Research Article

Managing Uncertainty for and With Family: Communication Strategies and Motivations in Familial Uncertainty Management for Hereditary Cancer

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Abstract

The management of uncertainty is integral to health and illness. Individuals manage uncertainty about their health through communication enmeshed in family systems, but existing theorizing focuses on individuals without accounting for family processes. An iterative qualitative analysis of 42 dyadic, family interviews (N = 84) revealed (a) moments in the context of hereditary cancer that involved individual-centered *and* familial uncertainty appraisal and management, (b) family members' communication strategies to prompt relatives to engage familial uncertainty, and (c) the communicative (re)creation and negotiation of family models for uncertainty management. The findings illuminate tensions that individuals encounter across their lifespan as they appraise and manage uncertainty about hereditary cancer risks. This study extends uncertainty management theory to encompass familial uncertainty management and contributes insights useful for the management of hereditary cancer.

Keywords

hereditary cancer; genetics; uncertainty management; family communication; family systems

To live with a hereditary cancer condition is to live with life-long, chronic uncertainty (Dean & Fisher, 2019; Galvin & Young, 2010). It is an exemplar of the centrality of uncertainty in health and illness in general (Brashers, 2007; Mishel, 1988). Individuals with a hereditary cancer condition have a prevalent family health history of cancer and/or have a pathogenic genetic variant associated with increased cancer risks (see National Cancer Institute, 2019, for a detailed description). Hereditary cancer conditions such as Hereditary Breast and Ovarian Cancer syndrome, Lynch syndrome, and Li-Fraumeni syndrome increase individuals' lifetime risks for developing certain cancer and have a 50% chance of being passed on to offspring. Understanding and empowering the management of these conditions should be important objectives for health research (Dean & Rauscher, 2018; Scherr et al., 2017).

Uncertainty management theory provides a framework that conceptualizes the communicative management of uncertainty and its effects on important health and illness outcomes (Brashers, 2001; Dean & Fisher, 2019). Per the theory, when individuals encounter uncertainty they cognitively appraise uncertainty by considering its goal relevance and goal congruence and emotionally appraise uncertainty (Hogan & Brashers, 2009). These appraisals influence how they manage their uncertainty and in turn how they manage their health and cope with illness. That individuals manage multiple goals as they appraise their uncertainty makes this process complex (Scott et al., 2011). Previous research also underscores the need for the study of uncertainty management as a collective process to reveal "the interactive, collaborative nature of uncertainty management" (Brashers et al., 2004), but uncertainty management research tends to focus on it as an individual process without conceptualizing the familial dimensions (Kuang & Wilson, 2017). This study investigated the nature of collective uncertainty management within the complex web of family for serious, shared health conditions to expand the study of illness uncertainty to encompass familial uncertainty management.

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In the following review of the literature, first, to provide context, we enumerate the risks associated hereditary cancer, and we then argue for the centrality of the family in health and especially the management of hereditary cancer conditions. We then explicate uncertainty management theory with a focus on familial uncertainty. This literature review makes a case for study of the interplay between individual and familial uncertainty and the communication involved in managing it. We then report a qualitative, interview-based study of 42 family dyads ($N = 84$). The findings demonstrated that individual and familial appraisals intertwine in uncertainty management, and that individuals manage uncertainty alone and in collaboration with others, focused on the self and focused on others. We conclude by articulating contributions of this study to health research: The study builds on theory of the management of uncertainty inherent to health and illness, reveals the importance of familial models in the health decisions, and makes recommendations for the more effective support of individuals and families dealing with hereditary cancer conditions.

Hereditary Cancer Risks

The risks associated with hereditary cancer conditions underscore their importance for health research. Women with Hereditary Breast and Ovarian Cancer syndrome have a 55–65% chance of developing breast cancer, 17–44% risk of developing ovarian cancer, and a 3.3–6.6% risk of developing pancreatic cancer over their lifetime (Nielsen et al., 2016). Men with Hereditary Breast and Ovarian Cancer syndrome are also at an increased risk for developing breast cancer, pancreatic cancer, prostate cancer, and melanoma over their lifetime (Lecarpentier et al., 2017). Individuals with Lynch syndrome face a 52–82% risk of developing colorectal cancer, a 25–60% risk of developing endometrial cancer, a 6–13% risk of developing gastric cancer, and a 4–12% risk of developing ovarian cancer over their lifetime (Idos & Valle, 2021). Individuals with Lynch syndrome also face additional cancer risks for hepatobiliary tract, urinary tract, small bowel, brain/central nervous system, and sebaceous neoplasms (Lindor et al., 2006). Less data is available for Li-Fraumeni syndrome, but cancers associated with Li-Fraumeni syndrome include breast cancer, osteosarcoma, soft tissue sarcomas, brain tumors, leukemias, and adrenocortical carcinoma (Vogel, 2017). The management of the uncertainty associated with these risks is a key challenge for individuals with these conditions, and these risks, not just for the individual, but for their families, make clear the importance of family for hereditary cancer.

The Centrality of the Family System in Health

Family is a fundamental and enduring social institution (Baxter, 2011). The socially constructed and shared worldviews of families can (un)consciously pattern attitudes, behaviors, and ideals for communication across generations (Bylund et al., 2010). It is important to understand how individuals manage uncertainty in the family system, as family systems have powerful, taken-for-granted influences on individuals' sensemaking and health. Families are discourse dependent (Galvin et al., 2006) in the sense that communication is the central process for defining families' identities and establishing families' shared sense of legitimacy (Baxter, 2011).

Family systems create patterns for interaction, involve interdependencies among members and the pursuit of individual and family goals (Galvin et al., 2006). As such, they likely affect how individuals appraise and manage illness uncertainty. Families communicate and model health attitudes and behaviors that influence the management of health risks (Dorrance Hall et al., 2021; Jones et al., 2004). Family communication shapes medical decision-making, including cancer treatment (Fisher, 2011), genetic testing (Fisher et al., 2014; Rauscher et al., 2015), and hereditary cancer prevention and surveillance (Hesse-Biber, 2014). Family provides support and caregiving, especially in contexts of managing long-term health risks (Fisher et al., 2021). Findings across this research demonstrate that families communicate to manage uncertainty about health, and that *how* they manage uncertainty merits investigation and further theorizing.

As components of family systems, dyadic relationships influence sensemaking relevant to health risks. Family systems organize into interpersonal sub-systems, such as dyads (Galvin et al., 2006; Law et al., 2021). Commonly studied and pervasive relationships that often characterize family systems include couple/spouse, parent-child, and sibling dyads. For example, previous research found interdependent and bi-directional effects of parent-young-adult dyadic communication on health attitudes and behaviors for diet and exercise behavior (Baiocchi-Wagner & Talley, 2013). Solomon et al. (2021) recently theorized the dyad as central to communication systems, underscoring the "dyadic essence" of communication (p. 2). Dyadic relationships are also central in understanding how family systems manage hereditary cancer risks and uncertainty (Law et al., 2021). For instance, spouse dyads negotiate disclosure and decision-making about family planning (Dean & Rauscher, 2018) while mother-daughter dyads manage dialectical tensions as they communicate risk (Fisher et al., 2014). Examining how dyads communicate to manage uncertainty about hereditary cancer can illustrate how uncertainty may be co-managed by family systems.

Familial Uncertainty Management

Previous uncertainty management research focuses on familial processes like social support provision or attending to family goals, and researchers have thus called for

attention to the "the interactive, collaborative nature of uncertainty management" (Brashers et al., 2004, p.327), but the theory does not conceptualize familial uncertainty management as such. The involvement of family in uncertainty management has been studied from the perspective of the individual receiving assistance (Brashers et al., 2004; Scott et al., 2011). For instance, Brashers and colleagues (2004) found that the burden of close others' uncertainty management created dilemmas for individuals receiving social support, especially if support was incongruent with their uncertainty appraisals. The incongruence exacerbated the individuals' stress and uncertainty (see also, Scott et al., 2011; Scott & Caughlin, 2012). Individuals resolved the incongruity by reappraising their uncertainty and creating new goals. Dean and Fisher (2019) found that women with Hereditary Breast and Ovarian Cancer syndrome experience chronic uncertainty and reappraise their uncertainty at different moments in the lifespan related to their healthcare (e.g., surveillance appointments, surgeries) and family (e.g., family planning, mothering offspring). Their research makes clear that family dynamics have inhibiting and enhancing relationships with health outcomes.

