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Knowledge and Understanding Differs Between African American Men and Caucasian Men When Diagnosed with Prostate Cancer

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Abstract

Purpose: African American (AA) men are diagnosed with Prostate cancer (PCa) approximately 3 years younger, more often in an advanced stage, and incurable, when compared to Caucasian American (CA) men. We seek to study whether this difference is due to factors related to, stress, and lack of knowledge of prostate cancer, race, or the combination of all these factors.

Methods: A questionnaire was administered to 389 participants (234 CA and 135 AA men) for a possible diagnosis of prostate cancer over 3 years. Quantitative data was collected from patients on demographic status along with their level of knowledge of prostate cancer and anxiety related to their diagnosis and possible treatment. Exact Pearson chi-square tests were used to test the independence between race and various socio-economic factors.

Results: In this study, for the first time, we investigated whether knowledge of the disease and anxiety following diagnosis and treatment could play a role in the disparity of prostate cancer among AA and CA men. We also confirmed that financial disparities among AA and CA men, with AA having more financial strain.

Conclusion: Our study showed that lack of knowledge of PCa screening and early detection, and lack of understanding of the diagnosis in combination with increased anxiety among AA patients, can play a role in PCa disparity.

Keywords: Prostate cancer • African American men • Disparity • Knowledge • Anxiety

Introduction

Prostate cancer (PCa) remains one of the leading causes of death in the United States, despite the use of Prostate Specific Antigen (PSA) screening to assist in early detection. In the United States, African American (AA) men are diagnosed more often with advanced stage, incurable prostate cancer than Caucasian American (CA) men. This is most commonly due to limited access to health care, socioeconomic status, and the lack of participation in early detection programs [1]. Clinically advanced stage prostate cancer is detected more often in AA men compared to any other ethnic group [2,3]. The reason may be that detecting prostate cancer early varies in different ethnicities and that could explain why AA men are more likely to be diagnosed with advanced stage disease. More specifically, knowledge, social disparity, treatment options, health inequality, and environmental factors may explain why AA men develop prostate cancer more precipitously than CA men in the United States.

Although multiple studies have measured PCa knowledge among AA men, most studies looked at it independent of the emotional reaction related to PCa. Otis L. Owens et al., [4] developed a scale using psychometric properties to measure prostate cancer knowledge for AA men and compared published knowledge based measures at the time. Marvella Ford et al., [5] conducted a cancer education intervention with racially diverse communities and showed intervention will significantly increase the knowledge for AA men. They administered a test for knowledge about cancer in general and PCa in specific before and after intervention and quantified the results. They showed cancer in general and prostate cancer knowledge scores increased following the intervention. Levi Ross et al., [6] compared the source of PCa information: interpersonal sources (e.g., friends, family, co-workers) and physician sources. Their findings emphasize the need to connect lower income and lower educated AA men to physicians as a source of prostate cancer control information. Otis L. Owens et al., [7] showed strong negative emotions among younger men, with men of all ages either surprised or concerned with their diagnosis. However, they did not look at the association between knowledge and emotion.

The novelty of our study is that we compared prostate cancer knowledge in AA men to that of CA men by examining if knowledge plays a role in their anxiety or vice versa. Does knowledge bring more peace of mind and better decision making? A better understanding of psychological effect associated with prostate cancer diagnosis, knowledge of the disease, and decision making can have a huge impact on cancer treatment and overall quality of life.

Methods

Study population

The study participants were patients accrued from Roswell Park Comprehensive Cancer Center (RPCCC) Urology Clinic and communities onsite who met the inclusion criteria, and who agreed to participate in this questionnaire based study, between (10/2018) and (01/2022). Inclusion criteria were males, more than 30 years of age with a diagnosis of prostate cancer or more than 40 years of age and being worked up for prostate

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cancer, with no history of other cancers except for non-melanoma skin cancer. After signing the informed consent according to the Internal Review Board (IRB) approved protocol, the participants completed a two part questionnaire. The first part was a de-identified Prostate Cancer Knowledge Questionnaire (PCKQ-40) [8] to assess their knowledge, awareness and perception of prostate cancer screening, diagnosis, and treatment. Examples of the questions used for knowledge pertained to the Gleason score, biopsies, and general questions on prostate cancer. The second part was the 12 item Short Form Health Survey [9] that assesses mental health of the participants in relation to prostate cancer diagnosis and possible treatment. Questions were answered related to relaxation, panic, appearance, and overall enjoyment after a prostate cancer diagnosis. Demographic data such as age, marital status, education level, ethnicity, employment, occupation, personal diagnosis with prostate cancer, and family history of the disease were also collected. This study was approved by RPCCC IRB under protocol number I44117. A total of 389 participants completed the questionnaire during the study period and were included in the analysis.

