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ORIGINAL RESEARCH

"I Don't Want to Be an Ostrich": Managing Mothers' Uncertainty during BRCA1/2 Genetic Counseling

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Abstract Families who face genetic disease risk must learn how to grapple with complicated uncertainties about their health and future on a long-term basis. Women who undergo BRCA 1/2 genetic testing describe uncertainty related to personal risk as well as their loved ones', particularly daughters', risk. The genetic counseling setting is a prime opportunity for practitioners to help mothers manage uncertainty in the moment but also once they leave a session. Uncertainty Management Theory (UMT) helps to illuminate the various types of uncertainty women encounter and the important role of communication in uncertainty management. Informed by UMT, we conducted a thematic analysis of 16 genetic counseling sessions between practitioners and mothers at risk for, or carriers of, a BRCA1/2 mutation. Five themes emerged that represent communication strategies used to manage uncertainty: 1) *addresses myths, misunderstandings, or misconceptions;* 2) *introduces uncertainty related to science;* 3) *encourages information seeking or sharing about family medical history;* 4) *reaffirms or validates previous behavior or decisions;* and 5) *minimizes the probability of personal risk or family members' risk*. Findings illustrate the critical role of genetic counseling for families in managing emotionally challenging risk-related uncertainty. The analysis may prove beneficial to not only genetic counseling practice but generations of families at high risk for cancer who must learn strategic approaches to managing a complex web of uncertainty that can challenge them for a lifetime.

Keywords Uncertainty · Communication · Breast cancer · Genetic testing · Family communication · BRCA1 · BRCA2 · Genetic counseling · Qualitative research · Disease risk · Coping

Introduction

> I did not do this solely because I carry the BRCA1 gene mutation. There is more than one way to deal with any health issue.. .. You can seek advice, learn about the options, and make choices that are right for you. Knowledge is power. – Angelina Jolie Pitt (2015, para. 11)

Just one year ago, Angelina Jolie Pitt announced in a 2015 *New York Times* op-ed piece that she had her ovaries and fallopian tubes removed to reduce her risk of ovarian cancer. This came two years after her decision to have a pre-emptive double mastectomy to reduce her risk of breast cancer (Jolie 2013). Her story ignited widespread awareness of what it means to live with a BRCA1or BRCA2 mutation and the difficult decisions women like her face. Following her first disclosure, online information seeking about the genetics of breast/ovarian

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cancers and risk reduction increased exponentially as did the demand for BRCA 1/2 testing, referrals to genetic services, and inquiries for risk-reducing mastectomies (Evans et al. 2014; Juthe et al. 2014). Still, despite this "Angelina effect," less than 10 % report an understanding of Jolie Pitt's risk or the risk of a woman without a BRCA 1/2 gene mutation (Borzekowski et al. 2014). Although her story boosted awareness, it did not enhance *understanding* of the complex genetic testing, diagnostics, treatments, and medical decisions women like Jolie Pitt are faced with (Borzekowski et al.). As Dean (2016) notes, this lack of understanding could be because the internet and news coverage only focused on Jolie Pitt's unique personal situation.

Interpreting genetics and understanding one's risk are complicated and laden with uncertainty. This uncertainty can challenge a woman daily, across her life span, and even across generations of her family. Each woman's experience is unique, and all women experience uncertainty about their risk. Both women at elevated risk for breast cancer (women with a prevalent family history with cancer) as well as women with a high risk (those who test positive for a BRCA 1/2 mutation) describe uncertainty related not only to their own risk but about the health and future of loved ones, particularly daughters (Bylund et al. 2012). For many women, uncertainty is a primary motivator to get genetic testing, and participation in genetic counseling can reduce uncertainty (Clark et al. 2000; Fisher 2014; Frost et al. 2004; Sachs et al. 2001). Genetic counseling is an opportune time for women to address their distinct personal risk and better understand it. Women express uncertainty during genetic counseling sessions about the testing process, personal risk, genetics in general, and the condition (disease) they are at risk for (Segal et al. 2004).Thus, genetic counselors play perhaps the most critical role in helping these women learn to manage this uncertainty in a way that both enhances understanding and minimizes risk.

Conversations about risk and genetics are challenging and, yet, vital to clients' well-being and risk management. Genetic counseling increases patients' reported self-efficacy in managing risk and can enhance psychological well-being over time (Bjorvatn et al. 2008). One of the most challenging aspects of risk conversations is helping clients navigate uncertain situations (Gaff et al. 2010). Clients have described the information they receive as too complex or presented in a non-preferable manner (Hallowell et al. 1997). Some also leave counseling sessions without understanding their risk (Bjorvatn et al. 2007). This may be, in part, due to how expressive clients are about their uncertainty (or allowed to be) during the session. Aasen and Skolbekken (2014) note that it may be especially important to allow clients to express uncertainty about their own unique situation to better ensure they understand the information they receive during the interaction.

Both practitioners and families need assistance in learning how to manage their uncertainty in the moment and across time to enhance their understanding of risk and inform future risk-reducing decision making. Thus, in this study, we aim to investigate how genetic practitioners help families manage risk-related uncertainty. To explore this further, we apply Uncertainty Management Theory (UMT). This lens brings to the forefront how the experience of uncertainty is ultimately a communicative one. How we manage uncertainty is an interactive process. By exploring these clinical interactions, we can produce knowledge beneficial to not only genetic counseling practice but for families in learning how to manage a complex web of uncertainty that can challenge them for a lifetime.

Managing Genetic and Family Related Uncertainty: Applying Uncertainty Management Theory (UMT)

Oftentimes women contemplating BRCA testing are already immersed within a prevalent family history of cancer (as well as mortality due to the disease) and, thus, a complicated and emotionally charged web of uncertainty. Uncertainty can stem from many sources, including whether to engage in testing, interpreting results, whether one will develop the disease, and what to do to minimize risk. While women value the personal risk information offered by BRCA counseling and testing, they also recognize the implications that testing will have on family members, especially daughters (Douglas et al. 2009). Previous research shows that just having a daughter can predict whether or not women get genetic testing (Eijzenga et al. 2014). Thus, genetic practitioners are faced with a dueling task: managing the client's uncertainty about herself as well as uncertainty as it pertains to her larger family system (Gaff et al. 2010; Peterson 2005). Research using an Uncertainty Management Theoretical lens (UMT) further supports the need to approach genetics- and risk-related uncertainty from a more relational approach, one that highlights an individual level of uncertainty (e.g., What does this mean for me?) as well as uncertainty experienced on social or relational levels (e.g., What does this mean for my daughter?).

