

Original Article

How men view genetic testing for prostate cancer risk: findings from focus groups

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Objective: To determine the values, beliefs, and attitudes that influence a man's intention to undergo or defer genetic testing for prostate cancer risk.

Design: Qualitative, using focus group interviews – 12 focus groups were conducted to identify key values and beliefs about genetic testing for prostate cancer risk in anticipation of its future availability.

Setting: Medium-sized, mid-west, US city.

Participants: Community sample of 90 lay men of diverse educational, ethnic, and age backgrounds.

Analysis: Descriptive statistics and immersion/crystallization to identify themes and sub-themes.

Results: The major areas of concern were distilled into the following themes: beliefs about consequences, expectations, benefits for patients, beliefs about barriers, and susceptibility concerns.

Conclusion: Identifying these men's values will help health professionals anticipate the informational and ethical needs of patients in the informed consent process. Men will need to understand how such testing may affect their planning regarding future prostate health, and how medical information is used outside of the physician–patient relationship.

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As molecular genetic technologies are used to investigate genetic factors that predispose men for prostate cancer risk (e.g., the hereditary prostate cancer 1, or HPC1, gene), there is a corresponding need to understand patients' values and beliefs about such screening. Genetic testing for prostate cancer risk of presymptomatic men holds the promise of becoming an important tool in combating prostate cancer. Yet, its appropriate use is not well understood by patients or the majority of health care professionals to whom they will turn for assistance. Understanding the motivations of men who may one day consider genetic screening for prostate cancer will allow for anticipation of their goals, concerns, fears, and objections when testing becomes available. This process can help physicians and other health professionals 1) counsel men and families about the risks and benefits of testing, 2) assist patients in overcoming irrational fears, and 3) facilitate provider respect for reasons leading to refusal.

While prostate cancer has been shown to have a genetic component, the degree of genetic versus environmental factors influencing cancer development is uncertain (1). Although many are trying to identify the HPC1 gene on both chromosome 1 and chromosome X, there are conflicting data as to its contribution to inherited forms of prostate cancer (2). It is likely that there will be more than one HPC gene – similar to the situation in other common solid tumors such as breast and colorectal cancer (3–6). The extent of the impact of environmental factors in the development of prostate cancer is open to question (7, 8). As the gene loci for prostate cancer are identified in the near future, it is likely that genetic testing for prostate cancer risk will be developed for the research setting.

As is being seen for breast cancer and colorectal cancer, genetic screening for prostate cancer risk will eventually move from the research to the clinical setting. Barring any technological barriers, the identification of these mutations may then eventu-

ally lead to a screening test for the non-research setting. Once screening is possible, it may have the potential use of identifying higher risk men needing increased or earlier initiation of surveillance. Testing positive for HPC may convey a higher risk of earlier onset and/or increased aggressiveness and metastasis, or instead may help clinicians identify those groups of men who would best benefit from specific treatments for prostate cancer. Thus, genetic screening for prostate cancer risk may help men in their decision between watchful waiting and a more aggressive approach to treatment when early prostate cancer is discovered.

The advent of genetic testing for prostate cancer risk will require efforts to educate both patients and professionals. An understanding of men's perspectives on the prospect of genetic testing for prostate cancer risk is crucial to the development of protocols for education/counseling and insuring informed consent. This testing may one day be used as a tool for identifying genetic prostate cancer risk (GPCR), but how will men respond to the opportunity to be tested and why? While surveys of preferences for or against such testing have been performed (identifying support for testing as high, 74–91%), the motivations from the patient's perspective have not been evaluated (9–11). One study did ascertain that perceived risk, emotional distress, and concern about treatment side-effects were predictors of intention to test (11). However, no study to date has yet undertaken comprehensive evaluation of the spectrum of values that may influence one's decision to pursue genetic testing for prostate cancer risk.

The ambiguity of the multi-factorial nature of prostate cancer, as well as how to respond to a positive test, may ultimately present a quandary to the patient. The efficacy of existing treatment options is not well established and the risks of treatment include incontinence and impotence (12, 13). Many of the concerns in prostate cancer revolve around the concept of quality of life, a topic of pertinent consideration in prostate cancer screening (14–18). The decision to test for genetic risk initiates a set of decisions that must be based on knowledge that is inherently uncertain. The ethical response to such uncertainty is relevant, in that the weighing of benefit and personal choice considerations are not clear-cut when the benefit to the patient is indeterminate (19–22). A critical omission in the theoretical discourse on the consequences of genetic screening has been in understanding the values of those who would be most affected – patients. In formulating a clinical plan, health providers should incorporate relevant values of the patient, as required by the ethical principle of respect for autonomy (23).