Statistical analysis

Participants' demographics and survey responses were summarized by race using means, medians, and standard deviations for the continuous variables and frequencies and relative frequencies for categorical data. Comparisons between races were made using the Kruskal–Wallis test for continuous or ordinal and Pearson chi-square tests for categorical variables.

Survey responses were dichotomized, and multivariable logistic models were used to determine the significant co-variates in predicting response. The co-variates included were race white and Black/AA, employment status (employed for wages, out of work, retired, unable to work), marital status (married or domestic partner, separated divorced or widowed, single), education (graduate degree, undergraduate degree, high school degree, no high school degree), income (=<$ 30,000, $ 30,000 to 69,999, >=$ 70,000), and occupation (manual work, skilled tradesman, professional, retired). Backwards selection was used to determine significant co-variates.

All analyses were conducted in SAS v9.4 (Cary, NC). All associations were considered statistically significant at an alpha error $p \leq .05$ (P value 0.05).

Results

Financial and health disparities among AA and CA men

As indicated above, there were three parts of the questionnaire: the demographics, the knowledge on prostate cancer, and the psychological impact of being diagnosed with the disease. The pertinent demographic comparison is depicted in Figure 1. There was a significant difference in the marital status (p<.001) as demonstrated in Figure 1, 26.9% of AA were surveyed are single and did not have the support that CA men had upon entering the clinic. This suggested that their decision making concerning their disease would be upon their shoulder without the input of significant others. AA men had lower income overall while more CA men had over $ 70,000 annual income (p<.004). With regards to current health status and how often they visit a primary health physician, we found that CA men visited a health care provider more than AA men. In addition, CA men had a better health status than AA men (p<.001). Figure 1 shows a fair health status of 18.4% for CA and 33.3% for AA men. While only 4.4% of AA men showed excellent health, status compared to 19.7% CA men. The insinuation here is that the men surveyed were not in good health when coming to the clinic, and that AA men exhibited adverse contributing health factors when it came time for their diagnosis. There were a limited number of individuals who declined to be surveyed for no reason other than they felt it was not connected to their diagnosis.

Differences of prostate cancer knowledge in AA men and CA men

Based on the data obtained from the questionnaire, the knowledge of prostate cancer varied widely between AA men and CA men. The results are summarized in Table 1 demonstrates that AA men have significantly less knowledge compared to CA men as evident in answering questions related to being diagnosed with prostate cancer and questions related to PSA, biopsy, and Gleason score. When answering the question "men diagnosed with prostate cancer should be treated immediately", there was a significant difference (p<.001) in the answers given between AA and CA men. We also asked if "all men should be tested for Prostate cancer" 1% of men said "True". Conversely, 9% men said "False", not all men should be tested. When asked "men of all ages can be diagnosed with PCa" 13.3% of AA men answered "False" compared to 3.8% of CA men that shows AA men have significantly (p<.001) less knowledge of PCa compared to CA men.

Table 1. CA men have more understanding of PCa, and more knowledge of the PSA, biopsy and Gleason score as compared to AA men.

CA		White	Black/African American	Overall	Pval
Q12 Have you ever been diagnosed with Prostate Cancer?	Yes	124 (53.0%)	35 (25.9%)	159 (43.1%)	<.001
	No	110 (47.0%)	100 (74.1%)	210 (56.9%)	
Q13 How worried are you about developing Prostate Cancer?	not at all	46 (20.7%)	47 (35.3%)	93 (26.2%)	0.008
	a little	138 (62.2%)	71 (53.4%)	209 (58.9%)	
	extremely worried	38 (17.1%)	15 (11.3%)	53 (14.9%)	
Q14 Men of all ages can be diagnosed with Prostate Cancer?	True	225 (96.2%)	117 (86.7%)	342 (92.7%)	<.001
	False	9 (3.8%)	18 (13.3%)	27 (7.3%)	
Q17 Men who have Prostate cancer need to get treatment immediately?	True	112 (48.7%)	107 (79.3%)	219 (60.0%)	<.001
	False	118 (51.3%)	28 (20.7%)	146 (40.0%)	
Q20 How much knowledge do you have of the meaning of the PSA results?	none	36 (15.5%)	23 (17.2%)	59 (16.1%)	0.099
	a little	130 (55.8%)	86 (64.2%)	216 (58.9%)	
	a lot	67 (28.8%)	25 (18.7%)	92 (25.1%)	

