Social Science & Medicine 242 (2019) 112592

Contents lists available at ScienceDirect

Social Science & Medicine

journal homepage: www.elsevier.com/locate/socscimed

"How do we rally around the one who was positive?" Familial uncertainty management in the context of men managing BRCA-related cancer risks

Emily A. Rauscher[a], Marleah Dean[b], Gemme Campbell-Salome[c,*], Joshua B. Barbour[d]

[a] Department of Communication, University of Utah, 255 S Central Campus Dr, Salt Lake City, UT, 84112, USA
[b] Department of Communication, University of South Florida, 4202 E. Fowler Ave, Tampa, FL, 33620, USA
[c] Genomic Medicine Institute, Geisinger, 100 N. Academy Ave, Danville, PA, 17822, USA
[d] Department of Communication, University of Texas, Austin, 2504A Whitis Ave. (A1105), Austin, TX, 78712-0115, USA

ARTICLE INFO

Keywords:
Uncertainty
Communication
Uncertainty management theory
Hereditary cancer risk
BRCA1/2
Family

ABSTRACT

Rationale: Men with BRCA-related cancer risks face increased disease risk as well as the prospect of passing on their risk to children.
Objective: This study investigates men's communicative appraisal and management of uncertainty related to BRCA-related cancer risks and decision-making.
Methods: Guided by uncertainty management theory (UMT), a directed content analysis approach was utilized to analyze interviews with 25 men who either carry a pathogenic BRCA variant or have a 50% chance of carrying a variant but have not yet been tested.
Results: Participants appraised their individual uncertainty as irrelevant or dangerous but appraised their familial uncertainty as dangerous. Men appraising their uncertainty as a danger exhibited more proactive information seeking healthcare behaviors—such as genetic testing and following recommended screenings—than men who appraised their uncertainty as irrelevant. Participants appraised familial uncertainty as a danger and were engaged in information management with family members, as well as encouraging family members to engage in proactive healthcare decision-making.
Conclusions: Men with BRCA-related cancer risks lack understanding about their risks and how to manage them. Increased attention should be paid to the development of interventions tailored specifically to men. Further, interventions focusing on strategically developing proactive family communication behaviors would also be beneficial to men and their families.

1. Introduction

According to the Centers for Disease Control, a growing number of tests are available to diagnose individuals with pathogenic gene variants predisposing them to increased risk for cancer. Two commonly tested genes that indicate increased risk for cancer are *BRCA1* and *BRCA2*. The National Cancer Institute reports that approximately one in 400–800 people in the general population have a germline pathogenic BRCA variant, which means an increased risk for breast, ovarian, prostate, pancreatic, and melanoma cancers (Weitzel et al., 2011). The increased accessibility of genetic information has complicated the fundamental processes through which individuals make sense of their health and the health of their family, leading to increased uncertainty in probability of disease development, processing of complex information, family communication, and decision-making (Dean, 2016; Rauscher and Dean, 2018; Sussner et al., 2013). Uncertainty involves situations in which details are ambiguous, complex, or probabilistic (Brashers, 2001). Indeed, research has been recently published highlighting the importance of managing uncertainty in genetic cancer contexts (i.e., Dean and Davidson, 2016; Torbit et al., 2016). Yet, little of this research has focused specifically on the ways in which men at risk for BRCA-related cancers experience cancer, communicate about their risk, manage uncertainty, and make decisions. As well, there has been recent attention from healthcare experts calling for more focus on men's risks and urgent calls for men to receive testing and engage in preventive care (Peshkin et al., 2019; Pritchard, 2019).

Men with a parent diagnosed with a pathogenic *BRCA1* or *BRCA2* genetic variant have a 50% risk of inheriting that variant and the same risk of passing it on to their children if they also test positive (Kuchenbaecker et al., 2017; Petrucelli et al., 2016). Men in the general

* Corresponding author. Genomic Medicine Institute, Geisinger, 100 N. Academy Ave., Danville, PA, 17822, USA.
E-mail addresses: emily.rauscher@hci.utah.edu (E.A. Rauscher), marleahdeank@usf.edu (M. Dean), gcampbell1@geisinger.edu (G. Campbell-Salome), barbourjosh@utexas.edu (J.B. Barbour).

https://doi.org/10.1016/j.socscimed.2019.112592
Received 23 July 2019; Received in revised form 30 September 2019; Accepted 5 October 2019
Available online 11 October 2019

population have a 0.1% risk of breast cancer, 1% risk of pancreatic cancer, 16% risk of prostate cancer, and 1%–2% risk of melanoma, but men with a pathogenic *BRCA1* variant have a lifetime breast cancer risk of 1%–5% and 2%–3% risk of pancreatic cancer. Male *BRCA2* carriers have a lifetime breast cancer risk of 5%–10%, 3%–5% risk of pancreatic cancer, 15%–25% risk of prostate cancer, and 3%–5% risk of melanoma (Mahon, 2014). In comparison, female family members with pathogenic BRCA variants are at even greater risk with *BRCA1* carriers having a 40%–87% risk of developing breast cancer and a 22%–65% risk for ovarian cancer. Similarly, female *BRCA2* carriers have an 18%–87% breast cancer risk and a 10%–35% ovarian cancer risk over their lifetime (Kuchenbaecker et al., 2017).

Because men facing BRCA-related cancer risks have not received much research attention, fewer risk management recommendations that are specific to men exist (National Comprehensive Cancer Network, NCCN, 2018; Petrucelli et al., 2016). The National Comprehensive Cancer Network's guidelines suggest that men should educate themselves about disease risks associated with *BRCA1/2* variants, perform breast self-exams and clinical breast exams every 12 months starting at age 35, and undergo prostate cancer screening at age 45 (recommended for *BRCA2,* only considered for *BRCA1)*. However, no specific screening guidelines for pancreatic cancer or melanoma are offered (NCCN, 2018). In contrast, women managing BRCA-related cancer risks have more options for prevention and treatment including preventive screenings, prophylactic surgeries, and chemoprevention (NCCN, 2018; Petrucelli et al., 2016). The lack of information surrounding men's BRCA-related cancer risks and the limited options and information available for prevention and treatment make men's BRCA-related cancer uncertainty management an important case for study.

Existing research investigating men's reactions to being BRCA carriers has found that men tend to be private about their *BRCA1/2* carrier status (Strømsvik et al., 2010), making it difficult to know (a) how they manage their own uncertainty, (b) what role they play in family communication about BRCA, and (c) how to help manage these conversations and uncertainty management processes. This research gap is problematic because current research offers men and their families limited information regarding how men manage the uncertainty involved in making decisions regarding BRCA-related cancer risks, exacerbating related gaps in guidelines for practice. Gaining a better understanding of such uncertainty management processes could inform genetic counseling guidelines for men, as well as for counseling at a familial level.

Therefore, the purpose of this study was to examine the process by which men who had, or were at 50% risk, for having a pathogenic *BRCA1/2* genetic variant manage their own uncertainty and the uncertainty of family members faced with making decisions regarding the pathogenic BRCA variant within their family. Identifying the nuanced processes men use to manage uncertainty for themselves and families could lead to better family support resources and more strategic advice for families co-managing BRCA-related cancer uncertainty. Due to the inherent uncertainty faced by these men, as well as its historical application to uncertainty in healthcare contexts, uncertainty management theory (UMT) is a useful framework to explicate and explore their process for managing uncertainty.