An Overview of UMT and Theoretical Assumptions

Brashers' Uncertainty Management Theory (UMT) takes a communicative approach to understanding how people assess and manage their uncertainty, particularly in illness contexts (Brashers 2007). Depending upon the situation at hand and complexity, individuals will encounter different types (i.e., sources) of uncertainty and enact various communicative approaches or responses (i.e., strategies) to manage those sources of uncertainty. Traditional communication and psychology scholarship framed uncertainty through a negative lens, linking it with deleterious feelings of anxiety. From this standpoint, there is only one response to uncertainty:

it must be reduced to promote health (Berger and Calabrese 1975; Ladouceur et al. 2000; Rosen and Knäuper 2009; Vanderpool and Huang 2010). UMT posits that uncertainty may not always be anxiety-inducing. It might also enhance coping and well-being, particularly illness-related uncertainty (Brashers 2007). UMT shifted the thinking about uncertainty from assuming one must *reduce* it to recognizing the most appropriate (or health-promoting) response is *managing* uncertainty, which may occur in a number of ways (Brashers 2001).

Brashers' theoretical approach emphasizes three facets of uncertainty. First, uncertainty is not always a deleterious state. Our response is influenced by perceived cognitive, emotional, or perceptual benefits. For example, a young-adult daughter of a BRCA-positive mother has uncertainty about her future health. However, she may delay genetic testing (not reduce that uncertainty) if she feels that the certainty of the result would do more psychological harm than good this early in her life span. Second, even if we are attempting to reduce uncertainty, it does not always happen. For instance, a client's family history may consist of many breast cancer incidences with a high mortality rate. She may seek genetic testing to "reduce" her uncertainty about her risk. If her result is negative, her uncertainty prior to testing may not change and may even increase. Third, attempts to reduce or eliminate uncertainty may spawn further uncertainty. For example, when a woman learns she is mutation-positive, she may feel certain about her BRCA status but uncertain about her future medical trajectory (or the implications for her children's future health).

Ultimately, from a UMT lens, simply reducing uncertainty is not the answer. Managing that uncertainty may come in various forms depending upon a number of personal and situational factors. These include the source of uncertainty and one's emotional response.

Identifying Sources of Uncertainty and Uncertainty Management Strategies

With these assumptions in mind, UMT can be used to identify both sources/types of uncertainty and the strategies used to manage that uncertainty. UMT-informed research in health-related contexts has demonstrated three common types of uncertainty: 1) medical (e.g., Does this mean I will get breast cancer?); 2) personal (e.g., How does having a genetic mutation alter my identity?); and 3) social (e.g., How does this affect my daughter?) (Brashers et al. 2003). Research specific to genetic counseling (but not from a UMT lens) also illustrates uncertainties from medical, personal, and social sources, like uncertainty about getting genetic testing as well as uncertainty about how one's risk affects loved ones' risk (Segal et al. 2004). We also investigated the experience of uncertainty in a previous study informed by UMT. We used data captured in situ—from the natural setting of BRCA genetic counseling. We explored mothers' sources of uncertainty as it pertained to their daughters, narrowing in on the "social" category of Brashers' uncertainty typology (Bylund et al. 2012). We found that mothers had uncertainty about daughters' 1) disease risk, 2) screening needs in the future, and 3) when and how to talk to daughters about risk and prevention. One could argue that these findings also mirror other categories from Brashers' typology (e.g., disease risk could be classified as medical uncertainty; how to talk about risk correlates with social uncertainty), which shows how various sources of uncertainty are intertwined.

Identifying the source of uncertainty in the specific context of health and illness enhances our understanding of families' needs in the clinical setting. From a UMT perspective, the next step is to explore how we communicatively manage those sources of uncertainty. UMT informed research shows that individuals typically respond with three strategic approaches: reducing, maintaining, or increasing uncertainty (see Brashers 2007 for a review). It is also important to note that uncertainty changes or fluctuates over time. Thus, individuals experiencing illness-related uncertainty may also respond by learning to adapt to chronic (i.e., ongoing) uncertainty—uncertainty one likely has in a genetic risk situation. For instance, that individual may learn to value or tolerate the uncertainty by developing practices and routines (i.e., if they can't predict what will happen they can control their stress by developing routine and structure) (Brashers 2007).

Brashers' UMT highlights how uncertainty management is ultimately an interactive process. UMT research has shown that because patients view their practitioners as important "medical experts," interactions with practitioners are a critical part of their uncertainty management experience, both at home and in the clinic (Brashers et al. 2006). "[Practitioners] provide medical information and decision-making criteria, they can be sources of stability and comfort, and they have access to sophisticated medical technology from the health care system" (p. 233). As such, they are also valued as "collaborators and partners" in managing illness-related uncertainty (p. 235).

Capturing Uncertainty Management in Practice

Genetic counselors are uniquely positioned to help mothers navigate the turbid waters of uncertainty (Tercyak et al. 2001). As noted, using UMT we previously examined daughter-related sources of uncertainty that emerge for women in genetic counseling sessions (Bylund et al. 2012). In the current study, we applied the next theoretical step of UMT, by examining how uncertainty is *managed* in the same setting. We examined the interactive nature of uncertainty management between the mother/client and genetic practitioner to illustrate how practitioners work with women constructively to manage

their uncertainty. This type of data is ideal to bring to the forefront the interactive process of uncertainty management. We paid close attention to mothers' expressions (or sources) of uncertainty broadly to contextualize these experiences, and in light of our previous research, also focused on uncertainty related to daughter-related concerns (Bylund et al. 2012; Fisher et al. 2014; Eijzenga et al. 2014). We posited the following inquiry:

> *RQ: What uncertainty management strategies are enacted during BRCA1/2 genetic counseling with elevated or high-risk women who also have daughters?*

Methods

Participants

Data for this study were based on a larger research initiative involving women who sought genetic counseling with Clinical Genetics Service of Memorial Sloan Kettering (MSK) Cancer Center. Our first examination of these data from an UMT lens resulted in a typology of uncertainty sources (Bylund et al. 2012). Women with a personal and/or family history of breast cancer with at least one biological daughter between 12 and 20 years old were eligible for participation. Sixteen English-speaking women consented and completed the current study, which involved a video-recorded and transcribed counseling session with one of 8 genetic health care practitioners (5 genetic counselors and 3 physicians). Mothers ranged in age from 41 to 57 years old (M = 48) and their daughters (N = 22) between 13 and 20 years old (M = 16). Thirteen mothers were non-Hispanic/White, 3 were Hispanic, and 4 were of Ashkenazi Jewish descent. Thirteen of the women had a personal history of breast cancer.

