A survey of barriers to screening for oral cancer among rural Black Americans

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Abstract

Objective: Research documents a disparity between Black and White Americans in mortality for oral cancer that appears to result in part from behaviors such as lower oral cancer screening among Black Americans. We examined barriers to oral cancer screening among Black Americans.

Methods: We surveyed Black Americans ($N = 366$) living in rural Florida to identify barriers to getting screened for oral cancer.

Results: Low knowledge/social attention, lack of resources, and fear/defensive avoidance predicted screening intentions, with lack of resources emerging as the largest barrier. Participants also reported that a recommendation from their provider was most likely to increase screening intentions, whereas encountering financial barriers was most likely to decrease screening intentions.

Conclusions: Low knowledge/social attention, lack of resources, and fear/defensive avoidance emerged as independent barriers to oral cancer screening, with the latter two barriers accounting for the most variance in intentions to get screened. Copyright © 2013 John Wiley & Sons, Ltd.

Introduction

Oral and pharyngeal cancer, or cancer of the mouth and throat (e.g., throat, larynx, nose, sinuses, and mouth) [1,2] represents a national health problem. Because treatment of oral cancer requires delicate surgery to the face and can be quite disfiguring, it is perhaps the most costly cancer to treat [3]. Moreover, each year, 8000 people die from oral cancer, and many more suffer from the severe monetary consequences of the disease [4]. The death rate exceeds that for other cancers that receive far greater publicity, including cervical cancer, Hodgkin's lymphoma, testicular cancer, and thyroid cancer.

Ironically, oral cancer is extremely treatable, if caught early (i.e., in stage 1 or 2) [5]. Unfortunately, late stage diagnosis (i.e., stage 3 or 4) is all too common [6]. Although several factors are potentially associated with late-stage diagnoses of oral cancer, the most obvious is failure to obtain an oral cancer screening from a dentist or physician [7]. Research suggests that people who are screened earlier are more likely to detect oral cancer at an earlier stage [8], which is associated with reduced mortality [5]. Research links lower stage diagnosis with earlier detection [8], and favorable outcomes from oral cancer increase substantially with early detection [5].

Mortality from oral cancer does not strike equally across groups. Despite similar incidence rates among Black and White Americans, Black men die from oral cancer at almost twice the rate of White men [5]. The discrepancy appears to arise from disparities in health behaviors such as screening [9,10]. Black Americans are more likely than

White Americans to be diagnosed with later stages of oral cancer [6]. The implication is that delays in oral cancer screening and detection contribute to later stage oral cancer diagnosis [8] and thus more negative health outcomes. Disparities in health outcomes are particularly evident in rural settings, where longer travel times and lower accessibility to health care, among other things, can undermine getting a cancer screening [11]. Detecting and treating oral cancer earlier in rural Black Americans could reduce the health disparities in oral cancer mortality. The present article explores barriers to oral cancer screening among rural Black Americans.

Barriers to screening for oral cancer

We know of two studies that have examined barriers to screening for oral cancer among Black Americans. The first investigated patients–providers communication and identified poor communication and low knowledge about oral cancer as barriers to screening [12]. Importantly, these findings are only suggestive because the study examined a limited number of barriers among urban Black Americans and did so only indirectly.

The second study involved qualitative analyses of focus group data and yields a rich picture of the barriers faced by Black Americans living in rural settings. The focus groups reported 12 distinct obstacles to oral cancer screening, which were distilled to three broad categories of barriers [13]. The first barrier was *low knowledge/social attention*. Many participants reported that they had never heard of oral cancer, and those who had did not regard it to be important because important others (physicians, community leaders,

news sources) were not discussing or advocating screening. The second barrier was *lack of resources*. Many participants reported that they lacked resources (money, insurance, time, or transportation) to get screened. The third barrier was *fear/ defensive avoidance*. Participants reported that a desire to avoid unpleasant news or situations deterred them from getting screened.

Although informative, the focus group findings are based on a small sample and may be overly influenced by the responses of a few, highly vocal participants. In addition, a concern with any qualitative study is that the researcher may inadvertently influence participant responses, leading to biases in the data. We examined here whether the focus group findings would replicate in a larger survey of community participants.

