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Cancer Risk Information Sharing: The Experience of Individuals Receiving Genetic Counseling for *BRCA1/2* Mutations

Ishveen Chopra¹ and Kimberly M. Kelly^{1,2}

¹Department of Pharmaceutical Systems and Policy, School of Pharmacy, Robert C. Byrd Health Sciences Center, West Virginia University, Morgantown, West Virginia, USA

²Mary Babb Randolph Cancer Center, West Virginia University, Morgantown, West Virginia, USA

Abstract

Genetic counseling and testing for familial cancer is a unique context for the communication of risk information in the family. This study utilized a theoretical framework based on the family systems perspective to understand intra-familial cancer risk communication patterns in the Ashkenazi Jewish population. Individuals (n=120) at an elevated risk for *BRCA1/2* mutations were included. Change in communication patterns over time was assessed using McNemar tests. Associations with communication patterns were assessed with multivariable logistic regression. Overall, the proportion of participants encouraged by others significantly ($P<0.001$) increased from pre- to post-genetic counseling. A higher proportion of participants were encouraged by female family members compared to male family members. Participants who were older, had no personal history of cancer, and had a higher cancer risk perception were more likely to be encouraged by others for genetic testing. Participant's intent to encourage family members for genetic testing from pre-counseling to post-receipt of genetic test results decreased by 16.7%. Participants who had no personal history of cancer and had informative test results for a *BRCA1/2* mutation were more likely to encourage other family members for genetic testing. In addition, qualitative findings suggested that closeness among family members, concern for family, especially future generations, and cognizance about cancer risk facilitates information sharing and encouragement for genetic testing. Our findings indicate that intra-familial cancer risk communication varies with structure of family relationships, where genetic counseling played an important role in improving intra-familial cancer risk communication.

Genetic testing affects both the individual and the entire family (Peterson et al., 2003). Genetic testing represents a specific area for the communication of intricate cancer genetic information to assist individuals in decision-making about cancer prevention and treatment (Hughes et al., 2002), particularly in the case of *BRCA1/2* mutations. These mutations confer an elevated risk of breast (*BRCA1* up to 82%, *BRCA2* up to 95%) and ovarian (*BRCA1* up to 63%, *BRCA2* up to 47%) cancer in women (Easton, Ford, & Bishop, 1995; Ford et al., 1998) as well as breast cancer in men (*BRCA1* up to 2.8%, *BRCA2* up to 12%) (Tai, Domchek, Parmigiani, & Chen, 2007). Genetic counseling aims to provide information

Address correspondence to Kimberly M. Kelly, Department of Pharmaceutical Systems and Policy, School of Pharmacy, Robert C. Byrd Health Sciences Center, West Virginia University, PO Box 9510, Morgantown, WV 26506, USA. kmkelly@hsc.wvu.edu.

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and support as individuals proceed through this challenging decision-making environment, initially to determine whether they want to pursue genetic testing and then to determine the course of action to manage the cancer threat (Hughes et al., 2002). Further, genetic counseling discusses the cancer risk implications for family members and encourages individuals to communicate this information to the members of their family (ASHG, 1998; Robson et al., 2010). Despite routine recommendation to individuals undergoing genetic testing about communicating risk to family, about 20–40% of at-risk family members remain unaware of relevant genetic information (Hodgson et al., 2014).

The family serves as a vital communication nexus for information exchange and for the adoption of cancer risk reduction strategies. Communication and support within the family affect participation in genetic counseling and testing (Koehly et al., 2003). Communication within the family about *BRCA1/2* mutations is important to assure that individuals understand and accurately convey risk information in a timely manner (Green, Richards, Murton, Statham, & Hallowell, 1997; Koehly et al., 2003). Therefore, informing family members of their cancer risk is often a key reason for seeking risk assessment and may motivate individuals to share information with family members with whom they have little contact (MacDonald et al., 2007).

Genetic counseling may play an important role in motivating individuals to communicate cancer risk with their family, which necessitates the examination of the impact of genetic counseling on different aspects of family communication. A family systems perspective for genetic testing proposed by Peterson and colleagues, offers a useful framework for understanding family communication, including information sharing related to cancer risk and genetic testing (Harris et al., 2010; Peterson, 2005; Walsh, 1998). This approach considers multiple dimensions of family functioning and the reciprocal nature of family relationships, and it includes three dimensions for understanding cancer risk communication patterns (Figure 1) (Bowen, Bourcier, Press, Lewis, & Burke, 2004; Peterson, 2005; Walsh, 1998): (1) *organization and structure of family relationships*, (2) *health-related cognitions, beliefs, and experience shared within families*, and (3) *family communication process*.

