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Barriers to early detection and treatment of head and neck squamous cell carcinoma in African American men

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Abstract

African Americans afflicted with HNSCCA have a strikingly worse survival than whites. One apparent cause is an advanced stage of presentation in African Americans. This study was designed to identify barriers to early treatment among African American men.

Methods—Twenty four African American male HNSCCA survivors completed structured interviews. Interviewers elicited the participants' experiences from symptom recognition to receiving definitive care.

Results—Most participants presented with advanced stage HNSCCA. Overall, 10% experienced barriers to obtaining early medical care, though 30% were hesitant to seek care due to perceived barriers. Definitive treatment began for 81% within three months of initially seeking care.

Conclusion—Once participants sought care, most received definitive treatment within a reasonable timeframe. To explain the advanced stage at presentation, either tumor growth rate was extremely rapid, or, participants sought care when the tumor was quite advanced. The themes suggested by this elicitation study require further validation.

Keywords

African American Men; cancer; tobacco use; early detection; Black Belt counties

INTRODUCTION

Racial and ethnic disparity in the survival of head and neck squamous cell carcinoma (HNSCCA) has been well documented. In the year 2000, mortality rates for oral cancer for African American men were 85% higher than for white men. That same year, mortality rates for all cancer sites for African American men were 42% higher than for white men.¹

Three causes of the racial and ethnic disparity for HNSCCA have been suggested. First, African Americans present with later stage disease than whites.^{2, 3, 4} Second, in some instances the treatment rendered differs between these groups.^{5, 6} Third, differences in host or tumor biology may result in a more aggressive form of disease in African Americans.^{7, 8}

9-10-11 Each cause is probably operative to some degree. Eliminating the disparity will involve looking more closely at each cause and identifying opportunities for intervention.

The current study focuses on late stage of presentation as an alleged cause of the disparity. Semi-structured interviews were completed with African American men who had recently been treated for head and neck cancer in the University of Alabama at Birmingham (UAB) Medical Center. The goal was to elicit barriers that were encountered by these individuals in obtaining cancer treatment. Elicitation research is designed to gather information about the attitudes, knowledge, preferences, or behaviors of a target group with respect to prevention issues. Elicitation studies are designed to identify themes and patterns of events that are later tested as causative. In this study, the investigators were interested in identifying the role that access to care played in delaying treatment.

METHODS

This study was part of a pilot project funded by the NCI sponsored UAB- Morehouse-Tuskegee partnership grant.(U54 CA118948). Twenty-four African-American males who had survived treatment for carcinoma of the head and neck were identified from the head and neck oncology practice of the senior author and agreed to participate. Entry criteria included patients who identified themselves as African American and had completed treatment for head and neck cancer. Patients residing in the rural “Black Belt” counties of south central Alabama were preferentially enrolled as our earlier studies had demonstrated a disproportionate incidence of HNSCCA in these counties¹². Participants received a small monetary stipend. The project was pre-approved by the Institutional Review Board for Protection of Human Subjects in Research.

Semi-structured interviews were administered by trained African American interviewers from the UAB School of Public Health and the UAB Recruitment and Retention Shared Facility. Four initial interviews were completed face-to-face. Twenty subsequent interviews were completed over the telephone. The interviewers utilized a question guide developed by the investigators. The questions were in three domains: a) demographic factors, b) patterns of tobacco use, and c) cancer detection and treatment experiences, including barriers encountered. Interviews lasted about 25 minutes. Responses were transcribed, entered into a cumulative database and combined with tumor staging information for later review. Responses were analyzed contextually for themes and patterns elicited. Three investigators reviewed the transcribed data independently and identified major explanatory factors related to the late stage at presentation. The lead investigator synthesized the independently identified factors to determine the predominant barriers elicited by the interviews.

RESULTS

Demographic factors and tumor staging (Table 1)

Twenty four African American male survivors of head and neck cancer participated. Ages ranged from 45 to 74 years with an average of 59 years. Most were from rural communities, had some form of medical insurance (primarily Medicare/Medicaid) and were unemployed. Other characteristics are included in Table 1. Tumor stage at presentation was confirmed from UAB staging records. Almost all participants (23; 95.8%) had stage III or IV disease at presentation. All participants had received standard-of-care treatment for their specific site and stage of malignancy.

Patterns of Tobacco Use

As shown in Table 1, all but one of the participants (23, 95.8%) used tobacco regularly. All used cigarettes and 10% used other forms of tobacco in addition to cigarettes. The average

amount smoked ranged from less than one pack of cigarettes per day (6; 26%), to two packs or more per day (3; 13%), with the majority (14; 61%) reporting they smoked a pack a day. Participants began using tobacco at a young age: 56% were less than 15 years old at initiation; 30% were between 15 and 20 years old; 13% were over age 20.

Health care availability and utilization

Most participants (76%) stated that there was a doctor or dentist in their community. Fifty-six percent had been seen locally. Frequency of doctor visits before the cancer diagnosis was described as rare for 59% and as less than one visit per year for 41%. Frequency of dentist visits was described as rare for 78% and yearly for 11%.