Procedures

The study was approved by the MSK's Institutional Review Board. Potentially eligible participants were identified from MSK Clinical Genetics Service client lists. Eligible participants were contacted by telephone prior to their genetic counseling session to describe the study, determine their interest in participation, and obtain informed consent. Nineteen women who met our eligibility criteria were approached, 17 consented, and 16 successfully completed the study. Women who did not provide informed consent over the phone did so upon arrival at the clinic. Counseling sessions were video-recorded during the initial pre-testing session or follow-up post-testing session. Fourteen of the sessions were pre-testing consultations and two were post-testing consultations where positive results were discussed. Sessions were 1 h to 2.5 h long, with an average length of about 1.5 h. Transcribed video recordings resulted in 231 single-spaced pages of data.

Data Analysis

Analyses were conducted using the constant comparative method within the grounded theory approach (Glaser and Strauss 1967; Strauss and Corbin 1998). Uncertainty Management Theory provided sensitizing constructs for analyzing the data in that we looked for *strategies* enacted to manage uncertainty and paid close attention to the *sources* of uncertainty being responded to. Unlike the first study we kept our focus on uncertainty open to recognize the complexity of uncertainty management in response to both personal and familial concerns. To become immersed in the data, the first three authors reviewed the transcripts in full multiple times prior to beginning analysis. Using analytical steps outlined by Strauss and Corbin (1998), the data were analyzed to assign conceptual codes to text (Step 1); grouped into categories using Owen's (1984) criteria to build thematic salience (Step 2); and identified properties to define categories and ensure thick description (Step 3). A coding manual was developed and continuously revised to establish a set a themes with defining characteristics (properties). Disagreements were addressed and agreement was sought prior to moving forward with future analyses.

The resulting analysis is a presentation of emergent themes that illustrate uncertainty management strategies enacted during genetic counseling. Frequency counts represent the number of counseling sessions in which the strategy was used. We included these counts to strengthen thematic saturation and the trustworthiness of findings. While women representing a particular population were sampled, taped consultations were random in terms of genetic practitioners they interacted with (Daly 2007). Given the interactive, fluid nature of uncertainty management, what is of interest is how often we see these various strategies randomly enacted in various counseling sessions.

Descriptions of themes are embedded within the context of genetic counseling to illustrate the uncertainty issue (source) they are responding to as well as the interactive nature (between practitioner and client) of the uncertainty management process. Thus, we also paid attention to who enacted the strategy (the mother or practitioner or both). We labeled these strategies as action-oriented statements rather than words or short phrases (codes) using Banning's (2003) "ecological sentence synthesis" approach to present the findings in Table 1. This approach involves summarizing each finding in sentence format (to bring together ideas) rather than only reporting codes. Doing so allows for the knowledge to be more easily translated into clinical practice as it showcases the actionability of the findings (Sandelowski and Leeman 2012).

Table 1 Strategies for managing uncertainty during genetic counseling for BRCA 1/2

To help mothers manage their uncertainty clinicians may	*To address*
Address Myths, Misunderstandings, or Misconceptions	Risk in general and/or pre-emptive tactics or risk- reducing behaviors.
Introduce Uncertainty Related to Science	How the future science and technology may lead to advancement that enhance one's health (reduce risk) or how the BRCA testing results are sometimes ambiguous.
Encourage Information Seeking or Sharing	The importance of sharing or seeking information with/from family about medical history to both reduce personal risk and protect family members.
Reaffirm or Validate Behavior	The appropriateness of one's previous decisions in managing risk or talking to loved ones.
Minimize Risk	The likelihood (or lack thereof) that one (or one's loved ones) will have the mutation or develop cancer in the future.

As was described in the methodology, we used an ecological sentence synthesis approach to present our results. Each finding (theme with associated properties) is meant to be read as a sentence beginning with the first column heading and then moving to the second column, to highlight how practitioners and interventionists can put the finding into action

Results

Analyses illustrate strategies genetic practitioners and mothers use to manage uncertainty expressed by mothers during genetic counseling sessions for BRCA1/2 testing. Five uncertainty management strategies emerged: 1) *addresses myths, misunderstandings, or misconceptions*; 2) *introduces uncertainty related to science*; 3) *encourages information seeking and sharing about family medical history*; 4) *reaffirms or validates previous behavior or decisions*; and 5) *minimizes the probability of personal risk or family members' risk*. Each theme and its associated properties (which characterize or define each theme) are described and presented in Table 1. The N size refers to the number of sessions in which the strategy emerged. When both providers and mothers used the strategy, this is indicated in the theme description. Strategies were often used in tandem. Therefore, conversational excerpts are used to demonstrate the complexity of managing uncertainty in a risk context and capture the interactive nature of uncertainty management. Names and identifying markers have been removed to protect participants' confidentiality. An "M" refers to a mother and a "P″ a practitioner.

Addresses Myths, Misunderstandings, or Misconceptions

The most common uncertainty management strategy enacted involved practitioners dispelling myths or misunderstanding mothers voiced during genetic counseling sessions ($N = 11$. At times, mothers' beliefs about personal risk, risk in general, or their daughter's risk were based on misinformation (or misleading information) they reportedly received from media, friends/family, or even other practitioners. While women may have misunderstood what they heard from various sources, their account of the information was inaccurate and led to practitioners clarifying or dispelling myths. This strategy was characterized by two properties: 1) clarifying mothers' uncertainty about risk in general and 2) managing uncertainty about pre-emptive tactics or risk-reducing behaviors.