Overview

We surveyed Black Americans in three rural counties in Florida to explore barriers to oral cancer screening. On the basis of the focus group study [13], we hypothesized that low knowledge/social attention, lack of resources, and fear/defensive avoidance would play a central role in participants' explanations for not getting screened for oral cancer. Examining the barriers in a survey allowed us to explore covariation among the barriers. For example, it is possible that participants are reporting a resource barrier to screening when the real reason for not getting screened is that they fear the results.

To aid possible future interventions, for a subset of the barriers, we explored how much introducing or removing the barrier would influence screening intentions. For example, for each resource barrier, we explored the extent to which providing the specific resource would increase screening intentions among participants who reported that they faced the barrier. We also explored whether removing the barrier would decrease screening intentions among participants who reported not having the barrier. In doing so, we could examine which barriers, if removed, would be most influential in increasing screening, and if added, would be most influential in deterring screening.

Method

Participants

We trained three interviewers to recruit, consent, and administer the survey orally to residents from three counties in north central Florida. One of the counties had one retired dentist, and one had five dentists. The third county had a mid-size city with a university hospital and dental school. However, we recruited participants from the rural edges of the county, a minimum of a 20-min drive from the university dental school. The interviewers consented 425 participants for the study. Because of procedural errors, however, we had to discard data from 59 participants, almost all occurring

in the first 75 participants run, at which point, we made modifications to the format of the survey to reduce interviewer errors and then retrained our interviewers. In the end, we had usable data from 366 Black American adults (216 women) ages 40–101 years ($M = 52.1$, SD = 10.6). The interviewers recruited participants by going door-to-door or in public places such as beauty salons and churches. Participants received a $10 gift card to a local retail store for their participation.

Procedure

Pilot testing suggested that many members of our target population needed assistance in completing our survey (e.g., reading the questions, understanding a scaled response format). We thus trained community members to administer the survey orally. In addition, pilot testing revealed that participants were more comfortable with the term mouth and throat cancer than with oral and pharyngeal cancer. Thus, we used the term *mouth and throat cancer* in our survey.

Focus groups conducted prior to the survey revealed that many participants struggled with Likert-type response formats. We thus presented our survey items in two steps. First, we asked participants if they agreed or disagreed with a statement such as, *I want to get a mouth and throat cancer exam in the next 12 months*. Second, if participants reported that they agreed, we asked if they slightly agreed, moderately agreed, or strongly agreed. Conversely, if participants reported that they disagreed, we asked if they slightly disagreed, moderately disagreed, or strongly disagreed. From these responses, we created a 6-point scale that ranged from 1, *Strongly Disagree* to 6, *Strongly Agree*. Although time consuming, this approach eliminated confusion and allowed for greater variability in participant responses. Unless otherwise specified, all items in the survey used this 6-point scale format.

When administering the survey, the interviewer read aloud a consent form that participants then signed. The interviewer then read instructions and read each item aloud. Participants provided responses verbally, and the interviewer recorded the responses on the survey instrument. Because of time constraints, we did not collect data on risk behavior.

Measures

Demographic items

We recorded participants' age, gender, education, and whether they had health insurance and dental insurance (both coded so that *no* = 0, *yes* = 1).

Past oral cancer screening

We assessed whether participants ever had an oral cancer screening with two items: (i) *Has a medical provider ever told you that he or she examined you for mouth and throat*

cancer?; and (ii) *Has a doctor or dentist ever examined your mouth*, *by pulling on your tongue*, *with gauze wrapped around it*, *and feeling under your tongue and inside your cheeks*? If participants responded *yes* to either item, we coded their response as yes (*no* or *don't know* = 0, *yes* = 1).

Intentions

We measured intentions using a two-item index ($\alpha = 0.89$): (i) *I want to get an exam for mouth and throat cancer in the next 12 months*; and (ii) *I am definitely going to get an exam for mouth and throat cancer in the next 12 months*.

Knowledge/social attention

We used four items to assess knowledge/social attention regarding oral cancer. The first two items asked participants, (i) *Have you heard of mouth and throat cancer before today*?; and (ii) *Do you know anyone with mouth and throat cancer*? (*no* = 0, *yes* = 1). The next two items used the two-step, Likert scale format described earlier, and participants indicate whether (iii) *My doctor or dentist has recommended I get examined for mouth and throat cancer*; and (iv) *Important people in my life (like my family or my pastor) are telling me to get a mouth and throat cancer exam*. Because these four items used different response formats, we treated them as separate predictors in our analyses.

