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What men want: Qualitative analysis of what men with prostate cancer (PCa) want to learn regarding genetic referral, counseling, and testing

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Abstract

Background: Guidelines have changed recently to include genetic counseling (GC) and/or genetic testing (GT) for all men with aggressive prostate cancer (PCa). This study aimed to identify what information men with PCa desire before and from GC.

Methods: Focus groups were conducted with men who have PCa. Audio recordings were analyzed for themes related to GT, the information they desired from health care providers, and implications for family members.

Results: Thirty-seven men with PCa participated in seven focus groups. Nearly all men felt GT was beneficial and impactful for their family and themselves. Most men were unaware of the risks to female relatives associated with hereditary cancer. Participants discussed that genetics should be incorporated at an appropriate time of their diagnostic journey.

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CONFLICT OF INTERESTS

The authors declare that there are no conflicts of interests.

Conclusion: This study showed that men valued GC and GT for personal and familial implications, and often did not associate PCa genetics with risk for female relatives to develop cancer. Consideration should be given to the GC timing in regard to where men are in their treatment process. Providers referring patients can leverage patient motivations and utilize their relationship with the patient to determine the appropriate timing and personalize discussion with the patient regarding GC and GT.

Keywords

BRCA1/2; genetic counseling; germline mutations; prostate cancer genetics

1 | INTRODUCTION

Prostate cancer (PCa) affects ~11.2% of men, though around half of those men have aggressive PCa (regional or metastatic) that requires treatment beyond local surgery and/or radiation.[1,2] There are many risk factors that may impact PCa risk, including Agent Orange exposure, diet, and so forth.[3,4] In the past few years, a strong body of evidence has emerged suggesting that men with aggressive PCa have an 8% to 12%, if not higher, chance of harboring a deleterious mutation in DNA-repair genes thought to contribute to inherited cancer predisposition such as BRCA1/2.[5–7] Furthermore, men with germline DNA-repair pathogenic variants may be candidates for targeted therapeutics such as PARP inhibitors.[8] As a result, National Comprehensive Cancer Network (NCCN)'s BRCA1/2 testing guidelines expanded in October 2017 to recommend germline genetic testing (GT) for all men with metastatic PCa.[9] More recently, NCCN's prostate cancer guidelines broadened to recommend germline GT for all men with aggressive, or high or very high risk PCa.[10]

The facilitation of GT is currently recommended to be performed by a certified genetic counselor. Strong evidence supports patients having high levels of informed decision making, satisfaction, and minimal distress when they utilize genetic counseling (GC) to determine if testing is appropriate for them. In general, the proportion of patients seeking GC referral is low, even in cancer diagnoses that have been indicated for GT for many years.[11,12]

There is limited information on men's perspectives regarding what information they would like to receive during a GC session.[13] A majority of this study has focused on women, showing that they want information regarding treatment implications, support in the process, and consideration of the pros and cons of GT.[14] Given noted differences between men and women's informational preferences,[15–17] both genetic counselors and referring providers should tailor discussions regarding genetics to their patient's preferences. This study aims to identify information men with PCa desire before GC from providers, both genetic counselors and referring clinicians.

2 | MATERIALS AND METHODS

2.1 | Study population

Eligible study participants were men with a known diagnosis of PCa, as defined by ICD-10 code C61. Participants were recruited to focus groups at two sites in one of three cohorts: Site 1 (Huntsman Cancer Institute [HCI]) patients before receiving GC, Site 1 (HCI) patients who had undergone GC, and Site 2 (George E. Wahlen Veteran Affairs) patients who had not undergone GC. All men completed a demographic and numeracy survey as a proxy for consent. Focus groups were held either over lunch or in the evenings at a time when most patients could attend. All focus groups were 1 hour in length, led by individuals (SS and SZ) trained in focus group facilitation and recorded. A genetic counselor (SG and VV) was present to answer questions and provide background during the discussions. The focus group discussion underwent transcription through the Qualitative Research Core at the University of Utah. The qualitative methodology was reflective of the Editing Approach by Miller and Crabtree, an interpretive approach developed to be consistent with research conducted in the health sciences.[18] Coding was performed by two trained qualitative analysts and was supervised by a qualitative expert (SZ). Data management was supported by the computer software program ATLAS.ti.

