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Perceived Family History Risk and Symptomatic Diagnosis of Prostate Cancer: The North Carolina Prostate Cancer Outcomes Study

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Keywords

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Introduction

Prostate cancer (PrCA) is the most common form of cancer and the second leading cause of cancer deaths among U.S. men, with an estimated 218,890 new cases and 27,050 deaths from it in the U.S. in 2007.1 Since 1995 incidence has increased by 1% annually while PrCA mortality has decreased by 4%.2 Despite this somewhat favorable trend, African American (AA) men remain at significantly greater risk of PrCA than men of other racial groups, with age-adjusted incidence and mortality rates of 258.3 and 64.0 per 100,000 men, contrasting with respective rates of 163.4 and 26.2 for Caucasian (C) men between 2000 and 2003.3 In North Carolina, this disparity is among the broadest in the nation, with AA men experiencing PrCA mortality nearly three times greater than that of C men (76.2 vs. 26.4 per 100,000, respectively).4 Many factors may contribute to these disparities, including differences in proactive health behaviors such as utilization of PrCA screening.5 However, a large portion of this difference remains unclear because the relevant characteristics and

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issues driving health behaviors are so tightly intertwined; thus, design of effective interventions to improve health behaviors and screening rates continues to be challenging.

PrCA screening, though controversial, can detect PrCA many years before a patient would present with symptoms.5–9 Compared to clinically-detected (e.g., symptomatic) PrCA, screening-detected cancers are predominantly early disease, for which the prognosis is considerably better than that of clinically-detected PrCA.7,10 Although PrCA screening allows for detection of disease at an earlier course, the effects of early PrCA detection on mortality rates still need to be rigorously investigated to identify quantifiable survival benefits and minimize the influence of lead-time and length-time biases.11

Regardless, many recommend screening 12,13 Men with a known family history of PrCA have demonstrated heightened perceived vulnerability to PrCA, which has predicted screening behavior.14,15 When present, knowledge of risk may only translate into information seeking behavior, and not into proactive health behaviors such as regular checkups and screenings.16,17 Many men with a family history of PrCA are unaware of their heightened risk or underestimate it. 15,17–19 Specifically, AA men have been shown to be less likely to appreciate family history and other prostate risk cancer factors than C men. 18,20

Given that AA men are diagnosed with more advanced PrCA than C men and have a demonstrated lower awareness of PrCA risk factors, improvement of risk awareness among AAs merits exploration as a point of intervention that may contribute to enhanced utilization of screening, consequent detection at an earlier, more treatable stage, and a potential reduction in racial differences in PrCA mortality. Studies addressing whether differences in awareness of risk or reduced tendency to act on knowledge of risk contribute to the disparities in the stage of PrCA diagnosis are scant. We therefore employed a questionnaire designed to disentangle the constituent elements commonly associated with race, socioeconomic status, and drivers of health care utilization to study a population of AA and C men newly diagnosed with PrCA. We describe racial differences in perceived risk of PrCA and examine (a) whether perceived high risk for PrCA translates into greater personal responsibility for prostate care, and (b) whether in turn greater personal responsibility for prostate care translates into earlier, pre-symptomatic PrCA diagnosis.

Conceptual Model and Hypotheses

The Health Belief Model postulates that an individual will act if he perceives himself to be susceptible to a health threat, but that perceived barriers may deter action.21 In this study, we hypothesize that men with a first degree relative who had PrCA will perceive themselves at higher risk, which will produce greater personal responsibility for their prostate health and proactive actions including getting screened. Further, we hypothesize that increased personal responsibility for prostate health will increase asymtomatic diagnosis. Finally, we hypothesize that barriers such as access to care, physician trust, and avoidance behaviors will affect the relationships between perceived risk, action, and mode of diagnosis.

METHODS

Sample

The study sample consisted of 555 Caucasian (C) and African American (AA) men newly diagnosed with PrCA between November 2001 and May 2004 who agreed to be surveyed. We excluded men who identified their race one other than C or AA. Figure 1 illustrates the method of sample derivation. Details of the patient population, sample derivation,

questionnaire, and data collection methods have been published elsewhere.22 The following measures were used for the analyses described herein.