Resources

Using the two-step Likert scale described earlier, we assessed the extent to which participants had resources relevant to getting an oral cancer screening or treatment for oral cancer. For example, one item stated, *I can afford treatment for mouth and throat cancer*. These items asked participants whether they could afford a screening for oral cancer, could afford treatment for oral cancer (measured with two items), had transportation to a screening location, had time to get screened, regarded getting screened as convenient, had health insurance to pay for screening, and knew where to go to get screened. We combined these eight items to create a resource index ($\alpha = 0.79$) and coded items such that higher values indicate greater resources.

Defensive avoidance

We assessed defensive avoidance using an eight-item information avoidance scale. The scale is adaptable to various threats and shows strong psychometric characteristics including strong predictive validity and test–retest reliability. We tailored the scale to assess avoidance of information about *having oral cancer*. An example item was *I don't want to know [if I have oral cancer]*. We combined the items to form a single index of defensive avoidance ($\alpha = 0.87$) with higher values indicating greater defensive avoidance.

Consequence of changing barriers

For a subset of items (the two knowledge/social attention items asking about recommendations, 7 of the 8 resource items), we included probes to examine whether participants believed that adding or removing the barriers would influence their screening intentions. For example, after reporting the extent to which they agreed or disagreed with the item, *I can afford treatment for oral cancer*, participants who reported that they slightly, moderately, or strongly disagreed next indicated if they would be *More Likely* (1), *Equally Likely* (0), or *Less Likely* (−1) to get screened if they could afford treatment. Conversely, participants who reported that they slightly, moderately, or strongly agreed next indicated if they would be *More Likely* (1), *Equally Likely* (0), or *Less Likely* (−1) to get screened if they could *not* afford treatment. We did not include these probes when it seemed nonsensical to do so (e.g., the items asking participants whether they had heard of oral cancer or knew someone with oral cancer, and the items asking about defensive avoidance).

Data analysis

We used correlation and multiple regressions to analyze predictors of screening intentions for oral cancer. We used one-sample *t*-tests that compared the mean for an item with zero to examine whether introduction or removal of a barrier would influence screening intentions. We conducted all analyses using IBM SPSS Statistics, 18.0 (IBM, Armonk, New York).

Results

Table 1 presents demographic information about our participants. Most (75%) reported having a high school education. Although a high school degree would presumably equate with adequate reading skills, we find that rural residents of north central Florida, even residents with high school degrees, have low literacy skills. The majority

Table I. Sample characteristics

Demographics	Female (%)	Male (%)
Gender	216 (59.0)	143 (39.0)
Education		
Less than ninth grade	30 (14.1)	24 (17.1)
Some high school	20 (9.4)	14 (10.0)
High school degree	110 (51.6)	68 (48.6)
Some college	30 (14.1)	20 (14.3)
College degree or more	23 (10.8)	14 (10.0)
	Yes (%)	No (%)
Have health insurance	259 (70.8)	107 (29.2)
Have dental insurance	189 (51.6)	175 (47.8)
Heard of oral cancer prior to today	287 (78.4)	77 (21.0)
Prior oral cancer screening	93 (25.4)	266 (72.7)

N = 366. Not all participants responded to all items, resulting in some missing data (e.g., seven participants did not report gender).

reported that they had some form of health insurance (70.8%), and about half (51.6%) reported that they had dental insurance.

Screening intentions

Table 2 presents the zero-order correlations between our predictor and outcome measures. Greater screening intentions correlated with participant reports that (i) their provider recommended screening; (ii) important people in their life recommended screening; (iii) they have more resources; and (iv) they are lower in defensive avoidance.

We next conducted hierarchical multiple regression to predict screening intentions in which we entered our predictors into the model in blocks. In Block 1, we entered demographic variables (i.e., age, gender, health insurance status, education level); in Block 2, we entered the items tapping low knowledge/social attention; in Block 3, we entered our index of lack of resources; and in Block 4, we entered our index of defensive avoidance.

