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Information Needs of Mothers Regarding Communicating *BRCA1/2* Cancer Genetic Test Results to their Children

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Abstract

Mothers who participate in genetic testing for hereditary breast/ovarian cancer risk must decide if, when, and how to ultimately share their *BRCA1* and *BRCA2* (*BRCA1/2*) test results with their minor-age children. One of the primary aides for mothers in making this decision is cancer genetic counseling. However, counseling is limited in how well it can educate mothers about such decisions without the availability of resources that are specific to family communication and genetic testing per se. In an effort to fill this gap and identify mothers most likely to benefit from such resources, surveys were conducted with 187 mothers undergoing *BRCA1/2* testing who had children 8-21 years-old. Data were collected weeks after genetic testing but prior to mothers' learning of their test results; quantitative assessments of informational resource needs (i.e., speaking with previous *BRCA1/2* testing participants who are parents regarding their experiences, reading educational literature about options and what to expect, speaking with a family counselor, attending a family support group, and self-nominated other resources), testing motivations, decision making vigilance, and decisional conflict regarding communicating test results to children were included. Mothers' most-to-least frequently cited information resource needs were: literature (93.4%), family counseling (85.8%), prior participants (79.0%), support groups (53.9%), and other (28.9%; e.g., pediatricians and psychologists). Seventy-eight percent of mothers were interested in accessing 3 or more resources. In multivariate regression analyses, testing motivations ($\beta=0.35$, $p=.03$), decision making vigilance ($\beta=0.16$, $p=.00$) and decisional conflict ($\beta=0.10$, $p=.00$) were associated with mothers' need level; mothers with a greater interest in testing to learn about their children's risks, those with more vigilant decision making styles, and those with higher decisional conflict had the greatest need. In conjunction with enhanced genetic counseling focusing on family disclosure, educational literature and psychosocial support may promote improved outcomes.

Introduction

Thousands of women have been tested for *BRCA1* and *BRCA2* (*BRCA1/2*) mutations to determine their inherited susceptibility to breast and ovarian cancer. One aspect of this testing that has far-reaching implications but which has not been well-studied is the impact of genetic testing on family kinship – specifically, the social and behavioral impact of a mother's *BRCA1/2* test result on her potentially at-risk children and their psychosocial and

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health education needs. The research literature mostly contains ethical debates of testing children for *BRCA1/2* mutations (Elger and Harding, 2000; Rhodes, 2006; Ross and Moon, 2000) and policy statements discouraging such testing (ASCO statement, 2003; ASHG statement, 1995; Borry *et al.*, 2006). However, little information exists about if, when, and how children learn of their mothers' test results and their interpretation of them. These issues are not unique to hereditary breast and ovarian cancer families, as the social and behavioral impact of genetic testing and the education needs of at-risk children applies to numerous diseases (Malpas, 2006).

It is well-established that although many women pursue testing in the hopes of gaining valuable information to assist with medical decision-making, another motivation is to obtain information about risk for relatives including one's children (Lerman *et al.*, 1996; Lynch *et al.*, 1997). Researchers have assessed disclosure patterns to adult relatives and the effects of such communication (Costalas *et al.*, 2003; Hughes *et al.*, 2002; Patenaude *et al.*, 2006). However, little information exists about mothers' disclosure of their *BRCA1/2* test results to their children. Studies indicate that approximately 50% of mothers share their *BRCA1/2* test result with their minor-age children within a month of learning them (Tercyak, Hughes *et al.*, 2001; Tercyak *et al.*, 2002); child gender does not appear to be related to this decision (Tercyak, Hughes *et al.*, 2001). However, no data exist regarding how this communication arose, who initiated it, what was discussed, what questions remain, and what the impact may have been on children. It is also not known what resources mothers utilized, if any, to help them make decisions about sharing information with their children, or to help them prepare for these conversations. Moreover, the fact that the decision to disclose is associated with elevated distress levels in mothers (Tercyak, Hughes *et al.*, 2001; Tercyak *et al.*, 2002) suggests that when mothers do talk with their children about genetic testing, it can be an emotionally-charged issue. This raises questions about how well prepared and comfortable mothers feel to initiate these conversations or to defer these communications until a later point in time. Currently, there are no patient education resources to assist mothers in making decisions about talking to their children about these issues, though mothers would likely be receptive to such resources if they existed (Huelsenman *et al.*, 2001). As a first step in developing such resources, the present study assessed mothers' informational resource needs and evaluated whether specific subgroups of women were more likely to desire such resources in conjunction with standard genetic counseling for *BRCA1/2* mutations.