Experiences with cancer detection and treatment (Table 2)

These questions were directed to the participant's a) knowledge level regarding signs and symptoms, b) recognition that a problem existed, and c) experiences encountered when seeking treatment. The qualitative data were quantified to the extent possible and are shown in Table 2.

Presenting symptoms included: pain (62%), mass (25%) and hoarseness (12%). Initially, most participants thought the symptoms were a variant of a normal upper respiratory infection or a result of minor throat trauma. Most did not equate symptoms with cancer. Nearly a third reported that they didn't know what might be causing the symptoms. For example, when asked, "What did you think it was at first?" one participant responded, "Well, I didn't think anything. I didn't even know a knot was up there." Another, who first thought the problem might have been his "tonsils" reported noticing a knot on his neck, "not quite as big as a lemon." Two participants thought that they might have cancer and both of these reported having had a visible neck mass. None of the participants with throat pain or hoarseness initially equated their symptoms with cancer. The participants were asked if they previously believed a "throat problem" could ultimately be life threatening and the majority said they did not. When asked why they eventually decided to seek care, most reported that the persistence of symptoms led them to seek care. A sizeable minority (about a third) sought care only at the urging of a family member.

Time from: Symptom recognition to seeking medical care

To define the interval from symptom recognition to first seeking medical care, participants were asked the question: "How long after first noticing the symptoms did you seek medical attention?" More than half of respondents began seeking medical care within a month of noticing symptoms, 20% waited 1–3 months, and 25% waited longer than 3 months. Once patients decided to seek medical care, the majority reported seeing a primary care physician (including ER physicians) as the first contact. Three were seen initially by an otolaryngologist or a dentist and none were seen by a general surgeon.

Time from: Initially seeking care to start of definitive treatment

Respondents reported how much time passed from initially seeking care for their symptoms until they began treatment at UAB. About half began receiving treatment within a month of first seeking medical care; for another third, treatment began from 1–3 months after initially seeking care; and for the rest (four patients) treatment began over three months after initially seeking care. The typical referral pattern was: primary care doctor to community otolaryngologist to head and neck oncology service at UAB. For those patients who could quantify the number of doctors involved, the number ranged from two to four doctors before treatment began. The longer delays for the four patients appear to be due to delay in diagnosis. A representative response was: "The ER doctor thought it was strep throat and

they gave me a shot of penicillin. I wasn't getting relief so I went back to emergency room and got another shot. The third trip to emergency I got mad 'cause they wanted to put me in the hospital for HIV testing. The fourth trip to the emergency room, another doctor noticed me coming in and wanted to know 'why he was back'? He referred me to an ENT, who did throat cultures and biopsy and said it was cancer."

When asked "were there any difficulties getting a doctor to see you for this problem", all but three respondents said there were none. Two patients who experienced difficulty being seen by a doctor identified transportation as the problem. Only one patient was initially refused care because of cost. Three patients reported they were hesitant initially to seek care due to cost. Respondents were questioned a second time about perceived barriers to earlier care: "Was there anything that stood in the way of you seeking treatment earlier for your cancer?" Most respondents stated they experienced no barriers, three were delayed by concerns regarding transportation and three by a perception of cost.

Discussion

The causes of racial and ethnic disparity for head and neck cancer survival are poorly understood. Stage of presentation, treatment type and differing tumor biology are proposed causes. African Americans typically present with higher stage disease and treatment differs across racial/ethnic lines in several reports.^{2,3,4,5,6} Racial and ethnic differences in HNSCCA tumor biology are being explored.^{10,11} Racial and ethnic variables are often closely interwoven and difficult to separate from socioeconomic factors (such as education, employment status, income). Socioeconomic factors may impact each of the variables above (stage of presentation, treatment type and biology). For example, lack of transportation could delay treatment; lack of insurance could impact availability of treatment options, and poor nutrition could impact host immunity. In a review of SEER data, Arbes et al. found that lower socioeconomic status, advanced stage at presentation and differences in treatment prescribed accounted for an estimated 86% of the survival disparity between black Americans and whites.¹³ Education level was an independent predictor of treatment outcome in a large study of radiation regimens for HNSCCA. Patients with post-secondary education had significantly improved overall survival and locoregional control, independent of stage of disease presentation.¹⁴ Horowitz and others have documented that the symptoms and risk factors of oral cancer are less well known to minority populations than to whites.^{15,16,17} Socioeconomic factors predicted access to dental care and type of treatment received in the longitudinal Florida Dental Care Study.¹⁸ In a review of ethnicity and oral cancer, Scully concluded that the increased mortality rate among African Americans reflects the lower socioeconomic status which impacted stage of presentation, access to care and treatment received.¹⁰

This study focused on advanced stage of presentation as a cause of disparate outcomes. The 24 participants were African American men aged 45–74 years. Most were from rural Alabama communities and 23 of the 24 used tobacco. Most presented with stage IV cancer, and all but one with either stage III or IV disease (95.8%). Although this sample is small, the late stage of presentation is consistent with trends in our clinical database and concurs with the findings of other investigators.^{2,3,4} All patients in this study received standard-of-care definitive treatment for their cancer. No racial bias in treatment selection was evident.