As evident in Table 3, adding each of our blocks of predictors significantly improved model fit, $Fs > 2.30$, $p < 0.05$, $R^2 s > 0.03$. The final model included only three significant predictors. The largest barrier was lack of

resources ($b = 0.49$); fewer resources corresponded with lower screening intentions. The second largest barrier was defensive avoidance ($b = -0.24$); the more participants wanted to avoid learning their screening results, the lower their screening intentions. The third barrier was whether a provider had recommended screening ($b = 0.14$); the absence of a recommendation corresponded with lower screening intentions. Surprisingly, none of our other three knowledge/social attention items—the largest barrier reported by participants in our earlier work—predicted screening intentions.

Effectiveness of changing barriers

Table 4 reports the results from the item asking participants how their screening intentions would change if each of the resource barriers was added or removed. The numbers on the left side of the Table represent the responses of participants with the barrier and how they would respond if the barrier were removed. The numbers on the right side of the Table represent the responses of participants without the barrier and how they would respond if the barrier were added. For each barrier, participants who reported having the barrier indicated that removing it would increase their

Table 2. Zero-order correlations

	Screening intentions	Heard of oral cancer	Know someone	Providers recommend screening	Others recommend screening	Lack resources
Screening intentions	—					
Heard of oral cancer	0.03	—				
Know someone with oral cancer	−0.02	0.26**	—			
Providers recommend screening	0.21**	−0.09	−0.08	—		
Others recommend screening	0.14**	0.02	−0.17**	0.39**	—	
Lack of resources	0.41**	0.28**	0.08	0.15**	0.17**	—
Defensive avoidance	−0.23**	−0.11*	−0.14**	0.06	−0.07	−0.17**

*$p < 0.05$.
**$p < 0.01$.

Table 3. Screening intentions

Block	Barrier	b	SE	t	ΔF	ΔR²
1	Demographics				2.30*	0.03
	Age	0.004	0.01	0.65		
	Gender	0.07	0.15	0.48		
	Education	0.05	0.06	0.82		
	Health insurance status	−0.15	0.18	−0.87		
	Prior screening	0.06	0.17	0.35		
2	Low knowledge/social attention				5.29**	0.06
	Prior knowledge of oral cancer	−0.22	0.19	1.18		
	Know someone with oral cancer	−0.11	0.16	0.69		
	Providers recommend screening	0.14	0.05	3.04**		
	Important others recommend screening	−0.02	0.04	−0.48		
3	Lack of resources	0.48	0.07	6.51**	42.29**	0.11
4	Defensive avoidance	−0.24	0.07	3.50**	12.24**	0.03
TOTAL		$F (11, 331) = 8.91$, $p < 0.001$, $R^2 = 0.23$				

*$p < 0.05$.
**$p < 0.01$.

Table 4. Screening intentions after removing or adding resources barriers

Barrier	Remove barrier			Add barrier		
	M	n	d	M	n	d
Low knowledge/social attention						
Others (do not) recommend screening	0.71	242	1.22*	0.08	114	0.10
Providers (do not) recommend screening	0.85	299	1.93*	−0.17	58	0.19
Resources						
(Do not) Know where to go	0.61	114	0.92*	−0.42	249	0.53*
(Do not) Have transportation	0.67	63	1.18*	−0.42	294	0.50*
(Do not) Have time	0.74	77	1.30*	−0.27	284	0.32*
(In)Convenient	0.74	101	1.28*	−0.25	263	0.29*
Can(not) afford treatment	0.75	158	1.32*	−0.43	196	0.51*
(Do not) Have money to pay	0.78	251	1.39*	−0.49	110	0.64*
(Do not) Have insurance	0.83	120	1.66*	−0.49	241	0.66*

*$p < 0.001$.

likelihood of getting screened. Conversely, with two exceptions, participants who reported not having the barrier indicated that having it would decrease their likelihood of getting screened. The two exceptions were the two knowledge/social attention items. Participants reported that they would still get screened even if providers or important people in their lives were not recommending screening.