Participants and Methods

Study population

The study population consisted of women with one or more children (8-21 years old). All women were participating in pre-test education, genetic counseling, and testing for *BRCA1/2* mutations at one of three East coast cancer centers (Lombardi Comprehensive Cancer Center, Washington, DC, Rutenberg Cancer Center at the Mount Sinai School of Medicine, New York, NY, Dana-Farber Cancer Institute, Boston, MA). These centers offer clinical research programs focusing on the identification and management of adult hereditary cancer syndromes, including hereditary breast/ovarian cancer.

Eligible participants were approached for possible inclusion in this study at the end of their pre-test genetic counseling appointment and following the provision of a blood sample for *BRCA1/2* mutation analysis. Potential participants were informed that the study was focused on parents' attitudes, behavioral intentions, and beliefs regarding the possibility of their sharing their *BRCA1/2* test results with their children, as well as their actual communication decisions and related psychosocial outcomes. Participants completed a baseline telephone survey conducted prior to mothers' receipt of their test results and two follow-up telephone surveys at one and six months following the receipt of test results. In the present report, only

baseline data were analyzed; follow-up data collection remains ongoing and will be analyzed at a later date.

Upon study enrollment, the ages and genders of all participants' children were assessed. For mothers with more than one child falling in the appropriate age range (8-21 years old), a computerized random selection algorithm was used to designate a target child of interest within that range. Subsequently, all survey items were oriented/responded to in reference to the target child only. Target child identification and reporting has been used extensively in family psychology research and has consistently been shown to be a reliable and valid procedure when used with parents (Burrows and Kelley, 1983; Siegel *et al.*, 1976).

To acknowledge mothers' time and effort, participants were offered a modest incentive for completing study-related telephone calls (i.e., \$10 gift certificates). All procedures were assessed and approved by the institutional review boards at each of the participating institutions.

Survey design and conduct of the survey

Data were collected using a telephone survey specifically designed for this study. The survey was comprised of several standardized measures--largely derived from the Conflict Theory of Decision Making (Janis and Mann, 1977) and the Ottawa Decision Support Framework (O'Connor *et al.*, 2002) on which the project was based. Demographic, clinical, and psychosocial items were used as well. All measures were pre-tested for readability and comprehension prior to use. Standardized measures used in other research included the vigilance scale from the Melbourne Decision Making Questionnaire (Mann *et al.*, 1997). As applied to decision making, vigilance refers to an individual's propensity to clarify decision objectives, consider and evaluate alternatives, and seek and incorporate relevant information (e.g., watchfulness regarding the decision to share one's *BRCA1/2* test results with children). The measure consists of six items rated on a three-point scale (0=Not true for me, 1=Sometimes true, 2=True for me); higher scores indicate more vigilant decision making ($M=10.7$, $SD=1.8$). In this sample, the internal consistency of the vigilance scale was adequate ($\alpha=0.77$). Participants also completed O'Connor's Decisional Conflict Scale (1999) (O'Connor, 1999), which measures an individual's perceptions of the difficulty of making a decision (e.g., perceived uncertainty in choosing among different options, feeling uninformed, unclear about personal values, feeling unsupported in decision making). In this study, higher scores indicate greater decisional conflict regarding whether or not to share cancer genetic test results with children ($M=1.56$, $SD=2.2$). The sample's internal consistency of the Decisional Conflict Scale was also adequate ($\alpha=0.83$).