To begin, family *organization and structure* may be defined by closer or distant relations and can exist at different levels, e.g., blood/non-blood, male/female, first-degree/second degree. Findings from studies of family risk communication of BRCA mutations indicate that women are concerned about relatives' cancer risks and share test results with at least one close family member, most often a female first-degree relative, generally within a few weeks after results disclosure (Bowen et al., 2004; McGivern et al., 2004; Patenaude et al., 2006; Sermijn et al., 2004). Studies also indicate that women discuss cancer risk information with their spouses (Forrest et al., 2003; Kenen, Arden-Jones, & Eeles, 2004; MacDonald et al., 2007).

Second, *health-related cognitions, beliefs, and collective experiences* may influence family members' interpretation and response to health risk communication. Findings from previous cross-sectional studies suggest that factors such as higher cancer risk perception (Wilson et al., 2004), increased cancer worry, having prior knowledge, and experience with cancer (personal or family history) are positively associated an individual's decision to

communicate cancer risk information with family members (Nycum, Avard, & Knoppers, 2009). Further, those with positive (carrier of *BRCA1/2* mutation) or informative negative (a family member tested positive for a mutation, but the individual tested negative for the mutation causing elevated risk in the family) results were more likely to communicate results than those with uninformative negative test results (the mutation cause for cancer in the family is unknown, and the individual was negative for the mutations tested) (McGivern et al., 2004; Wagner Costalas et al., 2003). However, little is known about cancer risk communication with respect to family support for genetic testing. Family members might assist the individual in making decisions about genetic testing, and understanding the type of relations that influence an individual's decision to test are critical elements of the decision-making context.

Third, *family communication processes* are central to a functional family system as well as to the context of genetic testing. Cancer risk communication within a family can take place at different time points and in different forms. An individual undergoing genetic testing for *BRCA1/2* mutations may have talked to family members prior to or after genetic counseling. Similarly, the individual may immediately share genetic test results with the family members or may wait for the "right time". Little information is available regarding how cancer risk communication changes over time and affects cancer risk information sharing with family members, and this is underspecified in the model. In that vein, little information is available on how the risk communication context of genetic counseling, as opposed to receipt of genetic test results, affects cancer risk communication with family members.

This study utilized a theoretical framework based on the family systems perspective in understanding intra-familial cancer risk communication patterns as well as the impact of genetic counseling and testing on this communication.

The purpose of the present study was to understand the extent to which (i) support for genetic testing (ii) intent to encourage family members for genetic- counseling and testing, and (iii) sharing of test results with family members, varies by relation type and time in the genetic testing process, as well as to understand the factors that affect cancer risk communication. Quantitative data was augmented with examples from genetic counseling to provide insight into patterns of intra-familial communication.

METHODS

Participants

Participants were recruited through newspaper articles, letters to local physicians, breast cancer support groups, and Jewish community groups. Eligible participants were 18 years of age or older, were of Ashkenazi Jewish descent, and had a personal (e.g., breast cancer before age 50, ovarian cancer, male breast cancer) or family history (e.g., maternal first degree or paternal second degree relative with male breast cancer, family member with a mutation) of cancer indicating elevated risk for a *BRCA1/2* mutation. Ashkenazi Jewish individuals have higher risk of carrying *BRCA1/2* mutations compared to the general population (Kirchhoff et al., 2004). Culturally, the population has a tendency to value

knowledge and altruism to society (Kelly et al. 2004). Prior research with this population indicated a strong motivation to test to benefit the family and society (Garg et al., 2016).

Of the 142 eligible individuals, 120 participants from 70 families completed the pre-counseling questionnaire and presented for genetic counseling. Most of them were women (89.2%) and were married (78.3%). They ranged in age from 18 to 83 ($M = 49.7$, $SD = 13.2$). Most had a high education level ($M = 16.8$ years of school, $SD = 2.4$), and 46.2% reported a family income of above \$100,000 (35.9% had income between \$50,000 and \$100,000). Nearly half (47.5%) had a personal history of cancer, and most (89.2%) underwent genetic testing. Regarding country of familial origin, distribution was Russian (68.1%), Polish (39.6%), and German (13.6%).