1.1. Uncertainty management theory (UMT)

According to Brashers (2001), "Uncertainty exists when details of situations are ambiguous, complex, unpredictable, or probabilistic; when information is unavailable or inconsistent; and when people feel insecure in their own state of knowledge or the state of knowledge in general" (p. 478). Because individuals with BRCA-related cancer risks are dealing with complex and often probabilistic information, such a definition and conceptualization of uncertainty is relevant in guiding this study. Indeed, those who carry or have a 50% chance of carrying a pathogenic BRCA variant, experience uncertainty regarding what their chances are of carrying a variant, what a BRCA variant means for their risk of developing cancer, what choices they should make regarding screening and/or prevention, and how to communicate these same risks and uncertainties to family members who may also be at risk (Forrest et al., 2003; Gaff et al., 2010).

According to UMT, how individuals *appraise*, or make sense of, their BRCA-related cancer risks is key for understanding how they make information management and important health decisions. Per UMT, appraisal involves making sense of uncertainty as danger, opportunity, or irrelevant (Brashers, 2001; Mishel, 1988). If individuals experience uncertainty as relevant and inconsistent with their goals—a negative, danger appraisal—they will communicate to reduce uncertainty. If individuals experience uncertainty as relevant and consistent with their goals—a positive, opportunity appraisal—they will communicate to maintain or increase their uncertainty. Uncertainty appraised as irrelevant will likely be ignored until an individual encounters information that motivates them to reappraise their uncertainty.

The process of uncertainty appraisals prompts individuals to then make decisions about information management strategies they want to employ (i.e., direct or indirect information seeking, avoidance), as well as what healthcare options they want to pursue (Brashers, 2001). In the process of information management, new sources of uncertainty can emerge inciting reappraisals of their uncertainty (Hogan and Brashers, 2009; see Fig. 1 for uncertainty management process). Because uncertainty is often chronic—in the context of genetic cancer risk it can span decades—the uncertainty management process is cyclical, with phases of appraisal, information management, decision-making, and reappraisal occurring repeatedly.

Historically, research utilizing UMT has examined the uncertainty management process from the viewpoint of how one individual manages his or her own uncertainty (Brashers, 2001; Kuang and Wilson, 2017). Across this body of research, *individuals'* uncertainty is the focus of uncertainty management, and *individuals*' management and coping involve communication with others for their *own* uncertainty management. For example, a woman might manage her own uncertainty by undergoing a preventive mastectomy. However, hereditary cancer risk in families also points to the need to expand beyond this historical focus on *individuals'* illness and *individuals* consulting with others to encompass familial uncertainty management.

Familial uncertainty management involves one or multiple family members communicating to co-manage uncertainty for themselves, other family members, and the family as a whole. Further investigation of processes of familial uncertainty management may reveal the implications of the interwoven individual and familial uncertainty

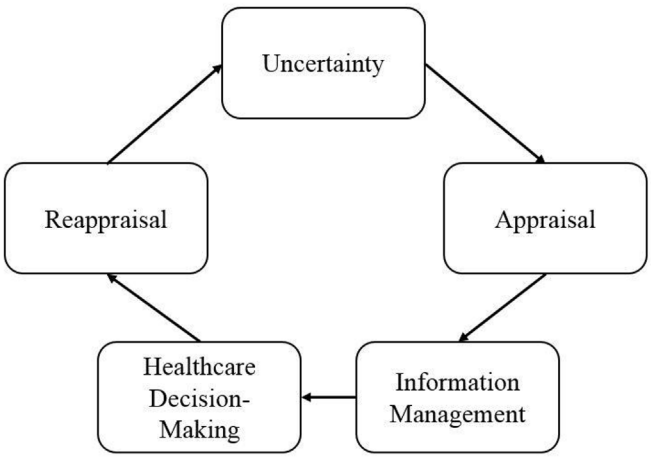

Fig. 1. Uncertainty Management Theory (UMT). UMT emphasizes that the relationship between health-related uncertainty and information management and healthcare decisions centers on how individuals appraise and reappraise uncertainty.

management processes. For example, while men are managing their own uncertainty about what their BRCA positive test result means for them, they may also be helping a daughter manage her uncertainty about undergoing genetic testing. Such co-management has implications for the ways men—and possibly their family members—make healthcare decisions to manage their BRCA-related cancer risks. The goal of this study was to investigate how men approach the individual and familial uncertainty management processes associated with a pathogenic BRCA variant.

2. Method

2.1. Recruitment

To be eligible for this study, participants were: (a) male, (b) 18-years of age or older, and (c) had tested positive for a pathogenic BRCA variant or had a first degree relative who tested positive for a BRCA genetic variant, which meant the participant had a 50% chance of having the same variant. The Texas A&M University Institutional Review Board (IRB) reviewed and approved the study (IRB2016-0339D) in June 2016. We then utilized purposive (Merriam, 2014) and snowball sampling (Creswell, 2007) to recruit participants until interviews produced recurring and overlapping information and little new information (Bowen, 2008; Morgan et al., 2002).

Purposive and snowball sampling methods were appropriate and necessary because of the difficulty identifying men at risk of developing BRCA-related cancers who are aware of those risks. Researchers employed a mix of recruitment strategies to maximize the range of experiences with individual and familial uncertainty management processes associated with a pathogenic BRCA variant. We posted IRB-approved flyers on the Facing Our Risk of Cancer Empowered's (FORCE) social media. FORCE is a non-profit organization committed to helping individuals who are at risk for hereditary cancers. We also posted the same flyer on a private Facebook group dedicated to male BRCA carriers or those who have a first-degree relative who is a BRCA carrier. We also contacted women who had participated in two previous studies conducted by the first and second authors to inform them of the project and ask them to refer male family members. Most participants explained in interviews that they were referred to the study via a female family member who saw the flyer through FORCE or social media.

2.2. Participants

Participants included 25 men who self-identified as Caucasian and ranged in age from 20 to 73 years (M = 49.8 years, SD = 16.5 years). Most participants had received positive *BRCA1* or *BRCA2* genetic test results (n = 17, 68%), and the time since receiving their positive genetic test results ranged from one month to 20 years (M = 6.3 years, SD = 5.73 years). Two participants reported a personal history of cancer. The remaining participants (n = 8, 32%) reported having a first-degree relative who had tested positive for BRCA, which put the participant at a 50% risk of also having the mutation. See Table 1 for participant characteristics.

Table 1
Participant characteristics (N = 25).

Participant characteristic	Number
Mean age of participant	49.84 years (Range: 20 to 73)
Ethnicity	
Non-Hispanic/White	25
Annual household income	
< $25,000	1
$50-$75,000	1
$75-$100,000	6
> $100,000	16
Prefer not to answer	1
Education level	
Some college	2
Bachelor's degree	8
Master's degree	10
Higher than Master's degree	5
Genetic testing status	
Tested	17
Not tested	8
Personal cancer history	
Yes	2
No	23
Mean time since receiving genetic test results	6.3 years (Range: 1 month to 20 years)
Type of *BRCA* mutation tested/at risk for	
BRCA1	10
BRCA2	14
Unknown	1
Marital status	
Married	18
Single	3
Partnered	1
Divorced or Widowed	3
Average number of children	1.7 (Range: 0 to 4)

2.3. Procedures

The first and second authors conducted semi-structured, phone interviews. That is, the researchers conducted formal interviews guided by specific, predetermined questions and deviated from those questions when appropriate to ask clarifying, follow-up, and additional questions inspired by the interview (Kvale and Brinkmann, 2008). After completing the informed consent process, participants answered demographic questions. Participants then answered open-ended questions about genetic testing, prevention and surveillance, and family planning. For example, questions included, “Why did you decide to undergo BRCA testing?” “Why have you not yet undergone BRCA testing?” “In what ways do you feel your genetic cancer risk impacts your life?” and “Describe for me any conversations you've had with family members regarding your genetic cancer risk.” After completing the interview, participants received a $75 Amazon gift card. Interviews ranged from 23 to 71 min (M = 42.6 min, SD = 10.19 min). Interviews were audio-recorded and transcribed.