An understanding of the values that men hold toward prostate cancer genetic screening would facilitate medical decision making in both the primary care and referral-based settings. Even if predictive testing will be made available to the public through speciality clinics, one must not overlook the eventual delivery of such services in the primary care setting, patients' initial requests for information and guidance concerning discussions of testing are likely to occur in primary care settings. Such forces may be exerted particularly if costs of genetic testing fall and make primary care genetic testing economically feasible. Hence, a thorough understanding of the values of men from the general population toward prostate cancer genetic screening would facilitate medical decision making in both the primary care and referral-based settings. We hypothesize that a man's beliefs, attitudes, social influences, and demographic characteristics will be salient in decision making on genetic screening for prostate cancer risk. This study seeks to identify the core values, beliefs, attitudes, and intended behaviors about prostate cancer genetic screening, with subsequent evaluation of men to quantify these data. Hence, this study is a 'first look' at the themes that men may hold toward genetic testing for prostate cancer risk. The development of a conceptual map of the moral, cultural, and other values important to the lay person in prostate cancer genetic screening is the goal of this project. These results should inform counseling and public policy for primary care genetic screening – particularly regarding disclosure needs in the informed consent process.

Method

Design

We conducted 12 focus groups with a total of 90 men from the general population, aged 18–70 years of age, excluding men who have or have had cancer. Within this group, men with positive family histories of prostate cancer were not excluded. We used focus groups to identify a broad spectrum of values, beliefs, social influence factors, and attitudes that were relevant to participants regarding prostate cancer genetic screening. Focus groups have been used in the past in marketing research, but the methodology is finding increased application as a means of refining hypotheses and insuring content validity of survey instruments throughout the social sciences (24–29). Persons are assembled to discuss a specific topic under the auspices of a moderator, who asks a series of probe questions. The respondents then offer their own insights and build upon the comments of the other participants

in the group. The project was conducted at the University of Michigan, and approved by the UM Institutional Review Board prior to any human subject's activity (# 1998-028).

Instrument development

We began with a systematic literature review of the lay (newspaper and magazine articles), medical, and bioethics literature on prostate cancer regarding genetic testing and genetic counseling from Medline and Bioethicsline. A list of relevant moral, cultural, and other themes concerning genetic testing for prostate cancer was generated from these articles. The list facilitated development of a discussion guide of 35 probe and broad open-ended questions for the focus groups (available on request). The primary variables of interest included subjects' values and attitudes about genetic screening for prostate cancer risk for them; their experience with prostate cancer in family members and friends; the motivating factors to accept and to refuse genetic testing for prostate cancer risk; and their views on the consequences for such testing. The discussion guide was refined after the first focus group. A short demographics instrument (not linked for identification to the subjects) assessed age, race, ethnic, cultural background, insurance status, and prior health history.

Participants

A research firm specializing in the conduct of focus groups on health topics, Personal Touch Marketing, was hired to recruit participants, assist in the development of the discussion guide, and moderate the focus groups. All groups were moderated by the same Caucasian male who identified himself as an employee of Personal Touch Marketing, contracted to conduct the focus groups from the local University. We recruited a total of 12 groups of men, and set up groups in proportion with the area population with eight Caucasian groups, separating groups by education (greater or less than 2 years of college) and age (18–39, 40–54, 55–70), with three African-American groups varying by age (18–39, 40–54, 55–70) and all educational backgrounds, and one Asian/Asian-American group, ages (18–70) and all educational backgrounds. A panel of men who identified themselves as willing to participate in focus groups to discuss 'men's health issues' was recruited through advertisements in local newspapers, and in posted notices at local churches, markets, and restaurants. Respondents to these notifications were screened by telephone, and those men meeting eligibility

criteria were consecutively placed into groups according to stratification criteria. As this study sought the values of non-high risk men from the primary care setting, men with a history of prostate cancer or other cancer were excluded from participation. Each focus group lasted 2 h.