Q21 Have you had a PSA test done in the past?	Yes*	201 (86.6%)	105 (78.4%)	306 (83.6%)	0.089
	No**	22 (9.5%)	23 (17.2%)	45 (12.3%)	
	I do not know	9 (3.9%)	6 (4.5%)	15 (4.1%)	
CA Q22 Did your provider explain to you the results and what they mean?	Yes	183 (89.7%)	92 (84.4%)	275 (87.9%)	0.171
	No	21 (10.3%)	17 (15.6%)	38 (12.1%)	
Q23 Did the PSA test results give you a peace of mind?	Yes	88 (42.9%)	63 (57.8%)	151 (48.1%)	0.02
	No	74 (36.1%)	24 (22.0%)	98 (31.2%)	
	Maybe	43 (21.0%)	22 (20.2%)	65 (20.7%)	
Q28 Have you any knowledge about what a prostate biopsy consists of?	none	46 (20.1%)	48 (35.8%)	94 (25.9%)	<.001
	a little	85 (37.1%)	59 (44.0%)	144 (39.7%)	
	lot	98 (42.8%)	27 (20.1%)	125 (34.4%)	
Q29 Have you previously had a biopsy?	Yes	132 (57.1%)	42 (31.1%)	174 (47.5%)	<.001
	No	90 (39.0%)	79 (58.5%)	169 (46.2%)	
	I do not know	9 (3.9%)	14 (10.4%)	23 (6.3%)	
Q30 Did your health care provider explain to you the pros and cons of having a biopsy?	Yes	130 (56.5%)	44 (32.6%)	174 (47.7%)	<.001
	No	62 (27.0%)	48 (35.6%)	110 (30.1%)	
	NA	38 (16.5%)	43 (31.9%)	81 (22.2%)	
Q31 Was a Gleason score ever explained to you?	Yes	107 (46.5%)	25 (18.5%)	132 (36.2%)	<.001
	No	80 (34.8%)	65 (48.1%)	145 (39.7%)	
	I do not know/ remember	19 (8.3%)	22 (16.3%)	41 (11.2%)	
	NA	24 (10.4%)	23 (17.0%)	47 (12.9%)	
Q32 Do you understand what a Gleason score indicates?	Yes	94 (40.9%)	21 (15.6%)	115 (31.5%)	<.001
	No	84 (36.5%)	66 (48.9%)	150 (41.1%)	
	Maybe	24 (10.4%)	15 (11.1%)	39 (10.7%)	
	NA	28 (12.2%)	33 (24.4%)	61 (16.7%)	
Q33 Were you ever told your Gleason score?	Yes	111 (48.3%)	23 (17.0%)	134 (36.7%)	<.001
	No	70 (30.4%)	60 (44.4%)	130 (35.6%)	
	I do not know	18 (7.8%)	24 (17.8%)	42 (11.5%)	
	NA	31 (13.5%)	28 (20.7%)	59 (16.2%)	

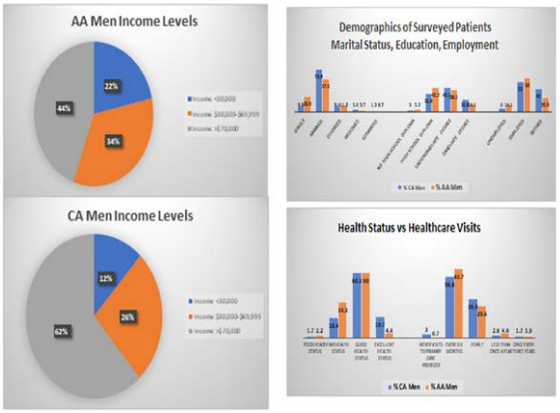

Figure 1. Financial and health disparities among AA and CA men.

Answers to the questions related to the understanding of prostate cancer diagnosis, general knowledge, biopsy, and Gleason score indicates that AA men have less knowledge as compared to CA men. Notably, 18.5% of AA men compared to 46.5% of CA men said that the Gleason score was explained to them, and 15.6% of AA men and 40.9% of CA men understood what a Gleason score indicates. Patient's Primary Care physician or Urologist would have been the one to explain what a Gleason score consist of. This question also leads to a finding of the knowledge of prostate biopsy. CA men at 42.8% compared to AA men at 20.1% stated that they knew a lot about what a prostate biopsy consists of. This provides further evidence of lack of prostate cancer knowledge. Additionally, based on the demographic data retrieved from this study AA men have less education and are more economically challenged then the CA men.