Procedure

This study is a part of the larger longitudinal study examining the impact of genetic counseling and testing for hereditary *BRCA1/2* mutations (Kelly et al., 2014; Kelly et al., 2015), approved by institutional review boards at the New Jersey Medical School and West Virginia University¹. Individuals interested in the study contacted genetic counselors ($n = 3$) and were screened for eligibility. A packet consisting of study details, an informed consent form, and a pre-counseling questionnaire [T1] was mailed to eligible participants. Upon completion, participants scheduled an appointment with a genetic counselor. Genetic counseling sessions were guided by an outline of a standard cancer genetic counseling session (NSGC, 2004), which included a discussion of the benefits and risks of genetic testing. One to two days after genetic counseling, participants completed a post-counseling telephone interview [T2]. Participant's decision to proceed with genetic testing was obtained in a subsequent telephone call. Participants received free genetic counseling and testing. For those interested in receiving test results, results were provided in a face-to-face meeting with a genetic counselor. One week after receiving test results (or at an equivalent time for those not testing), participants completed a post-results telephone interview [T3]. A follow-up questionnaire was mailed to participants approximately six months later [T4].

Measures

Demographic Data—Age, gender, marital status, race/ethnicity (German, Polish, Russian), and personal history of cancer (yes/no) were assessed at T1. Genetic test results were assessed at T3 and T4; possible results were positive, informative negative, and uninformative negative.

Health-related cognitions, beliefs, and collective experiences—At T1, cancer risk perceptions were assessed: “My chances of getting breast cancer in any single year following this year are: (0–100%)”. At T1, Lerman's Cancer Worry Scale (Cronbach's $\alpha = 0.80$) was used (Lerman, Kash, & Stefanek, 1994). The scale consisted of four items, and higher score indicated increased cancer worry (1 = not at all to 4 = a lot). A previously

¹All 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. Informed consent was obtained from all patients for being included in the study. The authors confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

validated scale was used to assess knowledge of cancer genetics and beliefs at T1 (Kelly et al., 2004). Subscales included mechanism of cancer inheritance (Cronbach's $\alpha = 0.55$), meaning of a positive test result (Cronbach's $\alpha = 0.87$), meaning of a negative test result (Cronbach's $\alpha = 0.80$), and frequency of inherited cancer (Cronbach's $\alpha = 0.94$). For each of these subscales, a higher score indicated higher knowledge.

Family communication processes—Encouragement by others was assessed at T1 and T2 by asking “to what extent are the following people (spouse, daughter, son, mother, father, sister, brother, aunt, uncle, friend, and others) actively encouraging you to take the genetic test.” Discouragement by others was assessed at T1 and T2 by asking – “to what extent are the following people (spouse, daughter, son, mother, father, sister, brother, aunt, uncle, friend, and others) actively discouraging you to take the genetic test”. Each item had a response scale ranging from 1 = not at all to 5 = very much. Intent to encourage family members was assessed at T1, T3, and T4 by asking (1) I would actively encourage my children to be tested for the *BRCA1* and *BRCA2* gene mutations; and (2) I would encourage my other family members to be tested for the *BRCA1* and *BRCA2* gene mutations. Sharing results with spouse/partner, female siblings, male siblings, daughters, sons, and parents was assessed at T3 and T4. Intent to encourage and sharing results had a 5-point response scale (1 = disagree strongly to 5 = agree strongly).

Plan for Analysis

A mixed methods approach facilitated understanding of intra-familial communication in the context of genetic counseling and testing. In questionnaires, quantitative data was analyzed at multiple time points, with the addition of narrative analysis of transcripts from genetic counseling sessions, giving the analysis both concurrent and sequential elements. A mixed methods approach allows for methodological triangulation and complementarity of qualitative and quantitative data (Creswell, 2011). Our approach provides a greater depth of understanding of the experience of those undergoing counseling and testing.

Quantitative analysis of questionnaire responses—Descriptive statistics summarized participant characteristics. Communication variables (encouraged by others, discouraged by others, intent to encourage family members, and sharing of test results) were dichotomized due to small sample size, skewed data, and non-normal distribution. For outcomes encouraged/discouraged by others, responses were dichotomized as no one encouraging/discouraging *versus* someone encouraging/discouraging. For intent to encourage family members and sharing of test results, responses were dichotomized as intent to encourage/share with no one *versus* intent to encourage/share with someone. Separate McNemar tests were used to assess change over time in encouraged/discouraged by others (T1 to T2), intent to encourage family members (T1, T3, to T4), and sharing of test results (T3 to T4).