Rauscher and colleagues (2019) defined familial uncertainty management as "one or multiple family members communicating to co-manage uncertainty for themselves, other family members, and the family as a whole" (p. 2). Individuals manage uncertainty about and with family members, and family members manage uncertainty in collaboration with each other. Communicating to co-manage uncertainty is a dynamic process, which involves overlapping and intertwined individual and familial processes. Past research found that individuals simultaneously manage uncertainty for the individual *and* the family, and they may prioritize one over the other over time (Rauscher et al., 2019).

The uncertainty family members experience for an individual can intensify their own uncertainty and influence their uncertainty management appraisal and strategies (Brashers et al., 2004). Individuals with a hereditary cancer condition may experience uncertainty about their own health risks (Rauscher et al., 2019), uncertainty for their family's shared health risks (Rauscher et al., 2019), and uncertainty for how their risks and decisions could affect their family system (Bylund et al., 2012). Familial uncertainty management involves related and cascading uncertainties in which the uncertainty management of one family member may affect how other members manage their uncertainty.

Familial uncertainty management includes (a) family members' appraisals of individual uncertainty for family members and the implications individual uncertainty management may have for family *and* (b) family members' attempts to co-manage or influence individuals' uncertainty management. For instance, Rauscher et al., 2019 found that men at risk for Hereditary Breast and Ovarian Cancer syndrome appraised familial uncertainty differently from their individual uncertainty, appraised their uncertainty for family as a danger, and discussed seeking information for family and persuading family members to seek information, get tested, and/or engage in preventive screenings. This research underscored the need to investigate how family members respond to these co-management attempts. To investigate uncertainty management as familial, we asked *what characterizes the interplay between individual uncertainty management and familial uncertainty management in the context of hereditary cancer (RQ1)?*

Previous research suggests family members communicate to help individuals manage uncertainty and influence appraisals and management (Rauscher et al., 2019; Brashers et al., 2004). For example, information provision by family may be categorized as the "unintentional acquisition of information" (Hogan & Brashers, 2009), but influence efforts may do more than share information or provide support. Building on research focused on familial uncertainty management from the point of view of the individual, this study examined the strategies families enacted as they communicated to influence a relative's uncertainty appraisal. We asked, *what are the communication strategies used to influence family members' uncertainty appraisals (RQ2)?*

Communicating to co-manage uncertainty may also create, perpetuate, and challenge family-specific models that prescribe how individuals and families should manage uncertainty. Family systems communicate to organize and maintain their own rules and patterns, creating notions of what it means to be a family, a good family member, and establishing familial goals (Scott & Caughlin, 2012). As individuals manage uncertainty within the web of their family system, family goals and models may influence the selection and efficacy of uncertainty management strategies (Dorrance Hall et al., 2021). For example, uncertainty management can involve tensions between how individuals appraise and seek to manage their uncertainty and how their family members try to assist and co-manage uncertainty with them. Brashers and colleagues (2004) theorized that managing these uncertainty dilemmas and tensions involved "realigning goals and actions to facilitate decision making, problem solving, identity management, and social integration" (p. 325). Family members may consider what is right for them as individuals as well as what they think is right as defined by their family, which may involve tensions between their individual identity management and social integration with family (Baxter, 2011; Pitts et al., 2009). Accordingly, we asked: *How do families communicate to (re)create models for familial uncertainty management (RQ3)?*

Method

Participants

After receiving Institutional Review Board approval, this study employed purposive, snowball sampling to recruit family dyads with a prevalent family health history of hereditary cancer (Merriam & Tisdell, 2015). To be eligible, participants were 18 years or older and met National Cancer Institute (2019) guidelines for having a hereditary cancer condition: Individuals have a prevalent family health history of cancer if they have a pathogenic or likely pathogenic genetic variant, and/or if they have three or more relatives with specific types of cancers that seem to be inherited, especially early onset, or if they have cancer at an early age, especially multiple forms of cancer.

Participants were recruited through patient advocacy and support organizations. Potential participants answered screening questions to ensure they met the inclusion criteria. Participants ranged in age from 18-76 years old (M = 46.1, SD = 13.89), and their time since diagnosis ranged from 2 months to 20 years (2–240 months, M = 87.7, SD = 71.0). They mostly identified as white (n = 75, 89.3%) and female (n = 63, 75.0%). Further, most participants had undergone genetic testing (n = 64, 76.2%), and slightly fewer than half of the participants (n = 39, 46.4%) reported a personal history of cancer (see Supplementary Table 1).

Individuals who met the criteria were asked to recruit a family member with whom they often communicated about hereditary cancer risks to improve ecological validity. Researchers prompted participants to define "family" as they wished for recruitment. This approach also meant participants were not limited to recruit another at-risk family member, but instead, they recruited an individual they saw as involved with their hereditary cancer risk management. Participating dyads represented multiple familial contexts including 29 biological dyads (e.g., parent-child, siblings), 12 spouse dyads, and 1 fictive-kin dyad (i.e., family of choice). The dyads included in this study also represent multiple relational contexts including immediate family, extended family, fictive kin; multiple familial roles, such as mother, father, caregiver; and diagnosis status, including individuals diagnosed with a hereditary cancer syndrome, hereditary cancer survivors, at-risk relatives, and relatives not at risk. The use of dyadic interviewing was valuable for this study (Law et al., 2021; Solomon et al., 2021). Dyadic interactions during interviews helped surface shared and divergent accounts of family systems, uncertainty appraisals and management of hereditary cancer risks, and made clearer the degree to which accounts were contested among family members. The interviewer could observe their interaction firsthand during the interview, and they discussed their own communication and relationship as well as their connections to their families. In total, 42 family dyads (84 individuals) participated.

Procedures

After completing informed consent, dyads completed in-depth phone interviews between April-November 2018. The first author who completed all interviews had extensive experience conducting phone interviews, which followed a semi-structured guide to facilitate conversation within the dyad. Dyads joined the same interview session. They were physically together during the phone interview or separate calls were merged to facilitate joint interviews. The guide included questions posed to both participants about their family's story and history of hereditary cancer, how they were making sense of their risk and uncertainty, and how they are emotionally coping (interview guide available in supplemental files). The goal of the semi-structured interviews was to ask questions that would make sense across the diverse range of dyads typical in families while also maximizing variation in the data collected. To facilitate conversation within the dyad, the interviewer did not interrupt participant interactions, waiting to ask follow-up questions until the dyad concluded their conversation and responses. Interviews varied in the balance of time each participant spent responding. The interviewer took care to prompt each participant to respond to each question, and the relative time spent talking provided insight into their relationship as well. After the interview, participants completed demographic questionnaires and received $20 Amazon gift cards. After interviews with 38 of the family dyads, the recurrence of similar stories indicated theoretical saturation, and data collection concluded with four already-scheduled dyads (Bowen, 2008). Interviews ranged from 22 to 64 minutes (M = 38 minutes) and comprised 508 singled-spaced transcribed pages.

Data Analysis

The two-member research team analyzed the data using an iterative approach, alternating among coding data, holding data analysis meetings, and consulting research on theories of uncertainty, family communication, and organizing (Miles et al., 2018). First, each team member (the first and second authors) separately completed open, line coding of a random sample of 10 transcripts (about a quarter of the data) to generate preliminary codes and wrote independent analytical memos during open coding. Through multiple analysis meetings, the team compared these open codes and memos to refine the research questions, identify and negotiate shared and different codes, and generate novel codes. This iterative approach sought to draw on the value of independent immersion and the

value of engaging with others to bolster sensemaking and interrogate ideas (Glaser & Strauss, 2017; Tracy, 2019). The team generated axial codes together, and the first author engaged in axial coding of the entire data set. We met periodically to modify the axial codes in response to the data, relevant literature, and emerging insights. In this process, we noted participants engaging in familial uncertainty management when they discussed how they appraised their uncertainty for relatives and/or how they reappraise individual uncertainty based on family-focused goals.

The research team ensured reliability and trustworthiness of findings by continuing data collection to maximize variation until reaching theoretical saturation, reflecting on biases in the analysis process, preserving the independence of researchers in early coding, and emphasizing thick description and methodological transparency (Tracy, 2019). The aim of analysis was crystallization that captured the variance in the data with authors representing multiple points of view to make sense of the data and present a multifaceted account (Ellingson, 2009).

