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Predictors of Women's Intentions to Communicate Updated Genetic Test Results to Immediate and Extended Family Members

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Genetic testing · Multigene panel · Hereditary breast and ovarian cancer · Family communication · Theory of planned behavior

Abstract
Introduction: Many individuals who previously received negative genetic test results are eligible for updated testing. This study examined intention to communicate updated genetic test results to relatives in participants who previously received negative genetic test results. ***Methods:*** Women with a personal or family history of breast or ovarian cancer who tested negative for *BRCA1/2* before 2013 were enrolled between April 2018 and October 2019. Proportions were calculated to assess intention to communicate updated genetic test results to living immediate family, extended family, and all family. Potential predictors of intentions from the theory of planned behavior (attitudes, subjective norms, perceived behavioral control) were assessed. The three outcomes were analyzed using generalized linear models with a quasi-binomial probability distribution. ***Results:*** 110 women completed the baseline assessment prior to updated testing. Participants intended to communicate genetic test results to 90% of immediate family, 51% of extended family, and 66% of all living relatives. Participants with higher subjective norms (aOR = 1.93, 95% CI: 1.08–3.57) had higher intentions to communicate genetic test results to extended family, while participants with more positive attitudes (aOR = 1.27, 95% CI: 1.01–1.60) had higher intentions to communicate to all family. Placing higher importance on genetic information was associated with higher intentions to communicate to immediate family (aOR = 1.40, 95% CI: 1.06–1.83). Lower subjective numeracy was associated with higher intentions to communicate to extended family (aOR = 0.50, 95% CI: 0.32–0.76). ***Conclusion:*** Attitudes and subjective norms were predictors of intention to communicate updated genetic information to at-risk biological relatives, and predictors may vary by degree of relationship.

Introduction

Genetic test results have ramifications that extend beyond the individual, as that information can also influence the health decisions of biological family members. For example, a positive test result might prompt relatives to receive genetic testing themselves or to consider

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personalized clinical management approaches (e.g., cancer screenings). Conversely, a negative genetic test result can let other family members know that they may not need to undergo genetic testing themselves.

In recent years, more genes contributing to cancer risk have been discovered and included in multigene panel tests [1, 2]. Because of these genetic developments, the National Comprehensive Cancer Network (NCCN) recommends that individuals who received a negative genetic test result for the *BRCA1* and *BRCA2* genes before 2013 should consider updated genetic testing with a multigene panel test [3]. This context provides the opportunity to learn about past communication within families about prior negative *BRCA1/2* genetic test results as well as family communication about updated results from multigene panel testing.

Previous research on family communication about genetic test results has examined how many biological family members or what types of family members (i.e., immediate family and/or extended family) a patient communicates with [4–11]. Other studies have examined reasons for sharing test results (e.g., encouraging relatives' testing and informing their medical decisions) [11, 12] or barriers to communication of results (e.g., lack of geographic proximity, loss of contact, distress, number of *BRCA*-related cancer deaths in the family) [6, 13]. Family functioning and family relationship quality have emerged as predictors of family communication of genetic test results [9, 13–15]. Lack of a close relationship has been identified as a barrier in sharing genetic test information with distant relatives [8, 11, 16], as have relationship dysfunction, preexisting communication patterns, and cross-generational issues [16]. Some psychosocial factors predicting family communication have been identified, including worry about genetic risks, interest in genomic information, cancer prevention fatalism, and perceived ambiguity in cancer prevention recommendations [17, 18]. Demographic factors (e.g., age, gender, race, income, numeracy) have also been shown to predict family communication intentions or behaviors [10, 12, 17, 19], although these findings are inconsistent between studies [7].

Most of the prior studies have focused on positive *BRCA1/2* genetic test results, and little is known about factors predicting family communication of updated genetic test results from multigene panel testing. Type of genetic test results has been shown to be a factor in family communication. For example, previous research showed that women who had a negative *BRCA1/2* genetic test result had less communication with family members compared to women with a positive test result [18]. One possible reason for this finding is the perception, among at least some women, that a negative test result does not have health consequences for family members [20]. It is therefore important to examine intentions regarding family communication about updated genetic testing among women who previously tested negative for *BRCA1/2* pathogenic variants.