Additionally, mothers were asked to complete a series of items regarding whether or not learning information about their children's hereditary cancer risks served as an important motivation for them to pursue *BRCA1/2* testing at this time (Lerman *et al.*, 1996) (1=Not at all important, 2=Somewhat important, 3=Very important), and whether it was among the most important and/or single most important reasons for being tested (Yes/No). These items were administered in an effort to further assess mothers' concerns over the implications of testing for their children, and to extend the study's understanding of mothers' information needs in this area. For mothers who responded that learning about their children's risks was among the most important reasons for being tested, an open-ended item immediately followed that probed this reason; these data were then subjected to qualitative analysis. For the qualitative analysis, mothers' open-ended responses were coded into categories by two independent raters. The categories were empirically derived through an iterative qualitative process based on mothers' responses and guided by Grounded Theory (Miles and Huberman, 1994). The coding system's inter-rater reliability coefficient fell in the excellent range ($\kappa=$

83), suggesting high agreement between the two raters in assigning one of five possible codes (Cicchetti and Sparrow, 1981).

With respect to informational resource needs, mothers were presented with a list of five possible resources: 1: speaking with another parent who already participated in *BRCA1/2* testing about options and what to expect; 2: reading literature about options and what to expect; 3: speaking with a family counselor with expertise in genetic testing about options and what to expect; 4: attending a parent support group; and 5: self-nominated other resources). Each was asked to indicate if the resource would be needed and helpful in making decisions about talking with children about *BRCA1/2* test results. From these five items, a measure of 'need frequency' was created by summing together the number of endorsed items. Scores on the need frequency measure ranged from zero (no resources indicated) to five (all resources indicated).

Statistics

All data were summarized descriptively, and potential predictors of mothers' resource need level were analyzed using bivariate and multivariate methods. All statistical analyses were conducted using SAS version 9.1.

Results

Demographics

A total of 187 mothers who had been counseled and tested for *BRCA1/2* mutations since 2003 completed the baseline survey, with a study consent rate of 80.6%; there were no demographic differences between mothers who did and did not consent to study (all p 's > .05). Demographic characteristics of these participants are shown in Table 1. The average age of the sample of mothers was 45.6 years-old and ranged from 30-59 years-old. The majority of participants were white, well-educated, living in affluent and partnered households, and had previously been affected with breast/ovarian cancer, and were the first persons in their families to be tested for *BRCA1/2* mutations (e.g., probands); slightly more than a third were Jewish and half had family histories of breast/ovarian cancer. With respect to their target children, the average target child age was 12.9 years-old and ranged from 8-21 years-old; half of the target children were female.

Child-focused testing motives

An overwhelming majority of mothers (80.1%; $n=149$) reported that learning about their children's risks of inheriting a mutation in *BRCA1* or *BRCA2* was a "very important" motivation for pursuing testing; 76.5% ($n=143$) went on to note that learning about their children's risks was among the most important reasons for being tested, and 27.3% ($n=51$) further noted it to be their single most important reason for testing.

Among the 143 mothers who endorsed strong child-focused testing motives, reasons behind their motivations are shown in Table 2. For the majority of mothers (44%), they believed that their genetic test results could be used to help prevent or control the onset of hereditary breast-ovarian cancer in their children--mostly through lifestyle and behavior modification undertaken at an early age (e.g., healthier diet and increased physical activity among children). Similarly, many mothers (37.1%) believed that their test results would benefit their children and other members of their family by allowing cascade testing to proceed (if indicated and when warranted). Fewer mothers (13.3%) noted concern over whether or not they (as mothers) would remain healthy enough to continue to serve as primary caretakers in the future, or raised psychological benefits of testing for the family (e.g., reducing the child's cancer-related worry or anxiety; 3.5%).

