I, Ayaka Suzuki, hereby submit this original work as part of the requirements for the degree of Master of Science in Genetic Counseling.

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Familial Communication of Positive BRCA1/2 Genetic Testing Results: A Relational Dialectics Theory Approach

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Familial Communication of Positive BRCA1/2 Genetic Testing Results: A Relational Dialectics Theory Approach

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ABSTRACT

Individuals who receive a genetic testing result revealing a pathogenic or likely pathogenic variant in the BRCA1 or BRCA2 (BRCA1/2) gene are encouraged to disclose this result to their biological family members. Various factors are known to influence the disclosure process and variations in the perceived importance of these factors make familial communication complex. The use of a theory grounded in the discipline of communication helped to explore the communicative processes involved in the familial communication of positive BRCA1/2 genetic testing results. By specifically focusing on the parent-adult child relationship, we gathered important knowledge on the unique dynamics that influence the BRCA1/2 experience in the individual and within the relationship. Semi-structured, dyadic interviews were conducted with an individual who received a positive BRCA1/2 genetic testing result together with his/her adult child. A total of fourteen dyadic pairs participated. Among the adult children, seven tested positive, three tested negative, and four had not pursued testing. Adult children seek parental input on testing and management options, but want to make their decisions autonomously. Family cancer history can impact how a parent and adult child contextualize personal and/or familial risk, sometimes inaccurately. Within the parent-adult child relationship, conversations related to the BRCA experience continue beyond the first disclosure. We discuss how our findings serve as a resource for clinicians to guide conversations with patients about the challenges and complexities of sharing results with family members, particularly with children.
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INTRODUCTION

Cancer most commonly occurs in a sporadic fashion, where age, lifestyle factors, and/or environmental exposures increase an individual’s risk of developing cancer. However, in 5-10% of cases, there is an underlying genetic cause. In these cases, a mutation in a cancer predisposition gene leads to an increased cancer risk (Garber & Offit, 2005). Referred to as hereditary cancer syndromes, more than 45 such genes have been described (Riley et al., 2012). Oftentimes the risk is found to be significantly higher than the general population risk of developing cancer sporadically, and most genes are associated with risk for malignancies in more than one area of the body. The average age of developing cancer is oftentimes younger than expected in the general population.

Hereditary Breast and Ovarian Cancer Syndrome (HBOC)

Hereditary breast and ovarian cancer syndrome is a hereditary cancer syndrome that is associated with the BRCA1 and BRCA2 genes. BRCA1/2 are tumor suppressor genes that play a role in helping to repair damaged DNA (Lindor, McMaster, Lindor, & Greene, 2008). Mutations in the BRCA genes prevent DNA repair from occurring readily, resulting in a higher likelihood of genomic instability — one of the genetic hallmarks of cancer development. In the National Comprehensive Cancer Network guidelines published in 2016, the prevalence of BRCA1 mutations is estimated to be 1 in 300, while BRCA2 mutations are less common and seen in approximately 1 in 800 individuals. So far, more than 1,200 deleterious mutations have been identified in BRCA1 and BRCA2 combined (Garber & Offit, 2005).

HBOC is associated with breast and ovarian cancers (Hampel, Bennett, Buchanan, Pearlman, & Wiesner, 2015) that tend to develop at younger ages compared to those without a genetic predisposition. Of the 5-10% of breast and ovarian cancer cases that are hereditary, 30-50%
can be contributed to mutations in the \textit{BRCA1/2} genes (Ferla et al., 2007). \textit{BRCA1/2} also confer an increased risk of developing multiple primary breast, prostate, pancreatic cancers and melanoma (Hampel et al., 2015). Table 1 (Appendix A) lists the lifetime risk of developing cancers where the associated risk numbers are known. The American Cancer Society defines ‘lifetime risk’ to be the “risk of being diagnosed with cancer over the course of a lifetime”.

Together with the information obtained at the initial genetic counseling session, positive genetic testing results are used to develop a plan of care for screening, prevention, and/or risk-reduction (Riley et al., 2012). Screening and management recommendations offered to individuals with a positive genetic testing result for \textit{BRCA1/2} can be found in Table 2 (Appendix B). There are also options for prophylactic surgeries — namely, the removal of the breasts and ovaries — that are known to substantially increase the chance of survival (Riley et al, 2012).

\textbf{Familial Communication of Genetic Risk}

Individuals who receive a genetic testing result revealing a pathogenic or likely pathogenic variant in the \textit{BRCA1} or \textit{BRCA2} (\textit{BRCA1/2}) gene are encouraged to disclose this result to their biological family members. The first person tested in a family is referred to as the index case (Douglas, Hamilton, & Grubs, 2009). The results of this individual’s testing can be used to test other relatives and determine if they are also at an increased risk of developing cancer. Encouraging family members to partake in testing and communicating available management steps can create a pathway to risk reduction practices. Therefore, the health implications of not informing family members of the results are thought to outweigh the potential psychosocial harm the information may cause (Gaff et al., 2007). The main objective of this study was to examine the relational dynamics surrounding the experiences with and disclosure of positive \textit{BRCA1/2} results between parents and their adult children.
The task of disseminating risk information to family members typically falls on the index case. Common reasons for considering disclosure include informing relatives of their potential risk, discussing the importance of testing, and fulfilling a perceived responsibility to inform (McGivern et al., 2004). However, while studies show that most individuals have the intent of informing relatives of their positive BRCA1/2 results, hereditary risk information is communicated more often to first-degree relatives (parents, siblings, and children) and to female relatives, compared to second/third-degree relatives or male relatives (Dancyger et al., 2011; Julian-Reynier et al., 2000; Wilson et al., 2004). In addition to preferential dissemination of results based on sex and genetic closeness of the recipient, various other characteristics have been reported to predict the likelihood of an individual disclosing to relatives. Reynier et al. (2000) found that women who were 45 years of age or older and had a personal history of cancer were more likely to inform their children of their positive results. Families with an open culture that encouraged communication fostered more positive attitudes towards sharing and have a higher incidence of disclosure (Dancyger et al., 2011; Rauscher, Hesse, Miller, Ford, & Youngs, 2015).