In addition, there is a need for additional examination of theory-based factors that predict different patterns of family communication. Identifying these factors is an important step in developing interventions to improve family communication of genetic test results. One possible framework is the theory of planned behavior (TPB) [21–23]. According to TPB, behavioral intentions are influenced by attitudes toward the behavior, subjective norms (i.e., beliefs about the expectations of others and motivation to comply with those beliefs), and perceived behavioral control [22, 23]. TPB has been utilized in previous studies to examine intentions to communicate genetic test results to family members [19, 24–26]. Global attitudes, specific subjective norms, and perceived behavioral control have all been shown to predict intention to communicate to first-degree family members about *BRCA1/2* genetic test results [24, 25]. Another study found that injunctive norms (i.e., perceptions of others' approval), but not attitudes, were positively associated with disclosure of genome sequencing results to children and siblings [27]. TPB has also served as the foundation for a family genetic risk communication framework [28]. However, TPB has not previously been utilized to examine communication of updated multigene panel genetic test results to both immediate and extended family members.

The aims of this study were therefore to (1) examine whether factors from the TPB (i.e., attitudes, subjective norms, and perceived behavioral control) and family functioning predicted intentions to communicate updated genetic test results among women who previously tested negative for pathogenic variants in *BRCA1/2* and (2) investigate whether the same factors predicted intentions for family communication with first-degree (i.e., parents, siblings, children) versus second/third-degree family members (i.e., grandparents, grandchildren, aunts, uncles, nephews, nieces, cousins).

Methods

Participants

Recruitment of participants has been described previously [29]. Briefly, women 18 years of age or older who had a negative *BRCA1/2* genetic test result before 2013, had a personal or family

history of breast or ovarian cancer, and had not received updated multigene panel testing were eligible to participate. Participants were enrolled by the Huntsman Cancer Institute (HCI) at the University of Utah between April 2018 and October 2019. Women were excluded if they had already received a multigene panel test, had *BRCA1/2* testing for a familial pathogenic variant, or had entered hospice care. Potential participants were identified by (1) using an HCI database of patients who had undergone clinical genetic testing; (2) ascertaining eligible women from a prior research study conducted from 2010 to 2013; and (3) approaching eligible patients attending HCI's genetic counseling clinic during the study's accrual period. All of these patients had been previously counseled by the cancer genetic counseling team at HCI with two contacts, a pretest genetic counseling appointment and an appointment to return the results from *BRCA1/2* testing. Women who completed the informed consent process and agreed to participate in the study were asked to complete a baseline survey prior to genetic counseling. These analyses are conducted with baseline survey data. This study was approved by the University of Utah Institutional Review Board.

Measures

Outcome Variables

Family Communication with First-Degree (Immediate) Relatives. The outcome measures were assessed as a proportion score (range 0–1) based on previous research [18, 30]. The first outcome measure indicated how many types of living first-degree relatives with which a participant was intending to share updated genetic test results. For the denominator, participants were asked if they had a living mother, father, brother(s), sister(s), daughter(s), or son(s). The denominator thus had a possible range of 0–6. Two participants reported having half-siblings, which were coded as first-degree relatives since open-ended comments indicated that they thought of these individuals as siblings. For the numerator, participants were asked, "Would you share your upcoming genetic test results with the following family members?" with the response options being "yes," "no," or "not applicable" for each of the six types of family members listed above. If participants marked intent to communicate with a type of relative they did not mark as living, the relative in question was coded as living.

Family Communication with Second/Third-Degree (Extended) Relatives. The outcome measure of communication to second- and third-degree relatives combined was assessed similarly as first-degree relatives. Participants were asked if they had living grandmother(s), grandfather(s), granddaughter(s), grandson(s), aunt(s), uncle(s), niece(s), nephew(s), female cousin(s), or male cousin(s). The denominator thus had a possible range of 0–10. The same question about intentions to share updated genetic test results was asked for the numerator. Data for a relative type were considered missing if participants indicated being unsure whether they had that relative type.

Family Communication with All Relatives. The data for first- and second/third-degree relatives were combined into a third outcome measure, meaning the denominator had a possible range of 0–16.

Predictor Variables

Attitudes. Variables assessing components of TPB were adapted from prior research [21, 22, 24, 25, 31]. Participants were asked to rate on a 7-point scale if talking to family members about genetic results would be as follows: bad (1)-good (7), unpleasant (1)-pleasant (7), foolish (1)-wise (7), and upsetting (1)-comforting (7) [21, 24, 25]. The score was calculated as an average of the four questions with higher values indicating more positive attitudes (continuous variable with range 1–7).