The participants signed an Institutional Review Board-approved written informed consent form before their participation. At the beginning of each group, participants viewed an educational video on the nature of genetic testing for prostate cancer risk. The video was designed with a neutral tone to minimize biases of participants for or against genetic testing for prostate cancer risk (transcript available on request). It briefly explained the location and function of the prostate, the concept of prostate cancer, and current screening options, and the available treatments for prostate cancer – with their attendant ambiguity of efficacy compared to non-treatment, as well as side-effects such as impotence, incontinence, and radiation proctitis. While obviously not as comprehensive as a genetics counseling session, this tape provided a common, palatable informational foundation for all subjects to discuss in the focus groups. The tape then described the likely availability of genetic testing for prostate cancer risk in the future, and the uncertainty about how this test would assess the risk or aggressiveness of future emergence of cancer. This method promoted interaction of the focus group members, thereby catalyzing increased individual reflection on screening benefits and consequences. The moderator then used the interview guide to elicit the broad spectrum of values, beliefs, and attitudes that were relevant to participants regarding prostate cancer genetic screening. The discussion involved a lively interchange of questions and concerns on the utility and consequences of genetic screening for prostate cancer. Each participant completed a brief demographics questionnaire. Subjects were compensated for their participation with a stipend of \$50 for their time and travel.

The proceedings of all groups were audio-recorded and subsequently transcribed. The resulting transcripts were analyzed using the techniques of immersion and crystallization to ascertain relevant themes regarding how screening is viewed, how screening can be prepared for, and how test results could be discussed (29). For the analysis, each investigator read the transcripts multiple times and independently identified major themes and sub-themes. These themes and sub-themes were discussed as a group to develop a conceptual map of themes and sub-themes that incorporated each investigator's input. Differences in interpretation were minimal and readily negotiated.

The themes identified during the focus groups were mailed to the original participants to conduct verification, a process of evaluating the accuracy of qualitative analysis (30). The themes were converted to a narrative format to facilitate participants' understanding. Forty-two of the 90 participants returned the feedback form, voicing support of the statements in the feedback form and provided further details on some statements. These additional data revealed the diversity of values in the various groups, and highlighted some of the differences that arose between ethnic groups. Some indicated they did not identify with some statements made by members of other ethnic groups, although no attribution to ethnicity was made in the feedback forms.

Results

Demographics

Participants ranged from 18 to 70 years of age. While most were married, single and divorced/separated men were well represented. Most participants were Caucasian, had more than 2 years of college education, and no family history of

Table 1. Demographics (total n = 90)

	n	Percent
<i>Subject age</i>		
18-29	13	14
30-39	7	8
40-49	25	28
50-59	22	24
60-70	23	26
<i>Ethnicity</i>		
African-American	22	24
Asian-American	10	11
Caucasian (non-asiatic)	58	64
<i>Marital status</i>		
Single	21	23
Married	53	59
Divorced/separated	16	18
<i>Education level</i>		
Less than 2 years of college	25	28
Greater than 2 years of college	65	72
<i>Family history of prostate cancer</i>		
Yes	8	9
No	82	91
<i>Insurance type (multiple responses allowed, so total > 100%)</i>		
Health Maintenance Organization	42	47
Private	24	27
Medicaid	8	9
Medicare	11	12
Self-pay	8	9
Other insurance	5	6
Unsure	3	3

prostate cancer.(Table 1) Most men who voiced a preference appeared to be favorably disposed toward genetic testing for prostate cancer risk, with increased support voiced by older men. For focus groups with men over 40, the majority had a physical with a digital rectal exam and/or prostate specific antigen (PSA) test in the previous 2 years.

Themes

The main themes that arose addressed the following issues (Table 2):

- Beliefs about consequences,
- Expectations,
- Benefits for patients,
- Beliefs about barriers, and
- Susceptibility concerns.

As seen in Table 2, each major theme comprised several sub-themes that captured positive and negative evaluative moral, pragmatic, and consequentialist concerns of participants' about prostate cancer genetic testing.

The first theme of **Beliefs about consequences** concerns the ability to obtain health and life insurance if one were to test positive for increased GRPC. Men wondered if they would have to continue to receive other forms of screening (e.g., PSA, digital rectal exam, and ultrasound) if they were to test GRPC-negative. They were curious about how to best follow up for a GRPC-positive result. Given the ongoing development of genetics research, subjects thought that further genetic testing may be still required in the future, regardless of their test results. One fear voiced was that they could lose their job or not get promoted if they tested GRPC-positive. Such test results could then result in stigmatization by other family members and by society at large. This concern seemed particularly important to African-Americans. African-Americans had increased suspicion regarding confidentiality and concerns of how use of testing results could be potentially abused. One prominent concern among participants was how would one break this 'bad news' to one's family.