To examine the factors that affect cancer risk communication, multivariate logistic regression analyses were conducted. Again, outcome variables included encouraged by others at T2, discouraged by others at T2, intent to encourage others at T3, and sharing of test results at T4. Predictor variables included baseline levels of the relevant outcome (e.g.,

encouraged by others at T1, sharing of test results at T3), demographics (age, sex), personal history of cancer, knowledge of genetics, cancer risk perception, cancer worry, and genetic test results (when applicable). For intent to encourage others at T3 and sharing of test results at T4, encouraged/discouraged by others at T2 were added as potential predictors. Given inadequate sample size, genetic test results were categorized into informative (positive/informative negative) versus uninformative (negative) results. Backward elimination method with significance set at $p < 0.1$ for consideration of trends was used to identify factors associated with cancer risk communication.

Qualitative analysis of genetic counseling sessions—Consultands were characterized into four groups based on the combination of family communication processes, i.e., encouraged/discouraged by others and intent/no intent to encourage others for genetic testing (e.g., encouraged by others and have intent to encourage others). From these, we identified participants representing the diversity of genetic counseling sessions (e.g., individual/multi-group, with/without personal cancer history, informative/uninformative test results), a form of theoretical sampling.

A narrative analysis was conducted guided by principles from Labov's narrative analysis (Labov, 2003; Labov & Waletzky, 1997). A narrative is a way of reporting past events, such as personal experiences. Narratives have been described as fundamental modes of thinking and have been used to share information, change beliefs, and inspire action (Green, 2006). Labov's narrative analysis posits that when individuals tell stories about themselves, four components of their stories tend to emerge: abstract (what is it about?), orientation (who, when, where?), complication (then what happened?), evaluation (why is it important?). This approach has been applied on diverse forms of communication (Garg, Vogelgesang, & Kelly, 2015; Labov, 2003; Labov & Waletzky, 1997; Stubbs, 1983), making it appropriate for understanding cancer risk communication (Green, 2006).

RESULTS

Quantitative analysis of questionnaire responses

Baseline characteristics of participants—Table 1 includes the baseline characteristics of participants with respect to cancer risk communication patterns.

Encouraged by others for genetic test—Table 2 summarizes the extent to which encouraged by others varies by relation type and time in the genetic testing process. The proportion of participants encouraged by spouse significantly increased from T1 to T2. A higher proportion of participants were women; most spouses were men (87.0%). In addition, encouraged by parents also significantly increased from T1 to T2. No significant difference was observed for encouraged by other family members or friends from T1 to T2. Findings also indicate that a higher proportion of participants were encouraged by female family members compared to male family members. As shown in Table 3, participants who were encouraged by others at T1, were older, had personal history of cancer (versus had no personal history of cancer), and had a higher cancer risk perception at T1 were more likely to be encouraged by others for genetic test at T2.

Discouraged by others from genetic test—As shown in Table 2, no differences were observed from T1 to T2. As shown in Table 3, participants who were discouraged by others at T1, were younger and had higher knowledge of the meaning of a negative test result were more likely to be discouraged by others from genetic test at T2.

Intent to encourage family members to have genetic testing—Participant's intent to encourage family members decreased by 16.7% from T1 to T3 (Figure 2a). As shown in Table 3, participants who had intent to encourage family members at T1, had no personal history of cancer (versus had personal history of cancer), and had informative test results (positive or informative negative) were more likely to encourage other family members at T3.

Sharing of test results with family members—A higher proportion of participants shared test results with their spouse compared to all other family members (Figure 2b). Further, a higher proportion of participants shared test results with female than with male family members. The proportion of participants who shared test results with their brothers, daughters or sons increased from T3 to T4, an increase of 9.3%, 10.4%, 14%, respectively. As shown in Table 3, those sharing results at T3, were older, were not discouraged by others at T2, and had lower knowledge on meaning of a negative result were more likely to share results with family at T4.

Qualitative Analysis of Genetic Counseling Sessions

Group I: Encouraged by others for genetic test and had intent to encourage family members (n=59)—Abstract: Participant #152 was a female with no personal history of cancer and had a positive genetic test result. Orientation: Genetic counselor, participant, and guest. Complication: She had a close relationship with her sisters and was concerned about her nieces as her sister had a diagnosis of breast cancer: “And then it’s my responsibility to get <her sister with breast cancer> here. I’ll just remind her that there are other people at stake here, our daughters”. Evaluation: Concern for family may positively affect intra-familial cancer risk communication, particularly in the context of informative results. Further, most important is the concern for the future generations in their family, particularly females.