Subjective Norms. Subjective norms were assessed using three items: "The people who mean the most to you think you should talk to family members about your genetic test results," "Most people like me talk to family members about their genetic test results," and "My family members have a favorable opinion that I learn about my genetic test results" [25, 31]. The items were answered with a 5-point Likert scale from "strongly disagree" (1) to "strongly agree" (5) and calculated as an average score (continuous variable with range 1–5). For motivation to comply, participants were asked "How motivated are you to do what these people want you to do?" [25, 31]. The item was answered with a 5-point Likert scale from "not at all motivated" (1) to "very motivated" (5) (continuous variable with range 1–5).

Perceived Behavioral Control. Four items were asked: "For me, talking to my family members about the genetic test results would be easy," "I am confident that I can talk to my family members about the genetic test results," "I have sufficient knowledge to share my genetic test results with family members," and "I will be able to explain the results to family members" [22, 25]. The items were answered with a 5-point Likert scale from "strongly disagree" (1) to "strongly agree" (5) and calculated as an average score (continuous variable with range 1–5).

McMaster's Family Assessment Device. To assess family functioning, participants were asked a series of 12 questions on a 4-point Likert scale (i.e., "Planning family activities is difficult because we misunderstand each other" or "We are able to make decisions about how to solve problems") [32–34]; the overall general functioning score was calculated as an average. The scores were calculated so that higher values indicated "healthier" family functioning (continuous variable with range 1–4).

Covariates

Covariates were identified based on previous research as factors related to family communication about genetic information [18, 30].

Cancer Worry. Participants were asked to rate the degree of worry for 3 items: future diagnostic tests, cancer besides breast or ovarian, and developing cancer or cancer returning [18, 35]. The items were answered with a 4-point Likert scale from "not at all" (1) to "very much" (4) and calculated as an average score (continuous variable with range 1–4).

Genetic Worry. Participants were asked to rate the degree of worry for 3 items: "Your genes put you at increased risk for developing a common disease like heart disease or diabetes," "You have a health condition that was caused primarily by your genes," and "Your relatives could be affected with a genetic condition that you have passed on" [18, 36]. The items were answered with a 7-point Likert scale from "not at all worried" (1) to "extremely worried" (7) and calculated as an average score (continuous variable with range 1–7).

Cancer Risk Perceptions. Participants were asked, "Compared to other people your gender, age, and race, how likely do you think you are to get each of the following types of cancer (breast, ovarian, uterine, colon) or develop each type of cancer again in your lifetime." The 4 questions (1 for each cancer type) were answered with a 5-point Likert scale from "a lot less likely" (1) to "a lot more likely" (5) and calculated as an average score (continuous variable with range 1–5).

Table 1. Participant characteristics (n = 110)

	Mean (SD) or *n* (%)	Possible range	Cronbach's alpha (# items)
Age	59.84 (0.72)		
Age categories, *n* (%)			
<50	17 (15.5)		
50–59	33 (30)		
60–69	31 (28.2)		
≥70	29 (26.4)		
Race, *n* (%)			
Asian	1 (0.9)		
White	105 (95.5)		
Missing	4 (3.6)		
Ethnicity, *n* (%)			
Hispanic/Latino	1 (0.9)		
Not Hispanic/Latino	104 (94.5)		
Missing	5 (4.5)		
Jewish ancestry, *n* (%)			
Not Jewish	105 (95.5)		
Jewish	4 (3.6)		
Missing	1 (0.9)		
Educational attainment, *n* (%)			
Some college or less	32 (29.6)		
College degree	32 (29.6)		
More than college degree	44 (40.7)		
Missing	2 (1.8)		
Marital status, *n* (%)			
Married	90 (82.6)		
Widowed/separated/divorced	16 (14.7)		
Never married	3 (2.8)		
Missing	1 (0.9)		
Sharing prior *BRCA1/2* results			
All family, *n* (%)	30 (27.8)		
Some family, *n* (%)	75 (69.4)		
No family, *n* (%)	3 (2.8)		
Missing, *n* (%)	2 (1.8)		
McMaster FAD general functioning[a]	3.38 (0.53)	1–4	0.837 (12)
Attitudes[b]	6.14 (0.93)	1–7	0.736 (4)
Subjective norms[c]	4.32 (0.74)	1–5	0.729 (3)
Motivation[a]	3.52 (1.16)	1–5	
Perceived behavioral control	4.46 (0.72)	1–5	0.848 (4)
Cancer worry[d]	2.54 (0.75)	1–4	0.792 (3)
Genetic worry	3.50 (1.40)	1–7	0.717 (3)
Cancer risk perceptions[c]	2.79 (0.91)	1–5	0.730 (4)
Importance of genetic information[d]	5.88 (1.48)	1–7	
Subjective numeracy[d]	4.74 (0.92)	1–6	0.849 (8)