Demographics

Self-reported study demographics included patient race, age at diagnosis, marital status (currently married or not), education level (college graduate or not), employment status (working or not), and whether the patient had a doctor's office (rather than a public clinic or emergency department) as their primary source of care.

Prostate Cancer Risk

Because family history of PrCA has been identified as the strongest known risk factor15, "risk" in this study was defined as familial risk. Men were asked if any relative had been diagnosed with PrCA, and if so, which relatives and at what age. Men were considered at "actual high risk" if they reported a first-degree relative (father, brother, or son) having had PrCA. For men with a first degree relative with PrCA, we asked at what age the relative was diagnosed.

A single-item measure of perceived risk was used.15,16 Each participant was asked what he thought his risk of getting PrCA was compared to other men: much greater than, greater than, the same as, less than, or much less than. We considered a stated risk of at least "greater than" other men to be a perception of high risk.

Using the above definitions for actual and perceived risk, we calculated variables for under- or over-estimation of risk. We defined "underestimated risk" for men who had a family history of prostate cancer but yet did not report that his risk for prostate cancer was at least "greater than" other men. Similarly, we defined "overestimated risk" for men who did not have a family history of prostate cancer but yet did report that his risk for prostate cancer was "greater" (or "much greater") than other men.

Physician Trust

For the current study, we measured patient's trust of physicians with items adopted from the Primary Care Assessment Survey's Trust in Physician Scale.23The scale is composed of the following items each answered on a 5-point Likert scale (α=0.77): (1) I can tell my doctor anything, (2) My doctor sometimes pretends to know things when he is really not sure (reverse coded), (3) I completely trust my doctor's judgments about my medical care, (4) My doctor cares more about holding down costs than about doing what is needed for my health (reverse coded), (5) My doctor would always tell me the truth about my health, even if it was bad news, (6) My doctor cares as much as I do about my health, (7) If a mistake were made in my treatment, my doctor would try to hide it from me (reverse coded), and (8) All things considered, how much do you trust your doctor? Trust indices were standardized to a 0 – 100 scale, where higher scores indicate more trust.

Personal Responsibility for Prostate Care

We adopted the concept of "personal responsibility" from the literature on breast cancer and the health belief factors related to screening mammography.24.25 This scale was measured by the following items (□=0.62): (1) I have been careful to have my prostate checked regularly, (2) I sometimes felt I should have my prostate checked but decided not to have it done (reverse coded), (3) My prostate cancer was found mostly due to luck (reverse coded), *(4) I have had regular PSAs.* As with the trust indices, responsibility indices were standardized to a 0 – 100 scale, where higher scores indicate more responsibility for prostate care.

Avoidance of Prostate Checkups from Fear

A high degree of avoidance behavior was assigned to men who agreed with the statement: Men delay getting their prostate checked from fear of what the doctor may find.

Prostate Cancer Diagnosis

Men were asked “What was the first evidence, test, or symptom that led to diagnosing your prostate cancer?” Men were asked to choose between “abnormal PSA blood test,” “doctor felt abnormal prostate,” “cancer found at surgery for benign prostate problem,” or “urinary symptoms or discomfort.” Men who answered “urinary symptoms or discomfort” were categorized as “symptomatic diagnosis” and all other men were categorized as “non-symptomatic diagnosis.”

Statistical methods

All data manipulation and statistical analyses were performed using PC SAS 9.1.26 Frequency distributions for survey variables by race and overall were generated to profile study participants. Bivariate analyses were conducted to assess racial differences in all sociodemographic, risk perception, and health belief variables. Satterthwaite t-tests with unequal variances for continuous variables and 2 × n □2 statistic or generalized Fisher's exact test for categorical variables were used for all bivariate analyses. Subsequently, multivariate logistic regression was performed using the general linear modeling procedures. Three multivariate models, each with distinct binomial outcomes and controlling for all other sociodemographic, risk perception, and health belief variables, were examined:

Model 1: Outcome = Perceived high risk for PrCA.

Model 2: Outcome = Personal responsibility for prostate care.

Model 3: Outcome = Symptoms at first evidence of PrCA.

When the outcome event is common (incidence of 10% or more), relative risk (RR) estimates are preferred over odds ratios (OR) because of the increasing differential between the RR and OR with increasing incidence rates.27›28 Because the three outcome variables had incidence rates in our sample at greater than 10%, we used the SAS GENMOD procedure, specifying a binomial distribution and log link, in order to get relative risk estimates for predictor variables in each of the three models. For a given model, the relative risk generated for each variable indicates the difference in magnitude of the likelihood of the outcome between levels of the variable.