Participants reported four key areas of information they wanted to receive from a genetics consultation: impact on current diagnosis, attribution of lifestyle to a current diagnosis, how a family is impacted by testing, and opportunities for screening and prevention. This information was asked using a focus group guide with background information on genetics in addition to the questions. Any misconceptions that arose during the focus group were addressed after discussion of the topic. All participants were compensated with a meal and a $10 gift card. The study was approved by the Institutional Review Boards of the University of Utah and George E. Wahlen VA.

2.2 | Site 1

From October 2017 to January 2018, men were recruited from HCI, an academic medical center and NCI-Designated Cancer Center, to four focus groups. Two of these focus groups included men before GC (pre-GC) and two of these focus groups included men who had already undergone genetic counseling (post-GC). The post-GC group was recruited if their geographic location was less than 2 hours away from HCI. The focus group facilitator focused on four key areas: information regarding GT received before referral, key information desired during a GC session, family communication, and the impact of genetics on personal and family health (Appendix A and B).

2.2.1 | Pre-GC cohort—Men with PCa who met institutional criteria for a referral but had not undergone GC were recruited. These men were identified through the GC referral queue and clinic schedules with the genitourinary oncology team. Men were contacted by the study coordinator via telephone and recruited to the study. After the focus group, these men were offered one-on-one GC appointments for individualized risk assessment and discussion of GT.

2.2.2. | Post-GC cohort—All men with an ICD-10 code C61 seen for GC from 1 October 2015 to 15 January 2018 were identified via electronic medical record for the post-GC cohort. Men who were deceased or lived more than 2 hours away were excluded from recruitment. Men were recruited via telephone by the corresponding author and study coordinator.

2.3 | Site 2

Men were recruited at the George E. Whalen Veteran Affairs Medical Center (VA) from November 2017 to March 2018. Patients receiving leuprolide were identified by the pharmacist and verified in the electronic medical record to have metastatic PCa. Recruitment letters along with a survey were mailed to potential participants. Men who returned the survey or called the VA were enrolled if they had not undergone GC (pre-GC only cohort). Men who had undergone GC at the VA were excluded. Patients were contacted 2 weeks after the mailing and/or in person for additional follow-up. The focus group guide focused on what the Veteran has been told about genetics, their understanding of environmental and inherited risk factors, key information desired during a GC session, and the impact of genetics on personal and family health (Appendix C).

3 | RESULTS

Twenty-five men were recruited from HCI and 12 men were recruited from the VA for a total of 37 participants across seven focus groups (Table 1). Twenty-two (59.5%) of these men had not undergone GC before their focus group. A majority of these men (89%) reported being White, with a wide representation of ages (46-87 HCI; 60-90 Site 2). At Site 1, most men had Gleason greater than or equal to 7 (n = 21, 84%) PCa, most of which were metastatic (n = 16, 64%) and therefore meeting NCCN criteria for testing. At Site 2, a majority of men had metastatic PCa (n = 10, 66.7%) with 35.7% Gleason greater than 7, though five participants had unknown Gleason scores.

3.1 | What do patients want to know about genetics?

Participants at both sites discussed wanting to learn about how GT would impact their current cancer diagnosis, notably if there was a therapeutic impact given certain test results (Table 2). One patient reported that they were not utilizing chemotherapy at this time, but would consider it if it was indicated based on GT:

"I'm trying to take alternatives [to treatment], but…maybe they say genetically your cancer, if the chemo treatment [has a] 80% to 90% success rate for your cancer, then all of a sudden my interest in that is gonna go up dramatically."—HCI participant, pre-GC cohort.