While these findings can be helpful in better understanding the process, more qualitative approaches show that familial communication does not fit a ‘one-size-fits-all’ pattern (Gaff et al., 2007; Hamilton, Bowers, & Williams, 2005). The disclosure of genetic testing results within families is a process, rather than a singular act of dissemination (Forrest et al., 2003). Factors within an individual, a relationship, and a family can each influence and further complicate the disclosure process (Montgomery et al., 2013). Upon reviewing 14 qualitative studies on familial communication, Chivers Seymour, Addington-Hall, Lucassen, and Foster (2010) found the following decision-making factors to be prevalent: the feelings of the informant (the individual disclosing positive results to relatives), perceived relevance of the information to others, anticipated reactions, closeness of familial relationships, family rules and patterns, timing, and accessibility of
support from healthcare professionals. For example, an informant may consider a family member’s emotionally and developmental readiness to hear the information. Readiness can be assessed by such things like age, life stage, and other possibly co-occurring events that may be causing emotional and/or physical burden (Dancyger et al., 2011).

Variations in the perceived importance of these decision-making factors illustrate the uniqueness and complexity of the familial communication of genetic testing results (Hallowell et al., 2005; Kenen, Arden-Jones, & Eeles, 2004). To provide effective result disclosure strategies, it is important to understand how the communication of genetic testing results occurs within families (Wilson et al., 2004).

**Relational Dialectics Theory**

The Relational Dialectics Theory (RDT) is a theory that describes an individual’s meaning-making processes through the method of communication, and this process is further contextualized by the specific dynamics that exist in each interpersonal connection (Baxter, 2011). In any relationship, communication lies at the core of its foundation, and it is employed not only to impart information, but also to create and manage the relationship (Wilson et al., 2004). For example, the goal of communicating positive *BRCA1/2* results can extend beyond the dissemination of risk information and include the seeking of emotional support and maintenance of open and honest relationships (Dancyger et al., 2011).

In RDT, relationships are described by the relational tensions that exist within them. Relational tensions can be further characterized into relational dialectics, which are defined to be the interplay between two opposing forces that constitute a relational tension (Baxter, 2006). RDT describes familial communication stemming from three major dialectics, each of which are defined by contradicting adjectives: (1) dialectic of integration – autonomy, independence, and separation vs.
connectedness, interdependence, and integration; (2) dialectic of certainty – stability, continuity, certainty, predictability, and routine vs. change, novelty, surprise, and newness; and, (3) dialectic of expression – openness, disclosure, and candor vs. discretion, privacy, and secrecy (Braithwaite & Baxter, 2006). It is important to note that contradictions defined by these relational dialectics should not be thought of as interpersonal conflicts (Baxter, 2011). The specific relational tensions that are present will differ depending on the identities within that relationship, and oftentimes, more than one relational tension can be identified. Relational tensions can also be influenced by personality, values, and social constructs, such as relational labels and social responsibility (Baxter & Montgomery, 1996).

By categorizing observed relational tensions into dialectics, RDT explores the role of communication in producing, managing, and challenging communicative tensions within a relationship. RDT helps orient the researcher to explore the qualitative data through the lens of looking at not just what participants say, but also how they say it (Morgan, 2010). In relation to familial communication of positive BRCA1/2 genetic testing results, differences in preferred communication patterns may influence the decision to share the information and how that information is shared (Forrest et al., 2003). Given the involvement of decision-making by the index case and the communication process with family members, the use of this theoretical model of communication can further augment empirical findings.

RDT allows the exploration of the interplay between existing family dynamics and communication patterns in the form of a dyadic interview. This approach is most effective when the dyad is a naturally occurring pair, such as a parent and a child (Greenbaum, 1998). The pre-existing relationship between a parent and an adult child allows the researcher to build on an already established common ground, which is an important basis for interactions in dyadic interviews (Hydén & Bülow, 2003). Furthermore, the theoretical basis of RDT is rooted in the meaning-making
process that emerges from communication between two individuals. Through dialogue, a parent and an adult child can co-construct a joint narrative of an experience. In addition to the decision-making process and shared communication of the results that will come to light in the interviews, the interaction between the participants is also of interest. “In dyadic interviews, the participants can both validate and challenge each other, and watching how [those in the dyad] attempt to modify each other’s accounts gives insights into how the dynamics of the relationship operate” (Morgan, 2016).

Overview of the Study

Individuals who receive a genetic testing result revealing a pathogenic or likely pathogenic variant in the \(BRCA1\) or \(BRCA2\) (\(BRCA1/2\) gene are encouraged to disclose this result to their biological family members. Factors within an individual, relationship, and family are known to influence the process leading up to the disclosure, the disclosure itself, and the resulting effects post-disclosure. Variations in the perceived importance of these factors make communication within each family unique and complex. However, only a handful of studies provide an in-depth, qualitative perspective on the familial communication of results. This study sought to gain a better understanding of the communicative processes that occur related to an individual receiving positive \(BRCA1/2\) results, specifically within the parent-adult child relationship.

Communication of positive \(BRCA1/2\) results within families is not just a single, isolated event; rather, it is a part of a complex process of managing the many relational tensions that are present in each relationship (Wilson et al., 2004). However, only a handful of studies provide an in-depth, qualitative perspective on the familial communication of results. None of these studies have employed theoretical models of familial or health communication. Employing an RDT perspective allows for an appreciation of the meaning and complications of a positive \(BRCA1/2\) mutation from
the perspective and lived experiences of the participant. Not only does RDT provide a more detailed look at the communication processes using an appropriate, yet unprecedented approach, it also allows the exploration of relationships from a dyadic perspective. By including both parties involved in the familial communication process (the informant and the recipient), genetic counselors will be better equipped to support individuals who have received positive \textit{BRCA1/2} genetic testing results in informing family members.

In the final analysis, we discuss how our findings serve as a resource for clinicians to guide conversations with patients about the challenges and complexities of sharing results with family members, particularly with adult children.
METHODS

Participants

The target population consisted of individuals who had received a positive \textit{BRCA1/2} genetic testing result (“parent”) with at least one biological child over the age of 17 (“adult child”). Additionally, both the parent and adult child were required to be aware of the parent’s positive \textit{BRCA1/2} genetic testing results prior to participating. Individuals requiring an interpreter to be present during the interview were excluded from the study.