Abstract: Participants #68, #69, #70. All were females, and one had a personal history of cancer. All had uninformative negative test results. Orientation: Genetic counselor and three participants. Complication: They were fearful about family and knew about familial cancer: “We’re a very close family, like we know who we are. We have a lot of functions. We see each other; so it’s not like we’re all around the country. And when we hear about it, it’s scary. You know, it’s hit every family.” In addition, family members encouraged each other: “That’s why I (#69) first came in here. He (a cousin) said to me (#69), ‘I (a cousin) think you ought to go into genetic counseling.’ Evaluation: Closeness of family members and strength of relationships may positively impact cancer risk communication in family. In this case, a male family member encouraged them to seek counseling. No other family members sought genetic testing after them.

Group II: Encouraged by others for genetic test and had no intent to encourage family members (n=34)

Abstract: Participant #38 was a 63-year old female with a personal history of cancer and had an uninformative negative genetic test result. **Orientation:** Genetic counselor and participant. **Complication:** Her close family members were aware of their family history of cancer and took preventive measures: “We’re all, my whole family is, very careful.”. However, she did not have a close relationship with her cousins and was not interested in communicating cancer risk information: “No, not that I know of (cousins). We’re not that close”. **Evaluation:** Knowledge and awareness about cancer risk among family members, specifically close family members (in this case, daughters and spouse) plays an important role in encouraging the participant for genetic testing. Lack of closeness among family members negatively affects communication of cancer risk with the distant relatives, particularly in the context of uninformative results.

Group III: Discouraged by others from genetic test but had intent to encourage family members (n=16)

Abstract: Participant #137 was a 49-year-old woman with no prior history of cancer and had an informative negative genetic test result. **Orientation:** Genetic counselor and participant. **Complication:** She had been married over 25 years. In the survey, she reported that a friend and her husband were actively discouraging her from testing. Yet, in the counseling session, she says her husband “supports anything I do.” In the context of medical decision making about prophylactic surgery, she explains that she “never really told him what the options are...but I figure that wouldn’t bother him either way...” So, while she may be uncomfortable talking before decisions were made, she knew he would ultimately be supportive. She planned to talk to her children, siblings, cousins, and therapist about results, but she did not want to tell her mother if she was positive, “No, she’d feel so guilty. I’m telling you, I just couldn’t do it. If she ever thought, it was her that had the gene and not her sister and then passed it on...”.

Evaluation: Concern for the family facilitates cancer risk communication, regardless if the participant herself was discouraged by family members from genetic test. Sometimes individuals might not share cancer risk information with parents to protect their feelings.

Group IV: Discouraged by others from genetic test and had no intent to encourage family members (n=11)

Abstract: Participant #39 was a 44-year old female with no personal history of cancer and had an uninformative negative genetic test result. **Orientation:** Genetic counselor and participant. **Complication:** She was discouraged to test by her father and spouse from genetic test, noting that her husband “felt the same ways, if we couldn’t do anything about it, then why do it? But it’s my decision, what I want to do.” Further, she had no intent to encourage family members for genetic testing. In her conversation, she mentioned that she did not have contact with her distant relatives. Further, she herself was not interested in taking any preventive action (e.g., prophylactic breast cancer surgery), in case she tests positive: “There are women who say if they test positive, they’re going to have prophylactic surgery, but I think I’m not prepared to do that at this point.” **Evaluation:** Participant did not appear convinced about significance of genetic testing, which may negatively affect communication of cancer risk communication with family members.

DISCUSSION

The purpose of this study was to understand intra-familial cancer risk communication patterns, and the impact of genetic counseling and testing on this communication in the Ashkenazi Jewish population. Consistent with previous studies in other populations, most were encouraged to test by spouse, sisters, daughters, and aunts, which suggests that close relatives played an important role in communication (MacDonald et al., 2007; Patenaude et al., 2006). However, our qualitative data indicated that a male cousin was instrumental in encouraging two of our participants to seek counseling. Research is needed to examine the role of cousins, particularly male cousins, who may be concerned for the risk of their daughters. Further, encouragement for genetic testing increased from pre- to post-genetic counseling, but discouraging from testing did not change. These differing results stress the importance of considering *both* who is encouraging and discouraging individuals from testing, and may indicate that individuals are seeking out a support network as they proceed with testing.