Though participants reported wanting to learn about the impact of GT on their personal treatment plan, others were simultaneously focused on family impact:

"My only concern about genetics would be what's gonna happen with my children. Nothing to do with me, because I've got it [PCa], I already have it…unless you can somehow change the treatment based on genetics."—HCI participant, pre-GC cohort.

Multiple participants cited the importance of screening and prevention, for both themselves and for family (Table 2). At both sites, it was noted that genetic test results may have impacted their screening habits, and noted that it would be crucial to encourage screening amongst relatives. Notably, participants mostly highlighted the impact on their sons, and did not mention the impact for their daughters:

"Am I carrying a gene that has been altered? I'd be interested in that…You know that'd be a great thing to know…I'd tell all three of my boys"—VA participant, pre-GC cohort.

"If I had known that [there was a hereditary risk], "hey you have the likelihood of having PCa," it would have been nice to know"—HCI participant, pre-GC cohort.

The two sites differed in their perspectives of how lifestyle contributed to their diagnosis of PCa. While patients at HCI discussed diet extensively and unprompted in their focus groups, patients at VA centered their exposure discussions around Agent Orange, which was widely used in Vietnam (Table 2).

3.2 | When, with who, and how much do patients want GC and testing?

Participants discussed the logistics of genetics in each focus group (Table 3). Overwhelmingly, these men felt that genetics referral should be discussed with someone they trusted. A wide range of providers was noted as options, ranging from surgeons to oncologists. Time was noted as a factor on both the patient and provider level that may impact the feasibility of discussing a genetic referral with patients:

Provider level: "Urologist, oncologist…nurse practitioner…those are the ones [that should] talk about this. Of course then you only have 15 minutes so…having…more time with it would be lovely."—VA participant, pre-GC cohort.

Patient level: "I'd rather my [primary care] doctor know [about genetics], because I may not be at the other [providers]"—VA participant, pre-GC cohort.

When it came to cost and the timing of when GC and testing should be introduced, participants had a wide range of answers. While some patients felt they could not afford any out of pocket, others cited being willing to pay in the thousands for GT. Given the federal nature of VA's coverage of genetic services, Veterans (Site 2) did not have a frame of reference for the costs of genetic tests (Table 3). Many felt that it should be a service covered by insurance and were willing to pay their expected contribution by plan:

"As far as I'm concerned [with] the cost of health insurance and everything in this day and age, I think it should be a co-pay."—HCI participant, pre-GC cohort

Participants also reported that the amount of information provided through the cancer process is variable and noted that patients may desire genetic referral and evaluation at different points in that process:

"I think different people would have interest at different time frames…it wouldn't be day 1, oh let's talk about genetics because I probably wouldn't be very interested at that point"—HCI participant, pre-GC cohort

4 | DISCUSSION

This is the first known qualitative study to evaluate what information men with PCa want regarding GC and testing. Utilizing focus groups, these results suggest men are focused on therapeutic, other cancer risks, and familial impact. Furthermore, while men may vary in when they would like genetics integrated into the process, and how much they are willing to pay, they believed that the recommendation to seek genetic evaluation should come from a provider they trust.

A majority of research on what patients want to learn from cancer GC has been conducted on women at risk for BRCA1/2 mutations.[13,14] Given the evidence that men may receive information differently, evaluating this population to compare and contrast desired information is crucial.[16,17] Similar to women, men were interested in engaging in discussion regarding GT with a provider they trust.[19] In this study, men wanted to learn about simGTilar topics related to their personal treatment and family implications. However, unlike research on women with breast or ovarian cancer undergoing GC and testing, men with PCa were not focused on implications for surgery, but rather therapeutics such as chemotherapy decisions.[20] Notably, given the advent of PARP inhibitors for therapeutic targets,[8] sharing with patients the potential treatment impact of GT is imperative. As scientific innovation continues to develop new precision treatments that rely on germline GT, providers will increasingly need to discuss the implications of GT on treatment to encourage referral for genetic evaluation.[21] Unlike women undergoing GT for decision making on breast cancer treatments, participants did not specify wanting to know about GT at the time of diagnosis, suggesting a difference between men and women on the timing of information preferences.[22]

