Engaging Men With BRCA-Related Cancer Risks: Practical Advice for BRCA Risk Management From Male Stakeholders

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Abstract
Men are at risk for developing hereditary cancers such as breast, prostate, pancreatic, and melanoma due to a pathogenic germline variant in either the BRCA1 or BRCA2 gene. The purpose of this study was to identify and provide practical advice for men managing their BRCA-related cancer risks based on men’s real-life experiences. Semistructured interviews were conducted with 25 men who either tested positive for a pathogenic variant in BRCA1/2 gene or who had an immediate family member who had tested positive for a pathogenic variant in BRCA1/2. A thematic analysis of the interview transcripts was completed utilizing the constant comparison method. Qualitative analysis produced three categories of participant advice for men who recently learned of their hereditary cancer risk. Specifically, participants advised the following: (a) know the basics, (b) engage in the family narrative, and (c) advocate for yourself. Results showed the need for men to know and understand their BRCA cancer risks and communicate that genetic risk information to their family members and practitioners. In particular, the findings stress the importance of addressing men’s risks and medical management from a family-focused approach. Overall, because men are historically undereducated about their BRCA-related cancer risks, this practical advice serves as a first step for men managing BRCA-related cancer risks and may ultimately assist them in making preventive and screening health behaviors.

Keywords
Genetic risk, hereditary cancer, BRCA, advice, men

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Individuals who test positive for a pathogenic variant in the BRCA1/2 genes have an increased risk for developing hereditary cancers. Both men and women are at risk for inheriting either of these genes and their accompanying cancer risks as well as passing them on to their children (“BRCA1 and BRCA2 in Men”). While women have a higher risk for developing hereditary cancer than men, men with a pathogenic variant in a BRCA1/2 gene are at risk for developing breast, prostate, pancreatic, and melanoma cancers (Ibrahim et al., 2018). During their lifetime, men who are BRCA1 carriers have between a 1% and 5% risk of developing breast cancer and a 2% to 3% of developing pancreatic cancer.1 Men who are BRCA2 carriers have between a 5% and 10% risk of developing breast cancer, 3% to 5% risk of developing pancreatic cancer, 3% to 5% risk of developing melanoma cancer, and between 15% and 25% risk of developing prostate cancer (Mahon, 2014; Petrucelli et al., 2016). These risks are in comparison to men in the general population who have a 0.1% risk of developing breast cancer, 1% risk of

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developing pancreatic cancer, 1% to 2% risk of developing melanoma cancer, and up to a 16% risk of developing prostate cancer.

Unfortunately, men are not well educated regarding their risk for BRCA-related cancers. This lack of knowledge may be due to several reasons. For one, there is a paucity of genetic risk information and resources geared toward men (Donovan & Flynn, 2007; Nieder et al., 2003; Rauscher et al., 2018; Skop et al., 2018). This lack of information causes men to be underinformed, and even misinformed, about their hereditary cancer risks, and they often report inaccurate cancer risks (Rauscher & Dean, 2017; Rauscher et al., 2018). Another factor is that health-care providers and practitioners are not knowledgeable about men’s hereditary cancer risks as well as men’s medical management options (Dean et al., 2019). For example, a recent systematic review found primary care physicians (PCPs) often have incomplete/inaccurate knowledge regarding hereditary cancer as well as lack confidence about genetic testing knowledge (Hamilton et al., 2017). A third reason for men’s lack in BRCA education may be the name of the genetic variant. In a 2019 editorial published in Nature, Dr. Colin Pritchard (2019), an associate professor of laboratory medicine at the University of Washington’s School of Medicine, stated,

In my view, part of the confusion stems from the fact that people with mutations in BRCA1 or BRCA2 are said to have hereditary breast and ovarian cancer syndrome, or HBOC [Hereditary Breast and Ovarian Cancer]. This term is not only misleading, it is also cumbersome and hard to remember. (par. 5)

This is not surprising as breast cancer is a feminized disease (Hesse-Biber & An, 2017; Skop et al., 2018). Whatever the reason(s), this lack of education ultimately leads to difficult care for men.

One example of this lack of education’s impact on men’s health is the discrepancy between existing national guidelines and men’s adherence to guidelines. National comprehensive cancer network (NCCN) suggests men who test positive for a pathogenic variant in the BRCA1/2 gene should perform breast self-exams and undergo clinical breast exams beginning at 35 years, and men who test positive for a pathogenic variant in BRCA2 should also undergo prostate cancer screening starting at 45 years; but there are no clear guidelines for pancreatic or melanoma cancer. Nonetheless, men neither tend to adhere to recommended guidelines (Rauscher & Dean, 2017), nor do they understand the connection between genetic information and their personal health behaviors (Miesfeldt et al., 2000). As such, more educational materials for men and families affected by hereditary cancer are needed to help men understand their risks and motivate proactive decision-making (Harris et al., 2009; Suttman et al., 2018).