Recruitment occurred through the following avenues: (1) Cincinnati Children’s Hospital Medical Center (CCHMC) Hereditary Cancer Program patient database – first, individuals with a positive \textit{BRCA1} or \textit{BRCA2} genetic testing result were identified through a database query. The year 2000 was chosen as the cut off to ensure the patient medical chart was not outdated. A medical record review was performed to confirm the fulfillment of inclusion criteria for the parent group. Recruitment letters were mailed to eligible participants. The letter included a request for parents to reach out to one of their adult children to participate in the study with them. An additional recruitment letter addressed to an adult child was also enclosed. A second recruitment letter was sent 2 months later if no response was received in the interim. (2) Facing Our Risk of Cancer Empowered (FORCE) support network – an overview of the study was included in the support group’s monthly newsletter between March-May 2017. The newsletter was distributed to all individuals subscribed to the mailing list. A recruitment flyer was also distributed to attendees of the Cincinnati/Northern Kentucky monthly FORCE support meetings from November 2016 to January 2017.

This study was approved by the CCHMC Institutional Review Board.
Instrumentation and Procedures

Semi-structured interviews were conducted in a dyadic fashion, with the parent and adult child interviewed together in the same session. Dyadic interviews, also known as joint interviews, are performed in the presence of two participants and the interviewer (Seale, Charteris-Black, Dumelow, Locock, & Ziebland, 2008). A dyadic interviewing approach was implemented to better observe the relational tensions present in the relationship. Three options of completing the interview were offered to each participant: (1) in-person at CCHMC, (2) through video Skype, or, (3) over the phone.

Verbal consent was obtained from both participants at the beginning of each interview. Each interview lasted between one to two hours, with only one interview exceeding three hours. Participants were notified that participation was voluntary and they could individually choose not to answer any question or end the interview at any point. The interview guide (Appendix C) consisted of open-ended questions that explored the dynamics and communication patterns within the family and parent-adult child relationship, the journey that led to testing, the decision-making process to communicate results, the actual disclosure of results, and the resulting outcomes of each participant and within the parent-adult child relationship. If the adult child had also pursued testing, in addition to asking about the experience with testing and receiving results, the disclosure process to the parent was explored. RDT was employed as a framework for the interview guide to allow questions to draw out relational tensions within the dyad. The interview guide was structured in a way that encouraged both participants to engage in each question.

Participants were offered the option of re-contacting the interviewer to share additional thoughts. Furthermore, participants were contacted in cases when additional information or clarification on what was discussed during the interview was needed. The dyadic approach was
maintained by reaching out to both participants whenever possible, regardless of who the question was targeting.

Using a comparative analysis method, interview questions were modified or added as data collection progressed in response to emerging points of interest. Interviews were audio recorded and transcribed verbatim by the first author (AS). Any identifiers were removed and participant names were replaced with initials during the transcription process. Audio recordings and interview transcripts were stored in a private folder. Recordings were only accessible to the first author, and de-identified transcripts were only available to members of the study team.

Data Analysis

Following grounded theoretical methods, analysis of the transcription data was performed concurrently with data collection (Strauss & Corbin, 1994). Once the transcripts were de-identified, first author (AS) engaged in a close line-by-line reading of the text to perform open coding, where all relevant or interesting excerpts were noted. Three transcripts were reviewed with last author (SS) to ensure inter-coder validity, consulting his expertise in the communication theory and qualitative research methods utilized in the study. Furthermore, due to the in-depth analysis demanded by RDT, all transcripts were also reviewed by a study member (ET). Upon individual coding of each transcript, 1-3 hours were spent discussing the coding for each in detail. Of note, the three main dialectics as defined by RDT were referenced throughout the analytic process as a framework to make sense of the interactions and relational tensions observed in each interview. Identified codes were organized into second-order categories, and as the final step, developed into larger thematic groupings. (Baxter, 2011)
RESULTS

Participant Demographics

A total of fourteen dyadic pairs participated in the study. Demographic information, including personal history of cancer and surgery pursued, are summarized in Table 3 (Appendix D). All participants apart from one adult child (dyad 12) were female and 13 dyads identified as Caucasian. One dyad (6) identified as African American, Caucasian, and Native American background. Among the adult children, seven tested positive (50%), three tested negative (21%), and four had not pursued testing (29%) at the time of their interview. Eight of the parents had a personal history of breast cancer (57%), while none of the adult children had ever received a cancer diagnosis. The average number of years since the initial disclosure of results from parent to adult child was approximately 7.5 years ago (1 month-18 years ago). The mean age of the adult child at that disclosure event was 21.8 years old, ranging from 8-44 years old. Adult children were notified at the same time as the parent up to within 10 years of the parent finding out their results. Four dyads used video Skype/video Skype (29%), one used video Skype/over the phone (7%), and nine used over the phone/over the phone (64%). The total audio duration of all interviews was 23 hours and interview transcripts amounted to approximately 615 pages.

Major Themes

The framework of RDT was also utilized in the data analysis phase. The identified themes were categorized into one of the three major dialectics of integration, certainty, or expression. We recognized that the thematic areas fell into the respective dialectics in a way that reflected the two sides of each dialectic spectrum. We summarize the findings and highlight representative relational tensions pertinent to BRCA for each dialectic.
Dialectic of Integration

The dialectic of integration is defined by the following opposing adjectives – autonomy, independence, and separation vs. connectedness, interdependence, and integration. Relational tensions within the dialectic of integration can emerge when the degree of autonomy or interdependence given by one does not match what is wanted or needed by the other. Importantly, how much is given or wanted may differ based on the situation as well. Within the BRCA experience, this tension was observed in discussions of the testing journey for the parent and the adult child. The testing journey begins with the decision-making on whether to pursue testing, which is followed by getting tested and hearing the results.

For the parents, their testing journey was typically carried out autonomously from the adult child. In all but one dyad (n = 13), parents purposely left the adult child out based on a deliberate, strategic decision. Three parents felt their children were too young to be involved.

I wouldn’t have looked to my kids for any involvement in that. I just think that’s an, that’s a real serious adult subject and I just wouldn’t have turned to them for support for that kind of thing. If they were, you know, in their 30’s maybe. – Parent (12)

Wanting to avoid unnecessary burden motivated two parents to keep their children in the dark, particularly in consideration of their life stage or circumstance.