The impact of genomic information on a patient's family is a common theme when identifying information patients want during genetic evaluation. The widespread impact the testing can have for the patient and their family is a motivator for patients to seek GC and testing. Many of the participants in our study highlighted the impact of genetics on their male relatives and did not include the potential implications for their female relatives. Notably, the quantitative risks for many hereditary cancer syndromes such as *BRCA1/2* are not as high in men as in women. Thus, educating men on the impact that germline testing could have for both their male and female relatives is crucial. Strong evidence suggests that family can serve as a motivating factor to pursue genetics due to the needs for social support or feelings of family obligation.[23] However, if patients' family relations are more socially and emotionally distant, then family concern may not be as motivating.[24]

The perception of exposures for how men believed their lifestyle may have impacted their diagnosis varied by site. While men at HCI discussed diet without prompting, Veterans highlighted their exposure to Agent Orange as a likely exposure-related tumor risk. Though exposures such as Agent Orange may increase the risk for PCa, environmental exposure

does not preclude a hereditary cancer risk. Educating patients on the intersection of lifestyle, exposures, and genetics can help patients understand the role genetic evaluation may play in their care. Notably, men may perceive their diagnosis to have a cause, and this may impact how discussions with these patients are tailored.

Opinions on how best to access GC and testing were varied. Among patients for whom therapeutic changes are imminent, introducing referral to genetics may need to occur early in the cancer treatment process. On the other hand, when men are responding well to their current cancer therapy and family may not have reached screening age, the genetic referral may be delayed so the patient and their family can adapt to the patient's health condition and needs.

A key topic that arose was the importance of trust in a patient's providers. Though patients differed in who they wanted to discuss and facilitate genetic referral and evaluation, they consistently mentioned it was crucial they knew and trusted that referring provider. Other studies have demonstrated that people's decision to seek genetic services is impacted because "their provider told them to."[25] Concordant with past research, our study highlights the importance of finding an appropriate time to discuss the referral and ensuring that a solid rapport has been built with the patient.

Though key themes achieved saturation during the coding process, this study is limited in its small sample population. Men were recruited if they lived within a 2 hour radius of HCI, and therefore there may be bias in this data's extrapolation to frontier populations. Notably, the majority of the participants identified as Caucasian. The lack of diversity in this population, especially given the disparities in morbidity and mortality for Black men with PCa,[26] may limit the generalizability to the broader PCa population. Additional research should select for a more diverse focus group composition.

Utilizing this data, opportunities to standardize genetic education for men with PCa can be considered for future research. For example, creating an educational tool, such as a video or chatbot, to inform men with PCa on the implications of GT on their treatment, familial impact, and other cancer surveillance, maybe one way to meet the growing need for GC in men with PCa. Furthermore, from this qualitative data, a quantitative study could be considered to better extrapolate information preferences in men with PCa. Ultimately, expanding the research on communication preferences in men with PCa when it comes to cancer genetics can allow this population to receive tailored information geared towards their preference.

5 | CONCLUSIONS

Health care providers across many specialties play a role in referring and discussing genetic evaluation for men with PCa. Utilizing a patients' specific background, therapeutic, and family implications can be leveraged to facilitate genetic evaluation at a time that is best for the patient in their cancer journey. Highlighting the impact of GT on both male and female family can be crucial. Ultimately, a tailored approach to discussing genetics with patients can maximize the likelihood men with PCa are willing to seek genetic evaluation.

ACKNOWLEDGMENTS

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APPENDIX A

Facilitator:

Hi and thanks for joining us today. My name is xxx and the team today includes xxx. You were invited to this discussion so we can learn from you and develop the right amount of information/education about prostate cancer genetics for you and other men with prostate cancer. So while you are talking today, we want you to share the information YOU would want, but also think of the other men who are getting care at HCI for their cancer diagnosis. Obviously everyone is not the same, but today you get to represent them as well.