For instance, practitioners often had to dispel myths or misconceptions about general risk issues. Sometimes this involved misunderstandings about genetic testing as this mother demonstrates: "I always had this theory that I already knew I was at an increased risk for breast cancer because I already had it so I didn't feel I needed to be tested for the gene." In other cases this involved dispelling myths about family history and the mutation as some mothers believed that a family history of breast cancer automatically meant one had the BRCA1/2 mutation. In addition, women assumed most cancer incidences in the family were genetically determined rather than sporadic. There was also confusion about one's risk should they test negative (given the prevalent family history of the disease) as well as about who should be tested (versus who did not need to be tested). Many practitioners also sought to manage mothers' uncertainty about associations between the BRCA mutations and other cancers (e.g., colon and prostate) and whether men could carry and pass on the mutation. The following excerpt illustrates how this strategic approach often involved addressing more than one misconception at a time:

M: My children should be tested because they have it through the mother, the
grandmother and me.
P: Well their grandmother, you're talking about the—your mother in law with colon
cancer?
M: Yes. No?

P: I wouldn't do any genetic testing based on her side. Your side we'll talk about in a minute.
M: Ohhhhhhh. Okay. I just tell them that they have cancer from both sides. That's
why they should be careful. Not that they listen to me.
P: It's good for them to be careful but we try to be a little more specific than that here. … What exactly do they need to be careful for … We'll make recommendations and put them on paper for you so you can show them what they should be doing. And most cancer is really not hereditary. Most of it really is what we call sporadic.

In addition to generalized uncertainty about risk, mothers also expressed uncertainty about pre-emptive tactics or risk-reducing behaviors they themselves (or their daughters) should be doing to reduce risk (e.g., whether to have an oophorectomy or the optimal age for daughters to begin screening). Practitioners were faced with dispelling mothers' misunderstandings about what was actually a risk factor, like taking birth control pills, having the HPV vaccines, and diet. For instance, mothers at times thought their daughters should never take birth control pillsor be vaccinated for HPV. The following conversation helps to illustrate such misperceptions.

M: I brought my older one to my gynecologist … and she had the injection. It's
the…[mom can't recall name]… for the papilom? Umm…
P: Oh yeah – Gardasil.
M: Gardasil.
P: Right.
M: … What I would have done is have her [nurse practitioner/physician assistant] speak to her about that. Not necessarily present it in a way that mom's positive so it's maybe not a good idea but to discuss with her that mom did have a history of breast cancer so maybe you should consider not taking this. …
P: You know it's always a balancing act because the risks of not to be too sort of forward about it but I mean the risks of early pregnancy balanced against the risks of a theoretical breast cancer risk is sort of…
M: You're throwing more into the equation now (laughs)
P: … I mean I think it's only an issue if…it's only an issue if there's actually a mutation.…The only reason I raise it is when the context of what way could this have an impact actually even though it doesn't necessarily have an impact on risk immediately. You know what way could it have an impact on decisions and things that need to be thought about. But it's not really an issue if her only risk if your history as opposed to a mutation because the risk…The increased risk to her at this point is relatively small and so if there is any further from the oral contraceptives is also going to be very small. So certainly for women whose only risk if having a mother with breast cancer, we don't really make a big deal about oral contraceptives in that setting. It's only if the breast cancer came about because of the mutation that we even raise it as a possibility or as a point of discussion.

Introduces Uncertainty Related to Science

Introducing uncertainty related to science was a management strategy enacted by both mothers and practitioners *(N* = 10). In order to manage present-day uncertainty, future-related scientific uncertainty was invoked. This strategy was characterized by two properties: 1) using the future advancements of science and technology and 2) using the ambiguity of BRCA testing.

For instance, both clients and practitioners used the uncertain future of science and technology as a means of managing present-day uncertainty about risk. This included referring to the possibility of a cure or vaccine in the future as well as better screening for breast or ovarian cancer down the line. This strategic approach was typically used to manage uncertainty mothers had about personal risk but oftentimes risk on a relational level or concerns about their daughter's risk. Uncertainty about daughters' future risk was often emotionally charged (it was not uncommon for women to become emotional when discussing this uncertainty). As is illustrated below, this uncertainty management strategy was used in tandem between both genetic practitioners and mother but also seemed to reframe the issue more positively:

P1: By the time they're [the mothers' daughters] doing that screening it may be totally different from what we're doing now. The imaging may be totally different so.
M: Much better maybe.
P2: Much. We hope much better. They may have a prevention. They may have a vaccine.

Practitioners also used scientific uncertainty regarding the genetic testing, specifically the potential ambiguity of a test result to manage mothers' uncertainty about their own or their family members' risk. Virtually all of the women were unaware that the result of their testing could be ambiguous or, in other words, neither positive nor negative, or that the test itself is somewhat ambiguous. This strategy was sometimes used in conjunction with another strategy, *minimizing risk*. For example, a practitioner explained to a mother,

It'd be most likely negative if you went onto the further testing. What I'm saying is that it would be more likely

that you would get one of these variations which are an uncertain result than you would get a positive result. So, the chance of getting a variant or ambiguous result on this test is about 12%.

Practitioners and mothers also communicated about the ambiguous meaning of test results that are negative or ambiguous as this practitioner does talking to a woman with a negative test result:

Well it's definite that you had a negative test result. What's not definite is that something else besides BRCA didn't cause their [mother's sisters'] breast cancers. So if they had—you know we don't know what the other genes are, but what if they were negative. Well then everyone's at risk.

Encourages Information Seeking or Sharing about Family Medical History

Practitioners also managed uncertainty by encouraging information seeking or sharing about family medical history (N = 10, 62 %). This strategy revolved around the idea that the pursuit of information about medical history (personal or a family member's history) may help the woman reduce her uncertainty about her personal risk. Furthermore, with respect to sharing information, this strategy reminded clients that genetic knowledge extends beyond the borders of the tested individual. Rather, entire families are affected by genetic testing and test outcomes. This uncertainty management strategy was characterized by underlying ethical dilemmas clients face in terms of seeking information from or sharing information with family members. This strategy was characterized by three properties: 1) information sharing with family members; 2) information seeking from family members; and 3) encouraging family members' involvement in a conversation with the practitioner as a means of sharing information.