SD, standard deviation. [a] n = 108. [b] n = 105. [c] n = 107. [d] n = 109.

Importance of Genetic Information. Participants were asked, "How important it is to learn more about how your genes may have affected your chance of getting breast cancer" [37]. The item was answered with a 7-point Likert scale from "not at all important" (1) to "very important" (7) (continuous variable with range 1–7).

Subjective Numeracy. The Subjective Numeracy Scale is an 8-item scale that assesses self-reported numerical ability and preferences [38, 39]. The scale consists of a numerical ability subscale and a numerical preference subscale with each item using 6-point Likert scale. The score was calculated as an average of the eight questions with higher values indicating higher subjective numeracy (continuous variable with range 1–6).

Sharing Prior BRCA1/2 Test Results. Participants were asked "Did you share your prior genetic test results (e.g., for the genes *BRCA1* and *BRCA2*)?" with the response options being "all family," "some family," or "no family." This was treated as a binary variable (some/no family vs. all family as the reference).

Table 2. Intentions to communicate about updated multigene panel test results with different types of family members (n = 110)

Relative	Report having type of living relatives	Intend to share information with living relatives[a]
Mother, *n* (%)	44 (40.0)	39 (88.6)
Father, *n* (%)	37 (33.6)	32 (86.5)
Sister, *n* (%)	82 (74.6)	74 (90.2)
Brother, *n* (%)	87 (79.1)	72 (82.8)
Daughter, *n* (%)	82 (74.6)	80 (97.6)
Son, *n* (%)	74 (67.3)	71 (96.0)
Grandmother, *n* (%)	4 (3.6)	4 (100)
Grandfather, *n* (%)	3 (2.7)	1 (33.3)
Granddaughter, *n* (%)	53 (48.2)	37 (69.8)
Grandson, *n* (%)	49 (44.6)	25 (51.0)
Aunt, *n* (%)	98 (89.1)	40 (40.8)
Uncle, *n* (%)	90 (81.8)	23 (25.6)
Niece, *n* (%)	89 (80.9)	69 (77.5)
Nephew, *n* (%)	86 (78.2%)	46 (53.5%)
Female cousin, *n* (%)	99 (90.0)	64 (64.7)
Male cousin, *n* (%)	95 (86.4)	39 (41.1)
Outcome measure	**Mean (SD)**	
First-degree relatives	0.90 (0.18)	
Second/third-degree relatives	0.51 (0.35)	
All relatives	0.66 (0.23)	

SD, standard deviation. [a]Denominator is the number of reported living relatives in the first column.

Other Covariates. Additional data were collected on the following demographic characteristics: current age, race, ethnicity, Jewish ancestry, marital status, and educational attainment. Age was analyzed as a continuous variable. Race (Caucasian/white vs. not Caucasian/white), ethnicity, Jewish ancestry, and marital status (married/living together vs. not married/not living together) were analyzed as binary variables; education (some college or less, college degree, more than college) was analyzed as a categorical variable.

Reliability. For variables calculated as an average of multiple items (attitudes, subjective norms, perceived behavioral control, McMaster family functioning, cancer worry, genetic worry, cancer risk perceptions, and subjective numeracy), internal consistency was measured using standardized Cronbach's alpha (alpha ≥ 0.90 as excellent, 0.80 ≤ alpha < 0.90 as good, 0.70 ≤ alpha < 0.80 as acceptable, 0.60 ≤ alpha < 0.70 as questionable, alpha < 0.60 as poor or unacceptable).