Thus, the purpose of this study was to identify practical advice for men managing their BRCA-related cancer risks based on at-risk men’s real-life experiences. Given the lack of education about genetic testing and hereditary cancer geared toward men, we argue at-risk men are currently the best resources as “key stakeholders” in their own care to develop clinical resources to bridge this gap. As key stakeholders, these men know what it is like to be at risk for BRCA-related cancers and thus may offer helpful advice for managing hereditary cancer risks. Moreover, viewing men who are BRCA1/2 carriers as key stakeholders by focusing on their lived experiences may assist in designing clinical and public health initiatives aimed at helping these men manage their BRCA-related cancer risks. Thus, we asked the following question: What advice do at-risk men offer for managing BRCA-related cancer risks?

Methods

Recruitment and Participants

Upon receiving institutional review board (IRB) approval from Redacted for Texas A&M University (IRB2016-039D), we employed purposive sampling (Merriam, 2014) and snowball sampling strategies to recruit participants (Creswell, 2007; Lindlof & Taylor, 2011). First, we posted a link to an IRB-approved flyer on FORCE2 Facebook and Twitter. Additionally, we shared the flyer on a BRCA-focused Facebook group targeting men at risk for and diagnosed with hereditary cancers. Yet, due to low numbers, we then contacted women who had previously participated in the first and third author’s research studies and had consented to be contacted again; specifically, we asked them to share the study’s flyer and information with their at-risk male family members. Eligible participants were male, 18 years or older, and had either tested positive for a variant in a BRCA1/2 gene or had a first-degree family member (such as a father, mother, sibling, or child), which put the potential participant at a 50% chance for testing positive for a pathogenic variant in the BRCA1/2 gene. See Table 1 for participants’ demographics. The majority of participants were identified as non-Hispanic/White, were highly educated, married, and earned over $75,000 per year. Despite the lack of diversity in this sample, the sample is homogeneous and thus fairly representative.

Procedures and Data Collection

Twenty-five phone interviews were conducted with men. The interview guide included the following categories of questions: (a) demographics, (b) genetic testing, (c) risk management, (d) uncertainty and information management, (e) communication, and (f) practical advice. Some practical advice questions included “How might
healthcare providers better assist BRCA+ men?; “What advice would you have for men also at risk for BRCA-related cancers?”; and “What resources might help you (and other men) be more open about your hereditary cancer risk?” Additional probing questions were asked to further investigate participants experiences managing their BRCA-related cancer risks. Interviews with participants lasted between 23 and 71 min (average of 42.6 min). Upon completing the interview, a $75 Amazon gift card was sent to the participant via email to express gratitude for sharing time and experiences.

Data Analysis and Verification

Interviews were recorded and conducted until theoretical or thematic saturation was met; in other words, until no new information was discussed by participants in response to the interview questions (Glaser & Strauss, 1967; Morgan et al., 2002; Tracy, 2013). Interviews were then sent to a professional transcription company for verbatim transcription. A “selective approach” (Bylund et al., 2012; van Manen, 1990) to data analysis was utilized, meaning we focused specifically on the last category of the interview guide—practical advice for men at risk for managing BRCA-related cancer risks.

After interviews were transcribed, all of with authors read all the transcripts to immerse ourselves in the men’s experiences. Next, the primary author selected participants’ responses that related to practical advice and suggestions and combined all these relevant quotes into one document for analysis. After compiling this data, the primary author employed the constant comparison method, which involves three main steps (Charmaz, 2014; Tracy, 2013). First, she utilized “open coding” whereby she summarized and sorted the data into codes (Strauss, 1987). Second, the primary author engaged in “axial coding” by grouping related codes, repetitious codes, and significant codes together based on participants’ experiences (Corbin & Strauss, 2007). Third, she refined and collapsed the second-level codes by identifying properties or subthemes. A final document with the emergent themes and subthemes was then sent to the second and third author, and both authors separately confirmed the data matched the themes.

Finally, to ensure credibility and consistency (Lindlof & Taylor, 2011), the primary and third author engaged in memo writing during the interviews, and all authors wrote notes during data analysis to assist in identifying common ideas and themes across the interviews. Last, was employed thick description—detailed descriptions of individuals’ experiences and accounts (Geertz, 1973; Tracy & Hinrichs, 2017)—when reporting the themes to provide readers the ability to determine if these results may be transferable to other settings (Creswell, 2007).

Results

This research was a part of larger research project, which found men at risk for BRCA-related cancers were largely uninformed about their hereditary cancer risks (Rauscher & Dean, 2017; Rauscher et al., 2018). Yet, an extended analysis found that these men still had opinions regarding practical advice for handling their own lack of education (and suggestions for future men in similar situations) that were informed by conversations with their family, friends, and healthcare providers. Therefore, the purpose of this manuscript is to report the three pieces of advice from men for other men to manage their BRCA-related cancer risks: (a) know the basics, (b) engage in the family narrative, and (c) advocate for yourself. In what follows, we discuss each of these themes and their associated properties by providing exemplar quotes from participants.

