Knowledge of Hereditary Prostate Cancer Among High-Risk African American Men

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Purpose/Objectives: To measure knowledge of hereditary prostate cancer in a group of high-risk African American men.

Design: Cross-sectional, correlational pilot study.

Setting: Four geographic sites: Detroit, MI; Houston, TX; Chicago, IL; and Columbia, SC.

Sample: 79 men enrolled in the African American Hereditary Prostate Cancer Study.

Methods: Telephone interviews.

Main Research Variables: Knowledge of hereditary prostate cancer.

Findings: Knowledge of hereditary prostate cancer was low.

Conclusions: The high percentage of incorrect responses on questions that measure genetic testing, prevention, and risk based on a positive family history highlights educational needs.

Implications for Nursing: A critical need exists for nurses to educate high-risk African American men about hereditary prostate cancer.

Key Points . . .

- Nurses need to educate high-risk patients about hereditary prostate cancer.
- Hereditary prostate cancer accounts for 5%–10% of all reported cases of prostate cancer.
- Knowledge of hereditary prostate cancer among high-risk African American families may be low.
- Older men may be more knowledgeable than younger men regarding hereditary prostate cancer.

The genetic revolution has led to the availability of genetic susceptibility testing for hereditary colorectal, breast, and skin cancers. Hereditary prostate cancer susceptibility testing is not currently available, but it is anticipated to become a reality in the future (Smith, Mettlin, Davis, & Eyre, 2000; Stanford & Ostrander, 2001). Cutting-edge published results from the African American Hereditary Prostate Cancer Study identified several regions of the human genome containing genes that, when altered, increase the risk of hereditary prostate cancer development (Baffoe-Bonnie et al., 2007; Kittles et al., 2006). Linkage analysis with 77 African American families found evidence of linkage to five hereditary prostate cancer linkage peaks (2p21, 11q22, 17p11, 22q12, and Xq21), supporting the existence of genetic susceptibility for hereditary prostate cancer (Baffoe-Bonnie et al.). Also, evidence for the association of the EphB2 nonsense mutation with the risk of prostate cancer is reported in this African American cohort (Kittles et al.).

Other cohorts have displayed additional hereditary prostate cancer regions (Karayi, Neal, & Markham, 2000; National Cancer Institute, 2006a). HPC1, the first major susceptibility locus for hereditary prostate cancer identified on the long arm of chromosome 1 (1q24-25) (Cooney et al., 1997; Goode et al., 2000; Gronberg et al., 1999; Gronberg, Isaacs, et al., 1997; Gronberg, Xu, et al., 1997; Hsieh et al., 1997; Xu, 2000), has been confirmed by four studies (Balbay et al., 1999; Berry et al., 2000; Cooney et al.; Goode et al., 2001). However, two studies have not found support for HPC1 at 1q24-25 (Goode et al., 2000; Xu). Additional loci that have been identified and confirmed are HPC2/ELAC2 (17p11 and 16q23) (Ostrander & Stanford, 2000; Rebbeck, 2000), HPCX (Xq27-28) (Xu et al., 1998), Xq25-q27 (Stephan et al., 2002), and HPC20 (20q13) (Berry et al., 2000; Bock et al., 2001; Schleutker et al., 2000; Zheng et al., 2001). However, Xu, Zheng, Carpten, et al. (2001) and Xu, Zheng, Hawkins, et al.

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(2001) did not find support for linkage at HPC2/ELAC2, and Wang et al. (2001) concluded that it played a limited role. Two additional loci on chromosome 1 that have been identified are CAP (1q42.2-43) (Berry et al.; Berthon et al., 1998; Cooney et al.) and CAPB (1p36) (Gibbs et al., 2000). A subset of hereditary prostate cancer probands provided evidence for linkage at 1p13 (Chang et al., 2002). Other chromosomes of interest include 8 (Xu, Zheng, Hawkins, et al.), 10, 11, 12, 14, and 16. Prostate cancer aggressiveness loci also have been reported (5q31-q33, 7q32, and 19q12). Polymorphisms in several genes, including androgen receptor, PSA, SRD5A2, VDR, and CYP isoforms, have been reported (Nwosu, Carpten, Trent, & Sheridan, 2001). Carpten et al. (2002) reported on the importance of RNASEL as a diagnostic value with prostate cancer. Mutations in MSR1 and HPC2/ELAC2 mutations are important. The androgen receptor CAG repeat has been supported by some researchers (Gibbs et al.) but not by others (Lange et al., 2000). Chang et al. (2001) concluded that the CYP17 gene had a minor role in hereditary prostate cancer. Susceptibility genes for colorectal cancer and breast cancer have been associated with increased prostate cancer risk. Adenopolyposis coli gene mutations increase the risk of prostate cancer (Lehrer et al., 2000). Gronberg et al. (2001) documented increased prostate cancer risk with *BRCA2* mutations.