We found that older participants, those with personal history of cancer, and those with higher risk perceptions were more likely to be encouraged to test by others. Those with a personal history of cancer were older and were more likely to be encouraged because they carried the most information for other family members. Thus, women who were younger and without a personal history depended upon, and likely encouraged, their parents or aunts to test. Although higher cancer risk perception was associated with greater risk information sharing with family members (Wilson et al., 2004), we identified no published studies examining cancer risk perception on being encouraged by others to test. Qualitative findings suggested that cognizance about cancer risk also facilitates information sharing among family members.

Further, younger participants and those with higher knowledge of the meaning of negative test result were more likely to be discouraged by others from genetic testing. As younger participants were less likely to have cancer, someone may have communicated the meaning of a negative result (a negative result is uninformative if the mutation cause for cancer is identified in the family), which may discourage a potentially uninformative negative person from testing. Indeed, in the case of the sisters who received uninformative negative results, no additional family members tested. These are novel contributions to the literature and further support the family systems perspective.

The intent to encourage family members for genetic testing decreased post receipt of genetic test results, contrasting the motivations noted in genetic counseling transcripts. One of the factors associated with intent to encourage family members was type of test result. Participants with uninformative negative test results (59% of the sample) were less likely to encourage family members to have genetic testing compared to those with positive or informative negative genetic test results. In the case of uninformative results, other family members should not be encouraged to test, unless they have the potential to provide more information (e.g., an aunt in addition to a mother that has cancer).

Previous studies indicate reasons to encourage others, which include concern about their family members also having risk of *BRCA* mutation and a perceived responsibility to inform (McGivern et al., 2004; Nycum et al., 2009). Our qualitative data also indicated that concern for family, especially future generations, played an important role in facilitating these intra-familial discussions in those with positive genetic tests. Further, the concern of having *BRCA* mutation was higher towards the immediate female family members of the subsequent generation (daughters and nieces). Concern for family facilitated communication of risk information with family members, regardless of the fact that participants had uninformative test results and/or not encouraged by family members for genetic test. Our qualitative data also indicated that a desire to protect individuals and a lack of closeness among family members, especially distant relatives, hinders intra-familial communication and sharing of cancer risk information. These impulses are complemented by the encouragement of genetic counselors to communicate risk information with family members who may be estranged.

Consistent with findings from other studies, most participants shared test results with their partner/spouse, followed by sister(s) and daughter(s) (MacDonald et al., 2007; Patenaude et al., 2006), and most shared results immediately (within one week of receipt of results) with these family members. Increased information sharing may be critical to provide vital risk information, as well as to obtain support (Hughes et al., 2002; Patenaude et al., 2006). Given that males are also at elevated risk of having *BRCA* mutation, as well as their daughters and sons, further research is needed to understand why males are informed less often and to improve risk discussion with male relatives. Further, sharing of test results with family members increased over the course of the study. This is consistent with findings from previous studies, where individuals may wait for the “right time” for communicating information (Nycum et al., 2009). Interestingly, those who had lower knowledge on the meaning of negative result were more likely to share results with family members. This may be of concern as they may “misinform” others based on their understanding of their uninformative negative result, resulting in other family members believing that they are no longer at risk for familial cancer. Therefore, it is important that genetic counselors reinforce the meaning of a negative result in counseling so that there is accurate intra-familial communication of test results.

Our study findings also showed that older participants were more likely than younger to share genetic test results with family members. Older individuals may be more inclined to feel a responsibility to inform family members about cancer risk due to generativity (Ashida & Schafer, 2015). However, those who were discouraged by others from genetic testing were less likely to share results with family members, which suggests that earlier cancer communication influences future communication. Family members who had discouraged participants from genetic testing might also have no desire to know test results, and hence the participant might not inform them. Further, sharing of test results with family members was less likely in those with higher knowledge of the meaning of a negative test result. As most received uninformative negative results and they understand that these results may not be meaningful, be confusing, and hard to explain, their reticence is understandable. In this case, efforts to communicate results by letter to family members may be helpful (Gallo, Angst, & Knafl, 2009).