Know the Basics

The first theme was knowing the basics. This theme encompassed two properties: (a) learning about men’s specific BRCA cancer risks and (b) proactive decision-making. To begin, participants recommended men be informed about specific BRCA-related cancer risks.
affecting men. For example, Ryan (age 73 years, BRCA2) stated men need “to be informed, and not be flippant that this isn’t a problem for you.” He explained further, saying men need to be careful about believing in a “false positive sense of security because [at-risk men] haven’t delved deeply enough” into understanding their risks.

Another part of being informed involved learning about men’s BRCA-related cancer risks. For instance, Michael (age 65 years, BRCA1) explained he was not aware that men could get breast cancer until one of his male friends was diagnosed with breast cancer and had to receive chemotherapy treatment. As such, he emphasized, “The number one [thing] is to make sure men know that men do get breast cancer.” He problematized that this ignorance is likely due to the fact that “nobody really talks about it unless you’re in that situation.” Yet, participants also talked about how men need to know that men are not just at risk for breast cancer. Randy (35 years, BRCA1) said, “Understanding also that for men [a pathogenic variant in BRCA] doesn’t necessarily mean a breast cancer risk, but it can lead to other types of cancer risks.” Being informed is essential as it enables men to make proactive decisions based on their genetic risks, which we discuss next.

In addition to knowing men’s BRCA cancer risks, these participants also encouraged making proactive decisions about screening, checkups, and physical exams. Michael (age 65 years, BRCA1) stressed getting “checked for all the different things that BRCA can make you at a higher level.” For some men, that involved attending physical exams and yearly checkups. For example, Gabe (age 26 years, BRCA in family) suggested, “Make sure that [men] give themselves physical exams. Make sure that they get their yearly checkups.” He continued discussing the importance for men to “be diligent about their own bodies, and make sure their doctor visits start earlier in life than they probably would have planned.” Scott (age 61 years, BRCA2) supported this idea further when he said, “It’s probably a good idea to do some screenings to keep track of what’s going on so we’re abreast of it. No pun intended.”

Tony (age 43 years, BRCA1) connected knowing men’s risks to screening. He stated, “I want [a] print out, a receipt that says, you know, ‘At age 40, go and do this. At age 42, go and do this.’” Jeff (age 46 years, BRCA1 in family) agreed that having clear guidelines for men would be helpful in making screening decisions. He shared,

I would be interested to learn more about what is out there in terms of men’s preventive measures or what men should do. [Like] if you test positive for it, here’s the things you should be considering and the things you should be doing, moving forward with it, for the future.

To assist in knowing and following appropriate guidelines, some men suggested finding and participating in a surveillance program to stay on top of cancer risks. David (age 58 years, BRCA2) recommended, “Figure out what your best surveillance program is going to be.” In short, one piece of advice men can use to manage their BRCA-related cancer risks is being informed about men’s specific BRCA cancer risks and then engaging in proactive decision-making to detect possible cancer. While knowing the basics may seem intuitive, participants in this study still emphasized the need for men to be informed about BRCA-related cancer risks as well as medical management of those risks.

Engage in the Family Narrative

The second theme stressed men’s involvement in the larger family narrative about hereditary cancer risks. A family narrative is the collection of family stories communicating the family’s history, identity, and shared values, which is often how family health history (FHH) and risk information is shared in families with hereditary cancer risks (Campbell-Salome & Rauscher, 2020; Trees et al., 2010). This theme included two properties: (a) partnering with female family gatekeepers and (b) sharing the family’s cancer narrative. First, the men in this study emphasized the important role that female family members play in men’s management of BRCA cancer risks. Men advocated partnering with female family gatekeepers (e.g., mothers, sisters, cousins, nieces) to assist men in sharing and understanding BRCA-related information.

For instance, Randy (age 35 years, BRCA1) explained his partnership with a female cousin to prepare a narrative that would assist his daughters in understanding the obstacles they would face if they test positive for a pathogenic variant in the BRCA1 gene. He recounted:

But as they see my cousin, as she goes through surgeries and those types of things, I think [my wife and I] will be more cognizant and aware to talk to them about [their risks] a bit more and explain why [my cousin] is [having preventive surgeries].

Additionally, men also stressed the importance of learning the narrative surrounding the family’s diagnostic journey—commonly initiated by female family members. For instance, Scott (age 61 years, BRCA2) explained that his niece was the one who initially discovered the pathogenic variant BRCA2 gene in their family, which led to Scott and other family members undergoing genetic testing. He explained:

She [was] into genealogy and... when she got herself tested, that’s when she found out that she was positive for the BRCA2 gene mutation, and she actually did go further, and they ran all kinds of tests, and she did have breast cancer. She had decided to get the double mastectomy. So, then, her
dad got tested, [and] he was positive. I got tested, and my sister got tested.