Examining the effect sizes reveals that removing any given barrier influenced intentions more than adding that barrier. Examining only the effects of removing barriers (the left column of numbers), participants reported that a recommendation from a provider would be most likely to increase screening intentions. Likewise, examining only the effects of adding barriers, participants reported that losing financial resources would be most likely to decrease their screening intentions.[1]

Discussion

The findings from our survey of barriers to oral cancer screening generally replicated the findings from the focus group study [13] with some interesting exceptions. Consistent with the focus group study, low knowledge/social attention, lack of resources, and fear/defensive avoidance emerged as independent barriers to getting screened. In contrast to the focus group study, low knowledge/social attention was not the dominant predictor of screening intentions. Indeed, the only knowledge/social attention variable that uniquely predicted screening intentions was whether a provider had recommended screening. We suspect that knowledge/social attention may have played a less important role because most participants in our survey (78.4%) had heard of oral cancer prior to the study. Finally, lacking resources—particularly, lacking financial resources—emerged as the dominant barrier to screening. Lack of financial resources no doubt contributes to a variety of related problems including a lack of routine dental checkups where people are most likely to undergo an oral cancer examination.

It is noteworthy that the three barrier groups correlated with each other. However, the correlations were generally small. Moreover, our regression analyses revealed that the three barriers independently predicted screening intentions. This finding is perhaps most important with regard to the third barrier—fear/defensive avoidance. We were concerned that many people would be unwilling to admit that they are fearful and that they would prefer to remain ignorant about an important health problem. Yet, we found that participants were quite willing to acknowledge their defensiveness. Moreover, defensive avoidance predicted screening intentions even though it entered last in the regression model.

Consequences of the barriers

We could have accessed the importance of each of the barriers to screening in many ways. The most straightforward approach is merely to examine which barrier predicts the most variance in screening intentions. Our analyses revealed that resource barriers were the strongest predictor of intentions, followed by fear/defensive avoidance and low knowledge/social attention. A second, more novel, approach is to ask people the likelihood that they would get screened if a barrier was added or removed. Although this approach was sensible for only a subset of barriers, the results yielded several important findings. First, removing barriers produces a bigger effect than adding barriers. The implication is that people without a given barrier may be able to find ways to get screened were they to encounter a barrier. Second, the analysis suggests that adding financial barriers would produce the largest decrease in cancer. Third, our findings suggest that a provider recommendation to get screened would produce the largest increase in screening. Interestingly, participants who reported receiving such recommendations said that an absence of a provider recommendation would not influence their screening intentions. Perhaps participants who report receiving provider recommendations in the

past have problems that make them sensitive to the importance or need for screening. Alternatively, other circumstances, such as the availability of personal and financial resources, may make these participants less reliant on recommendations from others.

Yet, there remains another alternative explanation that applies to all of the consequence probe items. The probe items asked participants to engage in counterfactual thinking [14]; to imagine another reality, a reality where they had resources or lacked them, or where others recommended screening or did not. Although people engage in counterfactual thinking all the time (e.g., imagining how the day would be different if they had left for work 10 min earlier), the alternative reality they imagine may not accurately reflect what would actually occur. People may fail to recognize what factors actually influence their behavior or might overestimate or underestimate how influential those factors are [15]. For example, our participants reported that the absence of provider recommendations would not influence their likelihood of getting screened. It is possible that these participants underestimate how crucially important a provider's recommendation is in their decision making. Clearly, we need research that tests the actual consequences of changing barriers.

Limitations

Our study sampled Black Americans living in rural north central Florida, and the findings may not generalize to groups living elsewhere. Indeed, a different set of barriers to screening for oral cancer may emerge for an affluent sample for which financial resources are less pertinent. In addition, we examined intentions rather than behavior. In our defense, this study was intended to identify reported barriers with an eye toward developing interventions to increase screening behavior. Nevertheless, we acknowledge that intentions are only moderately linked to behavior.

Conclusions

We began with the observation of race differences in mortality from oral cancer, a disparity that appears due in part to delays and lower rates of oral cancer screening among Black Americans. Our goal was to identify barriers to screening among Black Americans in rural settings. Our study is the second to show that low knowledge/social attention, lack of resources, and fear/defensive avoidance independently influence screening intentions. Whereas the prior study examined focus groups, we used survey methodology and recruited a larger sample. In contrast to the prior study, the present study suggests that lack of resources is the primary barrier to screening followed by fear/defensive avoidance. Finally, participants report that a recommendation from their provider was most likely to increase screening intentions, whereas encountering financial barriers was most likely to decrease screening intentions.

Acknowledgements

Conflict of interest

The authors have no conflict of interest.

Note

1. Analyzing the data after omitting participants who reported having a prior oral cancer screening did not change the results.

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