Information resource needs

In terms of resources mothers endorsed as helpful in making decisions about talking with their children about *BRCA1/2* test results, 79.0% (n=143) were in favor of speaking with previous *BRCA1/2* testing participants about their experiences, 93.4% (n=171) were in favor of reading educational literature about options and what to expect, 85.8% (n=157) believed speaking with a family counselor would be helpful, 53.9% (n=98) thought attending a family support group would be helpful, and 28.9% (n=52) self-nominated other resources (e.g., obtaining the advice of pediatricians and psychologists). The frequency distribution of mothers' endorsed needs is shown in Figure 1. It indicates that only a small percentage of mothers did not acknowledge a need for any (3.3%) or only one (3.8%) resource, 14.8% were interested in two resources, and 78.1% were interested in as many as three (20.8%), four (43.1%) or all five (14.2%) resources.

Predictors of need frequency

In order to identify potential predictors of the frequency of mothers' information needs, Pearson product-moment correlations between each of the demographic, clinical, and decision making variables with the frequency of needs endorsed (zero to five; see Figure 1) were computed. Only variables with correlations of $p < .05$ were considered significant and retained in a hierarchical multiple regression model (Cohen and Cohen, 1983). This reduced the number of potential predictors to six: 1) race ($r = -.23$), 2) education ($r = -.22$), 3) household income ($r = -.17$), 4) child-focused motivation for testing ($r = .19$), 5) decision making vigilance ($r = .25$), and 6) decisional conflict ($r = .20$). Multiple regression analysis revealed that mothers with greater child-focused testing motivations ($\beta = 0.35$, $p = .03$), vigilance ($\beta = 0.16$, $p = .00$), and conflict ($\beta = 0.10$, $p = .03$) were more likely to endorse more information needs. Taken together, these variables accounted for 16.8% of the variance in mothers' information needs.

Discussion

This study sought to identify the information needs of mothers for help in deciding about communicating their *BRCA1/2* cancer genetic test results to their children. Mothers' most-to-least frequently cited information resource needs were: literature, family counseling, prior participants, support groups, and other needs.

Given the relatively high rate of parental *BRCA1/2* test result disclosure to minor-age children (Tercyak, Hughes *et al.*, 2001; Tercyak *et al.*, 2002), it is important for researchers and clinicians to gain a better understanding of how parents make the decision to share this information and what the process entails. At present, there is a notable lack of information resources for both parents and professionals to rely upon to guide and inform decisions in this area. As noted previously, the data presented herein and elsewhere (Huelsenman *et al.*, 2001) suggest mothers would likely be receptive to such resources.

On balance, our data regarding mothers' motivations for testing suggest that children play a central role in motivating *BRCA1/2* testing among mothers. A substantial proportion of mothers held strong beliefs about the utility or benefits of information learned as a result of testing for their children. This source of motivation may or may not be associated with mothers' decisions to disclose their test results to their children. Nevertheless, the serve as a useful gauge of mothers' priorities for testing and, therefore, their information needs.

Particularly telling is that 78.1% of mothers surveyed in this research were interested in accessing 3 or more resources. The top three resources cited (literature, family counseling, and prior participants) are well-tried resources to assist individuals in making healthcare-related decisions (Davey *et al.*, 2005; Schwartz *et al.*, 2001; Shiloh *et al.*, 2006; Skinner *et*

al., 2002). They are also consistent with the information needs of most cancer patients, and their preferences to receive as much information as possible about their care (James *et al.*, 1999). Also consistent are findings by James and colleagues (1999) and others (Frederickson and Bull, 1995; Johnson and Meischke, 1991) regarding the formats that patients and their family members prefer to access information through--printed media and healthcare professionals. For those patients seeking genetic counseling and testing for hereditary breast and ovarian cancer, incorporating these types of resources into the counseling process is a natural element of contemporary practice (Smith, 1998; Trepanier *et al.*, 2004).