Female family members crafted narratives, which helped these men become more familiar with the family’s shared risks and, at times, spotlighted men’s risks, and these men acknowledged the importance of those conversations. In other words, without female family members, many men would not have resources for larger family conversations about hereditary cancer risks, nor would they be as likely to understand their own risks.

Becoming involved with the family narrative meant not just learning about the FHH of cancer and men’s risks but also using the narrative to continue the conversation with others. While female family members were more active in creating the family narrative of hereditary cancer, men often suggested sharing these familial narratives as important to disseminating risk information to relatives. For example, Patrick (age 39 years, BRCA2) said:

> With family, I would definitely be very upfront and very open, so that others would get tested, especially siblings [and] obviously, offspring [in order] to say, “Hey, look, this is something that I carry. You may have it, too. Here are all the risks that are associated.” That’s definitely the route that I would go.

Other men like Ryan (age 73 years, BRCA2) suggested it was important to share risk information contained in the narrative with the whole family. He recommended, “Reach out to the broader family and make sure that there is genetic mapping, and communicate with your cousins, uncles, aunts on the lineage that is exposed and urge those who are at greatest risk to get tested.” Participants further noted sharing the family narrative not only builds a clear understanding of the family’s cancer history but also encourages a common mindset and shared understanding for managing hereditary cancer as Ryan (age 73 years, BRCA2) later explicated, “With good information, it is all manageable, and as a family, as a team, you’re going to get through it.” In sum, men promoted engaging in the family narrative through partnerships with female family gatekeepers and encouraging proactive communication with other at-risk family members through sharing that narrative.

**Advocate for Yourself**

A final theme for managing BRCA-related cancer risks was engaging in personal advocacy, which included advocating for oneself and to practitioners. Advocating for oneself included proactively asking practitioners for information as well as sharing BRCA risk information with practitioners. For example, Shawn (age 69 years, BRCA1) suggested men need to write down relevant cancer information on their medical forms, and then when the practitioner asks, “What is your medical history?” men need to respond honestly “to give the doctor some idea of [their] potential [risk].” Likewise, Cody (age 46 years, BRCA in family) stressed the importance of “asking questions about family history and cancer to [practitioners]” in order to ensure effective care.

In addition to probing practitioners to discuss BRCA cancer risks, some participants brought up the need to educate practitioners. Later in the interview, Shawn (age 69 years, BRCA1) said, “educating the medical profession” whenever possible is also important because it enhances the likelihood that in future clinical interactions the practitioner will “bring this up whenever they’re in front of a male patient.” In other words, men believed personal advocacy would encourage the likelihood that more practitioners would be knowledgeable about men’s BRCA-related cancer risks as well as perform individualized health care. In short, men emphasized the importance of applying their knowledge about BRCA and understanding of their family’s history of cancer by advocating for oneself with their healthcare providers.

**Discussion**

By utilizing men’s real-life experiences, this study offers practical advice for men managing their BRCA-related cancer risks in order to enhance their overall knowledge and adapt their behavior to better manage their hereditary cancer risks. Participants in this study advised men to be knowledgeable about BRCA and medical management options, engage in the family narrative, and employ personal advocacy. We conclude by discussing the findings and articulating important implications.

The first piece of advice—know the basics—demonstrates the limited amount of BRCA cancer risk information for men. While a few websites have some information for men (e.g., see www.facingourrisk.org, www.breastcancer.org, and brcablue.com), the information is limited. Men need tailored information and advice regarding their specific BRCA cancer risks and medical management. For instance, content could encompass brief points about genetic risks, genetic counseling, and genetic testing as well as questions to help facilitate conversations between men and practitioners, family members, and partners (see Table 2). However, as the findings illustrate, the problem is not simply a lack of BRCA information for men, but that the information needs to be tailored to men. Recent research indicates men like bulleted lists and numbers, whereas women prefer information presented in narrative format (Dean et al., 2017; Rauscher et al., 2018). As such, social media educational efforts can target men with
BRCA-related cancer risks to provide tailored information. As an example, we created a tailored infographic to educate men on their BRCA-related cancer risks and medical management options (see Appendix A).

The second piece of advice was to engage in the family narrative of hereditary cancer. Family narratives play a significant role in family communication about hereditary disease, and patients use narratives in clinical consultations to share FHH (Campbell-Salome & Rauscher, 2020; Trees et al., 2010). Men in this study stressed the importance of increasing their own role in the family narratives. Further, when female gatekeepers made men the subject of the narrative, it motivated men to more actively think about their risks, despite lacking educational resources (Rauscher et al., 2018). As female gatekeepers are motivated and persuasive agents of FHH communication, genetic counselors can help women intentionally craft the family narrative to include at-risk men. While genetic counselors currently provide patients with letter templates to disclose genetic test results, at-risk families could benefit from tools in creating the family narrative (Campbell-Salome & Rauscher, 2020). Through such counseling, practitioners can advise female family members to make at-risk men the subject of the narrative at times to help men better recognize their risks. Receiving this genetic risk information from a trusted family