Coding was iterative, and the researchers met regularly throughout the coding process to discuss and refine emergent findings. First-level codes included descriptions such as "Familial Uncertainty Management_Information Sharing". Through constant comparative analysis, the researchers compared applicable data to each descriptive code and modified and aggregated codes to fit the data and avoid definitional drift (Charmaz, 2006; Gibbs, 2018). The research team moved into second-level coding by comparing descriptive codes and synthesizing codes to interpret and identify patterns in familial uncertainty management (Miles et al., 2018). For example, second level codes such as "Familial Uncertainty Management_Parenting" identified when participants described shifting from individual uncertainty management to familial uncertainty management. The research team review progressed from identifying patterns and groupings of codes to axial coding (Corbin & Strauss, 2014). They reviewed first- and second-level codes and analytic memos and had multiple meetings to group codes under hierarchical categories such as family-uncertainty-salient events, strategies to prompt reappraisal, and models of familial uncertainty management. This process refined themes by looking in the data for recurrent meaning, repetitive phrases and keywords, and forceful utterances.

Qualitative findings are organized by research question. Pseudonyms accompany the exemplary quotes. As the focus of this study was hereditary cancer in general, we do not make specific distinctions between types unless relevant to a participants' accounts, but to provide context in the reporting of the findings, we provide brief descriptions that indicate age ranges in years, relationship types, and hereditary conditions (Hereditary Breast and Ovarian Cancer syndrome, Lynch syndrome, and Li-Fraumeni syndrome). Exemplary accounts are reported within dyads to preserve the interactive dynamics from the interviews.

Findings

This study investigated the interplay between individual and familial uncertainty management in the context of hereditary cancer (RQ1), communication strategies participants described enacting to motivate their relative's reappraisal of uncertainty prioritizing familial goals (RQ2), and how families communicated to (re)create family models for familial uncertainty management (RQ3). The process discussed in the findings are captured visually in Figure 1 (see Supplemental Table 2 for a detailed summary of findings).

Shifting From Individual to Familial Uncertainty Appraisal and Management (RQ1)

Participants described shifting from individual-focused to familial-focused uncertainty management around family-uncertainty-salient events such as (a) after family crisis, trauma, or loss due to hereditary cancer, (b) when making family planning decisions, and (c) when considering how to manage hereditary cancer threats to children. As participants described weighing individual and familial goals, they discussed prioritizing familial goals and changing their initial approaches to uncertainty management, even when reappraisals or new management strategies conflicted with their original sensemaking.

Family Crisis, Trauma, or Loss. Participants told stories of watching family members go through painful cancer treatments and losing family members or even entire generations to hereditary cancer. They described these events as prompting them to reappraise their uncertainty and prioritize family goals, which changed their management strategies. For example, Sonya (30–39 years old, Hereditary Breast and Ovarian Cancer syndrome, sister dyad) and Rebecca (30–39 years old, sister dyad, Hereditary Breast and Ovarian Cancer syndrome) described the goals driving their (re)appraisals:

> S: I didn't want my kids to see me go through and struggle with cancer. My thought process was to do absolutely everything I could to prevent cancer. How about you?
>
> R: I'm probably a lot more reluctant than Sonya. I'll readily admit that. I really didn't want to undergo surgery, but what is similar with Sonya is that I do have a daughter. I'm listening to my doctors and the increased chances as well as the fact that my younger sister had gone through the prophylactic surgery and ended up with breast cancer. That made me decide that I had higher priorities, responsibilities

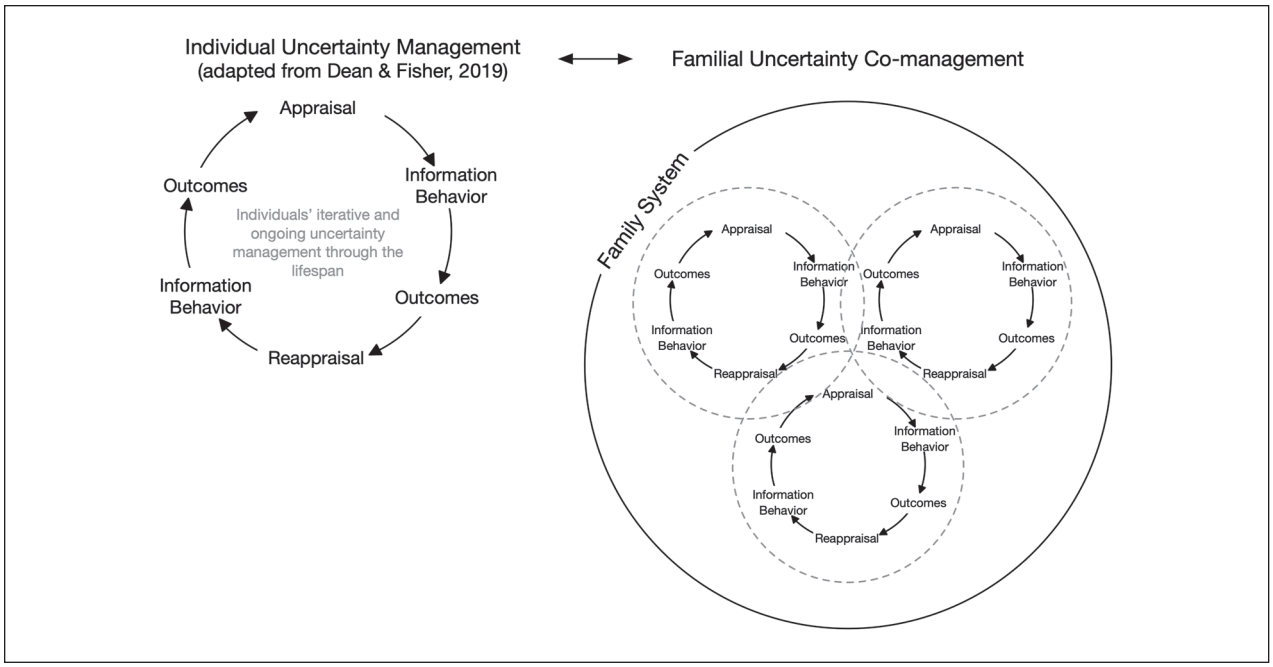

Figure 1. In uncertainty management, family may become the subject of appraisals as individuals consider and reconsider their goals (RQ1). Information behavior includes interaction with family, and outcomes may affect family members. Families may seek to influence appraisals or reappraisals of uncertainty (RQ2). Familial uncertainty management includes overlapping individual processes where appraisal and information behavior occurs in concert and outcomes are shared within family systems. Families model the "right" and "wrong" sort of uncertainty management behaviors (RQ3).

> than myself and what I look like and therefore I made the decision to go through surgery and I'm happy now that I went through, but the decision wasn't as for me, I would say.

Rebecca discussed how she and other family members watched Sonya suffer through chemotherapy. Later Rebecca said she didn't want to "have another cancer patient in the family," after her family went through Sonya's cancer treatment. Participants mentioned seeing what a cancer diagnosis and treatment did to family, their shared losses throughout the journey, and family members' struggle with uncertainty as especially painful. These experiences prompted participants to reappraise their uncertainty and the family's.

Navigating complex feelings of loss and duty to family also created tensions between individual and familial uncertainty appraisal. For example, Helen (30–39 years old, sister dyad, Hereditary Breast and Ovarian Cancer syndrome) described the tensions she and her sister felt:

> We have guilt that we know because our mom didn't get to know and then we really want to take care of our health because we know our mom didn't get the chance to know, so then we try and really take care of ourselves, but then sometimes we feel guilty that we have it, so we end up not wanting to take care of ourselves. It was just so much emotion because we're thankful to know, but then the wear and tear that it has on us sometimes. So then it's just like a blessing and a curse to know.

Helen's uncertainty appraisals were wrapped up in familial management. Her sister, Hannah (20–29 years old, Hereditary Breast and Ovarian Cancer syndrome), later added, "I really didn't want to [get tested] at first, I had a really hard time going to do it . . . I was just so sad about my mom and then I just decided that I should after my mom passed and I tested positive." The feelings of duty motivated participants to pursue information and care, even when they sometimes would rather avoid the topic.

Family Planning Decisions. In contrast, when making family planning decisions participants described planning for future uncertainty management. Family planning in this context included seeking information through genetic testing to learn if a spouse had a hereditary condition and considering whether to pursue assisted reproductive technologies to prevent future children from inheriting a hereditary cancer condition. For example, Kevin (30–39 years old, spouse dyad, at risk for Hereditary Breast and Ovarian Cancer syndrome) explained he would only get tested when he and Danielle (20–29 years old) begin family planning:

> K: I mean the first step is to get me tested just because that changes how all those decisions are made.
>
> D: The one thing that I said to Kevin is that I wouldn't have kids until he did get tested because it would just hit me hard.

> I would feel bad just saying to my kids, "Well, I knew there was a chance, but we never really got tested so hopefully, you don't have it." I couldn't do that. I told Kevin that. When he does get tested, if he comes back positive that tends to make me feel more hesitant of having biological kids.