Hereditary prostate cancer accounts for 5%–10% of all reported cases of prostate cancer (Baffoe-Bonnie et al., 2007; Cooney, 1998). Men with a first-degree relative with prostate cancer are twice as likely to develop prostate cancer as men without a first-degree relative (Bratt et al., 2000). Hereditary cancer is different from nonhereditary cancer. Two distinguishing clinical signs of hereditary cancer are earlier age of onset and occurrence in several family members (Sacco et al., 2005). Hereditary cancer may be associated with increased mortality in contrast to nonhereditary cancer (National Cancer Institute, 2006b).

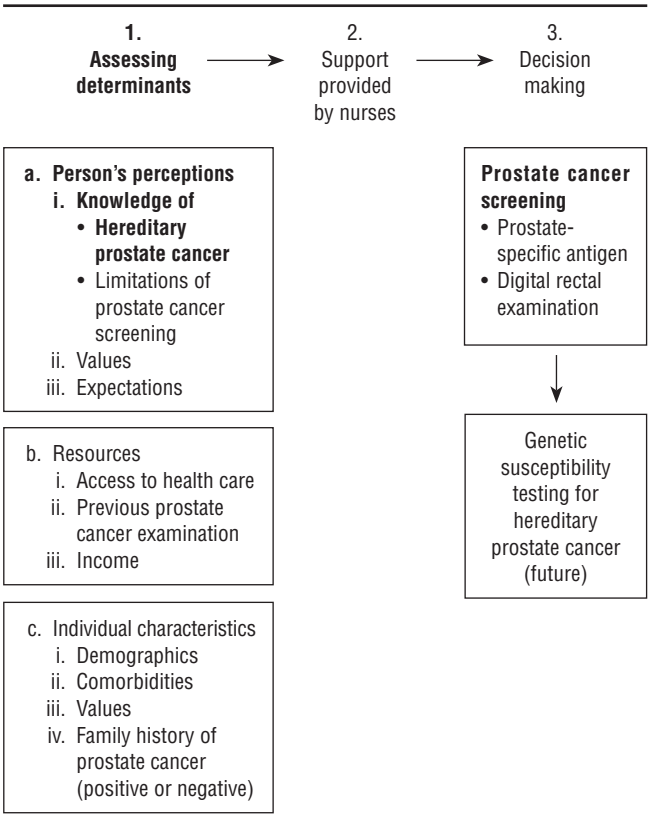
Now and in the future, when hereditary prostate cancer susceptibility testing becomes available, the public's knowledge about hereditary prostate cancer will be critical. However, prostate cancer genetic technology is evolving, and few published studies or instruments are available regarding knowledge of hereditary prostate cancer. In the one published study, one of four men failed to demonstrate an adequate understanding of the concept of the term "inherited tendency" (Miesfeldt et al., 2000). The subjects were 342 men from Virginia. Their lack of knowledge did not differ by family history, although it did vary by race. A greater percentage of African American respondents (51%) demonstrated inadequate knowledge in contrast to Caucasian respondents (Miesfeldt et al.). In the one published study on attitudes regarding inheritance of prostate cancer conducted in Sweden, most of the sons of fathers with prostate cancer had worries about increased risk of prostate cancer (60%), wanted to know whether it was inheritable (66%), and expressed interest in genetic screening (50%) (Bratt, Kristoffersson, Lundgren, & Olsson, 1997).