With any decision resource, it is unlikely that all patients will use it or derive benefit from its use. Thus, it is appropriate to ask who might benefit most from its availability? In response to this question, the data suggest several key demographic and decision making considerations. Demographically, it would appear that mothers who are the least well-represented in genetic testing research might benefit: namely, women from minority backgrounds and those with less personal and social resources (DeMarco *et al.*, 2006; Hughes *et al.*, 2004). Mothers who participate in testing to primarily learn about their children's cancer risks would likely benefit as well. In terms of decision making, women with more vigilant decision styles, and those with greater conflict regarding their decision to share or not share their test results with their children, present as especially eager. Consistent with other research on patient decision making, these latter individuals are likely to derive benefit (Kiesler and Auerbach, 2006; O'Connor *et al.*, 2003, 2005).

As mentioned above, little is known about the content of mother-child discussions about hereditary breast/ovarian cancer risks, or what needs or consequences may arise as a result of this disclosure. In situations where the mother has tested positive for a *BRCA1/2* mutation, the ethics of testing older children has been a matter of debate (Elger and Harding, 2000; Ross and Moon, 2000). However, most experts recommend deferring testing until age 18 or older because the potential medical and psychosocial benefits of *BRCA1/2* testing are not evident until adulthood (ASCO statement, 2003; ASHG statement, 1995). Moreover, there is potential for psychological harm if an emotionally immature or unprepared child undertakes genetic testing (ASHG statement, 1995). At the same time, it has been suggested that genetic counseling interventions be designed for adolescents and their families which address the family context and careful assessment of the child's preferences and autonomy (McConkie-Rosell and Spiridigliozzi, 2004).

The authors' own experiences in counseling mothers of children have revealed that mothers appear to understand and agree with the rationale for not offering genetic testing to their children. Yet, mothers remain concerned about what they may be able to do now, proactively, to improve their children's (especially their daughters') odds against the development of breast cancer. Commonly asked questions include, "Should I encourage my daughter to eat a better diet?" "Should she get more exercise?", "Should I discourage her from going on birth control pills?" The answers to these questions are unclear, but available data could be reviewed in detail in educational materials for mothers to address these questions (Narod, 2002; King *et al.*, 2003; Kotsopoulos and Narod, 2005).

Issues that are somewhat more difficult to address in the context of genetic counseling include maternal decision making about whether and when to discuss their test results with their children, and how to embark upon that conversation (Tercyak, 2003; Tercyak, Peshkin *et al.*, 2001). Mothers may also want to know how they can help their children to feel empowered, and less fearful, of developing breast cancer. Oftentimes, these conversations are more patient-directed and unfold over the course of time.

Patient education and decision making tools should be adapted to the knowledge and learning needs of the intended population. Interactive CD-ROMs and videos have been designed to assist patients with decision making around cancer genetic testing issues and to provide support around decision making (Green *et al.*, 2004; Kaufman *et al.*, 2003; Yale Cancer Center, 2004). With respect to print materials, several booklets are available online for patients to download, which are designed to inform decision making around genetic testing and as possible supplements to genetic counseling (Armstrong *et al.*, 2001; Bacon *et al.*, 2000a, 2000b; Burton *et al.*, 2004). A booklet and companion CD-ROM was designed specifically for children ages 8-13 about familial adenomatous polyposis (Ghate *et al.*, 2004; Hibbs, 2004). One of the goals of these resources was to promote self-protective health behaviors. Preliminary data showed that the resources increased knowledge and health protective behaviors (Hibbs, 2004). Print resources have also been developed to assist patients with family communication and support about a diagnosis of cancer and issues related to genetic testing (Daly *et al.*, 2001; Susan G. Komen Foundation, 2003a,b). These and other resources would appear to be well-received by this population of testing participants regarding communication decisions and their children. Currently, there do not appear to be any published resources developed specifically to facilitate decisions about communicating *BRCA1/2* genetic testing to children--though these have been called for (van Oostrom *et al.*, 2007).