The second part of the questionnaire focused on the psychological effects of being diagnosed with prostate cancer. As shown in Table 2, anxiety in AA men was significantly greater than in CA men once they were diagnosed with prostate cancer. It is possible that increased anxiety may have an impact on how an individual understands the disease. AA men with PCa compared to CA men were more restless and anxious when told of diagnoses, along with having a routine lifestyle change due to the stress of being diagnosed. In this study there is a disparity between the number of CA and AA men that participated, primarily because most of them came from our Urology clinic at Roswell Park Comprehensive Cancer Center (RPCCC) or a related community event held on site. We hypothesize that this disparity exists from medical mistrust and not having a complete knowledge and understanding

of what this may provide in your decision making in the future. With this we decided to investigate and incorporate other institutions for future studies.

Table 2. Anxiety results based on questions asked.

		White	American	Overall	Pval
F1 I feel tense or wound up	Not at all	69 (29.7%)	57 (42.2%)	126 (34.3%)	0.054
	From time to time, occasionally	122 (52.6%)	58 (43.0%)	180 (49.0%)	
	A lot of the time	24 (10.3%)	8 (5.9%)	32 (8.7%)	
	Most of the time	17 (7.3%)	12 (8.9%)	29 (7.9%)	
F2 I still enjoy the things I used to enjoy:	Definitely as much	141 (60.8%)	84 (62.2%)	225 (61.3%)	0.086
	Not quite so much	70 (30.2%)	32 (23.7%)	102 (27.8%)	
	Only a little	11 (4.7%)	15 (11.1%)	26 (7.1%)	
	Hardly at all	10 (4.3%)	4 (3.0%)	14 (3.8%)	
F4 I can laugh and see the funny side of things:	As much as I always could	180 (77.6%)	102 (75.6%)	282 (76.8%)	0.092
	Not quite so much now	41 (17.7%)	19 (14.1%)	60 (16.3%)	
	Definitely not so much now	7 (3.0%)	12 (8.9%)	19 (5.2%)	
	Not at all	4 (1.7%)	2 (1.5%)	6 (1.6%)	
F11 I feel restless as I have to be on the move: Not at all	Not at all	91 (39.2%)	57 (42.2%)	148 (40.3%)	0.040
	Not very much	94 (40.5%)	37 (27.4%)	131 (35.7%)	
	Quite a lot	37 (15.9%)	30 (22.2%)	67 (18.3%)	
	Very much indeed	10 (4.3%)	11 (8.1%)	21 (5.7%)	
F13 I get sudden feelings of panic: Not at all	Not at all	145 (62.5%)	80 (59.3%)	225 (61.3%)	0.642
	Not very often	69 (29.7%)	40 (29.6%)	109 (29.7%)	
	Quite often	14 (6.0%)	13 (9.6%)	27 (7.4%)	
	Very often indeed	4 (1.7%)	2 (1.5%)	6 (1.6%)	
F14 I can enjoy a good book or radio or TV program:	Often	185 (79.7%)	91 (67.9%)	276 (75.4%)	<.001
	Sometimes	40 (17.2%)	24 (17.9%)	64 (17.5%)	
	Not often	4 (1.7%)	7 (5.2%)	11 (3.0%)	
	Very seldom	3 (1.3%)	12 (9.0%)	15 (4.1%)	

Discussion

This is among the first studies that examined and presented an association between prostate cancer knowledge and anxiety using measures administered in our survey. On a consistent basis the answers to the questions related to the understanding of prostate cancer diagnosis, general knowledge, biopsy, and Gleason score indicated that AA men have less knowledge compared to CA men answering the same questions. One possible explanation for this discrepancy could be the fact that the healthcare providers did not convey the information necessary to the AA patients which suggested AA men asked less relevant questions basically because of the lack of knowledge which we showed in our survey. Lack of basic understanding of PCa may prevent patients to further seek additional information through their healthcare provider. The reported disparities for prostate cancer risk factors are categorized as genetic factors (e.g., family history), social factors (e.g., segregation), and psychological factors (perceived stress) [10]. However, there is a current gap in knowledge and emotion since there are more studies focused on the biological and socioeconomic factors contributing to prostate cancer risk compared to psychological disparities. Erim et al., [11] demonstrated that depression is a major challenge for prostate cancer survivors in the first 5 years after diagnosis. They showed that the African American race have a higher risk of depression, which could be related to more financial stress. They also stated that only negative emotions have been studied and positive emotions such as optimism, purpose of life and overall satisfactions need to be studied for their association with a reduced risk of prostate cancer. Otis L. Owens et al., [7] studied emotion after diagnosis and treatment however their sample size was very small 17 AA and 13 CA men and their focus wasn't the AA and CA men difference in emotional response. Levi Ross et al., [6] compared the source of PCa information: interpersonal sources of prostate cancer information (e.g., friends, family, co-workers) and physicians related to prevention and control. Their findings emphasize the need to connect lower income and lower educated AA men to physicians as a source of prostate cancer control information.