Data Analysis

The three family communication outcomes (first-degree relatives, second/third-degree relatives, and all relatives) were analyzed using generalized linear models with a quasi-binomial probability distribution [40]. Model selection was conducted using the Collett approach [41] which involves four steps: univariate selection (step 1), backward selection after fitting a multivariate model with all step 1 statistically significant ($p < 0.05$) univariate covariates (step 2), forward selection of all step 1 nonsignificant univariate covariates (step 3), and final pruning via stepwise selection and addition of interactions (step 4). For each model, only interactions with the main predictor were considered. For the models with all predictors, no interactions were explored. For each step, instead of looking at p values for the likelihood ratio test, the addition or elimination of covariates was determined using quasi-Akaike's information criterion. Any covariates statistically significant ($p < 0.05$) in the fully adjusted model were included in the corresponding parsimonious model despite quasi-Akaike's information criterion model selection procedures. Analyses were performed using R (version 4.0.3); statistical significance was assessed as $p < 0.05$.

Results

Characteristics of Participants

Out of the 113 women that were enrolled, 110 completed the pretest survey. Demographic characteristics of the participants are presented in Table 1. The mean (M) age was 59.8 (standard deviation [SD] = 0.7) years, and the majority were married/living with a partner (83%) and had at least a college education (70%). Slightly more than a fourth of participants (28%) shared prior *BRCA1/2* results with all of their family and two-thirds (69%) with some of their family. On average, participants had high McMaster FAD general functioning scores (M = 3.4), positive attitudes (M = 6.1), high subjective norm scores (M = 4.3), and high perceived behavioral control (M = 4.5)

Table 3. Univariate associations between predictors and covariates (crude odds ratio (95% CI)) on intention to communicate to family members about genetic test results

	First-degree relatives	Second/Third-degree relatives	All relatives
Predictors			
McMaster FAD (*n* = 108)	1.23 (0.60–2.47)	1.25 (0.76–2.08)	1.22 (0.84–1.76)
Attitudes (*n* = 105)	1.33 (0.90–1.90)	1.58 (1.17–2.19)***	1.35 (1.10–1.67)**
Subjective norms (*n* = 107)	1.09 (0.64–1.77)	2.28 (1.56–3.43)***	1.63 (1.27–2.11)***
Motivation (*n* = 108)	1.15 (0.83–1.59)	1.45 (1.16–1.85)***	1.29 (1.10–1.52)***
Perceived behavioral control (*n* = 110)	1.18 (0.70–1.83)	1.45 (1.00–2.18)	1.29 (1.00–1.68)
Sharing prior *BRCA1/2* results (*n* = 108)			
All family	Reference	Reference	Reference
Some/no family	0.37 (0.11–1.00)	0.71 (0.39–1.27)	0.65 (0.41–1.00)
Covariates			
Cancer worry (*n* = 109)	1.78 (1.08–3.00)*	1.24 (0.88–1.77)	1.30 (1.00–1.68)
Genetic worry (*n* = 110)	1.04 (0.80–1.38)	1.14 (0.95–1.38)	1.15 (1.00–1.32)
Cancer risk perceptions (*n* = 107)	1.29 (0.85–1.99)	0.98 (0.73–1.31)	1.05 (0.85–1.30)
Importance of genetic info (*n* = 109)	1.34 (1.07–1.68)*	1.32 (1.10–1.60)***	1.28 (1.13–1.45)***
Subjective numeracy (*n* = 109)	1.07 (0.70–1.60)	0.66 (0.49–0.89)*	0.78 (0.63–0.97)*
Age (*n* = 110)	0.98 (0.94–1.01)	0.98 (0.96–1.00)	0.98 (0.96–1.00)
Education (*n* = 108)			
Some college or less	Reference	Reference	Reference
College degree	0.82 (0.30–2.16)	0.89 (0.44–1.78)	0.93 (0.55–1.55)
More than college degree	1.09 (0.41–2.79)	0.91 (0.48–1.74)	0.99 (0.61–1.59)
Marital status (*n* = 109)			
Married/living together	Reference	Reference	Reference
Not married/living together	1.23 (0.47–3.95)	1.66 (0.83–3.42)	1.40 (0.82–2.43)

* $p < 0.05$. ** $p < 0.01$. *** $p < 0.001$.

related to communication about updated genetic test results. Variables that were calculated as an average of several items demonstrated acceptable to good reliability (standardized Cronbach's alpha 0.717–0.849).