Limitations to our study should be noted. First, the survey sample included only the Ashkenazi Jewish population. The focus on a specific cultural group limits the applicability and feasibility of the study applied to a general population. Second, the sample for the current study included people who responded to an advertisement or were otherwise directly approached regarding the potential for genetic testing; this is a very different group from those who are attending for genetic testing/counseling outside of an experimental study (i.e., those that actively seek out these services).

CONCLUSIONS

Our study findings demonstrate that communication patterns vary with organization and structure of family relationships (e.g., distance), as well as health-related cognitions, beliefs, and experience (e.g., knowledge of the meaning of negative results) within families. In addition, our study findings showed that cancer risk communication varies with time, extending the family systems perspective as previously described, where genetic counseling, along with genetic testing, can play an important role in improving intra-familial cancer risk communication.

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Figure 1.

Theoretical framework for understanding pattern of intra-familial communication initiated by affected individuals who underwent genetic counseling and/ or genetic testing (Adapted from Harris et al. 2010). The connecting arrows represent proposed relationship between constructs and do not imply causation.

Figure 2.

A participant's intent to encourage family members for the genetic testing and share test results. (2a) Intent to encourage family members for genetic test; (2b) Sharing genetic test results with family members. Time 1: Pre-counseling (N = 119); Time 3: Post-counseling/Post-test results, at 1 week (N = 113); Time 4: Post-counseling/Post-test results, at 6 months (N = 95). The variable intent to encourage family members for genetic test was grouped as "encourage", for responses agree and strongly agree; and "not encourage", for responses disagree strongly, disagree, and neither agree nor disagree. The variable sharing of genetic test results with family had same responses and was grouped as "share" and "did not share".

$P < 0.0001$; ** 0.0001 $P < 0.01$; * 0.01 $P < 0.05$

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Table 1

Characteristics of participants regarding cancer risk communication for a *BRCA1/2* mutation.

Characteristics	Encouraged by others for genetic testing ^a	Discouraged by others from genetic testing ^a	Intent to encourage family members to have genetic testing ^b	Sharing of genetic test results with family members ^b
	N = 120	N = 117	N = 119	N = 119
Age <i>in yrs</i> (Mean±SD)	49.5±13.3	44.5±10.8	48.7±12.4	51.7±14.2
Sex				
Male	11 (84.6%)	2 (15.4%)	10 (76.9%)	13 (100.0%)
Female	93 (86.9%)	28 (26.9%)	72 (67.9%)	90 (90.9%)
Marital status				
Married	81 (86.2%)	23 (25.3%)	61 (65.6%)	84 (94.4%)
Unmarried ^c	23 (88.5%)	7 (26.9%)	21 (80.7%)	19 (82.6%)
Personal history of cancer				
Yes	48 (84.2%)	10 (18.2%)	36 (64.3%)	47 (88.7%)
No	56 (88.9%)	20 (32.3%)	46 (73.0%)	56 (94.9%)
Race/ethnicity ^d				
Polish	42 (89.4%)	10 (21.7%)	27 (58.7%)	41 (93.2%)
Russian	65 (84.4%)	20 (26.3%)	54 (71.1%)	67 (90.5%)
German	13 (81.3%)	5 (33.3%)	10 (66.7%)	14 (93.3%)
Others	32 (94.1%)	7 (21.9%)	25 (73.5%)	31 (96.8%)

^aThe responses for variable encouraged by others for genetic testing were categorized as follows: “encouraged”, for responses - a little bit, moderately, quite a bit, and very much; and “not encouraged”, for response – not at all. The responses for variable discouraged by others from genetic testing were categorized as follows: “discouraged”, for responses - a little bit, moderately, quite a bit, and very much; and “not discouraged”, for response – not at all.

Percentages in the table are for those who were encouraged by others to test for a BRCA mutation. The proportion who were encouraged by people for test = 100% - “were encouraged for genetic test”. Similar interpretation for “those discouraged by others for test”.

^bThe variable intent to encourage family members for genetic test was grouped as “encourage”, for responses agree and strongly agree; and “not encourage”, for responses disagree strongly, disagree, and neither agree nor disagree. The variable sharing of genetic test results with family had same responses and was grouped as “share” and “did not share”. Percentages in the table are for those who had intent to encourage family members to test for a BRCA mutation. The proportion who did not encourage others = 100% - “who encouraged for genetic test”. Similar interpretation for “sharing of test results”.

^cUnmarried includes single, widowed, divorced, and separated.