2.4. Data analysis

The data were analyzed using a directed content analysis approach, wherein existing theory and research was used to focus the research question and explore relationships among concepts (Hsieh and Shannon, 2005). First, the first and second authors of this study engaged in memo-writing during the interviewing and data analysis processes noting common findings across interviews, and memos were shared among researchers after interviews as part of preliminary discussions about tentative findings. Memo topics included reasons for testing, screening and prevention practices, focus on children, general knowledge of risks, emotional response, levels of support, uncertainty, and avoidance of communication. At this stage the first and second authors noticed that men's uncertainty management process was a repeating theme.

Therefore, first-level coding for this study focused on the uncertainty management process. This reading of the transcripts focused on categorizing and summarizing data (Saldana, 2013) at once open to emerging data-driven threads and to “theoretical directions” suggested by the data (Charmaz, 2014, p. 114). This openness to theory included reflecting on specific research that might be a useful framework for making sense of participants’ uncertainty management. The authors independently observed that participants seemed to be managing uncertainty in ways that resembled research in the UMT tradition. More specifically, we noted their uncertainty management process involved a focus not only on themselves but also on their role in the management

of familial uncertainty.

During this second phase, we also compared participants who had and had not received testing, finding that they felt uncertainty about similar and different topics, but their processes for managing that uncertainty were similar. Because our primary focus was the *process* of uncertainty management rather than the *source* of uncertainty, and the *process* was similar between the two groups, we combined the two groups in further stages of data analysis. We kept the distinction in mind for emergent differences, and we report them here as a single group because the distinction was not meaningful for these findings.

The specific research question for this study emerged in this iterative process, and guided a third wave of data coding and analysis. In this third wave, the team worked together to explicate the process participants utilized in managing both individual and familial uncertainty. The first and last authors then engaged in coding to categorize the data by employing the constant comparison method (Charmaz, 2014; Tracy, 2013), focusing specifically on elements of UMT's uncertainty management process. After doing so, all authors critically examined exemplars, organizing and synthesizing hierarchical codes to address the specific research question through discussions of emerging interpretations.

3. Results

Overall, men in this study described a multi-stage process for managing individual and familial uncertainty surrounding BRCA-related cancer risks. The data showed they managed their own uncertainty by appraising it as either irrelevant or dangerous. Their appraisal of uncertainty had implications for how they (1) managed information about their disease risks and (2) made healthcare decisions (See Fig. 2).

3.1. Individual uncertainty management

3.1.1. Irrelevant appraisal

Most men in this study were aware of the uncertainty inherent in their BRCA-related cancer risks, but approximately half appraised it as irrelevant to how they were going to live their day-to-day lives. These men discussed two primary justifications for appraising their uncertainty as irrelevant. First, they perceived *few health risks* for men. Jeff (*BRCA1* family history, age 46, three children) said, “As a man, my exposure is limited, I guess. That's what I've understood is that it doesn't manifest itself nearly as aggressively in men as it does in women.” Second, men also appraised their uncertainty as irrelevant when they discussed a *lack of management options* for men—as compared to women—in managing BRCA-related cancer risks. Kyle (*BRCA2* family history, age 30, no children) noted, “I haven't done anything more than just go in for physicals or get a health screening. I guess to the best of my understanding the BRCA gene sounded like it was more a problem of higher-risk females.” It is important to note that men who appraised their uncertainty as irrelevant were commonly operating under insufficient or incorrect information about their own risks. Most were not able to accurately identify what cancers they were at risk for developing, what their percentage chance of developing cancer was, or what screenings were available for them.

3.1.2. Information management strategies

Men who appraised their uncertainty as irrelevant reported they were *less likely to actively seek information*, and instead chose to *passively accept information from family members*. Most participants, when asked if they had sought information about their risks, answered simply, “No”. Some noted they knew they *should* seek information, but had not yet done so. For example, Scott (*BRCA*2, age 61, four children) discussed how he should talk to a geneticist about his mutation, but had not yet been motivated to do so. He said, “I haven't spoken to a real geneticist to say, ‘Okay, this is my variant. What does that mean?’”

Whereas most men were not actively seeking information, many did note they were receptive to family members providing them with information. For instance, Josh (*BRCA1* family history, age 31, no children) noted not actively pursuing information, but he did indicate his sister was a source of information for him. He said, “Really, it's just whatever my sister sent me. I've never actually gone on a Google search and typed it in to see exactly what more information I can come up with.” A relatively lax approach to information management commonly led these men to a similarly unengaged approach in healthcare decision-making.

3.1.3. Healthcare decision-making

Those participants who appraised their uncertainty as irrelevant, in turn, (a) said they did not actively seek information about their BRCA-related cancer risks, and (b) said they did not *get genetic testing* or *consistently follow recommended screenings*. For example, when Josh (*BRCA1* family history, age 31, no children) was asked if he tested positive for a pathogenic BRCA variant if he would change any of his behaviors and follow recommended screenings. He said, “I don't think I would really change a whole lot.” Bruce (*BRCA1* family history, age 33, no children) also noted that even when he was given information about his risks from his sister he did not take any actions to undergo genetic testing, “I take the pamphlet and put it into this gigantically overstuffed folder I have that I just call health. And then I forget about it until later on when I'm looking for a bill and I wonder if I should do anything and then I don't do anything.” Overall, men who perceived their BRCA-related uncertainty as irrelevant were less likely to have been tested and/or to take action to manage their risks besides living a healthy lifestyle.

3.1.4. Danger appraisal

Whereas most participants described their uncertainty as inherent yet irrelevant to their lives, others showed a better understanding of what their risks were and what they should be doing to manage those risks. These men experienced uncertainty about their future cancer risks that they appraised as dangerous to their own health. These men primarily appraised their uncertainty as a danger due to a *family history of cancer* and their *own fear of developing cancer*. For instance, Ron (*BRCA2*, age 40, no children) noted his family history as the reason he wanted to reduce his uncertainty about his BRCA-related cancer risks. He said, “Well my mom had breast cancer when she was 38, and again when she was 48, and I would have been 16 the second time she had it.” Ron linked his family history with his own cancer risks, which led him to appraise his uncertainty about his risks as dangerous. Michael (*BRCA2,* age 65, four children) also appraised his individual uncertainty as dangerous by discussing his own possibility of developing cancer. He stated, “I'm not a doctor. I don't have all the machines to check myself daily. But you wonder about what's inside of you going on.” Roger (*BRCA2*, age 58, two children) mimicked that sentiment when he said, “And the one that really scares me is the pancreatic cancer.” By appraising their individual uncertainty as dangerous, these men explained they were inclined to actively seek information to reduce their uncertainty.