Practitioners encouraged mothers to share their own medical history with family members including plans to undergo genetic testing and test results. This was done when mothers expressed uncertainty about how much other family members knew about the inherited risk. As one practitioner said to a mother who expressed such uncertainty, "It is nice to let them know because you testing is like testing your siblings and your children as well. It's a little bit of a family test as opposed to just an individual test." Practitioners at times encouraged clients to bring family members to participate in a genetic counseling session or by talking to the practitioner via phone as a means of sharing information. As one practitioner expressed to a mother during counseling, "Some of the young women will want to come in for a conversation sometime around [age] 18 to 20 just to touch base … and get some information."

Relatedly, mothers themselves were not always certain about their family medical history. To manage that uncertainty, genetic practitioners encouraged them to seek information by speaking directly with family members. At times, information seeking was easier said than done if familial relations were strained or nonexistent. As one woman remarked, "I don't even know those cousins." In another case, a woman was estranged from immediate family members. In this situation, practitioners talked about the importance of putting family "differences" aside in the pursuit of survival (both for the mother/client and her estranged family members). The following excerpt shows two genetic practitioners advise a woman (who did not communicate with her mother) to share her genetic test results with her mother. Their conversation illustrates potential challenges with this uncertainty management strategy:

P1: Okay. So we've been in these situations before. I can tell you the kinds of things that we've tried. We usually look for a 3rd party. So is there—any family 3rd parties?
P2: Mom's physicians?
[Mom answers no]
P1: Don't know physicians? Maybe your father?
M: He's a waste of time also.
P1: He's not talking to her or—
M: No, he talks to her.
P1: Oh.
M: He does whatever she says.
P1: Okay, so he's not a line of potential communication?
M: Nope.
P1: We've done in the past with rabbis and priests at times we can actually go that route. She's a religious person?
M:No.
…
P1: So the other thing we tried is the carrot and the stick approach is—does she still have her ovaries in place?
M: I'm not sure.
P1: So the other way to do this is if you do it in a more—if you basically get a message to her through to your father and just say that you went to a place where they discovered these Jewish mutations and she's at risk. We're very concerned about her risk and her health. And that she could be at fatal risk. So you could scare her.

Reaffirms or Validates Previous Behavior or Decisions

Practitioners also validated or reaffirmed mothers' past behavior when expressing uncertainty about them (N = 9). This theme involved two properties defining practitioners' use of validation or affirmation of 1) mothers' previous behavior or 2) her past decisions. Oftentimes this centered on mothers' uncertainty

about how much to share with loved ones, especially their daughters.

For instance, the following excerpt demonstrates how practitioners used this strategy to manage mothers' uncertainty about what they had shared with daughters so far:

> M: Is there anything that you would suggest that I should and shouldn't say to them?
> P: About the BRCA genes, or in general?
> M: Okay, they know I'm here for testing. They know there's a gene and I'm finding out whether or not I have a mutation. They do know that.
> P: Okay.
> M: I don't know if they understand. [My daughter] probably understands the implications. She does—
> P: Yeah, it's tough. It really depends on where each child is individually sort of maturity level and whether or not they've had to deal with things like this before. They think about their own health. But I think you definitely you've shared your diagnosis with them, which some women don't. They could hide, which could be very probably easily done, because you didn't have chemotherapy but just to share that "Yes, mom had breast cancer and that does increase your risk slightly regardless of what this test shows." So as long as they sort of got that mind set I think that whatever you need to share with them in the future, be it these test results or anything else, I think that you've done the appropriate thing.

At times validating or reaffirming decisions/behaviors also involved guidance on how to handle the situation in the long run, especially regarding how to talk to daughters or enact another uncertainty management strategy (*sharing information*). Thus, the practitioners used the uncertainty management experience as a means of reducing one's uncertainty about how to handle things in the future (or how the daughter would be impacted down the line). This excerpt from a pre-test consultation shows how the in-the-moment management of uncertainty is important to help a mother manage her own (and her loved ones') uncertainty in the long run in a manner that is likely more health-promoting (i.e., being open and honest). This mother had shared with her two daughters and one of her siblings (a sister) that she was getting the testing done but had not shared this with all of her family members (e.g., parents and other siblings). She was also uncertain as to when she would tell them her results.

> M: If I'm positive, I'm not sure that I'm ready to share it with them [her daughters] right now, or with my sisters, and that's part of the reason why I didn't tell anyone because I want to digest it myself.
> P: Absolutely.
> M: And then decide how I would proceed with telling the family members.
> P: That's absolutely reasonable. That's absolutely reasonable. And if we have to worry about it we obviously will talk about it more at the follow up session at the results session. But I think like you said you need to take care of yourself first before you take care of other people.
> M: Umm hmm.
> P: So I think that everything you have done so far is absolutely correct. And you know and the way you handled it was great so.
> M: Okay.
> P: I think that you're set up, regardless of what the test shows, to be able to communicate this to them.
> M: Umm hmm. Umm hmm.
> P: We do send you a letter in the mail at the end of all of this, and it will even say that we recommend this for your daughters and we recommend this for your brothers and sisters. And even that can be a little kind of cold way to share it.
> M: Right. Right.
> P: But it can at least show that you know if they ever ask.
> M: Right. Umm hmm.
> P: I think it's great that they know. It's great that they know you're here.

Minimizes the Probability of Personal Risk or Family Members' Risk

Practitioners also managed mothers' uncertainty by minimizing the likelihood or probability of their own risk (e.g., having the BRCA1/2 mutation) as well as their children's risk ($N = 7$, 44 %). This strategy was characterized by two properties, with the second property emerging less often: 1) minimizing the mother's or daughter's risk of being mutation-positive or developing breast or ovarian cancer in the future, and 2) minimizing one's risk of other cancers, such as prostate cancer or melanoma.