The limitations to this study include a relatively homogenous and nonrepresentative sample which curtails the external validity of the findings. The study also reported on baseline information only. It would be interesting to determine if and how mothers' needs change as a function of learning their test results. The study also did not survey children and their needs directly--only indirectly through maternal reports. Finally, the study did not take into account if or how mothers' needs may differ based on characteristics of their children or families. For example, mothers may have different needs for older and younger children, and for their daughters and sons. More work is needed in this area to better determine these needs.

In spite of the limits of this study, the data identify both a need and ways in which to fulfill that need among mothers participating in *BRCA1/2* testing. In conjunction with enhanced genetic counseling focusing on family disclosure, educational literature, psychosocial support, and other information resources may help to promote improved outcomes among participants and their family members.

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References

- Armstrong D, Bacon J, Booker SV, Brensinger J, Chen P, Codori AM, Giardiello F, Grinnin CA, Johnson KA, Kim JW, Olsen S, Petersen G, Romans K, Sollenberger J. 2001 The Johns Hopkins guide for patients and families: Peutz-Jeghers syndrome. November 16, 2006 www.hopkins-gi.org/multimedia/database/hccIntro_42_PJS-Book.pdf Last accessed
- ASCO. American Society of Clinical Oncology policy statement update: genetic testing for cancer susceptibility. *J Clin Oncol.* 2003; 21:2397–2406. [PubMed: 12692171]

- ASHG. Points to consider: ethical, legal, and psychosocial implications of genetic testing in children and adolescents. American Society of Human Genetics Board of Directors, American College of Medical Genetics Board of Directors. *Am J Hum Genet.* 1995; 57:1233–1241. [PubMed: 7485175]
- Bacon JA, Booker SV, Brensinger JD, Celano P, Cox D, Giardiello FM, Hamilton SR, Hyland L, Krush AJ, Petersen GM, Potter K, Romans KE, Sollenberger JE, Traboulsi EI, Yardley J. 2000The Johns Hopkins guide for patients and families: Hereditary nonpolyposis colon cancer. November 16, 2006www.hopkins-gi.org/multimedia/database/intro_83_HNPCC%20Booklet.pdf Last accessed
- Bacon JA, Booker SV, Brensinger JD, Celano P, Cox D, Giardiello FM, Hamilton SR, Hyland L, Johnson KA, Krush AJ, Levin S, Petersen GM, Potter K, Romans KE, Traboulsi EI, Yardley J. 2000The Johns Hopkins guide for patients and families: Familial adenomatous polyposis. November 16, 2006www.hopkins-gi.org/multimedia/database/hccIntro_82_FAP-Book.pdf Last accessed
- Burrows KR, Kelley CK. Parental interrater reliability as a function of situational specificity and familiarity of target child. *J Abnorm Child Psychol.* 1983; 11:41–47. [PubMed: 6853880]