3.1.5. Information management strategies

Men who appraised their uncertainty as a danger often were *more likely to seek information* from healthcare providers, family members, and online. Patrick (*BRCA2,* age 39, two children) demonstrated his active information seeking by saying, “I did some research. I talked to the geneticist at [hospital]. I actually talked to a genetic counselor. I went online to the CDC [Centers for Disease Control] website and read a whole bunch of the research that had been posted.” Likewise, Aaron (*BRCA1* family history, age 20, no children) provided an example about how he was seeking information from his mother: “[Mom] actually told me she would like to educate me a little bit more about it because she thought it was important for me to learn a little bit more about it and know my risks and whatnot.” The active information seeking stimulated

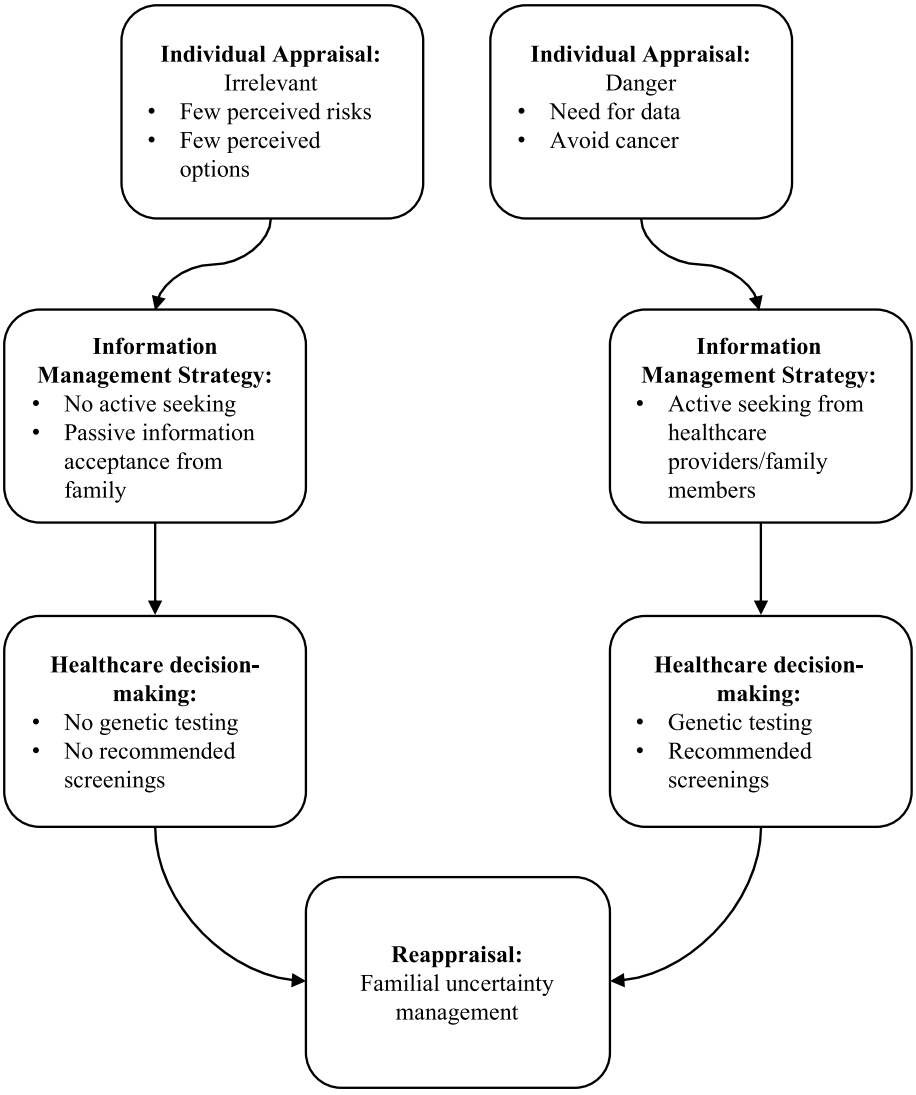

Fig. 2. Men's Individual Uncertainty Management. Participants' appraisals of their own uncertainty and their resulting information management and healthcare decisions reflected appraisals of the uncertainty as dangerous or as irrelevant.

by individual danger appraisals often led to more proactive healthcare decision-making.

3.1.6. Healthcare decision-making

Participants who appraised their uncertainty as dangerous, tended to *procure genetic testing* or have intentions to undergo testing in the future. For instance, Patrick (*BRCA2,* age 39, two children) noted his reason for undergoing genetic testing, "I think that as cancer research goes forward, if you know a lot about your mutations, then it's just another piece of the puzzle I can pick out. Knowledge is power." Here Patrick points towards a desire to reduce his uncertainty through garnering more information and a better understanding of his mutation. Aaron (*BRCA1* family history, age 20, no children), though he has not yet been tested, discussed his strong intent to get testing in the near future, "It's on my schedule. It's definitely important to me that I go get tested. It's really just a matter of time."

Additionally, participants who appraised their uncertainty as a danger tended to *engage in regular recommended screenings*. Michael (*BRCA2,* age 65, four children), for example, explained he has regular colonoscopies, endoscopies to check his pancreas, uses sunblock, does skin checks, and does an annual mammogram to manage his BRCA-related cancer risks. Roger (*BRCA2*, age 58, two children) said, "I'm concerned about it, and I'm going to the doctor and doing everything I'm supposed to do now." Overall, in this sample, men who perceived their BRCA-related uncertainty as a danger were more likely to have been tested and to be following at least some recommended screenings to avoid developing cancer. In other words, these men discussed doing everything they could to manage their individual uncertainty, and thus often turned their attentions to the medical prognosis (i.e., likely course of disease) of family members as a next step in their uncertainty management process.

3.2. Familial uncertainty management

The participants' uncertainty management processes encompassed their conclusion that their risks of developing cancer were low and their screening and prevention options limited (based on their interpretations of the information they had at the time of the interview), but participants also appraised or reappraised their uncertainty focusing on familial rather than individual disease risks. In these data, the process tended to be linear—individual-focused uncertainty management followed by and informed by familial uncertainty management. All participants appraised familial uncertainty as dangerous and discussed strategies for helping reduce family member uncertainty (see Fig. 3).

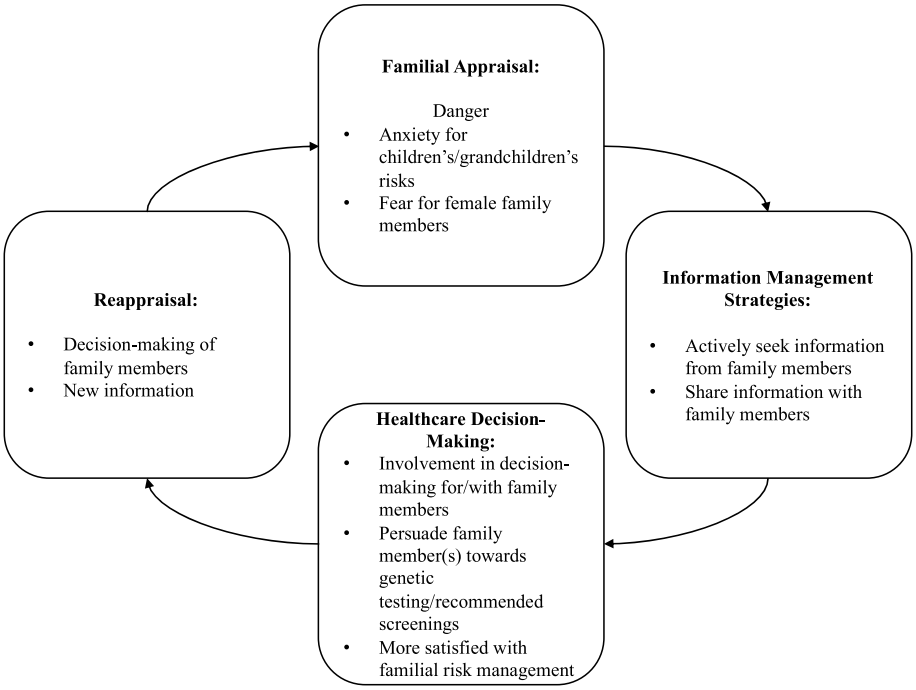

Fig. 3. Men's Familial Uncertainty Management. Participants' individual uncertainty management catalyzed and intertwined with appraisals, information management, and healthcare decisions focused on family members.