Obtaining cancer treatment includes specific steps from symptom recognition to treatment initiation.^{19,20} The steps include: recognition of symptoms, deciding that medical care is needed, acting to schedule medical care, receiving an appointment, diagnostic work-up, referral for definitive treatment, initiation of treatment. Delays at any step may result in disease progression and ultimately worse prognosis. Potential delays can be conceptually

grouped into three categories: a) patient delay, b) professional delay, and c) treatment delay. 21 Patient delays include failure to recognize disease and failure to act when disease is apparent. Professional delays include access issues such as: unavailability of a physician, scheduling delays, or refusal of care for insurance reasons. Treatment delays include missed diagnosis, inappropriate initial treatment, slow referral for definitive care, and scheduling delays with the final treating physician.

Initially, the investigators expected to find that access to care would be the limiting step in expeditious diagnosis and treatment. Suspected access to care issues included: limited numbers of primary care MD's and specialists in the area, lack of insurance / fear of out-of-pocket costs, and refusal of care due to lack of financial resources. In Allison's construct of delay, the expected barriers would be professional and treatment delays.²¹ These specific factors were investigated in the current study and a small number of responses fell into these categories. In general, however, once the patients recognized that a significant problem existed, definitive care followed reasonably quickly. Only three patients reported actual difficulty being seen by a doctor. Two patients were delayed by transportation and one by cost. More patients perceived possible difficulties with cost and might have delayed seeking care due to their perceptions. Generally, primary care doctors in the rural counties recognized the serious nature of the problem and initiated appropriate referrals. In four patients, however, definitive treatment was clearly delayed by providers beyond 3 months after first seeking medical care.

Definitive treatment appears to have been implemented within three months of initially seeking care for the majority. Exactly how this compares to norms for other demographic groups is unclear as norms for treatment delay for HNSCCA are not widely available. Several studies, primarily from Europe, have documented the time required for treatment initiation. These times range from 2.7 months from symptom recognition to diagnosis, to 4.9 months from symptom recognition to presentation for definitive care.^{22,23} A separate study documented that delays in treatment initiation correlate with decreased survival.²⁴ Whether African Americans with HNSCCA are delayed by the medical system disproportionately compared to other ethnic groups is unclear and warrants further study.

The majority of patients in this study presented to the UAB head and neck oncology service with very advanced disease. In reviewing the timelines from disease recognition to treatment, the professional and treatment delays elicited appear insufficient to explain the advanced stage of presentation for this patient group. Two possible explanations remain and neither is completely answered here. Either the tumors grew unusually rapidly in the 3–4 months that passed prior to definitive treatment or the tumors were already at an advanced stage when the participants recognized that a serious problem existed. Two findings support the latter explanation: a) a majority of respondents reported not recognizing the seriousness of their symptoms, and, b) there was typically little delay in referral by the initial primary care provider suggesting that these lesions were not subtle at presentation. The investigators suspect that patient delay is the more important variable in this sample. Again, the goal of this project was elicitation of potential barriers. Determining whether these barriers were indeed causative will be the subject of further study. As specific barriers to earlier detection are identified and validated, opportunities to intervene and eliminate the disparity will become apparent.

Acknowledgments

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Table 1

Demographic and tumor characteristics of participants. (n=24)

	N	%
Mean age = 59		
Resident of rural county	19	79
Insured	17	71
Medicare/Medicaid		(65)
Private		(35)
Regular tobacco user	23	96
Use cigarettes	23	96
Use additional forms of tobacco	2	10
Cigarettes per day		
Less than one pack (20 cigarettes)	6	26
One pack	14	61
More than one pack	3	13
Reported a doctor available in community	18	75
Seen locally by a doctor		56
Doctor visit frequency prior to cancer diagnosis		
Rare	10	59
Less than once per year	7	41
Tumor stage at presentation		
< Stage III	1	4.1
Stage III	5	20.8
Stage IV	18	75

Table 2

Summary of participants' experiences seeking care for cancer. Variations in "n"; reflect differences in comprehensible responses to questions.

Initial impression of symptoms (n=21)	Minor sore throat 62%	Possibly cancer 10%	Didn't know 28%
Time from symptom recognition to seeking care (n=20)	<= 1 month 55%	1-3 months 20%	> 3 months 25%
Time from seeking care to beginning treatment (n=21)	<= 1 month 48%	1-3 months 33% (total 81% <=3 mos)	> 3 months 19%
Actual difficulties encountered receiving care (n=20)	No 90%	Yes 10%	
Perceived difficulties before receiving care (n=20)	No 70%	Yes 30% 3 (15%) cost 3 (15%) transportation	