Results

Table 1 shows the bivariate comparison of C and AA men in terms of demographics, clinical measures, prostate cancer risk, and health beliefs and attitudes. AA men in our study were diagnosed, on average, 2.5 years younger than C men. Although equally likely to be currently employed, AA men were less often married, less often college graduates (both $p<0.01$), and less likely to receive primary care in a doctor's office (71.5% versus 86.2%, $p<.001$). While more often reporting first degree relatives with PrCA (30.4% vs. 21%, $p<.01$), AA men were no more likely to perceive themselves to be at higher risk. The age at PrCA diagnosis was lower in AA men's family histories-- 30% of AA men's relatives were diagnosed before the age of 60, compared to 12% of C men's relatives ($p<.05$). AA men estimated their risk less accurately than C men in both directions, underestimating their PrCA risk when they had a first degree relative with PrCA (18.8% vs. 9.8%, $p<.05$), and overestimating when they did not (11.1% vs. 7.2%, $p<.01$).

AA men had significantly lower mean physician trust scores than white men (86.1% vs. 89.8%, p<.01) and significantly lower mean responsibility scores than C men (69.7% vs. 83.9%, p<.01). Furthermore, almost 75% of AA respondents (compared to 57% of C men) indicated that they were likely to avoid getting their prostate checked for fear of what the doctor may find (p<.01). Screening in fact played a lesser role for AA respondents. Compared with C men, a larger proportion of AA men indicated that symptoms were their first evidence of PrCA (34.3% for AA vs. 24.4% for C, p<.01).

Table 2 shows the multivariate analyses results. For each of these analyses, all independent variables were entered into the models together (rather than in a stepwise fashion).

Model 1: Perceived high risk for prostate cancer

Multivariate analyses showed that when controlling for age, race, and other socio-demographic factors as well as health beliefs and attitudes, men with a first degree relative with PrCA were over twice as likely to perceive themselves to be at higher risk for PrCA than other men like themselves (p<.05), and having a relative diagnosed at a young age additionally increased the perception of high risk by 41% (both p<.05). In this adjusted model, race was not a significant predictor of risk perception, nor was age, marital status, health care source, or any health beliefs and attitudes.

Model 2. Personal responsibility for prostate care

Men who were married, college graduates and who had higher physician trust scores more often took personal responsibility for the care of their prostate (p<.05) In this adjusted model, race, age, actual PrCA risk, and perceived PrCA risk did not significantly predict the acceptance of personal responsibility for prostate care.

Model 3. Diagnosed symptomatically

Men who received primary care in a doctor's office, rather than an ER or clinic, were less likely have their PrCA detected by symptoms, rather than screening, as were men who expressed high personal responsibility for their cancer care (p<.05). Age was not a significant predictor of symptomatic diagnosis. Similarly, neither race, actual PrCA risk, nor perceived PrCA risk, were significant predictors after adjusting for other variables.

Discussion

Future efforts designed to reduce the racial disparity in prostate cancer outcomes should continue to educate men of their prostate cancer risk while at the same time encouraging further action and preventive behaviors, as this study found that risk perception did not predict screening behavior. Rather, future research could incorporate interventions designed to empower men to be personally responsible for their prostate health, including having regular prostate checks and not delaying check ups due to fear or fatalistic attitudes. Results described herein seem to indicate that merely understanding that one is at greater risk for prostate cancer is not enough.

Furthermore, because we found that risk does not predict behavior, but that physician trust does, research as well as clinical efforts could be made towards increasing AA's trust in physicians and ultimately strengthening the physician-patient relationship. Physician trust has been associated with willingness to seek care29, and the use of medical services by AA men, potentially reducing both their historically unequal treatment and current health disparities.30 In our multivariate analysis, lower physician trust predicted reduced likelihood to take active steps towards regular prostate exams. This indicates that the racial differences in seeking prostate care may be mediated in part through reduced trust. However, we found

evidence consistent with our observation elsewhere that reduced trust, in turn, arises from limited opportunities to establish a longitudinal relation with a physician.22 Therefore, future research efforts must address the causal relationship between trust and access, as well as address the reduced access to regular physicians in AA men as access to care is most likely a significant predictor of preventive and screening behaviors.