Hereditary prostate cancer research with African Americans is critical because race is a key risk factor for the incidence and mortality of prostate cancer. African American men develop prostate cancer 50%–60% more often than Caucasians and die from it at twice the rate of any other ethnic group (American Cancer Society, 2007). This research reports knowledge of hereditary prostate cancer in a high-risk African American cohort.

Theoretical Framework

O'Connor's Decision Support Framework provided the theoretical underpinnings for this research on knowledge of hereditary prostate cancer (O'Connor, 1995; O'Connor, Drake, et al., 1999; O'Connor et al., 2004; O'Connor, Fiset, et al., 1999; O'Connor, Rostom, et al., 1999) (see Figure 1). The framework includes three steps to decision making: assessing determinants, support, and decision making (O'Connor et al., 1998a, 1998b). Assessing determinants includes assessing a person's perceptions, resources, and individual characteristics. In addition, a person's perceptions are influenced by knowledge, values, and expectations.

The present research falls under the first step, assessing determinants as influenced by each person's perceptions, which is influenced further by knowledge (e.g., of hereditary prostate cancer), as shown in bold text in Figure 1. The second step is knowledge and support provided by the professional nurse to help each person make an informed decision. The third step in O'Connor's Decision Support Framework, decision making, also is conceptually relevant to this research, because each man must undergo his own decision-making



Note. Bold text indicates concepts applicable to this research.

Figure 1. O'Connor's Decision Support Framework: Prostate Cancer Screening

Note. Based on information from O'Connor et al., 2004; O'Connor & Jacobsen, 1998.

process regarding whether to undergo screening for prostate cancer. In the future, decision making for a man from a high-risk family also will include deciding whether to have genetic susceptibility testing, once it becomes available.

Instruments to measure knowledge of hereditary prostate cancer, such as that used in this research, are critical. Developing these instruments will become even more critical with the advent of genetic susceptibility testing for hereditary prostate cancer.

Methods

This cross-sectional, correlational pilot study measured knowledge about hereditary prostate cancer in a group of high-risk African American men during January and February 2002. The three hypotheses were that (a) overall knowledge of hereditary prostate cancer would be high among men from African American families with four or more men diagnosed with prostate cancer, (b) the majority of the men would know that the clinical risk signs for hereditary prostate cancer were multiple family members and early age of onset, and (c) having this knowledge would be positively correlated with education, age, and a previous diagnosis of prostate cancer.

Sample

Men from four geographic areas participated in this pilot study: Detroit, MI; Houston, TX; Chicago, IL; and Columbia, SC. All sites were part of a larger study, the African American Hereditary Prostate Cancer Study, which was funded from 1997–2004 to identify hereditary prostate cancer loci (Baffoe-Bonnie et al., 2007; Kittles et al., 2006; Powell et al., 2001; Royal et al., 2000; Weinrich, Royal, et al., 2002). Nationwide, more than 100 African American families with four or more family members diagnosed with prostate cancer were recruited to join the study, and DNA analyses were performed.

Approval from institutional review boards in each of the four areas was obtained before the research was conducted for the current study. Three families from each site were selected randomly, via a random list of numbers, leading to a potential study population of 108 subjects. Twenty-nine subjects were deleted from the 108 subjects because they did not meet the inclusion criteria for consent for the telephone interview (n = 14) and male gender (n = 15). Fourteen subjects did not consent because of death (n = 3), refusal (n = 2), inability to talk (n = 1), and inability to contact (n = 8). Fifteen women were eliminated because they were female. This left 79 subjects. Two of the 79 subjects answered six questions, not nine questions. The two subjects with the missing three questions were left in the analyses. The averages of the other 77 respondents' answers for the missing three questions were used for the missing answers of the two subjects. The 79 men included 38 men who had been diagnosed with prostate cancer.

Procedure

Telephone interviews, which followed a telephone protocol, developed by the first author, were conducted by the project coordinator at each site. The telephone protocol included directions for talking with the person who first answered the phone, who most often was female. It also included a script for describing the purpose of the study and procedures for gathering data. Participants were called as many as five times at different times during the day to establish contact. The project coordinators needed an average of 2.5 calls to reach each participant. Each call lasted an average of 15 minutes, with a range of 10–30 minutes. Copies of all completed data were mailed to the University of Louisvillein Kentucky for data entry and analyses. Confidentiality was maintained with the use of individual identification numbers.