Table 2. BRCA Cancer Risk Information for Men.

| Know the Basics                                                                 | Questions for genetic counselors:                                                                 | Questions for insurance:                                                                 |
|--------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------|
| • Know your cancer risks for breast, prostate, pancreatic, melanoma            | 1. I have breast cancer in my family. Should I get tested?                                        | 1. Does my plan cover genetic testing and genetic counseling?                             |
| • Don’t minimize risks because you are a man                                   | 2. I’ve tested positive for BRCA. What types of screening?                                         | 2. What screening is covered under health insurance?                                      |
| • Talk to a genetic counselor: Ask about recommended screening and at what age | 3. Are there any other risks I should be aware of?                                                 |                                                                                           |
| • Identify health and life insurance plans before testing                       | 4. When should I get life insurance?                                                              |                                                                                           |

| Engage in the Family Narrative                                                | Questions to create family health history (FHH):                                                  | Questions for partner regarding FHH:                                                                 |
|--------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------|
| • Collect family history information from as many family members as possible but especially target parents, siblings, and children | 1. Who in the family was diagnosed with cancer?                                                    | 1. How do you think this diagnosis impacts our family?                                           |
| • Talk to spouse/partner about your own risks, your own fears and concerns, their fears and concerns, family planning decisions including ART options | 2. What cancers were they diagnosed with?                                                          | 2. How do you feel about our family planning (if not finished with family)?                    |
| • Create a family narrative to help inform and support future generations in their health management and decision-making | 3. At what age were they diagnosed?                                                               | 3. How do you feel about ART options such as PGT?                                                 |
|                                                                                | 4. Has anyone tested positive for BRCA?                                                            | 4. When should we talk to our kids about the mutation and how should we disclose to them about our family’s risk? |
|                                                                                | In one sentence, write your family’s motto for coping with the familial history of cancer.       |                                                                                                  |
|                                                                                | What has your family learned from watching other family members make decisions/ handle their hereditary cancer risk? Make sure to include all family members who want to be included in this conversation |                                                                                                  |

| Advocate for Yourself                                                        | Statements/questions for doctors:                                                                   | Resources to share in hereditary cancer community:                                               |
|--------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------|
| • Disclose your FHH to your doctors                                          | 1. My family has a history of hereditary cancer. I’d like to explore genetic counseling and testing options. Can you please refer me to a genetic counselor? | Facing Our Risk of Cancer Empowered                                                              |
| • Ask your doctors about genetic counseling, genetic testing, and recommended guidelines | 2. I tested positive for BRCA. What are the recommended screening guidelines for men? Can we set up a plan for managing my risk? | www.facingourrisk.org                                                                            |
| • Be a resource for men in the hereditary cancer community                   | 3. I’d like to help other men who are at risk. Please contact me if any of your patients want to talk to someone about the risks | Basser Center for BRCA                                                                            |
|                                                                                |                                                                                                  | “BRCA Brotherhood” Facebook Group                                                                 |

ART = assisted reproductive technologies; PGT = preimplantation genetic testing.
member might enhance the likelihood that the men engage in information seeking about BRCA-related cancer risks, genetic counseling, and testing, and ultimately employ proactive decision-making (Rauscher et al., 2019).

Furthermore, as men stressed the importance of knowing and using the family medical history in clinical encounters, health systems need to facilitate FHH collection. Health organizations need to better incorporate FHH into patients’ electronic health records (EHRs). Extant research shows that even when patients bring in and discuss their FHH information, it is not well documented in their chart, and thus practitioners often miss it, skip it, and even fail to act upon the provided information (Christianson et al., 2012; Williams et al., 2011). Health systems need to develop EHRs that clearly incorporate FHH information as well as assist practitioners in taking this information and updating it over time as more family members may be diagnosed (Christianson et al., 2012). Collecting and acting on FHH information can reduce patient risk and better tailor care preventing hereditary cancers (Parrott & Hong, 2014). While men can consciously provide FHH and bring the information up in medical appointments, healthcare organizations should prioritize this information by having organizational procedures for collecting, reading, and utilizing the information.

The last piece of advice calls for men to be empowered patients in their own health care and leaders in their families. This advice may be difficult to translate to practice as past research shows men are less involved in actively collecting FHH information (Campbell-Salome et al., 2019) and require additional guidance on communicating genetic risk information (Gaff et al., 2005). One way to address these barriers is to better train general practitioners (GPs) regarding men’s BRCA-related risks. Focusing specifically on GPs is an advantageous target audience as many men only see GPs regularly, particularly younger men. Also, given the increase in genetic testing for prevention and treatment of diseases (Aronson & Rehm, 2015; Ashley, 2016; Collins & Varmus, 2015; Mata et al., 2017), medical schools could include a training program discussing genetic counseling and testing in order to arm medical students with at least basic information about genetic risk and the personal and familial implications associated with knowing genetic risk information. In addition to educating practitioners, educating men in patient advocacy (Dean, 2019; Dean et al., 2019) may assist in better equipping them to serve as advocates for their own health. Such education could be in the form of a social media health campaign or an online webinar. Ultimately, targeting multiple stakeholders in the knowledge about and prevention and care for hereditary cancer risks among men may be the turning point to fill the gender disparity in research, prevention, and care for men at risk for BRCA-related cancers.