Our study has limitations. Other than stage at diagnosis, all data are self-reported, which opens the possibility of recall bias. As reported in our previous study22, patients' recall regarding checkups and PSA usage may be inaccurate and influenced by subsequent events such as patient care and treatment. Further, long term outcomes are unavailable at this time, so we were unable to examine associations between the mode of diagnosis to PrCA mortality and other adverse events. In addition, the cross-sectional design limits conclusions regarding causation, and future longitudinal studies are warranted to more accurately assess the relationship among risk, behavior, trust, symptomatic diagnosis, and later outcomes.

The study focused on the perception of increased risk of PrCA from a history of PrCA in a first-degree relative. AA men, however, may have considered themselves at greater than average risk because of their race. If AA men factored in race as a risk factor for PrCA as well as family history, we would predict that AA men would overestimate their PrCA risk more and underestimate their risk less than their C counterparts. However, AA men both overestimated and underestimated their relative PrCA risk more frequently than C men, suggesting that the perception of race as a risk factor may not have been a major factor in their self-assessment of PrCA risk. Still, the opportunity for misclassification of PrCA risk among at least some AA men is a limitation for drawing conclusions from this study's results.

The importance of our study lies in the finding that the disproportionate number of AA men who are already symptomatic at the time of PrCA diagnosis arises not from less responsibility for prostate care due to inaccurate risk perceptions, rather from the racial disparity in access to a regular physician and physician trust, which ultimately leads fewer AA men to seek prostate care or screenings. Our results have a major implication: perception of risk, taking active responsibility for prostate care, regular access to a physician, and trust are related in a complex way. We hope that this study addresses some of the factors that contribute to the racial disparity in PrCA outcomes.

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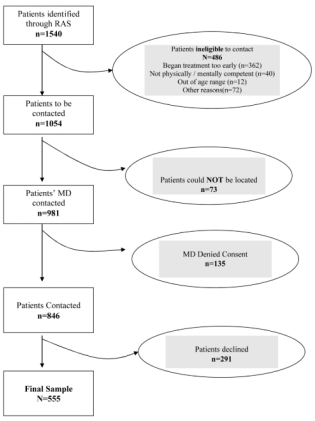

Figure 1.
Determination of study sample.

Table 1

Socio-demographics and health-related factors of a sample of men newly diagnosed with prostate cancer (n=555).

Study Variables	White (n=348)	Black (n=207)	Total Sample (n=555)
Demographics			
Diagnosis Age			
40 to 49	7 (2.0)**	13 (6.3)	20 (3.6)
50 to 59	92 (26.4)#	70 (33.8)	162 (29.2)
60 to 69	158 (45.4)	90 (43.5)	248 (44.7)
70 +	91 (26.1)**	34 (16.4)	125 (22.5)
Mean diagnosis age	64.5**	61.9	63.5
Married	303 (87.1)**	148 (71.5)	451 (81.3)
College Graduate	158 (45.4)**	33 (15.9)	191 (34.4)
Employed	167 (48.0)	94 (45.4)	261 (47.0)
Primary place for healthcare			
Doctor's Office	300 (86.2)**	148 (71.5)	448 (80.7)
ER / Public Clinic	48 (13.8)	59 (28.5)	107 (19.3)
Cancer Diagnosis			
AJCC Cancer Stage			
I	1 (0.29)	1 (0.5)	2 (0.36)
II	267 (76.7)	164 (79.2)	431(77.7)
III	33 (9.5)	15 (7.3)	48 (8.6)
IV	7 (2.0)	4 (1.9)	11 (2.0)
Not Reported	40 (11.5)	23 (11.1)	63 (11.3)
First Evidence of Cancer			
Symptomatic	85 (24.4)**	71 (34.3)	156 (28.1)
Non-symptomatic	263 (75.6)**	136 (65.7)	399 (71.9)
Prostate Cancer Risk			
Perceived High Risk	64 (18.4)	47 (22.7)	111 (20.0)
1st degree relative with PrCA	73 (21.0)**	63 (30.4)	133 (24.0)
Age Relative Diagnosed&			
< 50 years	1 (1.4%)*	5 (7.9%)	6 (1.1)
50 – 59 years	8 (11.0%)*	14 (22.2%)	22 (4.0)
60 – 69 years	37 (50.7%)*	21 (33.3%)	58 (10.5)
70 + years	27 (37.0%)	23 (36.5%)	50 (9.0)
Mean diagnosis age	67.7	65.0	
% High Risk and Perceive It^	53.4%#	38.1%	63 (11.4)
% Underestimate Risk@	9.8%**	18.8%	73 (13.2)