Measurement

The Knowledge of Hereditary Prostate Cancer Scale was developed in 1999 (Weinrich, Faison-Smith, Hudson-Priest, Royal, & Powell, 2002) (see Figure 2). The scale measures respondents' knowledge about the key concepts of hereditary cancer, multiple family members with cancer on the same side of the family, and earlier age of onset of cancer. A seven-stage process was used in development of the questionnaire. First, four nurse genetic consultants were asked to identify concepts critical for a layperson to understand genetic cancer susceptibility testing. Second, 45 men at a lo-

Directions: New knowledge in genetics is changing the way many cancers are found and treated. Because it is new, many people have not heard about it. Please answer the following questions as true (yes) or false (no) so we can learn from you.

Question	True (Yes)	False (No)	Don't Know
1. A gene is inherited from your brother or sister.	❑	❑	❑
2. The doctor or nurse can take your blood to test you for some cancer genes that increase your risk of getting some cancers.	❑	❑	❑
3. Genetics is the study of diseases that can be spread by coughing or touching someone.	❑	❑	❑
4. Smoking increases your chances of getting some cancers.	❑	❑	❑
5. If a man has hereditary prostate cancer genes, there is nothing he can do to stop prostate cancer.	❑	❑	❑
6. Men are more likely to get prostate cancer if they have three or more family members with prostate cancer.	❑	❑	❑
7. Hereditary prostate cancer can be inherited from the mother as well as the father.	❑	❑	❑
8. If there is a family history of prostate cancer, the men in that family may get prostate cancer at a *younger* age.	❑	❑	❑
9. A man will get prostate cancer for *sure* if he has a change in his genes that increases his risk for prostate cancer.	❑	❑	❑

Figure 2. Knowledge of Hereditary Prostate Cancer Scale

Note. Numbers 2, 4, 6, 7, and 8 are true. Numbers 1, 3, 5, and 9 are false.

cal bus stop were asked open-ended questions about genetics. Third, true-false questions were developed to measure the concepts. Fourth, laypeople as well as nursing research students were asked to give feedback and suggestions for the questions, and changes in content and wording were made based on that feedback. Fifth, the true-false questions were administered to 145 men (predominantly African American) on five occasions. Men with positive prostate cancer family histories were included in the group. Sixth, 16 graduate research students provided feedback. Finally, two genetics nurses and two genetics counselors provided consultation and suggestions for revisions.

Content validity was established using the proportion of agreement among three expert judges (Carmines & Zeller, 1979). Three items were deleted based on recommendations from the judges. The final Knowledge of Hereditary Prostate Cancer Scale has nine questions. The nine knowledge questions are answered true or false. The questions were read and scored by the nurse telephone interviewer. The reliability was low, 0.55, using factor analysis (theta) (Carmines & Zeller). Whereas a short questionnaire is preferred for telephone administration, a short questionnaire can lead to low reliability. Statistically, the effect of a short questionnaire can be measured using the Spearman Brown Prophecy formula. The Spearman Brown Prophecy formula tests what the reliability would be if the length of the questionnaire was doubled, assuming the additional questions would be of the same quality as the original questions (DeVillis, 1991). The application of the Spearman Brown Prophecy formula to this research assumes 18 questions rather than 9. It yields a satisfactory reliability at 0.71 using factor analysis (theta) (Carmines & Zeller).

Analyses

Analysis of variance and Wilcoxon nonparametric statistics were performed to examine relationships between demographic variables and knowledge.

Results

Sample

All levels of education were represented: 23 (29%) had a high school education or less, 33 (42%) had some college or trade school, and 23 (29%) graduated from college or had additional education after college (see Table 1). The average age of the men was 54 years, with a median age of 57. Almost half (n = 38, 48%) had been diagnosed with prostate cancer.