Even though mothers were uncertain about personal risk, in some ways they expressed "certainty" that they would have the genetic mutation or "certainty" that they would develop the disease given their prevalent family history and/or cultural heritage. This is an interesting dialectic of certainty and uncertainty that captures the unique risk context that such women face. Practitioners utilized this uncertainty management strategy of "reducing risk" to manage the dialectic, as is illustrated below:

> P: Yeah, and I think you also have Ashkenazi Jewish background and you have an early age of diagnosis for breast cancer which is suspicious.

M: It's going to look like I'm going to have this gene.
P: I would say it's less likely that you would, but—
M: Oh really?
P:But it's good to look.
P: Okay.

Mothers seemed more emotional when considering their daughters' future risk of the disease. Mothers wanted to manage their uncertainty about their own and their daughter's risk to protect themselves but, at the same time, it meant facing risk (and considering a threat to their daughter's life) which was quite emotionally difficult. Practitioners seemed to enact this strategy to quell their fears, as becomes clear through the following excerpt:

P: Well, I think it's important to think about these things ahead of time.
M: Right. Umm hmm
P: But not to worry so much.
M: No, I'm not worried. I just… (laughter, becoming emotional)
P: You just don't like talking about them and—
M: Right.
P: And the sense of having a risk.
M: Right.
P: I understand that.
M: It's why I'm here but—
P: Right. Yeah.
M: It's a double-edged sword.
P: Absolutely. But I think the biggest chance is that you're not going to be positive.
M: Right. Right. That's what I'm hoping.

Collectively, the analysis presented herein helps to illustrate how practitioners help mothers manage risk-related uncertainty during BRCA genetic counseling. The conversational excerpts bring to light the especially challenging nature of uncertainty management in this context and how flexible and responsive practitioners must be, weaving together multiple strategies in their effort to help mothers navigate this web of personal and familial risk-related uncertainty.

Discussion

I went through what I imagine thousands of other women have felt. I told myself to stay calm, to be strong… The beautiful thing about such moments in life is that there is so much clarity. You know what you live for and what matters. It is polarizing, and it is peaceful.
–Angelina Jolie Pitt (2015, para. 6)

This study captured in situ interactions in the genetic counseling setting thereby highlighting the interactive process between genetic practitioner and client in uncertainty management. In doing so, this study helps to highlight the invaluable role of the practitioner in these families' ability to manage risk-related uncertainty for years to come. Through these interactions, we see the complicated, multi-layered context of uncertainty that genetic counselors must respond to. We are also able to see how multiple strategies may need to be enacted in tandem to aid women in not only responding to sources of uncertainty but in learning how to manage that uncertainty when they leave the session. This uncertainty management experience undoubtedly has both individual and relational implications for women, particularly with regard to how women communicate with family members at home who also may be struggling with risk-related uncertainty. Our study not only illustrates how the genetic counseling interaction is an important opportunity for uncertainty management, but also how that interaction may function as a critical form of informational and emotional support for women at elevated or high risk for cancer.

Uncertainty Management: a Social Support Opportunity

Our study shows that the uncertainty management process for women at risk for or living with the BRCA 1/2 mutation is very much a familial one. Moreover, familial concerns are emotionally charged for women. Facing relational uncertainties for loved ones at risk means facing fears for their family members' welfare. It is not surprising then that women were, at times, emotional during these conversations, especially when talking about their daughter's uncertain future. Although these interactions clearly functioned as a means of managing uncertainty, they seemed to simultaneously function as social support. Supportive communication can be helpful in managing uncertainty and, at the same time, the uncertainty management process can function in a supportive manner. Related to this, Brashers and colleagues (2004) found that social support helped people living with HIV or AIDS manage uncertainty related to information seeking. They also found that it helped them develop coping and decision-making skills, validate feelings and plans, and reframe situations. Our findings reinforce Brashers' work in that the conversations illustrate how emotional support (e.g., validating behavior) is used to help women manage uncertainty. Yet, at the same time, these conversations are also emotionally or informationally supportive. In other words, the uncertainty management process can function also by fulfilling ones' support needs. We explore this further by looking at connections between uncertainty management and information or emotional support needs.

Informational Support and Uncertainty Management

The entire genetic counseling interaction can be viewed as a form of informational support. As one woman stated, "I don't want to be an ostrich." Women who seek genetic counseling make a choice about getting the information they need and facing their risk head on (as opposed to burying one's head in the sand), which is not emotionally "easy" to do. Throughout the session, women received information about their risk, what they can do, and what it means for their loved ones. Genetic practitioners in our study advocated that women *seek and share information* as a means of not only managing their uncertainty in the moment but in coping with their heightened risk in the long run. When practitioners provide such risk-related information and encourage information seeking and sharing, women also receive the informational support they need to make decisions and engage in health-promoting behavior (as noted previously, genetic counseling has been shown to increase women's sense of self efficacy in facing risk – see Bjorvatn et al. 2008).

It is also noteworthy that the practitioners *addressed myths, misunderstandings, or misconceptions* to manage women's uncertainty. This approach also served to provide informational support that is critical to improving health literacy. The fact that the women had inaccurate beliefs about their risk (and what they should do in terms of reducing risk) suggests an issue with health literacy that is likely tied to a combination of inaccurate messages received from a variety of sources (e.g., family stories passed down, hyped up or inaccurate media coverage, misinterpretation of new reports) (Borzekowski et al. 2014). Even health campaigns are not always enough to improve families' health literacy. For instance, the 2002 campaign about BRCA1/2 testing increased awareness but not knowledge. Although inquiries about testing increased, it was by women not at risk for a mutation (Bowen et al. 2010; Mouchawar et al. 2005). Deficits in health literacy are typically linked with poorer health outcomes, which further stress the importance of genetic counseling as a form of uncertainty management (and, ultimately, informational support). Moreover, the link with health literacy also heightens the need for genetic practitioners to debunk health-inhibiting myths by addressing women's uncertainty in a manner that is also comprehensible (Roter et al. 2007). We can see in the conversational excerpts the use of technical jargon, which may inhibit comprehension and complicate the uncertainty management process.