Study Variables	White (n=348)	Black (n=207)	Total Sample (n=555)
% Overestimate Risk[+]	7.2%[**]	11.1%	48 (8.6)
Health Beliefs/Attitudes			
Physician Trust			
< 75	30 (8.6)[**]	40 (19.3)	70 (12.6)
75 to 84	41 (11.8)	21 (10.1)	62 (11.2)
85 to 94	110 (31.6)	58 (28.0)	168 (30.3)
95 +	167 (48.0)	88 (42.5)	255 (45.9)
Mean Physician Trust Score	89.8[**]	86.1	88.4
Personal Responsibility for Prostate Care			
< 60	56 (16.1)[**]	73 (35.3)	129 (23.2)
60 to 74	16 (4.6)	10 (4.8)	26 (4.7)
75 to 84	63 (18.1)	49 (23.7)	112 (20.2)
85 to 94	28 (8.1)[#]	9 (4.3)	37 (6.7)
95 +	185 (53.2)[**]	66 (31.9)	251 (45.2)
Mean Responsibility Score	83.9[**]	69.7	78.6
Likely to avoid getting prostate care due to fear	197 (56.6)[**]	155 (74.9)	352 (63.4)

[*] p<.05

[**] p<.01

[#] p<.10

[&] % of all men who reported a 1st degree relative with prostate cancer (n=136).

[^] % of all men who had a first degree relative with PrCA (% of those at high risk)

[@] % of entire sample

[+] % of entire sample

Table 2

Logistic regression results. Relationship among demographic factors, family history of prostate cancer, perceived risk of prostate cancer, physician trust and personal responsibility for health and prostate cancer among a sample of men newly diagnosed with prostate cancer (n=555).

Socio-demographic and Health-Related Factors	Perceived High Risk for Prostate Cancer	Personal Responsibility for Prostate Care	Diagnosed Symptomatically
Demographics			
White (ref: Black)	0.85 (0.65, 1.12)	0.94 (0.81, 1.09)	0.81 (0.61, 1.08)
Diagnosis age 40 to 59 (ref: age 60+)	1.15 (1.11, 1.16)	1.02 (0.99, 1.06)	1.16 (0.85, 1.58)
Not Reported			
Married	1.20 (0.87, 1.65)	***1.36 (1.09, 1.70)***	1.14 (0.81, 1.61)
College Graduate	***1.43 (1.10, 1.87)***	***1.35 (1.18, 1.54)***	0.78 (0.55, 1.09)
Employed	1.15 (0.87, 1.52)	0.88 (0.76, 1.02)	1.10 (0.80, 1.50)
Doctor's office as primary source of care	0.80 (0.60, 1.07)	1.12 (0.92, 1.35)	***0.76 (0.56, 0.99)***
Prostate Cancer Risk			
1st degree relative with prostate cancer	***2.56 (1.95, 3.37)***	1.07 (0.90, 1.28)	0.91 (0.62, 1.32)
Perceived High Risk for prostate cancer	--	1.08 (0.93, 1.25)	0.89 (0.60, 1.30)
1st degree relative diagnosed at a young age	***1.41 (1.02, 1.96)***	1.04 (0.85, 1.27)	0.75 (0.53, 1.06)
Health Beliefs/Attitudes			
Highly trusting of physician	0.91 (0.71, 1.17)	***1.12 (1.00, 1.29)***	0.90 (0.69, 1.19)
Avoids: Fearful of getting prostate checked	0.96 (0.74, 1.25)	0.97 (0.85, 1.10)	0.99 (0.74, 1.32)
Highly responsible for prostate care	1.09 (0.83, 1.41)	--	***0.79 (0.60, 0.99)***

Note: Cells represent odds ratio and 95% confidence limits. Odds ratios in bold and italicized are significantly different from 0 ($p<.05$).