3.2.1. Familial danger appraisal

Overall, participants explained that, even if they experienced no individual uncertainty, the uncertainty their family members faced needed to be addressed and reduced. Jeff (*BRCA1* family history, age 46, three children) summed up familial danger appraisals well when he said, "It's just the black cloud that hangs over our family." Further, Josh (*BRCA1* family history, age 31, no children) discussed his anxiety about the uncertainty his future children might face. His solution for managing his future children's uncertainty was to get himself tested to help them manage their risks. He said, "When I want to have kids, I know that because of this I will go and get checked and tested just to make sure that I'm aware of what I could be potentially bringing into this world." Similarly, David (*BRCA2*, age 58, two children), discussed how to manage his daughters' uncertainty rather than his own:

> I'm more concerned about my daughters. I'm more concerned about them than I am about myself at this point because they are so young. With their diagnosis, their risks, as I understand it, are so much higher than mine are. There seems to be more the urgency.

Overall, these men perceived the uncertainty their family members faced as dangerous to the family members' health, thereby leading the men to do what they could to help reduce the uncertainty for the family member.

3.2.2. Information management strategies

Appraising familial uncertainty as a danger prompted men to engage in *seeking information* from family members, and also *information provision* to family members. Greg (*BRCA2,* age 61, two children) noted that he had multiple conversations with his cousin to glean information about their familial risks to help inform his daughters:

> As soon as I spoke to my cousin, she gave me all the genetic mapping information and connected me with the hospital that has been tracking our family and wanted additional information on my leg of the family tree and the new information that was added to their records. And they were the ones who were going to do the BRCA testing for me and, you know, connected us with the person to do it for both my daughters.

Likewise, Jeff (*BRCA1* family history, age 46, three children) discussed the importance of providing information to not only his own children, but his extended family:

> I want to make sure that my kids and my nieces and nephews all have information early in their adulthood so they can make those decisions for testing, and if they want to have children that they understand what the risks of that are.

These men were motivated to seek information about familial risk from family members and to share information among close and distant relatives to aid in proactive healthcare decision-making.

3.2.3. Healthcare decision-making

Participants who appraised familial uncertainty as a danger also became involved in the decision-making process with their family members, especially their daughters. These men reported feeling responsible for making sure their daughters were receiving proper preventive care and managing their risks to avoid developing cancer. David (*BRCA2,* age 58, two children) exemplified his involvement when he discussed his daughter's reproductive decision-making. His use of the word "we" is a particularly strong indicator of his perceived role as a co-decision-maker. He said, "Whatever we want to do with the ovaries. You know, do we want to harvest eggs? Do we freeze them? What does this mean down the road for having children?" Greg (*BRCA2* family history, age 61, two children) also exhibited his involvement in a similar way:

> The next thing was: How do we rally around the one who was diagnosed as positive to help her through the practical things that she has to do to both think about raising a family, of making sure that the BRCA mutation stops at her generation and never goes forward? And we've basically done the egg harvest egg selection. She has to have her ovaries removed in a fairly short order; the clock is ticking. She is pregnant with her first child, and she wants to have two, but she only has a two-year window to be able to have her family, and then she will have her ovaries removed.

Additionally, men who appraised familial uncertainty as dangerous

also were more likely to *seek testing for themselves* to find more certainty about their children's risks and *persuade other family members to get tested and/or engage in preventive screenings*. Travis (*BRCA2,* age 69, two children) discussed how his uncertainty for his children was what persuaded him to get tested himself, "One of the reasons that I was tested was not so much for me—I was concerned about my children inheriting the gene." Men also reported trying to persuade family members to be tested or engage in screening. For example, Scott (*BRCA*2, age 61, four children) explained his efforts to persuade his children to get tested for the gene variant after he got a positive genetic test returned: "We did talk about it when I found out that I was positive. … I tried to explain to them how I thought it worked—the risk factors and things like that. I decided I need to push for them to get tested." Similarly, Travis (*BRCA*2, age 69, two children) discussed engaging in familial uncertainty management with his son after his testing due to his concern for his son's health. He said, "My son is, he's another case. I pushed him. I said, 'You know, you need to be tested.' And he's, you know, 'Yeah, I'll do that.' But he hasn't."

Moreover, men who were more involved in decision-making with their family members also discussed feeling more satisfied with their own decisions and the decisions of their family members and *feeling more relational closeness* with their family members. Greg (*BRCA2* family history*,* age 61, two children) noted, "As it relates to the depths of my relationship with my daughter, it's profoundly different and stronger as a result of having to share the solving of this problem." David (*BRCA2,* age 58, two children) also said, "I think, you know, we have just really circled the wagons and pulled close."

Finally, these men were often part of a familial uncertainty management reappraisal loop where they would reassess either their own uncertainty or their familial uncertainty based on the information provided or actions of family members. For example, Michael (*BRCA2,* age 65, four children) noted that he anticipates a familial uncertainty reappraisal loop when his grandchildren get old enough to be tested, "When our grandchildren get old enough it's going to be up to the parents on what they want to do. They know our feelings about it, but that's up to them to do." Greg (*BRCA2* family history*,* age 61, two children) also discussed how the ways in which he and his daughter exchange information makes him re-evaluate familial risks, "She sits down with me, her father, and says 'Dad, you're at risk, you need to understand. Here's what I know and I'll share this with you.' So, I get the reinforcement from her. She's my advocate." He went on to discuss how he shares the information his daughter has given him with his son: "I keep telling him the things that he needs to know as precautions when I see him on a regular basis," indicating a familial uncertainty reappraisal loop being co-managed by Greg and his children. Overall, men in this study reported engaging in a dynamic process of not only managing their own individual uncertainty, but also actively managing family members' uncertainty with and for them. Whereas they often appraised their own uncertainty as irrelevant, they appraised familial uncertainty as dangerous and communicated to reduce uncertainty for family members through information management and involvement in healthcare decision-making.

4. Discussion

The purpose of this study was to examine the process by which men manage their individual and familial uncertainty regarding their BRCA-related cancer risks. Findings demonstrate that men appraised their *individual* uncertainty as either irrelevant or dangerous, while appraising *familial* uncertainty as dangerous. These findings make two contributions to better understanding the way men manage uncertainty about their BRCA-related cancer risks. First, the findings confirm that whether men appraise their uncertainty as irrelevant or dangerous has important implications for their own information management and healthcare decision-making. Second, the findings revealed that the men in this study were typically more engaged in familial uncertainty management with implications for the management of their own and their family members' uncertainty. For these men, a family focus in genetic counseling would be beneficial. The following section discusses the two primary contributions of these findings as well as practical applications given these contributions: (1) encouraging and guiding individual (re)appraisals and (2) engaging patients in familial uncertainty management.

4.1. Encouraging and guiding individual uncertainty (Re)Appraisals

Approximately half of the men in this study appraised their uncertainty about their disease risks as irrelevant, while the other half appraised that uncertainty as dangerous (see Fig. 2). The data that showed men often appraised their uncertainty as irrelevant supports previous research that men are often not very engaged in managing their risks (Suttman et al., 2018) and are generally confused by what their risks are and how to manage them (Rauscher et al., 2018). However, the men who appraised their uncertainty as a danger indicate that, with the right information and/or motivation, men can appraise their uncertainty in adaptive ways that lead to active engagement with information and management of BRCA-related cancer risks. Indeed, a danger appraisal reflected participants' perceived threat regarding their uncertainty about BRCA-related cancer risks. Such perceptions have been shown to mediate the relationship between family history knowledge and engagement with health education (Prom-Wormley et al., 2019). Men who appraised uncertainty as a danger were more active in information seeking and healthcare decision-making.

In addition, these findings highlight the importance of healthcare practitioners framing information in a way that addresses men's uncertainty and helps them manage that uncertainty. It is particularly important for healthcare practitioners to make sure men take time to address their *individual* uncertainties—because the uncertainty management process can happen rapidly with men neglecting their own uncertainties. As such, theory-based interventions should be developed to guide men through the process of appraising their uncertainty and should focus on areas where their knowledge about their risks is insufficient or inaccurate to activate their individual uncertainty process (see Fig. 2).