Of first-degree relatives, the highest proportion intended to share updated genetic test results with a daughter (98%) and the lowest to share with a brother (83%). Of second/third-degree relatives (with the exception of grandmothers), the highest proportion of participants intended to share with a niece (78%) and the lowest to share with an uncle (26%). On average, participants intended to communicate updated genetic test results to the majority of first-degree relatives (proportion of 0.90), about half of second/third-degree relatives (proportion of 0.51) and, overall, about two-thirds of all living relatives (proportion of 0.66) as seen in Table 2.

Univariate Models for Predictors of Family Communication

In univariate analyses (Table 3), none of the TPB or family functioning predictors were significantly related to intention to communicate to first-degree relatives. For the other two family communication outcomes, significant predictors of intention to communicate included higher perceived behavioral control (OR = 1.45, 95% CI: 1.00–2.18 for second/third-degree relatives and OR = 1.29, 95% CI: 1.00–1.68 for all relatives), positive attitudes (OR = 1.58, 95% CI: 1.17–2.19 for second/third-degree relatives and OR = 1.35, 95% CI: 1.10–1.67 for all relatives), higher subjective norms (OR = 2.28, 95% CI: 1.56–3.43 for second/third-degree relatives and OR = 1.63, 95% CI: 1.27–2.11 for all relatives), and higher motivation to comply (OR = 1.45, 95% CI: 1.16–1.85 for second/third-degree relatives and OR = 1.29, 95% CI: 1.10–1.52 for all relatives).

Significant covariates of intention to communicate included higher cancer worry (OR = 1.78, 95% CI: 1.08–3.00 for first-degree relatives), placing higher importance on genetic information (OR = 1.34, 95% CI: 1.07–1.68 for first-degree relatives; OR = 1.32, 95% CI: 1.10–1.60 for second/third-degree relatives; and OR = 1.28, 95% CI: 1.13–1.45 for all relatives), and lower subjective numeracy (OR = 0.66, 95% CI: 0.49–0.89 for second/third-degree relatives and OR = 0.78, 95% CI: 0.63–0.97 for all relatives).

Table 4. Impact of all predictors (adjusted odds ratio [95% CI]) on intention to communicate with family members about genetic test results

	First-degree relatives (*n* = 100)	Second/third-degree relatives (*n* = 99)	All relatives (*n* = 99)
McMaster FAD	1.22 (0.45–3.21)	1.10 (0.58–2.09)	1.10 (0.71–1.69)
Attitudes	1.24 (0.77–1.94)	1.38 (0.94–2.06)	1.27 (1.01–1.60)*
Subjective norms		1.93 (1.08–3.57)*	
Motivation	1.03 (0.67–1.55)	1.15 (0.84–1.56)	1.21 (1.00–1.46)
Perceived behavioral control	0.96 (0.45–1.75)	1.10 (0.68–1.81)	1.05 (0.78–1.40)
Genetic worry		1.15 (0.91–1.45)	1.13 (0.97–1.33)
Cancer risk perceptions	1.28 (0.77–2.16)	0.83 (0.57–1.21)	0.94 (0.74–1.20)
Importance of genetic info	1.40 (1.06–1.83)*		
Subjective numeracy	1.12 (0.67–1.83)	0.50 (0.32–0.76)***	
Education			
Some college or less		Reference	Reference
College degree		1.99 (0.82–4.99)	0.99 (0.57–1.71)
More than college degree		1.71 (0.71–4.21)	0.96 (0.57–1.61)
Marital status			
Married/living together		Reference	
Not married/living together		1.76 (0.73–4.38)	

Variables (predictors and covariates) for each family communication multivariable model were selected during a 4-step process using the Collett approach. Thus, different variables were retained in the final models for each outcome. * $p < 0.05$, *** $p < 0.001$

Multivariable Analysis of Predictors of Family Communication

In multivariable models, the tested TPB and family functioning variables were not significant predictors of intentions to communicate updated genetic test results to first-degree relatives (Table 4). Of the covariates, higher importance of genetic information was a significant predictor (aOR = 1.40, 95% CI: 1.06–1.83). For the model assessing predictors of intention to communicate updated genetic test results to second/third-degree relatives, higher subjective norms were a significant predictor (aOR = 1.93, 95% CI: 1.08–3.57). Lower subjective numeracy (aOR = 0.50, 95% CI: 0.32–0.76) was also significant in the adjusted model. For the model predicting intentions to communicate with all relatives, more positive attitudes (aOR = 1.27, 95% CI: 1.01–1.60) were a significant predictor.