- Burton S, Haidle JL, Hampel H, Eng C. 2004Cowden syndrome: a guide for patients and their families. November 16, 2006www.vh.org/pediatric/patient/cancercenter/cowden/index.html Last accessed
- Cicchetti DV, Sparrow SS. Developing criteria for establishing inter-rater reliability of specific items in a given inventory. *Am J Ment Defic.* 1981; 86:127–137. [PubMed: 7315877]
- Cohen, J.; Cohen, P. *Applied multiple regression/correlation analysis for the behavioral sciences.* Lawrence Erlbaum Associates, Inc.; Hillsdale, NJ: 1983.
- Costalas JW, Itzen M, Malick J, Babb JS, Bove B, Godwin AK, Daly MB. Communication of BRCA1 and BRCA2 results to at-risk relatives: A cancer risk assessment program's experience. *Am J Med Genet.* 2003; 119C:11–18. [PubMed: 12704633]
- Daly MB, Barsevick A, Miller SM, Buckman R, Costalas J, Montgomery S, Bingler R. Communicating genetic test results to the family: a six-step, skills-building strategy. *Fam Community Health.* 2001; 24:13–26. [PubMed: 11563941]
- Davey A, Rostant K, Harrop K, Goldblatt J, O'Leary P. Evaluating genetic counseling: client expectations, psychological adjustment and satisfaction with service. *J Genet Couns.* 2005; 14:197–206. [PubMed: 15959651]
- DeMarco TA, Loffredo CA, Sampilo ML, Tercyak KP. On using a cancer center cancer registry to identify newly affected women eligible for hereditary breast cancer syndrome testing: Practical considerations. *J Genet Couns.* 2006; 15:129–136. [PubMed: 16761104]
- Elger BS, Harding TW. Testing adolescents for a hereditary breast cancer gene (BRCA1): respecting their autonomy is in their best interest. *Arch Pediatr Adolesc Med.* 2000; 154:113–119. [PubMed: 10665596]
- Frederickson M, Bull PE. Evaluation of a patient education leaflet designed to improve communication in medical consultations. *Patient Educ Couns.* 1995; 25:51–57. [PubMed: 7603933]
- Ghate, S.; Leininger, A.; Solomon, CH.; Teed, N.; Trimbath, JB. *FAP and me: A kid's guide to familial adenomatous polyposis.* National Society of Genetic Counselors; Wallingford, PA: 2004.
- Green MJ, Peterson SK, Baker MW, Harper GR, Friedman LC, Rubinstein WS, Mauger DT. Effect of a computer-based decision aid on knowledge, perceptions, and intentions about genetic testing for breast cancer susceptibility: a randomized controlled trial. *JAMA.* 2004; 292:442–452. [PubMed: 15280342]
- Hibbs K. Assessment of educational materials for children at risk for inherited colon cancer. 2004 Graduate thesis submitted to the University of Minnesota.
- Huelsman, K.; Howell, K.; Parmar, S.; Pritzlaff, M.; Shanmugham, A.; White, S.; Everett, J. Literature needs for patients evaluated with hereditary cancer: Development of 5 new brochures. 20th annual education conference, National Society of Genetic Counselors; Washington, DC. 2001. p. 288abstract
- Hughes C, Lerman C, Schwartz M, Peshkin BN, Wenzel L, Narod S, Corio C, Tercyak KP, Hanna D, Isaacs C, Main D. All in the family: Evaluation of the process and content of sisters'