Such an approach could mitigate irrelevant appraisals and the passivity that accompanies them. Kazer, Bailey, Sanda, Colberg, and Kelly (2011), for example, designed an internet intervention based in Mishel's uncertainty in illness theory (Mishel, 1988), for men actively surveilling prostate cancer. The website designed for the intervention promoted cognitive reframing and self-management strategies with a goal of improving men's quality of life and self-efficacy. They found more views of the webpage were associated with improvements in these areas. Within ethical boundaries, a similar intervention could be designed to stimulate men's appraisal of individual uncertainty as dangerous and encourage productive strategies for mitigating that uncertainty. For example, an intervention guided by the extended parallel process model (Popova, 2012; Witte and Allen, 2000)—developed to create effective fear appeals—could include information framing the severity and susceptibility of BRCA-related cancers for men, which may stimulate desired emotions that motivate men towards proactive healthcare decision-making. Information framed to create a fear appeal should be coupled with clear explanations and recommendations on how men can best manage their risk to improve their self-efficacy and promote proactive medical decision-making. The findings of this study suggest that such interventions will be useful if they can guide men currently appraising their uncertainty as irrelevant to reappraise that uncertainty as dangerous. Creating an online tool such as this for men with BRCA-related cancer risks could help them better manage uncertainty across their lifespan and meet their needs for online tools designed specifically for men (Rauscher et al., 2018).

4.2. Engaging patients in familial uncertainty management

Findings from this study supported previous research showing men's primary concern when managing BRCA-related cancer risks is their family (Hesse-Biber and An, 2015). The findings build on this insight by showing that men typically began their uncertainty management process by managing their individual uncertainty, but, because they were often met with a lack of information and options for men with BRCA-related cancer risks, they transitioned into focusing more on their role in managing the uncertainty of family members (see Fig. 3). These findings extend Dean's (2016) work on familial uncertainty for women with BRCA-related cancer risks by investigating the process and outcomes of managing familial uncertainty.

Although these data suggest a linear transition from individual to familial uncertainty management, this linearity may accurately capture their journey or be an artifact of the interview process, or both. It is important to acknowledge that familial uncertainty management is more dynamic and intra-familial communication is complex. Indeed, a meta-analysis conducted by Metcalfe et al. (2008), investigating communication between parents and children, revealed a dynamic process with numerous considerations that influence disclosure, risk management, and uncertainty. Further, Hallowell et al. (2003) detailed ethical considerations of communicating risk information in families such as the tensions between autonomy of personal health information and the responsibility of sharing pertinent information with at risk family members. Men in this study may also have felt this tension between autonomy and responsibility, but did not discuss it perhaps due to prevailing, societal norms favoring protection of family through sharing of information and concern for family members' health risks. They may have been reticent to talk about their own health concerns when the cancer risks of female family members are so much higher.

Rolland and Williams (2006) note the interdependent nature of families where an action of one member impacts other members. A similar push and pull between the individual and familial uncertainty management processes is also occurring for families managing BRCA-related cancer risks. The actual process of individual and familial uncertainty management may suggest interdependent processes wherein individuals are managing uncertainty at multiple levels simultaneously and prioritizing different levels at different points in time across multiple generations. These data suggest that this familial uncertainty management involves ongoing reappraisals of individual and familial uncertainty when new information is introduced or families need to make disease risk prevention decisions. For instance, a family member's decision to undergo a preventive mastectomy could prompt other family members to reappraise uncertainty for that person as irrelevant because their disease risks have been reduced, while simultaneously appraising uncertainty for other family members as a danger if they had not undergone preventive surgery. These findings underscore that future research should examine how these processes involve multiple family members in simultaneous, overlapping, interdependent, and self- and other-focused uncertainty management.

These findings provide further evidence of the need to engage patients more in family interventions. Such interventions should include more family members and be more strategic in preparing patients for what to expect in these conversations. Although previous research has called for increased attention to family-level interventions (Mendes et al., 2018), little research has met that call. Indeed, the research has examined how many family members have been told and/or undergone testing themselves (i.e., Hodgson et al., 2016) without much focus on the interactional dynamics of those conversations and their implications for family relationships. As scholars continue moving towards models of familial interventions, our findings point towards several important elements of such interventions.

First, such interventions should prepare patients for uncertainty experienced by the entire family unit. The push and pull of family dynamics and the discordant appraisals of multiple family members can create dilemmas for patients taking on the role of co-decision-maker. Intervention materials might draw attention to the differences between managing uncertainty for oneself and managing uncertainty for the family by providing advice for managing uncertainty at these different levels. Furthermore, interventions might also seek to prepare men for their role in such conversations. The findings of this study suggest that men may be actively engaged in familial uncertainty management even if they lack the information they need to help manage familial uncertainty.

Additionally, familial interventions should not only happen when the first individual in the family learns of his or her genetic risk. Instead, these findings suggest they should happen repeatedly across the lifespan of disease risk in the family because of the reappraisals of uncertainty involved. Introducing new information and/or decisions into the uncertainty management process for family members can prompt them to reappraise their uncertainty and alter previous decisions (i.e., to go forward with genetic testing). Providing informational support for patients and families during or anticipating reappraisal presents practitioners with an opportunity to act propitiously. Knowledge of the interrelated cycles of individual and familial uncertainty management can allow providers to help patients and family reconsider the timing of their individual and familial uncertainty appraisals and possibly alter their management strategies (Derbez, 2018). Indeed, the temporal nature of genetic testing and its impacts for multiple generations of families makes it a compelling context for longitudinal interventions (Huijer, 2005).

These findings show that individual and familial uncertainty management take place at different points in the disease risk management process across the lifespan, even spanning into uncertainty management for children who have not yet been conceived. The findings from this study, in tandem with results from the work of Lapointe et al. (2013) who identified events in the family across the life span when communication about hereditary cancer risk most often occurred, could guide such temporally focused interventions by informing what life events encourage families' receptivity to guidance regarding their uncertainty management and health decision making. Repeated familial interventions would likely help family members better manage their individual and familial uncertainty, but research shows genetic counselors are already overburdened (Wright et al., 2019). Evidence-based, familial interventions are needed that utilize easily accessible technologies such as mobile apps, virtual reality, or online role-playing tools that engage multiple family members.

4.3. Limitations

Four limitations stand out for this study. First, the sample is largely white, affluent, and highly-educated. Although diversity is an overarching problem in genetic testing (Bentley et al., 2017), the lack of diversity is especially problematic in discussions of family dynamics and communicative behavior. The participants in this study do reflect the demographic of men most likely being tested for hereditary cancers, but men of different cultural backgrounds and of varying socioeconomic means may have different information needs, levels of uncertainty, frameworks for understanding family and health, and different familiarly uncertainty management processes. Additionally, recruiting via social media may produce a sample more engaged in communication and advocacy about the topic. In this study, in part because most participants were referred to the study, they reported little or no such engagement during interviews. They were largely uninformed about risks and uninvolved in advocacy groups. Thus, the sample may more closely resemble how men with BRCA risks manage uncertainty than an already engaged sample recruited exclusively from social media advocacy groups. This study should spark more research in this area, and the findings should be a useful starting point as the populations tested for hereditary cancers grows more diverse.

Second, men who both had and had not been tested were recruited

for this study and their experiences combined for this paper. While combining the two groups was based on empirical data, we acknowledge that the two groups can differ in their understanding of genetic cancer risks and interpretations of healthcare decision-making. We encourage future researchers to continue exploring similarities and differences of these two groups of at-risk men.