We wanted to let her know what was going on…but she also…was going through her own thing with her eating disorder and we didn't want to overwhelm her… It's like, is there any point in bringing [her] into this because it would just cause her undue stress. We don’t even know if I'm positive yet. – Parent (1)

As a representation of the autonomy that was established by the parent, four parent participants delineated that the involvement of the adult child began at the results stage.
Involvement in the decision-making stage of whether to pursue testing was considered to be unnecessary or have never crossed their mind.

[My daughter] is not really involved in the process, she's involved in the results…I didn't go to [her] until I, you know, came up with a plan and then I said, "Look, this is what I think I'm going to do"…I don't involve [her] in the decision-making, just the results. – Parent (9)

For the one parent (dyad 7) who did involve her adult child in her testing journey, she shared that it was “for another set of ears and support.” The parent let the adult child know that she was thinking of pursuing testing and the adult child, then, accompanied her to the genetic counseling appointments. Despite this involvement, parent (7) also did not involve the adult child in her decision-making process.

It wasn't...bouncing it off [adult child], “Do I wanna do this, or don’t I wanna do this?” It was like, “Nope, I'm doing it.” – Parent (7)

In comparison with the autonomous journey of their own testing, all 14 parents integrated themselves in their adult children’s testing journey. Integration began as early as the first disclosure event, when the parent communicated their results to the adult child for the first time, and presented in a variety of ways. During that first conversation, the timing of when the adult child should pursue testing was a common topic of discussion. Five parents shared with their adult child to defer testing until they were older. At the time of disclosure, their respective adult children were all under the age of 20, ranging from 8 to 19 years old.

You're too young, but at some point, we would, we would like, you know, to talk about maybe you getting testing when you're old enough. – Parent (14), quoting herself when looking back on her first conversation with adult child (14)

Considering the perceived clinical utility of the results, four parents reasoned with the adult child that their testing can be delayed till the time when the results would be actionable.
What’s the point [of getting testing]? You're not taking your breasts off in your 20’s…You're not taking your ovaries out because you want kids. – Parent (5)

In terms of when testing should be done, the use of the results to make medical decisions, such as pursuing prophylactic surgeries or reaching the age of 25 to begin high-risk screening, and timing related to family planning were mentioned. For dyad 12, the adult child had not pursued testing at the time of the interview and wished to wait. While the specific motivation was unclear, he brought up the inapplicability of the information at his current age and concerns with discrimination as possible reasons for deferring. In response, his mother felt that once he had children, testing could not be delayed any longer.

I think once you have kids…that’s kind of when you gotta kind of, like, in my opinion...suck it up and find out because…once you start having kids, then you really have to look to the future a little bit more. – Parent (12)

Contrary to the integration observed in the dyads described above, two adult children pursued autonomy and did not involve their parent with the decisions related to testing at all. However, parental involvement extended beyond the testing journey and was seen in other areas of the BRCA experience, such as decisions regarding which management option to pursue for breast cancer risk.

Responses by the adult children to the integration varied between appreciation and resistance, indicating the complexities of the tension between autonomy and integration. Parental involvement was met with appreciation by the adult child in dyad 11, who was initially interested in pursuing testing as soon as her mother shared the results with her. Her mother denied the request because the results would not lead to any immediate action at the age of 16.
Looking back now, I think my mom made the right decision. Like...a 16 year old doesn't need that information and doesn't need to carry that around with them until they're ready to act on it. – Adult child (11)

For adult child (4), her mother was involved in her testing journey through accompanying her to the pre-test genetic counseling appointment. At that appointment, her mother served as the primary historian when discussing the family cancer history.

I went with my mom for the initial genetic counseling and testing...It felt good having support. – Adult child (4)

Resistance precipitated in two ways during the interviews – direct or indirect. Direct resistance was observed in adult child (2). She avoided parental integration by refusing to discuss topics related to BRCA1/2 with her mother, particularly about management choices.

I just don't like to talk about it [b]ecause I know that we have different opinions...You can't tell me what to do...I sense that you...want me to get a prophylactic bilateral mastectomy and I don't wanna do that, and that's why I don't want to talk about [it]. – Adult child (2)

On the other hand, two adult children reacted indirectly in response to being asked what advice they would give other parents sharing their positive results with their children. Both felt that while important for parents to share their opinions, it was also crucial for parents to remain open in hearing their children’s wishes as well.

[Let the children] make the decisions. You can give your input, but...let them make them at the time that they want to make them. Don't have any expectations that they're going to do what you want them to do, when you want them to do it. – Adult child (5)

Some kids probably will not wanna do the testing because...they don’t want to know for whatever reason...Keep...all channels of communications open, and...try not to...be manipulative. – Adult child (7)
The balance between autonomy and integration was also reflected through the choice of language. Three parents shared opinions with their adult children in the form of guidance or encouragement and described avoiding language that may indicate control.

Directing you, or trying to, no, no, I would never do that…I want you to do what's right for you…You're in a different place, different age, obviously, and I understand. – Parent (2)

I was encouraging them to get tested, but, you know, I wasn't going to tell [them] they had to. – Parent (4)

The following example is presented here to illustrate how the tension between autonomy and integration may precipitate between a parent and an adult child:

Testing was not something I wanted her to do in that point in her life. And I told her, the recommended age is 25, why would you want to get tested now. And she told me, because it was something she wasn’t afraid of, she wanted that information, and she told me that as I was on my way taking her to the doctor for her yearly check-up. She said, “I’m going to get tested.” And so, I sort of was like…“Why? They don’t recommend it till you’re 25,” and that’s when she pretty much said, “No, mom, I’m going to get tested…I’m not afraid of the results and I don’t want to wait” And I said, “Okay!” – Parent (9)

Dialectic of Certainty

The tension between stability, continuity, certainty, predictability, routine and change, novelty, surprise, newness represents the dialectic of certainty. In the BRCA experience, the introduction of a positive BRCA1/2 result inevitably produced dynamics of change and challenged notions of stability for both parents and adult children. Various factors influenced the contextualization of cancer and hereditary risks and this meaning-making process was reflected in
the reactions to the results. The perception of these risks ultimately provided the reasoning behind which action item to pursue.