Emotional Support and Uncertainty Management

The uncertainty management process also provided women with emotional support. Deciding to get tested and face one's risk head on is just as scary as the fear that induces one to not seek information. Our analyses showed that validation was an uncertainty management strategy used by practitioners to *validate or reaffirm previous behavior or decisions*. Validation can serve an important emotional support function of acceptance and reassurance (Brashers et al. 2004), including when it comes to decision making about breast cancer treatment and risk (Fisher 2014). The genetic practitioners in our study tended to enact this strategy to help women manage uncertainty about talking to their loved ones (often daughters), an especially emotional context for the women. Helping the women manage this uncertainty also helped them manage distressful emotions. The practitioners also used validation in tandem with another strategy, *minimizing risk,* which seemed to be particularly helpful in managing this uncertainty and women's fears.

Interestingly, practitioners' and mothers' use of another uncertainty management strategy, *introducing uncertainty related to science,* seemed to reframe the situation in a way that might also function as emotional support in the midst of uncertainty management. They used this approach to frame the situation more positively. They introduced hope about one's future health in that science would be better down the line (i.e., time was on their side in that future scientific and technological advancements could protect their own and their daughter's health). Aasen and Skolbekken (2014) noted in their study of Norwegian genetic counseling sessions that hopeful communication seemed to be a strategy counselors use to help clients manage uncertainty. While their sample was small (6 interviews with 2 counselors and 6 sessions) these practitioners reported using this approach because in their past clinical experience it was helpful in buffering clients from psychological distress. In our findings, hopeful comments like "they may have a vaccine" or that there would be better screening in the future might be helpful in managing women's uncertainty while at the same time help them manage distressful emotions about the threat to life.

The potential helpful effect of this approach is intriguing given that previous research has suggested that the uncertainty of science in medical discussions can actually hinder a patient's trust in health care providers as well as patients' sense of well-being in the future. For instance, Brashers et al. (2006) found that advancements in medical knowledge and technologies can hamper HIV and AIDS patients' ability to manage uncertainty during clinical interactions. "Emerging advances in medical knowledge and technology, which may be speculative but widely reported, can lead patients to question the knowledge of providers" (p. 228), particularly if health care providers are not aware of advancements. Similarly, failures in medical technology can impede patients' trust in providers and, consequently, be ineffective in managing their uncertainty (Brashers et al. 2006). Our findings show another way of framing uncertainty about science/technology—that as science and technology continue to advance our health

can improve. Introducing this perspective of uncertainty about science seems to counteract one's feelings of certainty that the development of cancer is inevitable. Thus, rather than thinking that time is against you, time is actually on your side. Future scientific advancements might include a cure or vaccine. Ultimately, this uncertainty management strategy can be used to reframe clients' fears and uncertainty about the future in a more positive, hopeful light thereby providing emotional support as well.

Our study helps shed light on how uncertainty management and social support ultimately coincide, further highlighting the critical role of genetic practitioners. At the same time, the approaches practitioners use to help clients manage their uncertainty may not always actually be helpful (or health-promoting) in terms of providing emotional or informational support. We offer further insight on some of these challenges and also provide some suggestions for future research.

Exploring the Helpful/Unhelpful Outcomes of Uncertainty Management

Scholarship shows that whether these interactions are perceived as supportive and helpful (or not) in managing one's uncertainty depends on the other person in the interaction. Brashers et al. (2004) found that uncertainty management interactions were not necessarily beneficial when the patient's communication partner was also impacted by the health risk (e.g., talking to a loved one), as the patient was also worried about the loved one's individual support and uncertainty concerns. Relatedly, research on cancer survivors has shown that when survivors seek out support directly (as one does by consulting a health expert like a genetic practitioner), they are more receptive to it. As such, the interaction works to facilitate uncertainty management or support (as opposed to if a survivor does not want the information then when it is given unsolicited, s/he may avoid it) (Thompson and O'Hair 2008).

Collectively this research suggests that genetic counseling might be an optimal environment for uncertainty management and social support given their interaction partner is not related to the client and is also an expert. Women who seek genetic testing and counseling do not have to be concerned about burdening the practitioner (a concern they have for loved ones) (Brashers et al. 2004; Fisher et al. 2014). At the same time, because they choose to do genetic testing and counseling (since one is not required to do so), they make the autonomous choice to directly seek that support. As the previous research suggests, these women will be more receptive to the informational or emotional support, which is necessary to enhance uncertainty management (Thompson and O'Hair 2008).

Still, even though genetic counseling interactions are a key opportunity to attend to women's uncertainty and support needs, a practitioner's communication strategies might not always result in health-promoting outcomes. For instance, a practitioner may encourage a woman to share her genetic test result with loved ones to help her manage uncertainty about her loved ones' future well-being. Yet, by doing so, that client might then introduce more uncertainty that could prove distressing (e.g., worrying about whether a family member uses that information in a health-promoting manner or if s/he chooses not to do testing or share the information with his/her own children). Future studies should attempt to explore the potential health-promoting (or not) outcomes (both in terms of uncertainty management and fulfilling support needs) to better ascertain how these strategies may function differently depending upon the uncertainty source at hand as well as other influential factors (e.g., age, gender, culture). By further exploring the helpful or unhelpful outcomes of uncertainty management strategies (from both clients' and clinicians' perspectives), we can enhance clinical practice as well as teach family members healthy ways of responding to uncertainty.

Our results do reveal some aspects in which complications can arise that inevitably will affect whether or not uncertainty/support needs are met. Previous research has shown that congruence of goals is critical to uncertainty management. Brashers et al. (2004) found that.

> People with HIV may want to reduce, increase, or maintain uncertainty. Incongruence between the goal of the person with HIV and the actions of a support provider can present a dilemma. For example, the uncertainty management goal of the support seeker may be to avoid information to preserve uncertainty, yet the support provider may provide information. … Given the complexity of uncertainty management, these misperceptions of goals may undermine adaptation. (p. 317)

One area in which an incongruence of goals might occur in the genetic counseling session is with regard to the uncertainty management strategy of *seeking and sharing information.*

We noted that this context was also embedded within profound ethical dilemmas for both the woman/client and genetic practitioner, particularly when one's family situation was more complicated. This uncertainty management strategy may result in a conflict between one's autonomy and freedom of choice with the need to protect others from harm. A goal for the genetic practitioner is to help the client manage her uncertainty and, ultimately, improve health outcomes. Given the familial nature of genetics, that practitioner is also concerned with improving health outcomes for family members at risk. However, this goal might compete with a client's priorities.