The focus of the discussion is prostate cancer and the role of genetic testing, especially for men with metastatic prostate cancer which may or may not depict your current health status. A few articles have been published recently that are leading us to believe that there may be additional medicines of value for men with certain genetic markers. Those markers have other implications for family members as well, so today we want to explore that topic.

First, I want to share some ways in which other researchers have found that these discussions work best. We have a few note takers in the room today as well as the audio tapes. To maintain as much confidentiality as possible, we are planning to use first names only. Also, each of you has paper and a pen so you can jot down your ideas if someone else is talking. My job is to keep the conversation moving and generally on track, although in groups with lots of ideas, we all know that the focus can move. We can come back to any point, and we want to capture all your thoughts, so write them down and I will get back to you.

1. What, if any information have you heard about genetics and prostate cancer?
    a. Who did you get this information from? Physician, media, etc.
    b. If you haven't heard any of this information, where would you expect to get this information?
        i. Media, cancer provider, general medicine, genetic specialist, etc.
2. Some cases of prostate cancer are associated with hereditary cancer syndromes, which means patients and their families may be at increased risk for prostate and other cancers. Hereditary cancer syndromes can be identified through the use of genetic testing at a genetic counseling appointment. Hereditary cancer

syndromes are passed from generation to generation which means siblings and children may be at increased risk if you were identified to have a hereditary cancer syndrome. Genetic counseling is an appointment with a healthcare provider to discuss much more detail about hereditary cancer syndromes and genetic testing options. We will talk more about genetic testing as we go, and broadly want to know your thoughts on it right now.

- **a.** What would be important to know to decide if you are interested in seeking genetic counseling and/or testing?
  - **i.** Focus group may say: family impact, cost, treatment implications
- **b.** What information would you want from your providers here at HCI at the time of referral to decide whether or not you're interested in seeking genetic services?

3. For some men with metastatic prostate cancer, genetic testing, notably a mutation causing certain hereditary cancer syndromes, can impact their treatment. They may benefit from particular therapies that are targeted only at men with a genetic mutation.

- **a.** Would this impact your decision to undergo genetic counselling and/or testing? Why/why not?
- **b.** Who would you expect to give you this information?
  - **i.** Oncology provider or genetic counselor?
  - **ii.** Why?

4. If someone has prostate cancer and a family history of other cancers such as breast, ovarian, or pancreatic cancer, they may be referred for genetic testing for hereditary cancer syndromes. Genetic test results may indicate increased risk for other cancers in you (the patient).

- **a.** Would this impact your decision to undergo genetic counselling and/or testing? Why/why not?
- **b.** Who would you expect to give you this information?
  - **i.** Oncology provider or genetic counselor?
  - **ii.** Why?

5. Genetic testing for hereditary cancer syndromes can impact the family. Most commonly, if someone is identified to have a hereditary cancer syndrome, all of their first degree relatives (children, siblings, parents) have a 50% likelihood of also inheriting the cancer syndrome.

- **a.** Would this impact your decision to undergo genetic counselling and/or testing? Why/why not?
- **b.** Who would you expect to give you this information?

i. Oncology provider or genetic counselor?

ii. Why?

6. Many of the hereditary cancer syndromes associated with prostate cancer are often associated with female breast and other female reproductive cancers.

   a. How does impact your decision to get genetic counseling/testing?

   b. Describe the level of importance you place on learning aboutthe female cancer risks

      i. Why/why not?

      ii. If you didn't have female relatives, would this still be important?

      iii. If you didn't have female relatives, would you be more or less interested in seeking genetic services.

7. Would you share any of this information with family members?Why/why not?

   a. Who would you share this information with? What would you share with them?

   b. Would you share information differently with your sons vs daughters? Why/why not?

   c. Would you share information differently with your brothers vs sisters? Why/why not?

   d. Would you share information differently with your siblings vs children? Why/why not?