Danielle could not control how Kevin managed his own individual uncertainty, but family planning encompassed both spouses' uncertainty for their children. Danielle's uncertainty for her future family and her family goals to protect her future children created tension with Kevin's current uncertainty management, and Kevin later explained that he would pursue testing in the future. Participants described the uncertainty for future generations as prompting reappraisals that prioritized family goals, demonstrating the influence of family in uncertainty management.

Moreover, family planning did not always involve just reducing uncertainty for participants or their future children. For example, participants discussed embracing uncertainty and choosing not to use reproductive technologies to reduce the uncertainty of passing down the hereditary cancer condition. For example, Nathan (20–29 years old, spouse dyad) and Jenna (20–29 years old, Hereditary Breast and Ovarian Cancer syndrome) explained that they expect to deal with guilt if they pass the condition on to children, but Jenna also felt complex emotions about what her mother would have wanted:

> J: As much as I'm very comfortable and confident in the fact that I don't want to do any kind of preselection of embryos. I think there would still be a very heavy amount of guilt that I would feel if my child did have the gene. Even though, consciously in my mind I'm making that decision. I wonder if my mother had known what she would go through [with ovarian cancer], if she was in my position, what would she do. I think our answers would be different because she experienced fighting cancer versus I haven't.

They embraced uncertainty, and multiple, conflicting family goals were at stake, namely, what they wanted for their children versus what her mother would have wanted.

Hereditary Cancer Threats to Children. When participants discussed their uncertainty for their children and how to manage it, they used "we" language to describe collective and taken-for-granted effort of the family to help children. Participants described managing their individual uncertainty for the child as a parent *and* managing uncertainty on behalf of their child. For example, Amelia (50–59 years old, spouse dyad) and Kyle (50–59 years old, Lynch syndrome) explained the decisions they made to manage their children's uncertainty:

> A: We talk to our kids and our daughter's been tested and evaluated and—
>
> K: Our son will turn 18 this year and he'll be tested almost immediately.
>
> A: For our daughter, it was negative although I think testing has developed some since then so there's going to be a be question of whether we want to [test her again]. We did it really early with her because there's such an incidence of uterine cancer with Lynch syndrome. She has a long-term career plan that involves going to school. She's getting ready to start looking for a school to do her PhD I just wanted her to have choices. I didn't want her to wait too late and find out she was going to lose her uterus fairly early.

They appraised their daughter's uncertainty based on her long-term goals for education, a career, and family, rather than just on Amelia and Kyle's fear for her cancer risks. Further, participants explained that they would teach certain behaviors and attitudes in addition to disclosing risk information. For example, Caleb (50–59 years old, spouse dyad, Lynch syndrome) and Cheryl (40–49 years old) said:

> Ch: Our kids at times get a little nervous when dad goes to the doctor. You can tell they are trying to figure out what's going on and why.
>
> C: We've talked about what age and how we bring it up. We'll be up front and honest with them on the risk and percentages for certain cancers and tie it back to what happened to me. More than likely, they'll be genetically tested at that time when they're about 16. I think they'll bring a lot of thing together with their diet, how we want them to eat.

Parents appraised their individual uncertainty for children *and* tried to manage uncertainty on their children's behalf. Notably, parents did not discuss whether children agreed with their decisions.

Strategies for Influencing Appraisal in Familial Uncertainty Management (RQ2).

Participants described goals for influencing how relatives appraised uncertainty for hereditary cancer risks. They described efforts to motivate a family member's reappraisal, informed by family goals. Communication strategies included (a) stressing the threat of uncertainty to family, (b) highlighting efficacy to reduce uncertainty, (c) recalling other family members' sacrifices, (d) coordinating collective effort, and (e) forcing information-seeking.

Stressing the Threat of Uncertainty to the Family. Participants described stressing how uncertainty could threaten the family, especially children or grandchildren. For instance, Cynthia (50–59 years old, Lynch syndrome, sister dyad) and Shelia (50–59 years old, Lynch syndrome) described how they emphasized the risk for their brother and sister's children in interactions with their siblings to motivate their siblings to reappraise their uncertainty:

C: My brother and my sister put [genetic testing] off for a while and we were like, "You have to know because of your kids. Even if you didn't really want to know for yourself, you owe it to your kids to find out because if they had it, then they could start their screenings and hopefully prevent cancer versus waiting until it happens. You have to be responsible for making sure that your kids know." That was a big thing.

S: They finally went, but I thought they were going to run right out and do it. I wouldn't say they were resistors. I just don't think they've thought of it as a priority.

Sheila described how her brother and sister were not necessarily avoiding the information, but they seemed to appraise their individual uncertainty ambivalently and did not feel the same urgency for information seeking. Cynthia and Shelia pressed them to reappraise uncertainty at the familial level and consider how this uncertainty could threaten the next generation. Participants reported trying to stress the threat to the individual but explained that it was not enough to motivate a reappraisal. Instead, they said emphasizing the dangers of the uncertainty for other family members like children led to a reappraisal at the family level.

Highlighting a Family Members' Efficacy to Reduce Uncertainty. Participants also described communicating to highlight how family members could manage their uncertainty in ways unavailable to the participant. They shared stories of conversations with family members in which they compared their experience of receiving a cancer diagnosis with what might be possible for their family members. For example, Karen (50–59 years old, Hereditary Breast and Ovarian Cancer syndrome, mother-daughter dyad) explained what she and Amanda (20–29 years old) say to family members:

K: It's a hard thing to get that *BRCA* positive diagnosis, but even worse is getting a cancer diagnosis. Then I would tell you as a family member, "Go get tested because it might not be what you want, but it's not the same as getting the diagnosis and you can then make some choices about how to try to make sure that you don't get breast cancer."

A: Yes, that's good. I'm glad you shared that mom.

Like other participants, she contrasted this with her personal story of learning of her hereditary cancer condition "too late" or after she was already diagnosed with cancer. Further, participants described gathering and sharing information to highlight what could be done to reduce their relative's uncertainty and risks for cancer such as pursuing testing and undergoing prophylactic surgeries. For example, Peter (50–59 years old, Hereditary Breast and Ovarian Cancer syndrome, spouse dyad) talked with his wife about how he sought more information for his sister:

My approach is, the more information I can get, the better. That's what I communicated to [my sister]. Through my own genetic counselor, I've learned for a woman in her 50s, who has not had breast cancer like [my sister], it is reasonable to just have her tubes out and maybe even ovaries or a full hysterectomy. She's very reluctant [to do it]. She doesn't want to talk about it anymore. I communicated that to her. From my perspective, you've got to do everything you can to prevent, and she's taking a different approach. I'm now respecting her. Her wish was not to talk about this.

Peter sought information about his sister's risks and options and communicated this information to her to attempt to co-manage her uncertainty. Participants mentioned trying to emphasize the options available to prompt reappraisal, but family members communicated to rebuff them. Participants said their strategies were more prone to fail when their communication focused on the individual's goals (e.g., manage your own uncertainty by using this strategy) as opposed to family-focused goals (e.g., manage your relatives' uncertainty by using this strategy for them).

Recalling Other Family Members' Sacrifices. Participants discussed reminding family members about the sacrifices of other family, who went through cancer treatment and/or died. For instance, when Sophia (50–59 years old, mother-daughter dyad, Hereditary Breast and Ovarian Cancer syndrome) recalled how she talked with her sister about risks associated with Hereditary Breast and Ovarian Cancer syndrome:

I was very concerned about my sister because she was positive, and she was in her early 40s, and she was a bit in denial. In the middle of all of this, my mom passed away. I just was devastated, I just looked at her and was like, "Please do something about your breasts, because I don't want to sit next to your chemo chair. I don't want to do this with you. I don't want to lose you."

Sophia recalled the loss of their mother, that their mother did not have the same opportunity to prevent cancer, and the prospect of her own suffering if her sister did not act. Indeed, Chelsea (20–29 years old) recalled Sophia using similar strategies on her to pursue information about her risk, saying, "I wanted to know [if I had Hereditary Breast and Ovarian Cancer syndrome] but also to get my mom off my back, because she probably wanted to know the most." Chelsea sought information for her own individual uncertainty management, but she also sought information and testing to manage her mother's uncertainty for her. Participants described similar guilt and duty-based appeals as tending to work.