Many thought that patients who test GRPC-positive may be pressured to receive some sort of treatment before cancer actually occurs. This fear was coupled with that of compulsory testing (for insurance or employment), and that they might not want such testing, especially given these consequences. However, some believed that compulsory testing could be helpful for employees because it would encourage more preventive care. Some thought it would be better to know one's test results, as it could prompt one to follow a healthier

Table 2. Major focus group themes and sub-themes

Beliefs about consequences...

- On insurability
- Will have to continue other forms of prostate testing
- May need further genetic testing as technology develops
- Employment/ability to get promoted could be affected
- Stigmatization of myself
- How will I tell my family?
- Pressure to receive treatment
- Fear of compulsory testing
- Compulsory testing may be helpful for employees and lead to more preventative care
- Truth of knowing test results is good
- Could a positive test lead to precipitous action (for example, prophylactic surgery)?
- Non-traditional health measures may be helpful

Expectations...

- Who pays for this? (i.e., HMO/Insurance Co., but not me)
- If no cure currently, why get test?
- If it doesn't detect current cancer, why get the test?
- If a positive test, I can prevent disease by lifestyle changes
- Medical science will find a cure
- Who should I be seen by? Family physician vs. geneticist/specialist

Benefits for patients...

- Cost
- Family planning facilitated
- Society/medical science helped through testing
- Truth of knowing what is good
- May expedite finding a cure
- It could save my life
- It will give me peace of mind
- Knowledge could help other family members
- Will lead to more preventive screening tests

Beliefs about barriers...

- Future insurability
- Cost, who pays?
- No curative treatment
- Treatment for cancer will hurt my sex life
- Unnecessary surgery will result
- Lack of knowledge
- Decreased quality of life may result
- Accuracy problems of testing
- Self-treatment (such as lifestyle changes) are better than physician treatment
- Confidentiality
- Creates worry, anxiety and stress
- Procrastination could delay testing
- Could this knowledge be used for social or political ends?

Susceptibility concerns...

- Family history
- Current/past behaviors affect susceptibility
- Ethnic background

lifestyle through the 'control' of prostate cancer risk factors, e.g., pursuing a low-fat diet and increasing exercise. Others believed that being GRPC-positive could lead to precipitous action, e.g., prophylactic surgery. Some also thought that such testing could promote use of non-traditional health measures, such as herbs or meditation, to reduce one's risk.

The second theme of **Expectations** comprises practical concerns about the repercussions of testing GRPC-positive. The men, on the whole, felt strongly that testing should be a covered benefit under health insurance. Their opinion seemed grounded in a concern that this test should not be cost-shifted to them. Some pragmatic concerns arose as to how useful the test would be when there is no definitive cure, and since this testing would not detect current cancer. Again, men wanted to know if testing would result in dietary and exercise-based responses on their part to minimize their risk. Men were hopeful that widespread testing might help to better understand prostate cancer, and lead to its cure. They were concerned about whether they would be seen by their family physician for testing, with many perceiving that they may have to go to a geneticist. Some were not aware that this may be necessary (and some stated this was unwanted) and others were surprised about having to undergo any form of genetic counseling. Some men of Asian descent voiced interest in genetic testing for all employees based on an obligation of corporations to maintain employee health.

The third theme is **Benefits for patients**. Anticipated benefits were the basis for many to voice their support for genetic testing for prostate cancer risk. The cost of genetic testing was thought (or hoped) to be low. They envisioned that such testing would be helpful in considerations of family planning, with some stating that if they were still of procreative age, that a positive test may make them pause in having children. Many thought that testing would be helpful to society (in expediting a cure), and also a personal good (in easing their anxiety and leading to their own cure). Further, many respondents mentioned the good of helping other family members. In turn, greater emphasis will be made on preventive screening tests to reduce the likelihood of cancer.

Many concerns were raised by respondents that were included under the theme of **Beliefs about barriers**. As noted in the first theme, men voiced considerable consternation because of possible loss of insurability if they tested GRPC-positive. They feared that their ability to get or keep both life and health insurance could become compromised as a result of this information being shared with third parties. Confidentiality concerns were prevalent with all men, whether regarding their insurance, their employers or their families. They were concerned that the price of treatment would be too high if their own insurance would not cover testing. The lack of a definitive cure for prostate cancer made some reluctant to pursue testing.