^dThese were not mutually exclusive categories

Table 2

People who provided support to the participants for genetic testing for a *BRCA1/2* mutation.

Family members	Encouraged by others for genetic testing ^a		Discouraged by others from genetic testing ^a	
	Time 1 ^b	Time 2 ^b	Time 1 ^b	Time 2 ^b
Spouse	61 (63.0%)	72 (73.5%)*	13 (14.0%)	10 (10.2%)
Children				
Daughter(s)	37 (44.3%)	39 (45.6%)	5 (7.3%)	2 (2.2%)
Son (s)	12 (18.9%)	13 (19.2%)	1 (1.5%)	2 (2.9%)
Parent(s)				
Mother	25 (45.6%)	27 (50.9%)	2 (5.2%)	4 (7.5%)
Father	20 (38.5%)	21 (44.7%)	5 (11.1%)	2 (4.1%)
Sibling(s)				
Sister(s)	46 (56.2%)	43 (54.6%)	4 (3.6%)	6 (8.3%)
Brother(s)	12 (29.2%)	10 (21.8%)	5 (7.1%)	1 (1.8%)
Relative(s)				
Aunt(s)	14 (21.9%)	17 (22.3%)	3 (5.4%)	2 (2.5%)
Uncle(s)	5 (9.4%)	5 (7.1%)	1 (1.6%)	2 (2.9%)
Friend(s)	44 (40.4%)	48 (42.2%)	12 (12.0%)	9 (7.8%)
Others	23 (47.9%)	22 (45.8%)	3 (7.0%)	1 (2.3%)

^aThe responses for variable encouraged by others for genetic testing were categorized as follows: “encouraged”, for responses - a little bit, moderately, quite a bit, and very much; and “not encouraged”, for response – not at all. The responses for variable discouraged by others from genetic testing were categorized as follows: “discouraged”, for responses - a little bit, moderately, quite a bit, and very much; and “not discouraged”, for response – not at all. The percentages in the table are for those who were encouraged by people to test for a BRCA mutation. The proportion who did not receive support in the form of encouragement = 100% - “were encouraged for genetic test”. Similar interpretation for “discouraged by people”.

^bTime 1: Pre-counseling; Time 2: Post-counseling. Denominator is calculated as those having the respective living family member.

P < 0.0001;

**
0.0001 P < 0.01;

*
0.01 P < 0.10

Table 3

Multivariable logistic regression model to examine the factors that affect change in cancer risk communication over time.

Variables	Estimate	Standard error	P value
Encouraged by others for genetic test			
Encouraged by people at baseline (Yes vs. No)	4.7369	1.1381	<0.0001
Personal history of cancer (Yes vs. No)	2.0394	1.1780	0.0834
Age (years)	0.1148	0.0604	0.0572
Cancer risk perception	0.0338	0.0176	0.0552
Discouraged by others from genetic test			
Discouraged by people at baseline (Yes vs. No)	2.2733	0.5657	<0.0001
Age (years)	-0.0531	0.0243	0.0287
Meaning of a negative result (Knowledge)	0.5296	0.2839	0.0622
Intent to encourage family members to have genetic test			
Intent to encourage at baseline (Yes vs. No)	2.1646	0.6175	0.0005
Personal history of cancer (Yes vs. No)	-1.6815	0.5556	0.0025
Gene status (positive/informative negative vs. uninformative negative)	3.6369	1.1384	0.0014
Sharing of genetic test results with family members			
Extent of sharing results at baseline (Yes vs. No)	2.5257	0.5916	<0.0001
Discouraged by people at baseline (Yes vs. No)	-0.9871	0.5135	0.0546
Age (years)	0.0389	0.0191	0.0421
Meaning of a negative result (Knowledge)	-0.4405	0.2180	0.0433

The responses for variable encouraged by others for genetic testing were categorized as follows: “encouraged”, for responses - a little bit, moderately, quite a bit, and very much; and “not encouraged”, for response – not at all. The responses for variable discouraged by others from genetic testing were categorized as follows: “discouraged”, for responses - a little bit, moderately, quite a bit, and very much; and “not discouraged”, for response – not at all.

The variable intent to encourage family members for genetic test was grouped as “encourage”, for responses agree and strongly agree; and “not encourage”, for responses disagree strongly, disagree, and neither agree nor disagree. The variable sharing of genetic test results with family had same responses and was grouped as “share” and “did not share”.

Backward selection method was used. Significance level $P < 0.1$