The meaning-making process related to BRCA1/2 commonly began with the parent establishing predictability in reference to the personal and family cancer histories. The cancer types and ages of diagnoses formed a pattern that parents acknowledged to continue over subsequent generations. The resulting perception of familial cancer risk by the parent then influenced the way they contextualized the risk to their adult children. Conversations regarding the appropriate time to test or pursue certain management options included information from the family cancer history as evidence.

The cancer shows up later in our family, so it really gave [my daughter]…time to just, "Hey, let's not get tested and deal with that later." – Parent (1)

[My daughter] asked if she was going to have to have surgery and what point, and…I just remember saying to [her], "I was 47 years old [when I found out I was positive and did the surgery] and you're going to start worrying now? You've got a lot of years to start worrying." – Parent (9)

Similarly, the perception of the likelihood of whether the BRCA1/2 results would be positive or negative was also affected by this established predictability. Positive results affirmed the suspected presence of hereditary risk, while knowledge of family members that were negative formed expectations or gave hope for a negative result, particularly among siblings.

I just knew that I'd negative too because my sister was negative…I was hoping for negative, but expecting positive. – Parent (6)

Interestingly, physical similarities with family members of a particular mutation status were also found to contribute to the expectation of one’s own mutation status.
I knew [my daughter] would test positive. And the reason why I saw that is because we are so similar…like, we're the same height…we have the same body type…we look alike…My other daughter has not been tested and my gut says she won't test positive…I feel like she's a lot more similar to my ex-husband. – Parent (4)

In addition to predictability, positive BRCA1/2 results in the parent and its hereditary implications also caused uncertainty in both parents and adult children. However, the way they each reacted to the uncertainty contrasted between the two parties.

Parents looked to minimize the uncertainty introduced by the discovery of personal and hereditary risk through emotional and physical means. The most common reaction was to emphasize the knowledge the positive BRCA1/2 results provided. For six parents, the benefit of the new knowledge came from being able to take necessary action to counteract the increased risk.

If I had never been told that I was BRCA2 positive, I would have never been screening. Not at this point…I think it's a real positive thing that I found out. – Parent (3)

[The result] wasn’t a surprise, it was more empowering. It was, “Okay, what’s my next step, you know, to stop this cancer dead in its tracks, so it doesn’t get a hold of me.” – Parent (7)

The proactive mindset motivated 11 parents to pursue prophylactic measures to address the breast and ovarian cancer risks. Four parents specifically pointed out that their decision to pursue the invasive option was to address and overcome their fear of the risk of mortality related to cancer that they had known or seen through family members experiencing cancer. This feeling seemed to be stronger when the family member was a mother and the parent participant then did not want to leave their children mother-less themselves, much like they had experienced as a child. The parent in dyad 6 had experienced the death of her mother at a young age from ovarian cancer. The experience instilled a long-time fear of the possibility of a diagnosis and death from cancer.
I knew that it was either do this [prophylactic bilateral mastectomy] or eventually get cancer.

So it was, it was just not a choice...I’ve been processing fear for fifteen years, you know, and
at that point, I was like, nope we’re done…If this means that my chances go from here [up
high] to here [down low], then that’s what I want. – Parent (6)

Adult children, on the other hand, demonstrated an ongoing adjustment with or avoidance
of the hereditary risk information and associated BRCA experience. Dependent on whether they had
pursued testing, this approach indicated an embracement of the uncertainty with their mutation
status and/or cancer risks. With regards to mutation status, remaining in uncertainty was the
preferred option for three adult children. Notably, one of the three has tested as an adult since
feeling this way as an adolescent.

It's just given me some, one more thing I have to think about in regards to my own health,

one day...I’m not overly concerned and it’s, I’m okay just being in the dark a little bit longer.

– Adult child (12)

Ongoing adjustment was also observed after receiving results. For adult child (9), she pursued
testing and found out she was positive at 19.

For me, I'm glad that I did [testing] early and now have all these years to sort of, like, come
to peace with it. – Adult child (9)

For the cancer risks, in contrast with the 11 out of 14 parents (80%) who underwent the removal of
ovaries and breast tissues, only two of the six BRCA1/2-positive adult children (33%) pursued the
prophylactic mastectomy and the same number for the bilateral salpingo-oophorectomy. For the
breasts, high-risk screening with mammography and breast MRI is a viable alternative to
prophylactic surgery. However, while the prophylactic measure reduces the breast cancer risk by 90-
95%, the goal of surveillance is to catch the cancer at an early stage of development. The increased
cancer risk associated with BRCA1/2 and the greater uncertainty remains.
That’s not to say…that I don’t think I’m gonna *get* it…or that I…am not realistic that I could get it in the next few years, but…I mean, I’m doing all the screenings and stuff…I know my risk of developing cancer is higher, but they obviously have confidence in this screening processes, otherwise they won’t be doing that for people….At this point, at least, getting in the high risk clinics and doing surveillance. And, at some point, considering prophylactic surgeries as a[n] alternative. – Adult child (2)

Dialectic of Expression

The dialectic of expression involves a spectrum with openness, disclosure, and candor on one end, and discretion, privacy, and secrecy on the other. This tension was most prevalent in the communication about positive BRCA1/2 results between parents and adult children, particularly the first disclosure event.

With disclosure itself, attitudes of all 14 parents showed that it was not an issue of ‘if’ they were going to tell their children, representing openness.

There was never a doubt. I mean, I didn’t even think twice about it – Parent (11)

On the other hand, discussions of the parents’ decision-making process behind the ‘when’ and ‘what’ of disclosure revealed discretion due to the influence of various considerations. Six parents controlled the timing by delaying disclosure based on the circumstances of the child. Reasons included anticipated poor understanding of the child, lack of utility of the results for the child due to unavailable action items, and ongoing events unrelated to BRCA affecting the physical and/or mental capacity of the child.

I didn't follow-up for a little bit [with telling my children my results]…They were younger…my other [daughter] was only about, probably like twelve or something, so I wasn't, she wouldn't have understood anything then. – Parent (4)
I think when you’re BRCA positive, you share with your children when you think they’re mature enough to handle the information. – Parent (11)

In addition to the characteristics of the adult child, three parents first spent time adjusting to the results themselves before telling their children.