They also expressed beliefs that, if they tested GRPC-positive, treatment for cancer would hurt their sex life and could result in unnecessary surgery. These consequences could then cause decreased quality of life whether through an adverse treatment outcome, or from the anxiety of a possible cancer outbreak. Some thought that the creation of worry, anxiety and stress might make testing not worth the effort of combating cancer. Many men thought that lack of knowledge of genetic testing would result in fewer men seeking it. Some wondered if accuracy problems of testing could make the information less valuable, and questionable in its utility. Also, many thought that procrastination could delay men seeking testing. If one tests positive, some thought that self-treatment (such as lifestyle changes) are better than physician treatment. One concern of African-Americans reflected on abuse of the sickle cell screening programs of years past, and some participants wondered if genetic testing results could be used for larger social or political ends.

The last theme, **Susceptibility concerns**, describes how much these men perceived themselves at risk. Men who had a family history of prostate cancer, (or any form of cancer) did perceive that they were at higher risk than the average man. Men who had previous, non-cancer related prostate problems (such as benign prostatic hypertrophy and prostatitis) also thought they were at higher risk. African-American men acknowledged their higher risk, and some wondered if this was due to diet or some other non-genetic factor. On the whole, African-American men were less enthusiastic about testing.

Discussion

Those who voiced a preference appeared to support genetic testing for prostate cancer risk, with less support among African-Americans. Previous experience in both breast and colorectal cancer, though, have revealed that people often have initial high interest in testing when posed conceptually, but that the fall off from testing intention to getting a test drawn, and receiving the results, is dramatic, secondary to psychological and other concerns (31–33). In this qualitative investigation, intention to test was not the endpoint. Rather, an understanding of the spectrum of values that would influence their decision making for testing was the goal. Indeed, although the benefits and the disadvantages of genetic screening for prostate cancer risk are yet to be clarified, these men viewed genetic testing with considerable naivete. Concepts of risk, cost and perceptions of benefit revealed a

lack of sophistication about prostate cancer, and biases about how they think it can be somehow prevented. Concerns about others family members, a common primary concern in other genetic testing paradigms, was somewhat less prominent in these data, though noted by respondents. Of note, men seemed less concerned about concurring with their spouses' view on genetic testing, than following the counsel of their primary care physician.

By understanding the motivations of why men would want such screening and what barriers might preclude them, an informed consent process can be designed to educate men about the many influencing factors relevant to their informed choice. Even so, the factors that ultimately predict getting tested may be different than those expressed in this study. These data then highlight the following particular needs: 1) detailed education on prostate cancer and testing prior to genetic testing and counseling; 2) understanding concepts of risk and ambiguity regarding the interpretation of genetic test results and; 3) high quality pre- and post-test educational counseling.

The next phase of this research will quantitatively evaluate the values of men toward testing intention, and the measurement of the relative importance of each of these values. When, how and why men may or may not be receptive to prostate cancer genetic screening is likely to vary according to an individual's beliefs, attitudes, social influences, and demographic characteristics. Understanding how these factors are relevant to genetic screening decision making will help physicians and genetic counselors to tailor the informed consent process to the needs of their patients.

There were several limitations of this research. Self-selection bias of the recruiting approach used would likely favor men most interested in their health and prevention, a factor that may have biased them towards screening. Also, these subjects live in close proximity to a tertiary medical center known for its genetics research. Their attitudes toward genetic screening could be biased as a result of local media attention. Further, qualitative research is geared toward describing a spectrum of attitudes, rather than serving to describe the prevalence of opinions. This type of research does not allow for linking demographic characteristics of subjects to their responses, statistical analysis, or rank ordering of the themes. As noted above, future quantitative research will address these areas of interest. Lastly, this study did not endeavor to see how men's attitudes might be shaped by the method of intervention (as was noted in a previous study by Bekker et al.) (34). Such interventions may be possible with a larger sample population in future research.

Conclusions

Most, but not all, men in this study were very favorably disposed to genetic testing for prostate cancer risk. Further, this attitude appeared to be age related, i.e., increased support with age, and there are ethnic differences regarding the degree of suspicion with which men view such testing, i.e., increased with African-Americans and decreased among Asian men. Men will require considerable education to prepare them for genetic testing for prostate cancer risk. While these men have concerns about discrimination and negative social consequences that have proven important in women contemplating genetic testing for breast cancer risk, they also seem distinctly more pragmatic and less family-oriented in their thinking. Further research is now needed to examine quantitatively the relative importance of the identified factors as predictors that encourage or discourage men from obtaining genetic testing for prostate cancer risk. These results suggest that there are important age, ethnicity and co-morbidity predictors that merit further inquiry.

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