Overall Knowledge of Hereditary Prostate Cancer

Each individual item in the Knowledge of Hereditary Prostate Cancer Scale was answered true or false by the men. Each man's individual answer was scored as correct or incorrect based on the known correct answer for each item provided by the author. Then the total score of the Knowledge of Hereditary Prostate Cancer Scale was obtained by summing the nine individual items. The range of possible total scores was 0–9, with 9 being a perfect score. The range of scores obtained in this sample was 3.5–9. The mean score was 6.34 (SD = 1.11). The authors interpret this as low hereditary prostate cancer knowledge based on an average of six questions out of nine questions yielding 67%.

Three questions related to genetic susceptibility were most likely to be answered incorrectly or not answered. They were related to cancer genetic susceptibility testing (2), prevention of prostate cancer (5), and likelihood of diagnosis of prostate cancer with a positive genetic test (9). The question that measured knowledge of cancer genetic susceptibility testing (2) was answered incorrectly 68% of the time. The question that measured prevention of prostate cancer once positive for the hereditary prostate cancer genes (5) was answered incorrectly 64% of the time. The question that measured likelihood of diagnosis of prostate cancer with a positive genetic test (9) was answered incorrectly 57% of the time.

Two questions related to inheritance (1 and 7) were answered correctly by more than half of the men. Question 1, related to inheritance through a sibling, was answered correctly as false by 80% of the men. The question that measured susceptibility through a female rather than a male (7) was answered correctly by more than half of the men (56%).

Knowledge of the Clinical Risk Signs for Hereditary Prostate Cancer

The two questions (6 and 8) that measured knowledge of the clinical symptoms of multiple family members and early age of onset for hereditary prostate cancer were answered correctly by more than half of the men. Most men (n = 65, 82%) correctly answered true to question 6: "Men are more likely to get prostate cancer if they have three or more family members with prostate cancer." Of the men with prostate cancer, 28 (74%) answered correctly; among the men without prostate cancer, 37 (90%) answered correctly.

Similarly, most men (n = 50, 63%) correctly answered true to question 8: "If there is a family history of prostate cancer, the men in that family may get prostate cancer at a *younger* age." Of the men with prostate cancer, 20 (53%) answered correctly; among the men without prostate cancer, 30 (73%) answered correctly.

Table 1. Sample Demographics

	Men Without Prostate Cancer (N = 41)		Men With Prostate Cancer (N = 38)		Total Sample (N = 79)	
Variable	**n**	**%**	**n**	**%**	**n**	**%**
Education						
Graduated high school or less	11	27	12	32	23	29
Some college or trade school	17	42	16	42	33	42
Graduated college or more	13	32	10	26	23	29
Age (years)						
< 40	4	10	10	26	14	18
40–59	14	34	21	55	35	44
≥ 60	23	56	7	18	30	38
Geographic region						
Detroit, MI	18	44	9	24	27	35
Houston, TX	5	12	4	11	9	11
Chicago, IL	10	24	10	26	20	25
Columbia, SC	8	20	15	40	23	29

Note. Because of rounding, percentages may not total 100.

Correlation of Knowledge of Hereditary Prostate Cancer With Age, Education, Diagnosis of Prostate Cancer, and Family

Age and biologic family correlated with knowledge. Age was a predictor of knowledge ($p = 0.002$). Older men had more knowledge than younger men (6.50 versus 5.86) (see Table 2). Significant differences existed in knowledge by biologic families ($p = 0.04$), with greater knowledge in all of the family members in some families in contrast to other families. In contrast to what was hypothesized, education was not a predictor of knowledge. Similarly, no significant differences existed in knowledge in men diagnosed with prostate cancer than in men without prostate cancer.

Discussion

Knowledge of hereditary prostate cancer in the high-risk African American families in the current study was low, indicating the need for increased genetic education. Knowledge was especially low for three items measuring the concepts of genetic testing, prevention, and risk probability based on a positive test. Of special concern was the high percentage of incorrect or unanswered responses for the question measuring risk probability based on a positive test.

Cancer fatalism, the belief that death is inevitable when cancer is present (Powe & Weinrich, 1999), may have been a factor. Future research needs to measure fatalism in high-risk families, and nurses need to develop effective interventions to decrease fatalism, such as the spiritual educational intervention used by Powe with colorectal cancer screening (Powe & Weinrich).