For example, some women were encouraged to share or seek information from family members with whom they do not know or interact with, sometimes due to conflicts or dysfunction that led to estrangement. This presents an ethical

dilemma not only for the practitioner but also the client. While sharing the information is meant to save lives, at the same time, opening those communication lines with estranged family members may also impede a woman's health and, as such, not be in accord with the her goals (and well-being). Also, take for instance, mothers' strong desire to protect their young daughters at risk. A mother might want (and be encouraged by the genetic practitioner) to share information with her daughter. However, the daughter may want to avoid such conversations or information because receiving that information induces fear and anxiety, possibly due to her place in the life span (Fisher 2010). As such, a daughter may avoid interactions to protect her psychological well-being. She may even decide not to get tested during adulthood for the same reason. Ultimately these uncertainty management strategies may also be complicated by a conflict between personal autonomy/choice and wanting to protect loved ones or clients (or reduce cancer diagnoses or cancer-related death).

Our findings show that encouraging information sharing and seeking is not a simple uncertainty management strategy and is complicated not only by ethical dilemmas but variations in individual health needs. Thus, an awareness of congruence of goals is especially important if genetic practitioners are to be sensitive in helping clients manage their uncertainty and provide significant informational and emotional support (Brashers et al. 2004). This awareness may also be useful in better understanding why some communication strategies function in more health-promoting ways. While saving the lives of their client and the client's family members is critical, encouraging communication with estranged loved ones or within unhealthy relational contexts may not mesh with the client's individual health needs (or the family member's). At the same time, it can become a teaching point in the genetic counseling session for practitioners to help clients understand that their goals (or need for information) may not necessarily correlate with their loved ones' goals. Genetic practitioners are uniquely positioned to help mothers manage difficult decisions and interactions with their family members. It can be an opportunity to encourage respect for everyone's individual needs when it comes to coping with risk not only in the moment but also across the life span.

Study Limitations

Limitations of the study include the participants' awareness that their session was being recorded, which may have affected their behavior in unknown ways. Also, qualitative data are not intended to be generalized to the population of interest. Related to this, our study does not attend to cultural differences in how families perceive uncertainty, genetics, and cancer risk. Due to sampling restrictions of the study's clinical setting and practical reasons, only English-speaking women who were also predominantly Caucasian were included. Health beliefs are largely cultural (Lupton 1994) and can certainly play a role in how genetic practitioners can help women manage uncertainty. Moreover, cultural groups like Latinas are underrepresented in genetic counseling for hereditary breast and/or ovarian cancer (HBOC) even though breast cancer is more life-threatening and the most common form of cancer-related death for Latina women (Wideroff et al. 2003). Research on Latina women's perceptions of the benefits of BRCA testing/counseling (among those who had not yet received testing/counseling) showed that cultural beliefs (familismo) would strongly motivate them to get tested to protect family, and younger generations were especially enthusiastic about pursuing testing / counseling (Sussner et al. 2015). Future research and practice should take into account the unique cultural needs and beliefs of clients and their families regarding uncertainty management. These findings are also gendered in that we focused on women at risk for breast and ovarian cancer. As such, future research should also explore men's approaches to risk as they may perceive uncertainty management differently. In addition, women without daughters or children may also respond differently or have variant needs and warrant further attention.

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Practice Implications

We hope that the results of this study provide genetic practitioners with insight on uncertainty management in the genetic counseling setting. We hope the results highlight the types of uncertainty that women may be struggling with (therefore warranting attention during the counseling session) and how the genetic counseling interaction is concurrently a vital means of support for these women. Our results shed light on the various communication strategies that both practitioners and women may enact to manage uncertainty. At times, these strategies may be helpful to clients in managing their uncertainty but, in other instances, the approach may not be as health-promoting. It may be helpful for practitioners to identify the client's approach to managing uncertainty and mirror it when it also enhances a congruence of goals, encourages trust between practitioner and client, and facilitates health-promoting behavior. Yet, we also believe that clients are learning how to manage their uncertainty through these interactive experiences with genetic practitioners. They can model the same uncertainty management strategies at home or when they interact with family members who are also at risk. The findings do suggest that clients also have variant family relationships and situations and some may be more turbulent than others. With this is mind, it is critical for practitioners to be cognizant of ethical challenges that might arise during the uncertainty management process. With future research, we hope that these findings lead to scholarship that can test the effectiveness of these various strategic approaches, both from the client and practitioners' perspective.

Research Recommendations

An important next step in this research agenda is to evaluate the effectiveness of each uncertainty management strategy from the patient/client's perspective or, as discussed, the potential helpful and unhelpful outcomes. Based on women's responses, we could infer that some strategies appeared to be helpful in managing uncertainty, coping with emotions, or in attaining emotional or informational support. However, these assumptions must be tested by seeking the recipient (the client's) perspective. Researchers should also pay close attention to influential variables that may impact whether the communication strategy is health promoting. For instance, our sample included mostly women receiving pre-testing counseling, with only two women in post-test sessions. Each group of women will certainly overlap in their uncertainty management needs but also may differ in some ways. More research on the health outcomes of uncertainty management approaches will offer more comprehensive information for medical education and training. This research could also lend insight into how families can cope with these uncertainties in the most health-promoting manner across their life span and help loved ones manage their uncertainty as well. This seems particularly critical given the longitudinal nature of how genetics impacts not only individuals but family generations to come.

Conclusions

This study builds on previous research (Bylund et al. 2012; Fisher 2014; Fisher et al. 2014; Maloney et al. 2012) and provides a more comprehensive picture of not only living with risk but also in treating people facing heightened cancer risk. The findings demonstrate how uncertainty is not only a defining feature of these families' unique situations but also how managing that uncertainty is inherently a communicative process rich with social support opportunities.

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Compliance with Ethical Standards

Conflict of Interest Authors Carla L. Fisher, PhD, Thomas Roccotagliata, MA, Camella J. Rising, MS, RDN, David W. Kissane, MD, Emily A. Glogowski, MS, MSc, and Carma L. Bylund, PhD declare that they have no conflict of interest.

Human Studies and Informed Consent All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (5). Informed consent was obtained from all patients for being included in the study.

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