Discussion

This study explored factors affecting family communication intentions among women who previously tested negative for *BRCA1/2* and were eligible for an updated multigene panel test. In our multivariable analysis, we found that participants that placed higher importance on genetic information had higher intentions to communicate with immediate family; those with higher subjective norms and lower subjective numeracy had higher intentions to communicate with extended family; and those with positive attitudes had higher intentions to communicate with all family. Consistent with previous research, participants indicated that they intended to communicate more with first-degree relatives (90%) than second- or third-degree relatives (51%) [4–11], and consistent with our prior work, they had higher intentions to communicate with female than male relatives [18]. These findings suggest barriers to sharing updated genetic test results with male relatives as well as extended family members. Past studies have aimed to identify these barriers. Healey et al. [6] (2007) found that loss of contact, closeness of relationships, and geographical separation were barriers to sharing *BRCA1/2* genetic test results with extended family members, specifically cousins. McGivern et al. [4] (2004) found that participants wanted more emotional support from female relatives and suggested that methods for communicating genetic test results to male relatives may be different from methods used for female relatives. This study also found a greater sense of urgency in communicating genetic test results with female relatives than with male relatives. Higher frequency of communication

has been associated with communication with immediate family members [42], while the lack of a close relationship may be a barrier to sharing with extended family members [8]. Furthermore, the assumption that extended relatives would be told about a result by other relatives rather than directly by the patient can be a barrier to communication with second/third-degree relatives [4, 8].

Our study adds to this literature by examining whether the same variables predict intentions to communicate with immediate and extended family members. We found that different variables were predictive based on degree of relationship, suggesting that different family communication processes may be acting as information spreads through a family network. Our prior research with Lynch syndrome families has suggested that processes for informing immediate relatives about genetic test results are different from those for extended family members [8], but little research has explored this issue for families receiving other types of genetic test results. Notably, our study population was different than that of many previous studies in this area. While the majority of previous studies recruited individuals that tested positive for *BRCA1/2*, the participants in our study were those that had previously tested negative.

Of the tested predictors drawn from the TPB, as well as family functioning, none were significantly associated with intentions to communicate with first-degree relatives. However, we did find associations as suggested by the TPB in the other models, which showed that subjective norms were significantly associated with intentions to communicate with second/third-degree relatives, and attitudes were associated with overall family communication intentions. Notably, these findings suggest that different variables are predictive of communication with immediate versus extended family members. The findings presented here for immediate family members are not consistent with prior literature on TPB-related variables, which has shown that attitudes, subjective norms, and perceived behavioral control are related to intention to communicate *BRCA1/2* genetic test results to first-degree family members [24, 25]. Our results may differ because the population studied here had already had the opportunity to communicate with family members about negative *BRCA1/2* results, and different predictors may be important in conversations that would update the family's understanding of their genetic risk. For example, we did not investigate attitudes and experiences explicitly related to those prior conversations, which might predict future communication. Less research has investigated predictors of communication with extended family members, but our prior research has shown less communication with extended family members about genetic test results compared with immediate family members [8]. It is possible that these differences in prior experiences may lead to different predictors of intentions to communicate in the future, as observed here.

Prior literature has also suggested that family functioning may be a predictor of family communication of genetic test results [9, 13–15]. In the present study, however, family functioning was not associated with intentions to communicate with family members of any degree of relationship. It is possible that family functioning is more predictive of initial disclosure of genetic test results than with updated results. For example, because almost all of the participants in this study had the experience of communicating with at least some family members about their prior *BRCA1/2* results, they may have built more of a foundation for future conversations about genetic information. In addition, the participants reported fairly high levels of family functioning, and family functioning may be more predictive in families with lower functioning. In our study, the distribution of family functioning was negatively skewed with limited variability; this could explain why it was not associated with intentions to communicate. Future studies could also examine functioning of specific familial relationships rather than overall family functioning and associations with family communication of genetic test results.

In addition to our findings for the main predictors, we found that higher perceived importance of genetic information predicted greater intention to communicate updated genetic results to first-degree relatives. These findings are complementary to prior work that has found that if genetic test information is thought not to be important, individuals might not disclose the information [43]. These findings, taken together, therefore suggest that interventions to promote family communication about genetic test results to immediate family members may need to emphasize the importance of the genetic information for biological relatives. For example, genetic counselors could emphasize in a return of results visit the implications of a positive or negative result for both immediate and extended family members. This verbal information could be supplemented by a letter for patients to share with family members that includes the information.