Participants also described family members' efforts that made them feel guilt. For example, Helen (30–39 years old, sister dyad, Hereditary Breast and Ovarian Cancer syndrome) retold her and her sisters' experiences with family:

> They are very encouraging of us to do [our preventive screenings] and that our mom really wanted us to. They always say, "What would mom want? Take that chance that mom didn't get and stay on top of your stuff."

Helen and Hannah (20–29 years old, Hereditary Breast and Ovarian Cancer syndrome) highlighted the message from family, "What would mom want?" Yet, they described wanting to avoid information *because* of the difficult memories. When Hannah became emotional, Helen went on to also describe the complex emotions Hannah experiences as she manages familial uncertainty:

> My sister Hannah has a son, my nephew, she really wants to try and be on top of her stuff because now that she's a mom she can't imagine what it would be like to have to lose your child, to say goodbye to your child, to know that you're not going to be there for your kids. My mom was a single mom. My sister is a single mom, too.

Talking about anticipatory loss if a family member did not reduce uncertainty and recalling the loss of family members created guilt, motivating uncertainty reappraisal. Drawing on family memories to influence appraisals may have also meant forcing family members to recall difficult memories and consider their own mortality's effect on family.

Coordinating Collective Effort. Participants shared stories of bringing together family for an intervention when a relative had avoided for "too long" or when their avoidance could put other relatives at risk. For instance, Karen (50–59 years old, mother-daughter dyad, Hereditary Breast and Ovarian Cancer syndrome) and Amanda (20–29 years old, Hereditary Breast and Ovarian Cancer syndrome) described how Amanda, her husband, and her parents assembled to have a family conversation about her brother's duty to disclose his uncertain risk status to his fiancé. They explained coming together when he married out of concern for his wife and their possible children.

Other participants chose less obtrusive coordinated approaches. They described reaching out to an influential family member for help. For example, Kyle (50–59 years old, spouse dyad, Lynch syndrome) and Amelia (50–59 years old) discussed how they may try to communicate with their nephew's wife:

> K: My sister who [has Lynch syndrome] has children. One of her oldest children has not been tested. Young man. We're just like, "We just can't believe you won't take the time to go and do it." We told him over and over, "You're just playing with fire here."
>
> A: Somebody needs to talk to his wife because I think if she knew, I think she would be pushing harder for it. Especially now that they have two young sons.

In this case, direct strategies failed, so they considered reaching out to another family member who was a closer relation and has more influence to prompt a reappraisal. When discussing these coordinated approaches, this family-level effort involved identifying whom to include, strategizing with other family, and coordinating communication together.

Forcing Information-Seeking. Participants also told stories of family forcing information seeking by scheduling relatives' appointments with clinicians. For example, Blair (20–29 years old, mother-daughter dyad, Hereditary Breast and Ovarian Cancer syndrome) told this story with her mother, Liz (50–59 years old, Hereditary Breast and Ovarian Cancer syndrome):

> B: I remember my mom taking me to the genetic counselor and we sat there and talked about so many different things, what the genetics of breast cancer look like and what the social implications. And just all kinds of stuff and I wasn't even eligible for testing at that point because I was 16 or 17. It was a two-hour appointment and we left and the whole entire building was empty because everybody else had gone home.
>
> L: Yes, I really like that genetic counselor. She was really thorough, kind, and informed.

Blair later explained that the appointment gave her more information than she could manage and that she felt overwhelmed at having to wait 1–2 years before she could test. Her mother, Liz didn't respond to Blair's description of how she felt and later said that she wanted to have as much information as she could and thought her daughter would want the same. Participants whose parents pushed them to seek information and pursue testing mentioned feeling hesitant to follow through because "I feel like that would be terrifying to me, to be positive and have to tell [my mother]" (Blair). Her uncertainty management was familial in the sense that it involved considering the devastation a parent might feel learning they had passed on the risk to their child.

Other participants recalled similar experiences when a parent had pushed them to seek information, but they saw this involvement as helpful. Agnes (40–49 years old, cousin dyad, Li-Fraumeni syndrome) recalled how her mother made the appointment to see a genetic counselor when she likely would have avoided the information on her own. She described her mother's involvement as emboldening her to seeking information, and she said she ultimately felt thankful.

(Re)Creating Familial Uncertainty Models (RQ3)

Participants told stories of uncertainty management that included cautionary tales with family pariahs and family heroes. Pariahs tended to focus only on their own goals

without considering family issues. Heroes tended to try to manage family goals or family and individual goals in concert if they conflicted. Participants described sharing these stories with family members and others managing hereditary risk and uncertainty as models for how they and their family *should* manage familial uncertainty.

Heroes and Pariahs of Familial Uncertainty Management. Participants told stories of relatives' uncertainty management choices that either became cautionary tales for other relatives or exemplars to be upheld and replicated by family members. As participants recounted the exemplars, they cast the relatives in the model as martyrs, heroes, or pariahs. Heroes did everything they could to reduce uncertainty by seeking information about their personal and, therefore family, hereditary cancer risks. For instance, Britney (40–49 years old, aunt-niece dyad, Hereditary Breast and Ovarian Cancer syndrome) described how her aunt Sarah (70–79 years old, Hereditary Breast and Ovarian Cancer syndrome) became a family hero:

> B: Sarah was the first to know. Whenever I talk about this, Sarah saved all of us.
>
> S: Well, don't flatter me, but thank you.
>
> B: None of us would have known, not really. Sarah, unfortunately, it was a cancer diagnosis, that was how she ended up being tested for the mutation.

Sarah was heroic because she pursued information and testing, then shared information about her risks with family. Britney later reflected on how her aunt's familial uncertainty management supported her own uncertainty management, which lead her to discover that she had cancer at an early stage. In their story, Sarah is a hero who sought information for herself, but also on behalf of the family, which helped the family make sense of their cancer history and provided opportunities for management.

In telling exemplar stories, participants also commented on how their own behavior compared to the model. For example, Rebecca (30–39 years old, sister dyad, Hereditary Breast and Ovarian Cancer syndrome) described how her younger sister, Sonya (30–39 years old, Hereditary Breast and Ovarian Cancer syndrome) and her mother managed uncertainty: "Sonya and my mom they're very strong and they took all the right steps and we're very grateful for that." The family members in exemplars were heroes or martyrs (getting cancer despite doing all the right steps) and a model for participants to consider how they should manage uncertainty. Rebecca then reflected on her own avoidance saying, "Sonya's experience was even more influential in my decision." Sonya's model factored into Rebecca's reappraisal and decision to seek information.

In contrast, participants described cautionary tales in which family members managed uncertainty the "wrong way" and they expected bad things to happen to those relatives. For example, Margaret (60–69 years old, mother-daughter dyad, Lynch syndrome) and Meredith (30–39 years old, Lynch syndrome) said:

> Marg: No one else has gotten tested or a desire to be tested. I've tried to explain to them, [that if] my siblings got tested and they were negative, then their children would be negative, but if they test positive then their children all have to be tested. They feel that it's not going to happen to them or to their family. They just don't want to know right now. They will be surprised when [cancer is] in an advanced stage.
>
> Mer: We've been really open with our family about the gene and felt like we've explained it really well, how it can affect them. I agree, a lot of them just don't feel like it would happen to them.

This account assigned future blame and guilt to those who failed to act. Compared with the exemplar models, participants emphasized the personal accountability of the subjects of cautionary tales when/if they got cancer because they brought it on themselves.

Participants described the subjects of cautionary tales as also withholding information that could be pivotal to familial uncertainty management. For instance, April (20–29 years old, twin sister dyad, Hereditary Breast and Ovarian Cancer syndrome) and Rachel (20–29 years old, Hereditary Breast and Ovarian Cancer syndrome) recalled how their family knew of the risk for HBOC, but did not inform them:

> A: I guess they just didn't really see the information as immediately important. That is something that we regret, that they didn't pass on the information—This was like 10 years before [Rachel] was diagnosed, that they did their own genetic testing and . . . they didn't pass on the information to us. That was pretty frustrating.
>
> R: I don't want to do the same thing to my family from Mexico. I want to try to connect with them and give them information too.

When participants discussed pariah's withholding information, as was the case here, they expressed shock and anger that relatives ignored their duty to family. Likewise, Abigail (60–69 years old, sister dyad, Hereditary Breast and Ovarian Cancer syndrome) described how her cousin's side of the family withheld potentially life-saving information:

> Two weeks before my mom died, [my cousin] called to say goodbye. She goes, "Well [your mother's nephew] has *BRCA1*, and that's why he died of pancreatic cancer, and two of his three girls also tested years back and had all the preventive surgery." I still harbor anger that they didn't reach out to my mother.