8. Recent technology has allowed us to use genetic testing panels, which means we're able to test for multiple hereditary cancer syndromes at once.

   a. What information would you need to determine if multigene panel testing was something you were interested in?

   b. How would this information impact your family? (Would you tell them?)

   c. Who in the health care system would you rely on/expect to provide you knowledge regarding your genetic testing outcomes?

   d. How would you feel if you had a genetic test tell you that your risk was higher than the risk based on family history?

   e. How much would you be willing to pay out of pocket for this type of information through genetic testing?

APPENDIX B

Facilitator:

Hi and thanks for joining us today. My name is xxx and the team today includes xxx. You were invited to this discussion so we can learn from your experiences with genetic counseling and genetic testing and develop the right amount of information/education you and future patients. So while you are talking today, we want you to share the information YOU have benefitted from (or would have desired) during your genetics session, but also think of the other men who are getting care at HCI for their cancer diagnosis who will likely be getting genetic counseling and testing in the future. Obviously everyone is not the same, but today you get to represent them as well.

The focus of the discussion is prostate cancer and the role of genetic testing, especially for men with metastatic prostate cancer. You have already undergone genetic counseling and/or testing for this diagnosis. You are NOT required to disclose your results in the group today, as we are looking to gain more information about your experiences prior to genetic testing. We may ask about the conversation you had with your genetic counselor related to your results, and you are not obligated to share those results, but your experience with that conversation.

First, I want to share some ways in which other researchers have found that these discussions work best. We have a few note takers in the room today as well as the audio tapes. To maintain as much confidentiality as possible, we are planning to use first names only. Also, each of you has paper and a pen so you can jot down your ideas if someone else is talking. My job is to keep the conversation moving and generally on track, although in groups with lots of ideas, we all know that the focus can move. We can come back to any point, and we want to capture all your thoughts, so write them down and I will get back to you.

1. Before you were referred to genetics, what, if anything, did your health care team (oncologists, surgeons, etc.) tell you about genetics and prostate cancer?
    a. What information did you not receive that you wish your providers would have told you PRIOR to your genetic counseling experience?
2. What factored into your decision to schedule and attend your genetic counseling appointment?
    a. That is, doctor told them to, family impact, treatment options related to certain genetic markers, etc.
3. Did you bring anyone to your genetic counseling session? Why/why not?
4. What were the key points you took away from your genetic counseling session?
    a. What else did you want to know about during your genetic counseling session?
    b. What information did you share with other family members?

i. Which family members did you share this with?

ii. Did you share this before or after your genetic test results came back, if applicable?

c. Did you feel like genetic counseling was a good use of your time? Why or why not?

5. People choose to undergo genetic testing for multiple reasons.

a. What were your main concerns about genetic testing prior to your genetic counseling session?

b. What one piece of information was most helpful during the genetic counseling session to make your decision?

c. What factors played a role in your decision making?

i. Prompt: How did the impact of genetic testing on your family play into your decision making?

ii. Prompt: How did the impact of genetic testing on potential treatment options play into your decision making?

iii. Prompt: How did the impact of learning about other cancerrisks play into your decision making?

d. What information would you have liked to have before you made your decision?

6. After you received your genetic testing results:

a. What were the most important factors during the genetic counseling session that helped you process your test results?

b. Who in the health care system do you rely on/expect to provide you knowledge regarding your genetic testing outcomes?

c. Have you shared any of this information with family members? Why/why not?

7. Many of the hereditary cancer syndromes associated with prostate cancer are often associated with female breast and other female reproductive cancers.

a. How did impact your decision to get genetic counseling/testing?

b. If you already knew this information, were you more or less interested in seeking genetic services

c. Describe the level of importance you place on learning about the female cancer risks

i. Why/why not?

ii. If you didn’t have female relatives, would this still be important? Why/why not?