When I found out I was positive, it was a process that I needed to, to take in myself. So, I didn't come home and tell them right away. – Parent (3)

Notably, most parents (n = 13) communicated the results to their adult children in-person. The parent in dyad 12 prolonged the first conversation until the holidays when her adult children, who all lived out-of-state, would return home, in order to tell them the results in-person.

Similar to the parental discretion exhibited with the timing, control by the parent was also observed with the content of the first conversation. Three parents selectively filtered information related to BRCA1/2 based on perceived age-appropriateness.

You were a little girl…So it was…age-appropriate stuff. – Parent (9)

They were younger, you know, at the time…If they were older…I probably would’ve talked more about them getting tested. I didn’t even really go into that a whole lot at the time. But, you know, they’re old enough now, I think, that they could probably handle whatever result it was. – Parent (12)

Five parents purposely focused on the positive aspects, some of whom were motivated by minimizing the causes of concern for their adult children.

[My husband and I] were real careful about…not alarm[ing] her…That's why when we talked to her, we were like, "Here, this is what's going on, this is what's going on with me. But really, you just need to put this on the back shelf for a while because they're going to fix this.” – Parent (1)
Descriptions of the use of a particular tone also reflected discretion shown by parents. When sharing the results with their adult children, five parents described using a matter-of-fact tone.

There wasn't any, you know, big conversation with crying or...anything...very emotional. It was just, it was more factual, I guess. – Parent (4)

Two of the five parents specifically delineated that they consciously left emotion out of the conversation.

It's not an easy thing to, to separate...your emotional response to cancer and your, your intellectual response to cancer...All of that information [about the family history] started coming in and I had to really take a look at it and...approach it from...not an emotional response [but]...It was very intellectual and matter-of-fact. – Parent (9)

I think I kept it casual enough...Nobody wants to think about losing their parents and, you know, I wouldn’t wanna get somebody all worked up and worried about that...I think I was pretty matter-of-fact about it. – Parent (12)

The adult child may also direct the openness and discretion. For two dyads, the timing of the first disclosure was prompted by questions from the adult child. Notably, the parent had decided to delay disclosure for both dyads.

When my mom actually went to get tested, she, she kind of kept it away from us for a little while because we were young...So, I was unaware of what was going on...Eventually, I kept asking my mom, I was like, "Mom, why are you going to the doctors?" And she probably told us, "Hey, this is what's going on, I didn't want to tell you if I was negative, but." And she went through the entire [family] history. – Adult child (6)

Adult children reacted to the openness and discretion in different ways. Their parents’ decision with timing was appreciated by three adult children, specifically in reflection of the age they were told. One parent had delayed disclosure until her daughter reached college-age (dyad 4), one
parent had disclosed after adjusting to the news herself (dyad 11), and for the third dyad, the adult child had initiated disclosure (dyad 14)

I feel like I actually found out at a good age because I still like, I found out at a time where I was impacted by it and I was curious about it and I wanted to know more about it. – Adult child (11)

I feel like it was the right time, especially because I was curious about it at that point...If they had told me like when mom had gotten her result, like, I would not have understood it. I mean, I was like six, I mean, I was not gonna get it. I didn’t really know what was happening to her, so it, it wouldn’t made sense to tell me then. – Adult child (14)

On the other hand, discretion led to confusion or fear from not being able to fully comprehend the situation, results, or other aspect of the parents’ BRCA experience for five adult children.

I still didn't understand all of it. I understood the part about, like, they're going to take all her stuff out and make sure that my mom doesn't have cancer. I understood that part, I was very grateful for that. But after that was all done, I still didn't quite understand what they had done to my mom. – Adult child (6)

I think that the stress just, like, not fully understanding what was happening because I was too young to really get…I literally slept on my parents' floor for months. I guess I was just scared in general. – Adult child (9)

Importantly, conversations were found to continue beyond the initial conversation between the parent and adult child. Dyads described episodes indicating the gradual sharing of risk information related to BRCA1/2 over time. Events within the adult child’s BRCA experience encouraged discussions on BRCA1/2 to be revisited.

Once [she]...got to the point when she was deciding to...get tested, we talked about it a little bit more. – Parent (4)
Information-sharing could also be prompted by questions from the adult child.

I just felt that whatever I shared with [adult child] was going to be questions that she had for me. And when she had questions for me, I was going to answer them honestly…So, as she grew up and she started asking those questions, I answered them. – Parent (9)

Two parents sought the support of healthcare providers – the one who provided the parent their results – as an alternate source of information for the adult child. Both parents accompanied their adult children to this appointment, indicating another instance where the parent and adult child built on the first disclosure event.

I think that’s one reason we went to go see...my oncologist...because I felt like…I was giving her as much as I can give her and that maybe talking to an oncologist...would be a help as well. – Parent (14)

Support and Resources from Healthcare Providers

At the end of each interview, participants were asked about the support and/or resources they received or wished they had received from healthcare providers as part of their BRCA experience.

The most commonly mentioned theme was the frustration with having to educate providers about the implications of a positive BRCA1/2 result.

When I walk into an office and I know more than my primary doctor about [BRCA], that is frustrating to me. – Adult child (5)

Two adult children felt that hearing how to contextualize their parents’ positive results for themselves from a healthcare provider would have been helpful.

When you…hear [the news]…it’s…scary and confusing…You want to go look online and online doesn’t always [have] the best descriptions of things…It would’ve been more
beneficial to me…[to have] an actual doctor…[tell me] you could or you could not have it, [but] this is what it means for you. – Adult child (1)

For the two adult children whose parents had sought provider support to better inform them about the results, while some pieces of the information was redundant, they appreciated the opportunity to hear it from the expert and ask any questions they had.

Three participants wished their results disclosure could have been better. Parent (9) and her sister went to the initial genetic counseling consultation together and sought testing at the same time. The plan was for them to receive their results in the same in-person disclosure session. However, they received individual calls about their results. For adult child (2), the ordering provider had left a short voicemail just mentioning her positive results and did not follow-up further. Adult child (3) was notified that she was negative through “a piece of paper in the mail” and no discussion occurred with the provider.