Abigail also described the withholding of information as hastening the death of her mother and potentially her own, and she explained that they stopped communicating altogether. Subjects of cautionary tales became pariahs and participants discussed ostracizing these family members.

Participants also reflected on being a model for the family. For instance, Zoey (40–49 years old, father-daughter dyad, Hereditary Breast and Ovarian Cancer syndrome) and Logan (70–79 years old, Hereditary Breast and Ovarian Cancer syndrome) recalled:

> Z: [My cousin] was very overwhelmed, understandably because her situation was different than mine, she had an active cancer diagnosis. She was going to need chemo, she was going to need radiation, all that. She was very overwhelmed with all the choices. She eventually wound up having the same surgery that I did because she was like, "You did all the research and you found the best people so I'm just going to do what you did."
>
> L: Everybody in her family was giving her a different opinion of what she should do and she just felt overwhelmed that she was almost paralyzed and unable to make a decision.

In this example, Zoey recalled that her cousin and extended family initially thought she had overreacted by pursuing prophylactic surgery, but later followed her approach. Logan added that without Zoey's model, her cousin was stuck in uncertainty. Participants described following family models from these stories by replicating hero's strategies to manage uncertainty and making similar health decisions. As exemplars, they were central in family discourse about how to manage uncertainty, what worked well, and what the "right choices" were.

Discussion

This study demonstrated that familial uncertainty management is comprised of enmeshed individual and familial uncertainty appraisals of hereditary cancer risks (see Figure 1). A theme that cut across the data made clear that familial uncertainty management was related to, but distinct from individual uncertainty management and took place around family-uncertainty-salient events. These events prompted participants to weigh individual- and family-focused goals in their uncertainty appraisal and marked shifts from individual uncertainty management to familial uncertainty management. Further, family members' accounts indicated several strategies for communicating to influence relatives' uncertainty reappraisals to motivate genetic testing or adherence to preventive health behaviors. Finally, family members described storytelling centered on models that would communicate the "right" management strategies for familial uncertainty management.

This study makes three key contributions to qualitative health research: First, it builds on uncertainty management theory by investigating how uncertainty appraisal and management interact with family systems, creating dialectical tensions for family members. Family members may put these tensions at the forefront in their communication purposefully to influence one another's uncertainty appraisals and health decision-making. Second, it reveals how family models may create normative beliefs about family communication that shape uncertainty management processes through the force of beliefs about what it means to be a good family member. Third, it makes clear the broad relevance of family across the communicative management of uncertainty and in health decision-making.

Dialectical Tensions Inherent to Familial Uncertainty Management

A key contribution of this study is extending uncertainty management theory (UMT) by elucidating when individuals prioritize family goals as they manage uncertainty about a hereditary cancer condition and how families can influence individual uncertainty appraisal. These findings also build on Dean and Fisher's (2019) work illustrating chronic uncertainty management related to key moments in the lifespan for women with Hereditary Breast and Ovarian Cancer syndrome by demonstrating how individuals with hereditary cancer may shift to familial uncertainty management around such moments, including the loss of family members and future family planning. Familial uncertainty management represents the intertwining of individual and familial uncertainty management as individuals evaluate salient and sometimes competing goals that color their appraisal. Participants described considering individual and familial goals, feeling the tension among these goals, and often prioritizing family goals for uncertainty management, even when it conflicted with individual goals. Their navigation of competing discourses of individual autonomy and familial connection reflected another theme that cut across the data.

Familial uncertainty management heightened the negotiation of tensions inherent in family communication between uncertainty and certainty as well as between autonomy and connection in health decision-making (Baxter, 2011; Pitts et al., 2009). Participants considered how their individual uncertainty management could affect their family after experiencing events of trauma or loss due to the hereditary cancer condition and how their uncertainty management could affect unborn children and children currently at-risk for the hereditary condition. Spouse, parent, and parent-child dyads described how

they communicate to co-manage uncertainty such as discussing competing goals for family planning, choosing to reduce or embrace uncertainty, and managing fear as a parent as well as children's goals for future by making uncertainty management decisions on behalf of children. Fisher et al. (2014) found similar dialectic tensions in their examination of the interdependent, shared breast cancer experience between mother-daughter dyads as daughters attempt to support mothers through breast cancer treatment and mothers manage difficult information sharing with daughters who face breast cancer risks. This study builds previous research on supportive communication and managing multiple goals (Scott & Caughlin, 2012; Scott et al., 2011), by exploring the competing and overlapping goals shaping familial uncertainty management among multiple types of dyadic relationships and among hereditary cancer conditions. The tensions expressed by participants also echo societal tensions in medicine's struggles to honor patient privacy while simultaneously honoring families' right to know, offering insights for precision medicine and the expansion of healthcare to include the family contribution to health (Mendes et al., 2018). They offer a rich target for future research aimed at developing health interventions that include families.

Second, another theme that cut across the data was that health-related uncertainty management took place in a web of family relationships and mutual influence. For example, participants engaged in communication work as they choose strategies, coordinated with other family members, and actively designed their messages to prompt reappraisal (Donovan-Kicken & Caughlin, 2011). Family members also stressed the individual's efficacy in managing uncertainty in ways congruent with family values, which is important as efficacy assessments can moderate appraisals and management strategies (Lee et al., 2008). Although previous research finds people with cancer communicate with family to balance positivity and maintain hope in uncertainty (Donovan-Kicken et al., 2012), these findings showed communication highlighting the danger of uncertainty. Findings support the connection between danger appraisal and negative emotions like anxiety (Kuang & Wilson, 2017), but also feelings of guilt in efforts to prompt reappraisal. Participants described guilt-based appeals to encourage information seeking as well as avoiding information due to guilt. Family members' attempts to co-manage uncertainty may backfire when they depress or anger instead of empower family members. Future research should consider how the salience of strategies to influence appraisal may depend on how individuals reconcile their uncertainty management with familial values. In this study, reactions to forceful strategies depended on the degree to which participants felt efficacy as well as the passage of time.

Family Models for Uncertainty Management

By telling stories of family heroes, martyrs, and pariahs, families (re)created implicit and explicit values for how family members should manage uncertainty and make health decisions, which can play a role in uncertainty appraisal and prioritizing familial goals. Family values reflected a mix of the family's distinctive experiences with the hereditary condition, but also the social construction of family and what it means to manage familial uncertainty. The results indicated that communicating stories highlighting the "right way" to manage uncertainty socially constructed family values for familial uncertainty management and challenged or sustained family relationships. Communication in the context of values and familial uncertainty management can alter family structures. Participants described collective management bringing them closer together at times, and upholding family values for uncertainty management let them avoid guilt for putting the family through a cancer diagnosis and treatment. These values may complicate social support efforts (Donovan-Kicken et al., 2012) as participants suggested pariahs bore responsibility for a cancer diagnosis. Future research should explore how individuals navigate familial ideals embodied in the stories of family members in their management of health and illness and in uncertainty management in general. For example, previous research has found that family ideals, which are also reflected in the law and health care policy, shape the management of uncertainty about novel health technologies (Rauscher et al., 2017). Family models may be key in conversations about health informed by advances in genetic testing.

Family as Integral Across Uncertainty Management Processes

These insights also have value for health and family contexts outside of hereditary disease because family plays a key role in shaping communication behavior. For example, individuals likely also manage familial uncertainty in family planning and reproductive decisions, vaccination choices during public health crises, and managing other health risks that could put the family at-risk or in emotional peril. Future research should examine how individuals negotiate multiple goals and family values in health information behavior and decision making.

This study also indicated the potential value of future research that investigates the connections between relational uncertainty and familial uncertainty management.

Relational uncertainty encompasses the uncertainties or questions partners have about the nature of their relationship (Knobloch et al., 2016). In managing relational uncertainty, partners may grapple with external factors affecting their relationship such as career trajectories, whether to have children, and how to manage a difficult diagnosis (Knobloch et al., 2016). In this study, participants grappled with questions of whether to pursue assisted reproductive technologies, how to disclose genetic test results, and how to raise children to be prepared for their potential hereditary cancer risks. These questions represent topics of uncertainty that may involve interacting uncertainties about the nature of relationships and if/how to communicate about these topics with family.

Practical Implications

In the context of hereditary cancer conditions, family communication about family health history is essential to alerting an individual to their inherited disease risks. Healthcare policymakers and practitioners already understand the critical role family can play in determining health outcomes but need concrete frameworks for bringing the family into interventions. Conceptualizing uncertainty management as familial highlights the family communication systems that such interventions might target. For example, follow up genetic testing among relatives is low across hereditary conditions, presenting a significant public health concern (Whitaker et al., 2021). Re-focusing uncertainty management on how individual choices are intertwined with family may prove effective for prompting reappraisal and motivating adherence to recommended care.