We also found that those with lower numeracy had higher intentions to communicate with extended family members about updated test results. Our prior research had found that self-reported numeracy preferences were related to interest in learning genetic test results, and those with higher numeracy were interested in more information about a genetic test result [44, 45]. Other research has

found that higher numeracy is associated with correct interpretation of uninformative genetic test results [46]. However, little research has been done on how numeracy ability and preferences impact communication about genetic test results, which often include numeric presentations of risk. These findings therefore highlight the importance of examining how to support patients with a range of numeracy in conveying genetic information to their family members. For example, future research could test different approaches to letters for patients to share with relatives that explain the genetic information utilizing best risk communication practices (e.g., icon arrays) and/or provide verbal interpretation to accompany numeric risks [47].

The results of this study should be considered in light of its limitations. The study participants had limited variability in race and ethnicity and were from a single region in the USA, and the findings may therefore not be generalizable to other populations. The small sample size of our study ($n = 110$) is another limitation. However, it should be noted that many of the previous studies also had small sample sizes ($n < 150$) [4, 5, 8, 9, 11–14, 16, 17, 19, 20]. Although our study consisted of multiple analyses, our methods did not include an adjustment for multiple hypothesis testing. As has become standard practice, $p < 0.05$ was the threshold for statistical significance in all of our analyses. If a Bonferroni correction for multiple hypothesis testing was implemented, many of the predictors and covariates in the models would still be statistically significant under an adjusted threshold ($p < 0.01$), as shown in Tables 3 and 4. We examined only intent to communicate with biological family members and did not examine intent to communicate with other members of patients' social networks [48]. In addition, the communication measures were not able to assess the content of family communication or communication with individual family members, which are important areas for further investigation. Lastly, our study examined intentions to communicate, which may not reflect actual communication to family members after undergoing updated genetic testing. However, our theory-based results can be utilized in developing interventions to improve family communication.

Conclusion

Our study suggests that factors from the TPB, particularly attitudes and subjective norms, may be effective potential points of intervention to enhance family communication about updated genetic test results. However, the findings also highlight that different communication processes may affect communication with immediate and extended family members, and different intervention strategies may be needed for these different processes to ensure that more distant family members receive the genetic information. Genetic providers play a key role in emphasizing the importance of communicating genetic test results to family members and providing strategies to overcome barriers to this communication. Genetic providers could place an emphasis on the importance of communicating genetic test results to male and extended relatives and help provide strategies to overcome the barriers to this communication.

Future studies could explore effective counseling interventions to assist patients in disclosing genetic testing to male and extended relatives. For example, intervention approaches that might support communication with extended family members could include group education to a family, provided by a genetic counselor or health educator, or letters designed for patients to share with extended family members. The importance of sharing genetic test results related to breast and ovarian cancers with male family members may also need to be emphasized in these interventions, as the potential of these results for men's cancer risks and the risks of their children may not be as clear. The results of this study can therefore inform the development of a family communication intervention to diffuse updated genetic information throughout a family so that relatives are able to make decisions about genetic testing and clinical management for themselves.

Statement of Ethics

This study protocol was reviewed and approved by the Institutional Review Board at the University of Utah, approval number IRB_00102175. 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. Written informed consent was obtained from all patients before being included in the study.

Conflict of Interest Statement

The authors have no competing interests/conflicts of interest to declare that are relevant to the content of this article.

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Author Contributions

Conceptualization: Ashley Elrick, Wendy Kohlmann, and Kimberly Kaphingst; methodology and funding acquisition: Ashley Elrick and Kimberly Kaphingst; statistical analysis: Carolyn Winskill, Melody Goodman, and Kimberly Kaphingst; writing – original draft preparation: Carolyn Winskill, Brianne Daly, and Kimberly Kaphingst; writing – review and editing: Carolyn Winskill, Melody Goodman, Brianne Daly, Ashley Elrick, Ryan Mooney, Whitney Espinel, Wendy Kohlmann, and Kimberly Kaphingst; resources: Whitney Espinel and Kimberly Kaphingst; supervision: Kimberly Kaphingst. We confirm that the manuscript has been read and approved by all named authors and that there are no other persons who satisfied the criteria for authorship.

Data Availability Statement

All data generated or analyzed for this study are included in this article. Further inquiries can be directed to the corresponding author.

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