Furthermore, participants’ responses advising other at-risk men to become informed, engage in the family narrative with female family members, and advocate for themselves by also educating their providers on men’s risks point to how gender and masculinity constructs complicate the care and decision-making of men with BRCA-related cancer risks (Hesse-Biber & An, 2017; Moynihan et al., 2017; Skop et al., 2018). Much research on men’s health communication and management finds that due to hegemonic societal norms for “male characteristics,” men communicate less about their health (Ginossar, 2008; Koehly et al., 2009), are slower to seek health-care services (Galdas et al., 2005), and are less open and active in managing health (Galdas et al., 2005; Rauscher & Dean, 2017). Results from this study counter the masculine beliefs that men are not interested in or open about health issues, as participants themselves are interested in managing BRCA risks and try to encourage other men to empower themselves through information seeking and proactive medical decision-making, similar to women with BRCA-related cancer risks (Dean, 2019; Moynihan et al., 2017). Indeed, men in this study specifically cautioned other at-risk men against stoically brushing off their cancer risks due to the gendered embodiment of BRCA risks (Skop et al., 2018). However, results also demonstrate how men with BRCA-related cancer risks used gendered family roles to partner with at-risk female family members to manage information about FHH and risk (Jones et al., 2004). Further, in partnering with female family members, men are taking on more “feminine” roles in the family communication of HBOC while also challenging providers’ gendered expectations and responses (Courtenay, 2000; Moynihan, 1998). In short, this research highlights important inconsistencies in the role masculinity plays in how men with BRCA-related cancer risks manage and communicate about health.

While this work has many benefits, it is not without limitations. First, this advice is specific to men facing BRCA cancer risks and thus advice would likely be different for men who face statistically higher risk of developing cancers such as Lynch syndrome. Thus, more research is needed to investigate the ways to better reach men with a variety of hereditary disease risks. Second, although generalization is not the focus of qualitative research (Lindlof & Taylor, 2011), this study’s sample size is not diverse and does not allow for transferability and thus may not be representative of all men at risk for BRCA-related cancers. At the same time, given the homogeneity of this sample, these results are fairly representative. However, we are also conscious of the fact that these participants were recruited via social media and through their female family members and therefore may be more motivated to participate, in comparison to the broader population. In short, given the paucity of information for men, this study serves as a first step in providing advice for men at risk for BRCA-related cancers.
Conclusions

Finally, the results of this research suggest opportunities for interventions in order to improve education about BRCA-related cancer risks and encourage health behaviors. We recommend future research should develop interventions focused on facilitating involvement of multiple family members (i.e., the patient as well as the at-risk and not-at-risk family members) in proactive health-care decision-making. Concentrating on several different family members could assist families in better engaging in more effective communication about hereditary cancer and ultimately impact health behaviors such as participating in genetic counseling sessions, undergoing genetic testing, and attending cancer screening appointments. Overall, we hope the practical advice offered in this manuscript helps men, their families, and practitioners in managing BRCA-related cancer risks.

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Supplemental Material

Supplemental material for this article is available online.

Notes

1. While published cancer risks suggest that the pancreatic cancer risk is increased in individuals with a BRCA2 variant, and it remains unclear what risks individuals with BRCA1 have for developing pancreatic cancer, the National Comprehensive Cancer Network (NCCN) guidelines suggest that individuals with either BRCA1 or BRCA2 variants consider pancreatic cancer screening, especially in the context of a family history (for more information, see NCCN Guidelines Genetic/Familial High-Risk Assessment: Breast, Ovarian, and Pancreatic).

2. Facing Our Risk of Cancer Empowered (FORCE) is a nonprofit organization dedicated to ensuring no one experiences hereditary cancer alone.

References

Aronson, S. J., & Rehm, H. L. (2015). Building the foundation for genomics in precision medicine. Nature, 526(7573), 336–342.

Ashley, E. A. (2016). Towards precision medicine. Nature Reviews Genetics, 17(9), 507–522.

Basser Center for BRCA. “BRCA1 and BRCA2 in Men.” https://www.basser.org/sites/default/files/2018-03/Basser%20Male%20Fact%20Sheet%202016.pdf

Bylund, C. L., Fisher, C. L., Brashers, D., Edgerson, S., Glogowski, E. A., Boyar, S. R., Kemel, Y., Spencer, S., & Kissane, D. (2012). Sources of uncertainty about daughters’ breast cancer risk that emerge during genetic counseling consultations. Journal of Genetic Counseling, 21(2), 292–304.