This study illustrated how family caregivers, especially parents, help those managing uncertainty, but may also attempt to co-manage uncertainty. Family members may often attend genetic counseling appointments together, which situates genetic counselors well to protect patient autonomy. These findings suggest the importance of protecting young adults' right not to know (right now), even when a parent is requesting the appointment. Genetic counselors may re-orient consultations to discussing information needs and facilitate more adaptive uncertainty management by guiding parents' attempts to co-manage uncertainty for their child as well as the child's uncertainty management for themselves and family.

Limitations

Multiple limitations to this study should be noted in the interpretation of these findings. Recruitment via advocacy organizations could have produced a selection bias toward individuals more intolerant of uncertainty. Dyadic recruitment may have also affected this issue as participants may have chosen relatives to include or exclude as part of their own values-driven uncertainty management. For example, no participants recruited a co-interviewee they would describe as a poor model of uncertainty management. This limitation points to the need for additional research that captures the experience of being an avoidant family member who finds themselves ostracized for violating values for familial uncertainty management.

Dyads who were not physically together during the interview may have interacted differently compared to dyads who were physically together. Dyads who were physically together during the interview may have had richer communication and more immediacy since they could see one another during the interview (Kashian & Mirzaei, 2019). Additionally, technical problems interrupted two interviews. In those cases, the interviewer paused the research conversation until all participants were able to rejoin the call. These concerns notwithstanding, the researchers did not observe differences in participants' level of involvement or interaction length between communicating in person or via phone.

The dyads interviewed here likely varied in the extent to which they captured the full scope of the family systems theorized as important in the management of uncertainty about health. In this study, dyadic data were valuable (a) theoretically given the centrality of the dyad in interaction and in family systems (Solomon et al., 2021; Law et al., 2021) and (b) empirically because dyadic interactions during interviews helped surface shared and divergent accounts of family systems, uncertainty appraisals and management of hereditary cancer risks, and made clearer the degree to which accounts were contested among family members. The dyads studied include ones that have been the subject of previous research such as spouse, parent-child, sibling dyads as well as less often studied extended family and fictive kin dyads.

The value of these data notwithstanding, interviewing only dyads limited the information that might have otherwise been available. For example, interviewing additional family members might have identified uncertainty circulating in the family unrelated to health that was nonetheless important for illness-related uncertainty management just as coping with a cancer diagnosis may have powerful echoes in family systems that affect family dynamics unrelated to health. Future research that studied focal dyads while also sampling other family members would help further uncover the interactions between individual and familial uncertainty management. It would be resource intensive, but this study makes clear the potential value of such research and the efficacy of the dyad as the focus of inquiry. Future research might also expand the scope

of interviewing beyond health conditions to consider memorable, meaningful family events or family models relevant to but distinctive from the management of the health concerns.

Finally, the participants in this study were predominately Caucasian, affluent, and well-educated, which limits the transferability of these findings. For example, Babrow and Kline (2000) contended Western cultures value the idea that uncertainty is bad and should be reduced by seeking information. Participants' accounts may have overrepresented this idea, and they echoed a similar tendency for patients and clinicians to prize certainty in the context of hereditary disease (Han et al., 2019). Future research should examine familial uncertainty management in contexts where information seeking/provision may be avoided or uncertainty may be "accepted as a basic feature of existence" (Babrow & Matthias, 2009, p.19).

Conclusion

Research that treats the family system as just part of individual uncertainty management misses the profound implications of the *collective*, communicative management of uncertainty. Broadening the conceptualization of uncertainty management to encompass collective dynamics makes the importance of communication processes among peers, friends, family, and co-workers all the more apparent, especially for communication related to health and illness. This study documented the nature of familial uncertainty management, and it accounted for a key mechanism through which family members may influence each other's health attitudes, decisions, and outcomes.

Individuals do not just think about family-focused goals during appraisal, but live immersed in the family stories of models and pariahs of uncertainty management. Family members negotiate the prominence and priority of individual and family-focused goals. As they weigh competing goals, they may at times prioritize familial goals and reinforce family values for uncertainty management. Doing so, involved tensions between connection and autonomy as well as certainty and uncertainty. Familial uncertainty management can alter family relationships and networks by creating, strengthening, or dissolving bonds among family. Overall, this study illustrates the power of the family system in uncertainty management and health decision-making and its importance for understanding and mitigating hereditary cancer risks.

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References

Babrow, A. S., & Kline, K. N. (2000). From "reducing" to "coping with" uncertainty: Reconceptualizing the central challenge in breast self-exams. *Social Science & Medicine*, *51*(12), 1805–1816. https://doi.org/10.1016/s0277-9536(00)00112-x

Babrow, A. S., & Matthias, M. S. (2009). Generally unseen challenges in uncertainty management: An application of problematic integration theory. In T. D. A. W. A. Afifi (Ed.), *Uncertainty, information management, and disclosure decisions: Theories and Applications* (pp. 9–25). Routledge.

Baiocchi-Wagner, E. A., & Talley, A. E. (2013). The role of family communication in individual health attitudes and behaviors concerning diet and physical activity. *Health Communication*, *28*(2), 193–205. https://doi.org/10.1080/10410236.2012.674911

Baxter, L. A. (2011). *Voicing relationships: A dialogic perspective*. Sage Publications.

Bowen, G. A. (2008). Naturalistic inquiry and the saturation concept: A research note. *Qualitative Research*, *8*(1), 137–152. https://doi.org/10.1177/1468794107085301

Brashers, D. E. (2001). Communication and uncertainty management. *Journal of Communication*, *51*(3), 477–497. https://doi.org/10.1111/j.1460-2466.2001.tb02892.x

Brashers, D. E. (2007). *A theory of communication and uncertainty management*. Explaining communication: Contemporary theories and exemplars (pp. 201–218).

Brashers, D. E., Neidig, J. L., & Goldsmith, D. J. (2004). Social support and the management of uncertainty for people living with HIV or AIDS. *Health Communication*, *16*(3), 305–331. https://doi.org/10.1207/s15327027hc1603_3

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. https://doi.org/10.1007/s10897-011-9400-y

Bylund, C. L., Galvin, K. M., & Gaff, C. L. (2010). Principles of family communication. In C. L. G. C. L. Bylund (Ed.), *Family communication about genetics: Theory and practice* (pp. 3–17). Oxford University Press.

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. sage.

Corbin, J., & Strauss, A. (2014). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. Sage publications.

Dean, M., & Fisher, C. L. (2019). Uncertainty and previvors' cancer risk management: understanding the decision-making process. *Journal of Applied Communication Research*, *47*(4), 460–483. https://doi.org/10.1080/00909882.2019.1657236

Dean, M, & Rauscher, EA (2018). Men's and women's approaches to disclosure about BRCA-related cancer risks and family planning decision-making. *Qualitative Health Research*, *28*(14), 2155–2168. https://doi.org/10.1177/1049732318788377

Donovan-Kicken, E., & Caughlin, J. P. (2011). Breast cancer patients' topic avoidance and psychological distress: The mediating role of coping. *Journal of Health Psychology*, *16*(4), 596–606. https://doi.org/10.1177/1359105310383605

Donovan-Kicken, E., Tollison, A. C., & Goins, E. S. (2012). The nature of communication work during cancer: Advancing the theory of illness trajectories. *Health Communication*, *27*(7), 641–652. https://doi.org/10.1080/10410236.2011.629405

Dorrance Hall, E., Ma, M., Azimova, D., Campbell, N., Ellithorpe, M., Plasencia, J., Chavez, M., Zeldes, G. A., Takahashi, B., Bleakley, A., & Hennessy, M. (2021). The Mediating role of family and cultural food beliefs on the relationship between family communication patterns and diet and health issues across racial/ethnic groups. *Health Communication*, *36*(5), 593–605. https://doi.org/10.1080/10410236.2020.1733213

Ellingson, L. L. (2009). *Engaging crystallization in qualitative research: An introduction*. Sage.

Fisher, C. (2011). *Her pain was my pain": Mothers and daughters sharing the breast cancer journey*. In *Family communication, connections, and health transitions*(pp. 56–76).