Multiple factors are associated with PCa knowledge as it is related to AA men and their health care professionals [6]. One of the most important components of PCa patients and physicians' conversations should involve PCa screening and the benefits and/or harms that are contributed to AA men [12]. Preferably, these conversations should enhance the knowledge in AA men and contribute to an effective decision making outcome [13-16]. It is known that AA men if not receiving sufficient information from their health care providers regarding PCa, it is impossible for them to make an informed decision on their treatment [6].

In this study we also looked at the psychological effect of prostate cancer disparity in relation to knowledge of the disease, and both positive and negative emotions such as anxiety, and whether the patient still enjoys activities that made him happy before the diagnosis. To study the different levels of knowledge, we conducted a questionnaire that asked AA and CA

men their understanding of prostate cancer, their knowledge of the disease, decision making after diagnosis, and the psychological effect following diagnosis and treatment. Our findings suggest that fear significantly impacts AA men because of the negative answers provided regarding their daily life after being diagnosed with PCa. Overall AA men need more knowledge of PCa, and a better interaction with their primary health care providers to increase their understanding. Lack of knowledge of PCa screening and early detection, diagnosis, and unawareness of sources of information, such as health care provider guidance, in combination with increased anxiety among AA patients can play a role in PCa disparity and higher prevalence of the disease in AA men that needs further research. PCa that is undetected early may advance further and lead to an increase in treatment costs and poor quality of life. This may in turn lead to PCa financial toxicity and strain and potentially more disparity. In this study we highlighted the financial disparities among AA and CA men, with AA men having more financial strain. To connect knowledge, anxiety and financial toxicity and strain in AA men with PCa, we developed another survey that includes patients from RPCCC and Buffalo Veterans Administration Medical Center (VA). This study is currently in the accrual phase.

Conclusion

Despite the use of PSA screening to assist in early detection, PCa remains one of the leading causes of death in the United States. Several factors may explain why AA men develop PCa more precipitously than CA men in urban communities. These factors may include a lack of education, and knowledge about PCa, social disparity, treatment factors, and health inequality. We must address how important it is for healthcare providers to help their patients in decision making and evaluating the outcome of their decision when receiving treatment. Awareness of their patient's knowledge and beliefs regarding PCa and the importance of screening will help in the decision making for the patient. Communication should be simplified through utilizing standardized decision aids which can emphasize shared information between the healthcare provider and patient. Patients must have a trusting relationship with their healthcare provider and the healthcare system to make an informed decision based on the disease and the quality of life they seek to establish after treatment. Patients' families and care givers also aim for a trusting relationship with healthcare providers to enhance the patient's understanding and improve the patient's satisfaction with long term outcomes following treatment.

There were some limitations in this study, the first one is recruiting AA men to participate was challenging mainly due to the fact they were not interested in divulging their information. The second limitation was getting the surveys returned after patients were consented. This became a challenge based on the IRB recommendations and process for reaching out to patients. Further research is needed on developing tools that will assure the less fortunate to have the same ability to enhance their knowledge and to have a similar fighting chance for a better quality of life. AA men may not be able to change their lifestyle which may decrease the risk of developing PCa or detect the disease early. Also, we suggest that educators should focus their efforts on teaching students in the medical profession on the importance of patient education early on in their careers.

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Competing Interests

The authors have no relevant financial or non-financial interests. Adam Sumlin, Zahra Fayazi, Susan Camacho, Ali Houjaij, Oussama Darwish, Adrienne Groman, and Alan Hutson declare they have no conflict of interest.

Authors Contributions

AB Sumlin: protocol and Project development, manuscript writing and editing, S Camacho: data collection and analysis, Z Fayazi: data collection and analysis, A Houjaij: data collection, OM Darwish: data collection, A Groman: data analysis, A Hutson: data analysis.

Data Availability

The datasets generated from this study are deposited at RPCCC Redcap and are available from the corresponding author.

Ethical Approval

This study was performed in line with the principles of Declaration of Helsinki and was approved by RPCCC IRB under protocol number I44117.

Consent to Participate

Informed consent was obtained from all individual participants included in this study.

Consent to Publish

Additionally, participants were consented on the study data and result publication.

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