Campbell-Salome, G., & Rauscher, E. A. (2020). Family storytelling about hereditary cancer: Framing shared understanding of risk. Journal of Genetic Counseling, 1–13. doi:10.1002/jgc4.1218

Campbell-Salome, G., Rauscher, E. A., & Freytag, J. (2019). Patterns of communicating about family health history: Exploring differences in family types, age, and sex. Health Education & Behavior, 46(5), 809–817. doi:1090198119853002

Charmaz, K. (2014). Constructing grounded theory (2nd ed.). Sage Publications.

Christianson, C. A., Powell, K. P., Hahn, S. E., Blanton, S. H., Bogacik, J., Henrich, V. C., & Genomedical Connection. (2012). The use of a family history risk assessment tool within a community health care system: Views of primary care providers. Journal of Genetic Counseling, 21(5), 652–661.

Collins, F. S., & Varmus, H. (2015). A new initiative on precision medicine. New England Journal of Medicine, 372(9), 793–795.

Corbin, J., & Strauss, A. (2007). Basics of qualitative research: Techniques and procedures for developing grounded theory (3rd ed.). Sage Publications.

Courtenay, W. H. (2000). Constructions of masculinity and their influence on men’s well-being: A theory of gender and health. Social Science and Medicine, 50(10), 1385–1401.

Creswell, J. W. (2007). Qualitative inquiry & research design: Choosing among five approaches (2nd ed.). Sage Publications.

Dean, M. (2019). “You have to be your own advocate”: Patient self-advocacy as coping mechanism for hereditary cancer. In J White-Farnham, B. S. Finer, & C. Molloy (Eds.), Women’s health advocacy: Rhetorical ingenuity for the 21st century. Routledge. ISBN: 9780429201165.
Dean, M., & Rauscher, E. A. (2018). Men’s and women’s approaches to disclosure about BRCA-related cancer risk and family planning decision-making. *Qualitative Health Research, 28*(14).

Dean, M., Rauscher, E. A., Gomez, E., & Fisher, C. (2019). *Expectations versus reality: The impact of men’s expectation violations in conversations with healthcare providers about BRCA-related cancer risks.* *Patient Education & Counseling, 102*(9), 1650–1655.

Dean, M., Scherr, C. L., *Clements, M., **Koruo, R., **Martinez, J., & *Ross, A. (2017). “When information is not enough”: A model for understanding BRCA-positive previvors’ information needs regarding hereditary breast and ovarian cancer risk. *Patient Education & Counseling, 100*(9), 1738–1743.

Donovan, T., & Flynn, M. (2007). What makes a man a man? The lived experience of male breast cancer. *Cancer Nursing, 30*(6), 464–470.

Galdas, P. M., Cheater, F., & Marshall, P. (2005). Men and health help-seeking behaviour: Literature review. *Journal of Advanced Nursing, 49*(6), 616–623.

Geertz, C. (1973). *Thick description: Toward an interpretive theory of culture.* In Y. S. Lincoln, & N. K. Denzin (Eds.), *Turning points in qualitative research: Tying knots in a handkerchief* (pp. 143–68). AltaMira Press.

Ginossar, T. (2008). Online participation: A content analysis of differences in utilization of two online cancer communities by men and women, patients and family members. *Health communication, 23*(1), 1–12.

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research.* Aldine Publishing Company.

Hamilton, J. G., Abdiwahab, E., Edwards, H. M., Fang, M. L., Jdayani, A., & Breslau, E. S. (2017). Primary care providers’ cancer genetic testing-related knowledge, attitudes, and communication behaviors: A systematic review and research agenda. *Journal of General Internal Medicine, 32*(3), 315–324.

Harris, J. N., Bowen, D. J., Kuniyuki, A., McIntosh, L., Fitzgerald, L. M., Ostrander, E. A., & Stanford, J. L. (2009). Genetic testing among affected men from hereditary prostate cancer families and their unaffected male relatives. *Genetics in Medicine, 11*(5), 344–355.

Hesse-Biber, S., & An, C. (2017). Within-gender differences in medical decision making among male carriers of the BRCA genetic mutation for hereditary breast cancer. *American Journal of Men’s Health, 11*(5), 1444–1459.

Ibrahim, M., Yadav, S., Ogunleye, F., & Zakalik, D. (2018). Male BRCA mutation carriers: Clinical characteristics and cancer spectrum. *BMC Cancer, 18*(1), 179–188.

Jones, D. J., Beach, S. R., & Jackson, H. O. P. E. (2004). Family influences on health: A framework to organize research and guide intervention. In A. L. Vangelisti (Ed.), *Handbook of family communication* (pp. 647–672). Lawrence Erlbaum.