Regarding resources, six dyads pointed out the specific population groups that they felt would benefit from targeted materials related to BRCA1/2: males, about sex-specific cancer risks (3 dyads); children, about cancer and hereditary risks associated with BRCA1/2 (2 dyads), such as story books, coloring books, and guidelines for parents on how to communicate their results to children; and, individuals discovering their positive mutation status in their 70’s, about the cancer risks to anticipate at that age (1 dyad).

Thinking about how young my children were…we tried to look for resources that would help…There really is nothing out there to explain this to kids and it's scary as a[n]…adult, so how do you break it down for a child about a scary problem. You can't. It's hard. It's a hard thing to go through and, really, there's no way to, you know, color it up for fun. – Parent (6)
Additionally, the parent and adult child in dyad 14 felt educational materials to help children understand a parent’s cancer diagnosis and guidance from other parents or providers on how a parent can navigate their diagnosis with their children would have been helpful as well.
DISCUSSION

This study explored the relational dynamics involved in the communication of positive BRCA1/2 results between parents and adult children. The complexities of the communication of BRCA1/2 have not been investigated using a theory of communication thus far. We believe that our observations using this unprecedented approach helped us explore the unique factors that influence the conversations between parents and adult children regarding hereditary risk information. Through dyadic interviews, we were able to gather the perspectives from both the parent and adult child. Furthermore, by interviewing both parties together, we were able to better observe the relational tensions that may influence communication in the play-by-play construction of their BRCA narrative.

The dichotomy of autonomy and integration is apparent when comparing between the testing journey of the parents and adult children. All parents made decisions related to testing autonomously. On the other hand, the adult children’s testing journey illustrated the varying degrees of autonomy the adult child can have and the integration the parent may seek. Responses to the parental integration indicated that adult children seek parental input on testing and management options, but want to make their decisions autonomously without control by the parent. Past studies have presented examples of the tension. In Clarke, Butler, and Esplen (2008), parents were found to struggle with their child’s decisions on testing when it was at odds with their own beliefs and wishes. Peterson et al. (2003) showed that there was incongruence between the motivations for testing for family members between index cases and at-risk relatives. Index cases saw testing as a necessity for health and communicated their strong desire for relatives to seek testing; however, relatives saw testing as an opportunity to know about hereditary risk. Parents and adult children may benefit from conversations about navigating the balance between autonomy and integration for the adult child’s BRCA experience.
Reactions to a positive BRCA1/2 result also varied between the parent and adult child groups. The consequent discovery of personal and/or familial risk reflected predictability or novelty depending on the perception of the cancer and hereditary risks. The influences of this risk perception on management decisions and adjustment to the results shaped how and which aspects of the BRCA experience were incorporated into an individual’s meaning-making process of a known familial risk of BRCA1/2 (Foster, Eeles, Ardern-Jones, Moynihan, & Watson, 2004; Tercyak et al., 2013). Family cancer history can impact how a parent and adult child contextualize personal and/or familial risk, sometimes inaccurately (Dancyger et al., 2011). Incorrect contextualization of risk can impact how and when information is shared with children, such as the appropriate age to begin considering testing or prophylactic surgeries. Clinicians may benefit from asking about a patient’s understanding of risk to themselves and to family members to clear any misconceptions the patient may have.

Characteristics of the results disclosure showed complex tensions between openness and discretion. The timing, content, and tone of the first disclosure event were primarily controlled by the parent. Many parents shared their challenges with determining when, what, and how to tell their children, which finding is consistent with past studies (Dancyger et al., 2011; Forrest et al., 2003; Hallowell et al., 2005; Tercyak et al., 2013; Wilson et al., 2004). Notably, similar themes were seen in the conversations that continued beyond the first disclosure. This indicates the ongoing nature of the relational tension and of the communication related to BRCA between parents and adult children. There are studies that describe the disclosure process to include three phases (Clarke et al., 2008; Gaff et al., 2007; Lafreniere, Bouchard, Godard, Simard, & Dorval, 2013). Our study suggests that these phases may occur continuously over time, providing further evidence that risk communication is a dynamic, multi-layered process (Bradbury et al., 2007; Lafreniere et al., 2013). When discussing disclosure to children, anticipatory guidance can be given to patients that
conversations do not have to be a one-time event and can be revisited over time. Guidance in the form of counseling or creation of support materials can show parents which aspects of BRCA may become relevant at what age or life stage. Delineating what will be appropriate to discuss at each time point may also promote continuous conversations about BRCA. Many families also wished for more age-appropriate and child-friendly educational booklets, such as story books and pamphlets. Collaboration with a childhood education specialist and a child development expert may address this need.

A common motivation for seeking testing is to inform family members, especially children, about the potential risk. The unique complexities of the relationship and communication dynamics in each parent-child pair were evident in the findings. This indicates the importance of exploring these dynamics in clinical settings to better support familial communication of positive BRCA1/2 results. Offering personalized guidance in consideration of the concerns and dynamics shared by the patient can facilitate conversations about hereditary risk in families.

Limitations

We recognize that our findings are not generalizable to all populations. The findings of this study were based on parents who have disclosed their positive BRCA1/2 results to their adult children. There was limited representation of males, which is a commonly observed phenomenon in BRCA1/2-related studies, and of ethnically/racially diverse individuals. We tried to seek greater diversity of our sample by extending recruitment to the national level and offering multiple interviewing methods. While our participants resided in many different states, ranged widely in age, and had various educational backgrounds, only one dyad identified as non-Caucasian.
Future Directions

In addition to achieving a greater sample size and increasing the representation of males and ethnically/racially diverse participants, hereditary risk communication within the family of other hereditary cancer predisposition genes and Mendelian genetic disorders can be explored. Lastly, we encourage the use of communication theories, such as the Relational Dialectics Theory, to further explore the patient and family experience related to such things like genetic testing within the larger context of interpersonal relationships.
CONCLUSION