8. Have you been in touch with your genetic counselor since you've received your genetic test results? Why/why not?
    a. If you had additional questions about your genetic test results, who would you contact?
    b. If a family member was recommended to get genetic testing, who would you contact in the healthcare system to arrange this testing?
9. Looking back, what additional information do you wish you would have had at any point throughout the process?
10. Any additional thoughts?

APPENDIX C

All italicized statements will be applied to men at HCI that have not undergone genetic counseling/testing.

Facilitator:

Hi and thanks for joining us today. My name is xxx and the team today includes xxx. You were invited to this discussion so we can learn from you and develop the right amount of information/education for you and (*other men with prostate cancer*) for other Veterans. So while you are talking today, we want you to share the information YOU would want, but also think of the other (*men who are getting care at HCI for their cancer diagnosis*) veterans who are getting care at the VA. Obviously everyone is not the same, but today you get to represent them as well.

The focus of the discussion is prostate cancer and the role of genetic testing, especially for men with metastatic prostate cancer (*which may or may not depict your current health status*). A few articles have been published recently that are leading us to believe that there may be additional medicines of value for men with certain genetic markers. Those markers have other implications for family members as well, so today we want to explore that topic.

First, I want to share some ways in which other researchers have found that these discussions work best. We have a few note takers in the room today as well as the audio tapes. To maintain as much confidentiality as possible, we are planning to use first names only. Also, each of you has paper and a pen so you can jot down your ideas if someone else is talking. My job is to keep the conversation moving and generally on track, although in groups with lots of ideas, we all know that the focus can move. We can come back to any point, and we want to capture all your thoughts, so write them down and I will get back to you.

Do you have any questions before we start?

1. OK, as I mentioned, we are going to be talking about prostate cancer. I would like to start with each of you taking between 2 and 5 minutes to share your story regarding your own diagnosis and the treatment journey so far.

Thank you so much—we may come back to parts of that during our conversation today.

2. Next we are interested in knowing what, if anything, your healthcare team has told you about genetics and prostate cancer? (anticipate that there is minimal information or a focus on somatic testing)

3. Short explanation about difference between somatic and germline testing. Work with the group to draw graphic representations of the difference between somatic and germline genetics. Alternatively, graphic will be premade and group will give feedback.

   After this and each of the other topics: What would be important for you to know to decide if you are interested in genetic testing? How are the graphic representations helpful (or not) in understanding this concept?

4. Short explanation about role of family history related to germline testing. Work with the group to draw graphic representations of the difference between sporadic and familial histories. Alternatively, graphic will be premade and group will give feedback.

5. Short explanation about the personal medical implications of germline genetic testing. About 10% of men will have germline mutation. Work with the group to draw graphic representations of management implications. Alternatively, graphic will be premade and group will give feedback.

6. Short explanation about the familial implications of germline genetic testing. Important regardless if positive or negative—family history will probably play a role. Work with the group to draw graphic representations of familial implications. Alternatively, graphic will be premade and group will give feedback.

   What would be important for you to know regarding telling other family members about the result?

   (Men undergoing focus groups at HCI prior to genetic counseling will not work with graphics after each of these questions and instead ask the key questions about each topic listed above) Additional questions to be asked at HCI focus groups may include:

7. Short explanation about multigene testing and implications of results.

   a. What information would you need to determine if multigene panel testing was something you were interested in?

   b. How would this information impact your family? (Would you tell them?)

   c. Who in the health care system would you rely on/expect to provide you knowledge regarding your genetic testing outcomes?

d. How would you feel if you had a genetic test tell you that your risk was higher than the risk based on family history?

e. How much would you be willing to pay out of pocket for this type of information?