Koehly, L. M., Peters, J. A., Kenen, R., Hoskins, L. M., Ersig, A. L., Kuhn, N. R., Loud, J. T., & Greene, M. H. (2009). Characteristics of health information gatherers, disseminators, and blockers within families at risk of hereditary cancer: Implications for family health communication interventions. *American Journal of Public Health, 99*(12), 2203–2209.

Lindlof, T. R., & Taylor, B. C. (2011). *Qualitative communication research methods* (3rd ed.). Sage Publications.

Mahon, S. M. (2014). Cancer risks for men with BRCA1/2 mutations. *Oncology Nursing Forum, 41*(1), 99–101.

Mata, D. A., Kachi, F. M., & Ramasamy, R. (2017). Precision medicine and men’s health. *American Journal of Men’s Health, 11*(4), 1124–1129.

Miesfeldt, S., Jones, S. M., Cohn, W., Lippert, M., Haden, K., Turner, B. L., Martin-Fries, T., & Clark, S. M. (2000). Men’s attitudes regarding genetic testing for hereditary prostate cancer risk. *Urology, 55*(1), 46–50.

Morgan, M. G., Fischhoff, B., Bostrom, A., & Atman, C. J. (2002). *Risk communication: A mental models approach.* Cambridge University Press.

Moynihan, C. (1998). Theories of masculinity. *British Medical Journal, 317*(7165), 1072–1075.

Moynihan, C., Bancroft, E. K., Mitra, A., Ardern-Jones, A., Castro, E., Page, E. C., & Eeles, R. A. (2017). Ambiguity in a masculine world: Being a BRCA1/2 mutation carrier and a man with prostate cancer. *Psycho-Oncology, 26*(11), 1987–1993.

Nieder, A. M., Taneja, S. S., Zeegers, M. P. A., & Ostrer, H. (2003). Genetic counseling for prostate cancer risk. *Clinical Genetics, 63*(3), 169–176.

Parrot, R., & Hong, S. J. (2014). Personalized medicine. In T. L. Thompson (Ed.), *Encyclopedia of health communication* (pp. 1051–5054). Sage.

Petrucelli, N., Daly, M. B., & Pal, T. (2016). BRCA1-and BRCA2-associated hereditary breast and ovarian cancer. In M. P. Adam, H. H. Ardinger, R. A. Pagon, S. E. Wallace, L. J. H. Bean, K. Stephens, & A. Amemiya (Eds.), *GeneReviews [Internet]*. University of Washington.

Pritchard, C. (2019, July 3). New name for breast-cancer syndrome could help to save lives. *Nature: An International Journal of Science, 571*, 27–29. https://www.nature.com/articles/d41586-019-02015-7.

Rauscher, E. A., & Dean, M. (2017). “I’ve just never gotten around to doing it”: Men’s approaches to managing BRCA-related cancer risks. *Patient Education & Counseling, 101*(2), 340–345.

Rauscher, E. A., Dean, M., & Campbell-Salome, G. M. (2018). “I am uncertain about what my uncertainty even is”: Men’s uncertainty and information management of their BRCA-related cancer risks. *Journal of Genetic Counseling, 27*(6), 1417–1427.

Rauscher, E. A., Dean, M., Campbell-Salome, G., & Barbour, J. B. (2019). “How do we rally around the one who was positive? Familial uncertainty management in the context of men managing BRCA-related cancer risks. *Social Science & Medicine, 242*, 112592. https://pubmed.ncbi.nlm.nih.gov/31629161/.

Skop, M., Lorentz, J., Skop, M., & Barbour, J. B. (2019, July 3). New name for breast-cancer syndrome could help to save lives. *Nature: An International Journal of Science, 571*, 27–29. https://www.nature.com/articles/d41586-019-02015-7.

Strauss, A. (1987). *Qualitative analysis for social scientists.* Cambridge University Press.
Suttman, A., Pilarski, R., Agnese, D. M., & Senter, L. (2018). “Second class status?” Insight into communication patterns and common concerns among men with hereditary breast and ovarian cancer syndrome. *Journal of Genetic Counseling, 27*(4), 885–893.

Tai, Y. C., Domchek, S., Parmigiani, G., & Chen, S. (2007). Breast cancer risk among male BRCA1 and BRCA2 mutation carriers. *Journal of the National Cancer Institute, 99*(23), 1811–1814.

Tracy, S. J. (2013). *Qualitative research methods: Collecting evidence, crafting analysis, communicating impact*. Wiley-Blackwell.

Trees, A. R., Koenig Kellas, J., & Roche, M. I. (2010). Family narratives. In C. L. Gaff, & C. L. Bylund (Eds.), *Family communication about genetics: Theory and practice* (pp. 184–198). Oxford University Press.

van Manen, M. (1990). *Researching lived experience: Human science for action sensitive pedagogy*. Suny Press.

Williams, J. L., Collingridge, D. S., & Williams, M. S. (2011). Primary care physicians’ experience with family history: An exploratory qualitative study. *Genetics in Medicine, 13*(1), 21.