Third, few participants in this study had been diagnosed with cancer or talked about their role in the familial management of an actual cancer diagnosis. Instead, they were more focused on individual and familial uncertainty regarding prevention. Research shows that if someone is already diagnosed with cancer, their primary concern is often treating the cancer and not necessarily what the implications are for their family members (Wright et al., 2019). The process of individual and familial uncertainty management would likely look different from the perspective of men diagnosed with cancer or with family members currently facing a cancer diagnosis.

The final limitation of this study was the inclusion of just one family member, rather than analyzing familial uncertainty from the perspective of multiple family members. Although these men shared a sense of how they conceived their role in the familial uncertainty management process, we do not have data about the experiences and perceptions of their family members. This shortcoming might be important, for example, if father wanted to be a co-decision-maker in his daughter's reproductive choices in ways the daughter found intrusive. Future research should investigate how communication regarding individual and familial uncertainty intertwines to affect uncertainty management and decision-making across and within levels. Specifically, these findings indicate that future research needs to examine how family members individually appraise their own uncertainty in tandem with their familial uncertainty. Such family-focused theorizing will be of increasing importance as more advances are made in genetic testing—implicating risks for the family, the individual, and the social systems in place to manage that risk (Scherr et al., 2017).

5. Conclusions

Results of this study showed men with BRCA-related cancer risks lack understanding about their risks and how to manage them, which leads them to appraise their individual uncertainty as either irrelevant or dangerous. However, in this study, all men appraised familial uncertainty as dangerous. Increased attention should be paid to the development of interventions tailored specifically to help men recognize and manage their individual uncertainty. Further, interventions focusing on strategically developing proactive family communication behaviors would also benefit men and their families.

Examining familial uncertainty management in the context of hereditary cancer should provide insights into how managing uncertainty and making healthcare decisions is often a distributed or shared process. More work needs to examine the ecological context patients are situated in and how networks of important others, such as family and close friends, influence uncertainty management and contribute to healthcare decisions (Rolland and Williams, 2006). For example, patients' family and close friends can be important sources of information, influencing health decisions, improving feelings of preparedness, and bolstering coping and adaptation (Berry et al., 2018).

Research should also consider how individuals communicate to manage the uncertainty of others including family members. In this study, through their family roles, at-risk men were involved in the uncertainty management and decision-making processes of other at-risk family members, and communication from family members motivated these at-risk men to reappraise their individual uncertainty. Managing uncertainty about *others'* health is important and understudied communication work that is nonetheless integral to health and illness (Donovan et al., 2012). Interventions should be designed mindful of the embedded, collective nature of uncertainty management and communication about health and illness (Barbour et al., 2018). A family-centered approach to healthcare for patients with hereditary conditions that includes familial uncertainty management can better guide family communication and information exchange, promoting family members' adherence to recommendations throughout the cancer prevention and control continuum. Although we often conceptualize the individual at the center of the experience and management of health and illness, others and especially family members in the context of genetic risk and hereditary illness matter a great deal in how individuals make sense of and manage their health and their families.

Acknowledgments

The authors received funding for this project from the Texas A&M College of Liberal Arts Seed Grant Program. An early version of this article was presented at the 2018 National Communication Association annual convention in Salt Lake City, UT, USA.

The last three authors dedicate this article to the first author, Dr. Emily A. Rauscher, who passed away in September 2019. Emily was our colleague, friend, collaborator, and teacher. This article exemplifies Emily's brilliant intellect and perseverance. She believed in this scholarship and its importance, and her drive and expertise made this research possible. Thank you, Emily.

References

Barbour, J.B., Gill, R., Barge, J.K., 2018. Organizational communication design logics: a theory of communicative intervention and collective communication design. Commun. Theor. 28, 332–353. https://doi.org/10.1093/ct/qtx005.

Bentley, A.R., Callier, S., Rotimi, C.N., 2017. Diversity and inclusion in genomic research: why the uneven progress? J. Community Genet. 8, 255–266. https://doi.org/10.1007/s12687-017-0316-6.

Berry, D.L., Blonquist, T.M., Pozzar, R., Nayak, M.M., 2018. Understanding health decision making: an exploration of homophily. Soc. Sci. Med. 214, 118–124. https://doi.org/10.1016/j.socscimed.2018.08.026.

Bowen, G.A., 2008. Naturalistic inquiry and the saturation concept: a research note. Qual. Res. 8, 137–152. https://doi.org/10.1177/1468794107085301.

Brashers, D.E., 2001. Communication and uncertainty management. J. Commun. 51, 477–497. https://doi.org/10.1111/j.1460-2466.2001.tb02892.x.

Charmaz, K., 2014. Constructing Grounded Theory, second ed. Sage Publications, Thousand Oaks, CA.

Creswell, J.W., 2007. Qualitative Inquiry & Research Design: Choosing Among Five Approaches, second ed. Sage Publications, Thousand Oaks, CA.

Dean, M., 2016. "It's not if I get cancer, it's when I get cancer": *BRCA*-positive patients'(un)certain health experiences regarding hereditary breast and ovarian cancer risk. Soc. Sci. Med. 163, 21–27. https://doi.org/10.1016/j.socscimed.2016.06.039.

Dean, M., Davidson, L.G., 2016. Previvors' uncertainty management strategies for hereditary breast and ovarian cancer. Health Commun. 33, 122–130. https://doi.org/10.1080/10410236.2016.1250187.

Derbez, B., 2018. Is there a "right time" for bad news? Kairos in familial communication on hereditary breast and ovarian cancer risk. Soc. Sci. Med. 202, 13–19. https://doi.org/10.1016/j.socscimed.2018.02.022.

Donovan, E.E., Tollison, A.C., Goins, E.S., 2012. The nature of communication work during cancer: advancing the theory of illness trajectories. Health Commun. 27, 641–652. https://doi.org/10.1080/10410236.2011.629405.

Forrest, K., Simpson, S.A., Wilson, B.J., Van Teijlingen, E.R., McKee, L., Haites, N., Matthews, E., 2003. To tell or not to tell: barriers and facilitators in family communication about genetic risk. Clin. Genet. 64, 317–326. https://doi.org/10.1034/j.1399-0004.2003.00142.x.

Gaff, C.L., Galvin, K.M., Bylund, C.L., 2010. Facilitating family communication about genetics in practice. In: Gaff, C.L., Bylund, C.L. (Eds.), Family Communication about Genetics: Theory and Practice. Oxford University Press, Oxford, pp. 243–272.

Hallowell, N., Foster, C., Eeles, R., Ardern-Jones, A., Murday, V., Watson, M., 2003. Balancing autonomy and responsibility: the ethics of generating and disclosing genetic information. J. Med. Ethics 29, 74–83. https://doi.org/10.1136/jme.29.2.74.

Hesse-Biber, S., An, C., 2015. Within-gender differences in medical decision making among male carriers of the *BRCA* genetic mutation for hereditary breast cancer. Am. J. Men's Health 1–16. https://doi.org/10.1177/1557988315610806.

Hodgson, J.M., Metcalfe, S., Gaff, C.L., Donath, S., Delatycki, M.B., Winship, I.M., et al., 2016. Outcomes of a randomized controlled trial of complex genetic counselling intervention to improve family communication. Eur. J. Hum. Genet. 24, 356–360. https://doi.org/10.1038/ejhg.2015.122.

Hogan, T.P., Brashers, D.E., 2009. The theory of communication and uncertainty management: implications from the wider realm of information behavior. In: Afifi, T.D., Afifi, W.A. (Eds.), Uncertainty, Information Management, and Disclosure Decisions: Theories and Applications. Routledge, New York, NY, pp. 67–89.

Hsieh, H., Shannon, S.E., 2005. Three approaches to qualitative content analysis. Qual. Health Res. 15, 1277–1288. https://doi.org/10.1177/1049732305276687.