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TABLE 1

Demographics of focus group participants

		Huntsman Cancer Institute			Veteran Affairs*		
		n	%	Range	n	%	Range
Total participants		25			15		
Cohort							
	Pre-GC	10			15		
	Post-GC	15					
Gleason score							
	<7	4	16		4	28.6	
	≥7	21	84		5	35.7	
	Unknown	0			5	35.7	
Metastatic		16	64		10	66.7	
Race/ethnicity							
	White	24			12		
	Asian	1					
	Latino/Hispanic				1		
	No response				2		
		Mean (range)			Mean (range)		
Age		64.28 (46–87)			75.79 (60–90)		
Age at diagnosis		60 (45–79)			66 (50–86)		
Highest education level							
	Junior high or some high school	0				2	
	High school	0				4	
	Some college	7				4	
	College degree	5				2	
	Graduate degree	13				1	
Marital status							
	Married	19				8	
	Divorced	5				2	
	Widowed	1				1	
	No response					2	
Military era							
(VA only)	WWII					2	
	Korean					4	
	Vietnam					8	
	Post-Vietnam					1	

Abbreviations: GC, genetic counseling; VA, George E. Whalen Veteran Affairs Medical Center.

*n = 14 VA participants with pathologic information.

TABLE 2

Topics participants want addressed at genetics visit

Topic	All participants (quotes come from both sites)	
Impact on current diagnosis	"I can see some people saying [about genetics]—all I care about is can you help me [and my care]?" "I already have it [cancer], unless you can somehow change the treatment based on genetics…" "Studies out there [that show] that particular agents are affected for your particular genetics…that would be absolutely gold"	
How family is impacted by testing	"I think anyone with siblings or children would certainly want…to learn what they can…to protect their family. I say "protect" but, [I mean] "help"" "You can help your family…if they're prone to just one of the markers…I'm glad that they should know" "It's worth it to know [if] our children are probably susceptible" "That's a fact that influences whether I want to do the testing…the fact that it might impact by children in anyway: my son or my daughter" "It could be passed on from me…I think you have to tell them…you need to be tested"	
Opportunities for screening/ prevention	"I look back on it and I wish I had known if I had a genetic tendency towards this because I would have been looking for the signs and symptoms" "If I've got a ten percent chance [of developing cancer], am I going to do anything different? I don't know" "If someone were able to look at their [my children's] DNA and predict what things they might [get]…they might be able to have an impact on it [screening] at a much earlier time period. It would be hugely helpful"	
	HCI	**VA**
Attribution of lifestyle to current diagnosis	Diet	Agent Orange
	"Recognizing the root of it [cancer] was…diet and natural medicine" "The foods we eat, where we live, the lifestyle… can turn those [cancer factors] on"	"I believe mine's [PC diagnosis] due to Agent Orange" "We know ours [PC diagnoses] is environmental, but we don't know if there's a genetic [component]"

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TABLE 3

Participants opinions on the logistics of genetic incorporation to medical care

Topic	HCI	VA
Who should discuss genetics referral with the patient	"Whether you see an ad in the paper and get it done. I don't know if it works. But if you hear if from [doctor's name], it takes some credibility" "You'd probably want to consider who people trust…certainly my doctors, once I get to know them"	"I'm thinking that [the] entire system…should be made aware of the testing" "I would like my doctor to have access to it so they can help me make an informed decision."
How much patients are willing to pay	"As far as cost, you spend more money on your car…trying to maintain it. Let's try to maintain this body…and prevent these things" "Keep the cost down as low as possible…I would be comfortable— maybe up to $500 and if insurance would pick up the rest of it, that would be great"	"I couldn't afford any out of pocket" "If you're gonna do it at no cost…it's okay, but if you're gonna charge somebody $500–1000. forget it"
Timing of when genetics should be introduced	"Information overload—all the information's out there but we don't know what's true…how could they [patients] possibly discuss all these things with your doctor in the 5 minutes that you're with them?"	"I like to know what the end results is likely to be, not all the mumbo-jumbo that leads up to it"

Abbreviations: HCI, Huntsman Cancer Institute; VA, George E. Whalen Veteran Affairs Medical Center.