This study sought to gain a better understanding of the communicative processes involved in the sharing of positive \textit{BRCA1/2} results from parent to adult child. The use of a theory grounded in the discipline of communication helped to explore the communicative processes involved in the familial communication of positive \textit{BRCA1/2} genetic testing results. By specifically focusing on the parent-adult child relationship, we gathered important knowledge on the unique dynamics that influence the \textit{BRCA1/2} experience in the individual and within the relationship. Furthermore, we gathered this information in an organic setting using a dyadic interview approach and allowed the exploration of the experience from the perspectives of both parties. Our findings suggest the importance of placing the \textit{BRCA1/2} experience within the context of each relationship dynamic. Understanding the factors that influence the hereditary risk communication process between parents and adult children also serve to better inform clinical practice. We hope this study can serve as a resource for clinicians to guide conversations with patients about the challenges and complexities of sharing results with family members, particularly with their children.
REFERENCES


Appendix A: Table 1 – Lifetime risk of developing cancer with BRCA1/2

<table>
<thead>
<tr>
<th>Type of cancer</th>
<th>Women</th>
<th>Men</th>
<th>BRCA1</th>
<th>BRCA2</th>
</tr>
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<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breast</td>
<td>50-85%</td>
<td>1-2%</td>
<td>6%</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(30-50% risk of developing before age 50)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ovarian</td>
<td>25-50%</td>
<td>15-30%</td>
<td>(N/A)</td>
<td></td>
</tr>
<tr>
<td>Prostate</td>
<td>(N/A)</td>
<td>Increased</td>
<td>20%</td>
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</tr>
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</table>
Appendix B: Table 2 – Screening/management recommendations for BRCA1/2 positive individuals

<table>
<thead>
<tr>
<th>Sex/Type of cancer</th>
<th>Screening</th>
<th>Frequency</th>
<th>Recommended age to begin</th>
</tr>
</thead>
<tbody>
<tr>
<td>WOMEN: Breast</td>
<td>Self-breast exam</td>
<td>Monthly</td>
<td>18</td>
</tr>
<tr>
<td></td>
<td>Clinical breast exam (*performed by health care professional)</td>
<td>Every 6 months</td>
<td>25</td>
</tr>
<tr>
<td></td>
<td>Breast MRI</td>
<td>Annual</td>
<td>25</td>
</tr>
<tr>
<td></td>
<td>Mammogram</td>
<td>Annual</td>
<td>30</td>
</tr>
<tr>
<td>WOMEN: Ovarian</td>
<td>Transvaginal ultrasound</td>
<td>Every 6-12 months</td>
<td>25-35</td>
</tr>
<tr>
<td></td>
<td>Measurement of CA-125 serum levels</td>
<td>Every 6-12 months</td>
<td>25-35</td>
</tr>
<tr>
<td>MEN: Breast</td>
<td>Self-breast exam</td>
<td>Monthly</td>
<td>30</td>
</tr>
<tr>
<td></td>
<td>Clinical breast exam</td>
<td>Annual</td>
<td>30</td>
</tr>
<tr>
<td></td>
<td>Mammogram</td>
<td>Only baseline needed</td>
<td>35</td>
</tr>
<tr>
<td>MEN: Prostate</td>
<td>Digital rectal exam + PSA blood test</td>
<td>Annual</td>
<td>40</td>
</tr>
<tr>
<td>BOTH: Pancreatic and melanoma</td>
<td>Dependent on the family history - consultation with appropriate health care professional needed</td>
<td></td>
<td></td>
</tr>
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Appendix C: Interview guide

Family dynamics/communication patterns

1. Tell me about your family.
   a. How would you describe the communication patterns within your family?
   b. Specifically, how do you talk about health or medical matters in your family?

2. Tell me about your relationship (with each other).
   a. Follow-up: How would you describe the communication style between you two?

3. How do you each take care of your health?
   a. Tell me about a time when you talked about a medical issue with each other.

BRCA testing: PARENT

1. Testing: What led to getting the genetic test?
   a. For adult child: How were you involved in that process?

2. Receiving the results: Tell me about when you got your results.
   a. For adult child: How were you involved?

3. Decision-making process: Tell me about the process you (parent) went through when deciding to share your results with (adult child name).
   a. For adult child: How were you involved in that process? How do you remember it?

4. Disclosure: How did you (parent) tell (adult child name) your positive result for BRCA1/2?
   a. For adult child: How do you remember it?
      i. Follow-up: What were your reactions? What went through your mind?

BRCA testing: ADULT CHILD

1. Testing: How did you (adult child) come to decide to get testing?
a. For parent: How were you involved in that process?

2. Receiving the results: Tell me about when you got your results.
   a. **Follow-up:** How did you feel?
   b. For parent: How were you involved?

3. Disclosure: Tell me how you told (parent) about your results.
   a. For parent: How do you remember it?

**Beyond disclosure**

1. Beyond disclosure
   a. What does the positive result mean for you today?
   b. Knowing the impact BRCA1/2 has had on you individually, how has it influenced your relationship?

2. What do you wish had gone differently?

3. Advice/suggestions
   a. What advice do you have for other parents considering disclosing their positive BRCA1/2 results to their children?
   b. What do you wish the healthcare provider who gave you the results had provided you to help talk about your results with your child (and other family members)?
### Appendix D: Table 3 – Participant demographics

<table>
<thead>
<tr>
<th></th>
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<tr>
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<tr>
<td>2</td>
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<td>Yes (breast, &lt; 50)</td>
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<td>3</td>
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<td>Yes (after testing)</td>
<td>40-49</td>
<td>BSO (planning on proph bilat mast)</td>
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</tr>
<tr>
<td>6</td>
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<td>Yes (after testing)</td>
<td>Yes (after testing)</td>
<td>18-19</td>
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<td>8</td>
<td>70-79</td>
<td>Yes (leukemia)</td>
<td>No (planning on proph bilat mast)</td>
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<td>Negative</td>
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<tr>
<td>9</td>
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<td>11</td>
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<td>No (lumpectomy for cancer, planning on proph bilat mast)</td>
<td>Yes (after testing)</td>
<td>30-39</td>
<td>Proph bilat mast</td>
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<td>Yes (after testing)</td>
<td>Yes (after testing)</td>
<td>20-29</td>
<td>No</td>
<td>Negative</td>
</tr>
</tbody>
</table>

(P: parent; AC: adult child; < 50: under the age of 50; BSO: bilateral salpingo-oophorectomy (removal of the ovaries); Proph bilat mast: prophylactic bilateral mastectomy; *: male)