Fisher, C. L., Maloney, E., Glogowski, E., Hurley, K., Edgerson, S., Lichtenthal, W. G., Kissane, D., & Bylund, C. (2014). Talking about familial breast cancer risk: Topics and strategies to enhance mother-daughter interactions. *Qualitative Health Research*, *24*(4), 517–535. https://doi.org/10.1177/1049732314524638

Fisher, C. L., Wright, K. B., Hampton, C. N., Vasquez, T. S., Kastrinos, A., Applebaum, A. J., Sae-Hau, M., Weiss, E. S., Lincoln, G., & Bylund, C. L. (2021). Blood cancer caregiving during COVID-19: Understanding caregivers' needs. *Transl Behav Med*, *11*(5), 1187–1197. https://doi.org/10.1093/tbm/ibab021

Galvin, K. M., Dickson, F. C., & Marrow, S. R. (2006). Systems theory: Patterns and (W) holes in family communication. In *Engaging theories in family communication—multiple perspectives engaging theories in family communication: Multiple perspectives* (pp. 309–324). Sage Publications, Inc.

Galvin, K. M., & Young, M.-A. (2010). *Family systems theory*. Family communication about genetics: Theory and practice (pp. 102–119).

Gibbs, G. R. (2018). *Analyzing qualitative data* (Vol. *6*). Sage.

Glaser, B. G., & Strauss, A. L. (2017). *The discovery of grounded theory: Strategies for qualitative research*. Routledge.

Han, P. K. J., Babrow, A., Hillen, M. A., Gulbrandsen, P., Smets, E. M., & Ofstad, E. H. (2019). Uncertainty in health care: Towards a more systematic program of research. *Patient Education and Counseling*, *102*(10), 1756–1766. https://doi.org/10.1016/j.pec.2019.06.012

Hesse-Biber, S. (2014). The Genetic Testing Experience of BRCA-Positive Women: Deciding Between Surveillance and Surgery. *Qualitative Health Research*, *24*(6), 773–789. https://doi.org/10.1177/1049732314529666

Hogan, T. P., & Brashers, D. E. (2009). The theory of communication and uncertainty management: Implications from the wider realm of information behavior. In T. D. Afifi & W. A. Afifi (Eds.), *Uncertainty, information management, and disclosure decisions* (pp. 45–66). Routledge.

Idos, G., & Valle, L. (2021). *Lynch syndrome*.

Jones, D. J., Beach, S. R. H., & Jackson, H. (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 Associates.

Kashian, N., & Mirzaei, T. (2019). Understanding communication effectiveness, communication satisfaction, self-efficacy, and self-care management among patients with chronic disease. *Science Communication*, *41*(2), 172–195. https://doi.org/10.1177/1075547019834566

Knobloch, L. K., Sharabi, L. L., Delaney, A. L., & Suranne, S. M. (2016). The role of relational uncertainty in topic avoidance among couples with depression. *Communication Monographs*, *83*(1), 25–48. https://doi.org/10.1080/03637751.2014.998691

Kuang, K., & Wilson, S. R. (2017). A meta-analysis of uncertainty and information management in illness contexts. *Journal of Communication*, *67*(3), 378–401. https://doi.org/10.1111/jcom.12299

Law, W. K., Yaremych, H. E., Ferrer, R. A., Richardson, E., Wu, Y. P., & Turbitt, E. (2021). Decision-making about genetic health information among family dyads: A systematic literature review. *Health Psychology Review*, ■■■(■■■)1–18. https://doi.org/10.1080/17437199.2021.1980083

Lecarpentier, J., Silvestri, V., Kuchenbaecker, K. B., Barrowdale, D., Dennis, J., McGuffog, L., Soucy, P., Leslie, G., Rizzolo, P., Navazio, A. S., Valentini, V., Zelli, V., Lee, A., Amin Al Olama, A., Tyrer, J. P., Southey, M., John, E. M., Conner, T. A., Goldgar, D. E., & Ottini, L. (2017). Prediction of breast and prostate cancer risks in male BRCA1 and BRCA2 mutation carriers using polygenic risk scores. *Journal of Clinical Oncology*, *35*(20), 2240–2250. https://doi.org/10.1200/JCO.2016.69.4935

Lee, S. Y., Hwang, H., Hawkins, R., & Pingree, S. (2008). Interplay of negative emotion and health self-efficacy on the use of health information and its outcomes. *Communication Research*, *35*(3), 358–381. https://doi.org/10.1177/0093650208315962

Lindor, N. M., Petersen, G. M., Hadley, D. W., Kinney, A. Y., Miesfeldt, S., Lu, K. H., Lynch, P., Burke, W., & Press, N.

(2006). Recommendations for the care of individuals with an inherited predisposition to Lynch syndrome: A systematic review. *JAMA*, *296*(12), 1507–1517. https://doi.org/10.1001/jama.296.12.1507

Mendes, Á., Metcalfe, A., Paneque, M., Sousa, L., Clarke, A. J., & Sequeiros, J. (2018). Communication of information about genetic risks: Putting families at the center. *Family Process*, *57*(3), 836–846. https://doi.org/10.1111/famp.12306

Merriam, S. B., & Tisdell, E. J. (2015). *Qualitative research: A guide to design and implementation*. John Wiley & Sons.

Miles, M. B., Huberman, A. M., & Saldaňa, J. (2018). *Qualitative data analysis: A methods sourcebook*. SAGE.

Mishel, M. H. (1988). Uncertainty in illness. *Image: The Journal of Nursing Scholarship*, *20*(4), 225–232. https://doi.org/10.1111/j.1547-5069.1988.tb00082.x

National Cancer Institute. (2019, March 15). *Genetic testing for inherited cancer susceptibility syndromes*. https://www.cancer.gov/about-cancer/causes-prevention/genetics/genetic-testing-fact-sheet

Nielsen, F. C., van Overeem Hansen, T., & Sørensen, C. S. (2016). Hereditary breast and ovarian cancer: New genes in confined pathways. *Nature Reviews Cancer*, *16*(9), 599–612. https://doi.org/10.1038/nrc.2016.72

Pitts, M. J., Fowler, C., Kaplan, M. S., Nussbaum, J., & Becker, J. C. (2009). Dialectical tensions underpinning family farm succession planning. *Journal of Applied Communication Research*, *37*(1), 59–79. https://doi.org/10.1080/00909880802592631

Rauscher, E. A., Hesse, C., Miller, S., Ford, W., & Youngs, E. L. (2015). Privacy and family communication about genetic cancer risk: Investigating factors promoting women's disclosure decisions. *Journal of Family Communication*, *15*(4), 368–386. https://doi.org/10.1080/15267431.2015.1076423

Rauscher, E. A., Young, S. L., Durham, W. T., & Barbour, J. B. (2017). I'd know that my child was out there: Egg donation, the institutionalized "ideal" family, and health care decision making. *Health Communication*, *32*(5), 550–559.

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.

Solomon, D. H., Brinberg, M., Bodie, G. D., Jones, S., & Ram, N. (2021). A dynamic dyadic systems approach to interpersonal communication. *Journal of Communication*, *71*(6), 1001–1026.

Scherr, C. L., Dean, M., Clayton, M. F., Hesse, B. W., Silk, K., Street, R. L., Jr, & Krieger, J. (2017). A research agenda for communication scholars in the precision medicine era. *Journal of Health Communication*, *22*(10), 839–848. https://doi.org/10.1080/10810730.2017.1363324

Scott, A. M., & Caughlin, J. P. (2012). Managing multiple goals in family discourse about end-of-life health decisions. *Research on Aging*, *34*(6), 670–691. https://doi.org/10.1177/0164027512446942

Scott, A. M., Martin, S. C., Stone, A. M., & Brashers, D. E. (2011). Managing multiple goals in supportive interactions: Using a normative theoretical approach to explain social support as uncertainty management for organ transplant patients. *Health Communication*, *26*(5), 393–403. https://doi.org/10.1080/10410236.2011.552479

Solomon, D. H., Brinberg, M., Bodie, G. D., Jones, S., & Ram, N. (2021). A dynamic dyadic systems approach to interpersonal communication. *Journal of Communication*, *71*(6), 1001–1026. https://doi.org/10.1093/joc/jqab035

Tracy, S. J. (2019). *Qualitative research methods: Collecting evidence, crafting analysis, communicating impact*. John Wiley & Sons.

Vogel, W. H. (2017). Li-Fraumeni Syndrome. *Journal of the Advanced Practitioner in Oncology*, *8*(7), 742–746. https://doi.org/10.6004/jadpro.2017.8.7.7

Whitaker, K. D., Obeid, E., Daly, M. B., & Hall, M. J. (2021). Cascade genetic testing for hereditary cancer risk: An Underutilized Tool for Cancer Prevention. *JCO Precision Oncology*, *5*, 1387–1396. https://doi.org/10.1200/PO.21.00163