved family communication will likely enhance the satisfaction of African American caregivers (and patients) with cancer treatment and care.

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Table 1

Sample demographics

Variable	Caregivers	
	White (<i>n</i> =173) <i>N</i> (%)	Black (<i>n</i> =26) <i>N</i> (%)
Age (mean/SD)	57 (13)	49 (14) **
Gender		
Female	128 (74%)	22 (85%)
Marital status		
Married	145 (86%)	17 (68%) *
Education		
High school	67 (42%)	12 (48%)
Some college	52 (32%)	10 (40%)
College	42 (26%)	3 (12%)
Household income		
\$25,000	31 (18%)	10 (38%) *
\$50,000	79 (46%)	9 (35%)
>\$50,000	63 (36%)	7 (27%)
Relationship to the patient		
Spouse or partner	104 (60%)	8 (30%) **
Children	43 (25%)	9 (35%)
Others	26 (15%)	9 (35%)
Patient's health insurance ^a		
Private insurance	93 (72%)	8 (36%) **
Medicare & supplements	23 (18%)	1 (5%)
Medicaid	6 (5%)	9 (41%)
Other government including VA	5 (4%)	2 (9%)
No insurance	1 (1%)	2 (9%)

SD, standard deviation.

^a *p*-value based on the Fisher–Freeman–Halton exact test due to small cell counts.**
p 0.01.*
p 0.05.

Table 2

Caregiver's racial difference in attitude and preference about treatment and care

Variable	White		Black		p
	N	N (%) ^a	N	N (%) ^a	
<i>Treatment trade-off</i>					
Goal of treatment is to cure cancer (yes)	158	41 (26%)	25	12 (49%)	0.03
<i>Decision making and communication</i>					
Children have a responsibility to make treatment decisions (yes)	158	65 (41%)	25	4 (17%)	0.03
Patient talked with family because of needs of emotional support (yes)	151	115 (76%)	25	10 (41%)	0.001
Patient talked with family because of family's expectations (yes)	151	5 (3%)	25	4 (16%)	0.01
Fully satisfied with involvement in making decision (yes)	158	120 (76%)	25	12 (52%)	0.05
<i>Hospice care</i>					
Hospice is where people go to die in peace (yes)	152	11 (7%)	24	5 (24%)	0.01
Hospice equated to hopelessness and dying (yes)	152	9 (6%)	24	6 (26%)	0.01
Prefer to have hospice care outside home (yes)	145	5 (3%)	22	4 (19%)	0.01

^a All rates are adjusted for the following covariates: age, gender, marital status, education, household income, and caregiver's relation to the patient.