Weinrich et al.'s (2004) previous research on knowledge of prostate cancer screening (in contrast to hereditary prostate cancer as reported here) reported that education was not a predictor of knowledge. The current research indicated similar results with regard to hereditary prostate cancer. However, the present study's findings of significant differences in knowledge scores by age differ from Weinrich et al.'s (2004) findings that knowledge did not differ significantly with age.

Limitations

Results of this pilot study should be interpreted with caution because of the small sample size. Results apply nationwide to African American families with four or more men with prostate cancer. Future research should measure knowledge of hereditary prostate cancer in the general population (in contrast to a high-risk population such as the current cohort).

Implications for Nursing

In the current genomic healthcare system, nurses must understand that knowing and providing genetic health education are critical (Jenkins, Grady, & Collins, 2005). Recent genetic advances offer promises for early detection of many cancers and improved treatment based on genetic findings. Future research needs to measure nurses' knowledge of hereditary prostate cancer.

Populations to be targeted for genetic education based on the current research are African American men younger than 40 years of age who have a positive family history for prostate cancer. The clinical relevance of the need for education in this group of men is related to early detection, diagnosis, and treatment in men at higher risk. Earlier detection can lead to increased survival. The American Cancer Society (2007) recommends prostate cancer screening for African American men and men with a positive family history at the age of 45, which is earlier than age 50 recommended for men in the general population. The Knowledge of Hereditary Prostate Cancer Scale provides a tool nurses can use to measure patients' knowledge of hereditary prostate cancer. Assessment of this knowledge is a prerequisite for nurses in providing support for informed decision making concerning prostate cancer screening (see Figure 1). Although knowledge alone does not ensure that screening, early detection, diagnosis, and treatment will occur, a lack of knowledge implies decreased likelihood of prostate cancer screening.

The high percentage of incorrect responses to questions that measured knowledge of genetic testing, prevention, and risk based on a positive family history highlights specific educational needs among high-risk African American men. Education needs to be culturally sensitive and presented in ways that are easily understood by the target population.

The good news is that most men from high-risk families knew the clinical symptoms for hereditary prostate cancer of having multiple family members with the disease as well as early age of onset. Also, most of the men knew concepts related to inheritance that included the potential for inheritance from the mother as well as the father. The results should be interpreted with caution, because they could be explained by interaction and education from personnel of the African American Hereditary Prostate Cancer Study, the parent study from which the men were recruited. Knowledge could be lower in other high-risk groups of African American men who have not participated in a genetic research study.

The study findings of significant differences in knowledge by biologic family highlight the need for nurses to address knowledge of hereditary cancer and ethical issues that will evolve once hereditary prostate cancer susceptibility testing is available. Nurses who work with adults traditionally have provided care and health education to individuals instead of

Table 2. Mean Knowledge Scores by Demographic Variable

Variable	Score
Education	
Graduated high school or less	6.26
Some college or trade school	6.23
Graduated college or more	6.59
Age (years)	
< 40	5.86
40–59	6.40
≥ 60	6.50
Diagnosed with prostate cancer	
Yes	6.20
No	6.48
Geographic region	
Detroit, MI	6.04
Houston, TX	7.00
Chicago, IL	6.50
Columbia, SC	6.30

N = 79

families. However, genetic results affect families, rather than just individuals. A positive result in one family member has implications for the entire family. The family impact raises ethical issues about which nurses need to be aware, including an awareness of the ramifications of an individual decision with regard to genetic testing on an entire family.

The Knowledge of Hereditary Prostate Cancer Scale can be used as a baseline assessment of knowledge. Administration and scoring of the questionnaire can provide a framework for genetic education that builds on each individual's current knowledge. Knowledge concerning hereditary prostate cancer is new and evolving, as is the entire field of genetics. The correct responses for each individual item were based on current knowledge of hereditary prostate cancer. The reader is urged to evaluate the Knowledge of Hereditary Prostate Cancer Scale against the evolving genetic knowledge that will continue to emerge in the future.

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