Huijer, M., 2005. Orchestrating time in the genomic era: timescape perspective on the

changing practice of hereditary breast cancer prevention. Configurations 13, 421–434. https://doi.org/10.1353/con.2007.0020.
Kazer, M.W., Bailey Jr., D.E., Sanda, M., Colberg, J., Kelly, W.K., 2011. An internet intervention for management of uncertainty during active surveillance for prostate cancer. Oncol. Nurs. Forum 38, 561–568. https://doi.org/10.1188/11.ONF.561-568.
Kuang, K., Wilson, S.R., 2017. A meta-analysis of uncertainty and information management in illness contexts. J. Commun. 67, 378–401. https://doi.org/10.1111/jcom.12299.
Kuchenbaecker, K.B., Hopper, J.L., Barnes, D.R., Phillips, K., Mooij, T.M., the BRCA1 and BRCA2 Cohort Consortium, 2017. Risks of breast and ovarian, and contralateral breast cancer for BRCA1 and BRCA2 mutation carriers. J. Am. Med. Assoc. 317, 2402–2416. https://doi.org/10.1001/jama.2017.7112.
Kvale, S., Brinkmann, S., 2008. InterViews Learning the Craft of Qualitative Research Interviewing. Sage Publications, Thousand Oaks, CA.
Lapointe, J., Cote, C., Bouchard, K., Godard, B., Simard, J., Dorval, M., 2013. Life events may contribute to family communication about cancer risk following *BRCA1/2* testing. J. Genet. Couns. 22, 249–257. https://doi.org/10.1007/s10897-012-9531-9.
Mahon, S.M., 2014. Cancer risks for men with *BRCA1/2* mutations. Oncol. Nurs. Forum 41, 99–101. https://doi.org/10.1188/14.ONF.99-101.
Mendes, A., Metcalfe, A., Paneque, M., Sousa, L., Clarke, A.J., Sequeiros, J., 2018. Communication of information about genetic risks: putting families at the center. Fam. Process 57, 836–846. https://doi.org/10.1111/famp.12306.
Merriam, S.B., 2014. Qualitative Research: A Guide to Design and Implementation. John Wiley & Sons.
Metcalfe, A., Coad, J., Plumridge, G.M., Gill, P., Farndon, P., 2008. Family communication between children and their parents about inherited genetic conditions: a meta-analysis of the research. Eur. J. Hum. Genet. 16, 1193–1200. https://doi.org/10.1038/ejhg.2008.84.
Mishel, M.H., 1988. Uncertainty in illness. *Image*. J. Nurs. Scholarsh. 20, 225–232. https://doi.org/10.1111/j.1547-5069.1988.tb00082.x.
Morgan, M.G., Fischhoff, B., Bostrom, A., Atman, C.J., 2002. Risk Communication: A Mental Models Approach. Cambridge University Press.
National Comprehensive Cancer Network, 2018. NCCN Clinical Practice Guidelines in Oncology: Genetic/Familal High-Risk Assessment: Breast and Ovarian [v.2.2018]. Retrieved from: https://www.nccn.org/professionals/physician_gls/f_guidelines.asp.
Peshkin, B.N., Ladd, M.K., Isaacs, C., Sega, H., Jacobs, A., Taylor, K.L., et al., 2019. The genetic education for men (GEM) trial: development of web-based education for untested men in *BRCA1/2*-positive families. J. Cancer Educ. https://doi.org/10.1007/s13187-019-01599-y. online.
Petrucelli, N., Daly, M.B., Pal, T., 2016. BRCA1-and BRCA2-associated hereditary breast and ovarian cancer. In: GeneReviews® [Internet]. University of Washington, Seattle.
Popova, L., 2012. The extended parallel process model: illuminating the gaps in research. Health Educ. Behav. 39, 455–473. https://doi.org/10.1177/1090198111418108.
Pritchard, C.C., 2019. New name for breast-cancer syndrome could help save lives. Nature 571, 27–29. https://doi.org/10.1038/d41586-019-2015-7.
Prom-Wormley, E.C., Clifford, J.S., Bourdon, J.L., Barr, P., Blondino, C., Ball, K.M., … Newbille, C., 2019. Developing community-based health education strategies with family history: assessing the association between community resident family history and interest in health education. Soc. Sci. Med. 1–10. https://doi.org/10.1016/j.socscimed.2019.02.011.
Rauscher, E.A., Dean, M., 2018. “I’ve just never gotten around to doing it”: men's approaches to managing BRCA-related cancer risks. Patient Educ. Couns. 101, 340–345. https://doi.org/10.1016/j.pec.2017.015.
Rauscher, E.A., Dean, M., Campbell-Salome, G., 2018. “I am uncertain about what my uncertainty even is”: men's uncertainty and information management of their BRCA-related cancer risks. J. Genet. Couns. 27, 1417–1427. https://doi.org/10.1007/s10897-018-0276-y.
Rolland, J.S., Williams, J.K., 2006. Toward a psychosocial model for the new era of genetics. In: Miller, S.M., McDaniel, S.H., Rolland, J.S., Feetham, S.L. (Eds.), Individuals, Families, and the New Era of Genetics: Biopsychosocial Perspectives. W.W. Norton & Company, Inc., New York, NY, pp. 36–78.
Saldana, J., 2013. The Coding Manual for Qualitative Researchers. Sage Publications, Thousand Oaks, CA.
Scherr, C.L., Dean, M., Clayton, M.F., Hesse, B.W., Silk, K., Street Jr., R.L., Krieger, J., 2017. A research agenda for communication scholars in the precision medicine era. J. Health Commun. 22, 839–848. https://doi.org/10.1080/10810730.2017.1363324.
Strømsvik, N., Råheim, M., Øyen, N., Engebretsen, L.F., Gjengedal, E., 2010. Stigmatization and male identity: Norwegian males' experience after identification as *BRCA1/2* mutation carriers. J. Genet. Couns. 19, 360–370. https://doi.org/10.1007/s10897-010-9293-1.
Sussner, K.M., Landorf, L., Thompson, H.S., Valdimarsdottir, H.B., 2013. Barriers and facilitators to BRCA genetic counseling among at-risk Latinas in New York City. Psycho Oncol. 22, 1594–1604. https://doi.org/10.1002/pon.3187.
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. J. Genet. Couns. 27, 885–893. https://doi.org/10.1007/s10897-018-0214-z.
Torbit, L.A., Albiani, J.J., Aronson, M., Holter, S., Semotiuk, K., Cohen, Z., Hart, T.L., 2016. Physician trust moderates the relationship between intolerance for uncertainty and cancer worry interference among women with Lynch syndrome. J. Behav. Med. 39, 420–428. https://doi.org/10.1007/s10865-016-9711-4.
Tracy, S.J., 2013. Qualitative Research Methods: Collecting Evidence, Crafting Analysis, Communicating Impact. Wiley-Blackwell, Malden, MA.
Weitzel, J.N., Blazer, K.R., MacDonald, D.J., Culver, J.O., Offit, K., 2011. Genetics, genomics, and cancer risk assessment. *CA*. Ca - Cancer J. Clin. 61, 327–359. https://doi.org/10.3322/caac.20128.
Witte, K., Allen, M., 2000. A meta-analysis of fear appeals: implications for effective public health campaigns. Health Educ. Behav. 27, 591–615. https://doi.org/10.1177/109019810002700506.
Wright, S., Porteous, M., Stirling, D., Young, O., Gourley, C., Hallowell, N., 2019. Negotiating jurisdictional boundaries in response to new genetic possibilities in breast cancer care: the creation of an ‘oncogenetic taskscape’. Soc. Sci. Med. 225, 26–33. https://doi.org/10.1016/j.sociscimed.2019.02.020.