- communication about BRCA1 and BRCA2 genetic test results. *Am J Med Genet.* 2002; 107:143–150. [PubMed: 11807889]
- Hughes C, Peterson SK, Ramirez A, Gallion KJ, McDonald PG, Skinner CS, Bowen D. Minority recruitment in hereditary breast cancer research. *Cancer Epidemiol Biomarkers Prev.* 2004; 13:1146–1155. [PubMed: 15247125]
- James C, James N, Davies D, Harvey P, Tweddle S. Preferences for different sources of information about cancer. *Patient Educ Couns.* 1999; 37:273–282. [PubMed: 14528553]
- Janis, IL.; Mann, L. *Decision making: A psychological analysis of conflict, choice and commitment.* The Free Press; New York: 1977.
- Johnson JD, Meischke H. Women's preferences for cancer information from specific communication channels. *Am Behav Sci.* 1991; 34:742–755.
- Kaufman EM, Peshkin BN, Lawrence W, Shelby R, Isaacs C, Brown K, Rispoli J, O'Neill S, Hurley K, DeMarco T, Brogan B, Grumet S, Jandorf L, McKenna K, Valdimarsdottir H, Schwartz MD. Development of an interactive decision aid for female BRCA1/BRCA2 carriers. *J Genet Couns.* 2003; 12:109–129.
- Kiesler DJ, Auerbach SM. Optimal matches of patient preferences for information, decision-making and interpersonal behavior: Evidence, models and interventions. *Patient Educ Couns.* 2006; 61:319–341. [PubMed: 16368220]
- King MC, Marks JH, Mandell JB. Breast and ovarian cancer risks due to inherited mutations in BRCA1 and BRCA2. *Science.* 2003; 302:643–646. [PubMed: 14576434]
- Kotsopoulos J, Narod SA. Towards a dietary prevention of hereditary breast cancer. *Cancer Causes Control.* 2005; 16:125–138. [PubMed: 15868454]
- Lerman C, Narod S, Schulman K, Hughes C, Gomez-Caminero A, Bonney G, Gold K, Trock B, Main D, Lynch J, Fulmore C, Snyder C, Lemon SJ, Conway T, Tonin P, Lenoir G, Lynch H. BRCA1 testing in families with hereditary breast-ovarian cancer. A prospective study of patient decision making and outcomes. *JAMA.* 1996; 275:1885–1892. [PubMed: 8648868]
- Lynch HT, Lemon SJ, Durham C, Tinley ST, Connolly C, Lynch JF, Surdam J, Orinion E, Slominski-Caster S, Watson P, Lerman C, Tonin P, Lenoir G, Serova O, Narod S. A descriptive study of BRCA1 testing and reactions to disclosure of test results. *Cancer.* 1997; 79:2219–2228. [PubMed: 9179070]
- Mann L, Burnett P, Radford M, Ford S. The Melbourne Decision Making Questionnaire: An instrument for measuring patterns for coping with decisional conflict. *J Behav Decis Making.* 1997; 19:1–19.
- McConkie-Rosell A, Spiridigliozzi GA. “Family matters”: A conceptual framework for genetic testing in children. *J Genet Couns.* 2004; 13:9–29. [PubMed: 15248319]
- Miles, MB.; Huberman, AM. *Qualitative data analysis: An expanded sourcebook.* 2nd. Sage Publications; Newbury Park, California: 1994.
- Narod SA. Modifiers of risk of hereditary breast and ovarian cancer. *Nat Rev Cancer.* 2002; 2:113–123. [PubMed: 12635174]
- O'Connor, A. *Decisional conflict scale.* 4th. University of Ottawa; Ontario: 1999.
- O'Connor AM, Jacobsen MJ, Stacey D. An evidence-based approach to managing women's decisional conflict. *J Obstet Gynecol Neonatal Nurs.* 2002; 31:570–581.
- O'Connor AM, Stacey D, Entwistle V, Llewellyn-Thomas H, Rovner D, Holmes-Rovner M, Tait V, Tetroe J, Fiset V, Barry M, Jones J. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev.* 2003;CD001431. [PubMed: 12804407]
- O'Connor AM, Graham ID, Visser A. Implementing shared decision making in diverse health care systems: the role of patient decision aids. *Patient Educ Couns.* 2005; 57:247–249. [PubMed: 15893205]
- Ross LF, Moon MR. Ethical issues in genetic testing of children. *Arch Pediatr Adolesc Med.* 2000; 154:873–879. [PubMed: 10980789]
- Schwartz MD, Benkendorf J, Lerman C, Isaacs C, Ryan-Robertson A, Johnson L. Impact of educational print materials on knowledge, attitudes, and interest in BRCA1/BRCA2: testing among Ashkenazi Jewish women. *Cancer.* 2001; 92:932–940. [PubMed: 11550168]

- Shiloh S, Gerad L, Goldman B. The facilitating role of information provided in genetic counseling for counselees' decisions. *Genet Med*. 2006; 8:116–124. [PubMed: 16481895]
- Siegel LJ, Dragovich SL, Marholin D. The effects of biasing information on behavioral observations and rating scales. *J Abnorm Child Psychol*. 1976; 4:221–233. [PubMed: 972206]
- Skinner CS, Schildkraut JM, Berry D, Calingaert B, Marcom PK, Sugarman J, Winer EP, Iglehart JD, Futreal PA, Rimer BK. Pre-counseling education materials for BRCA testing: does tailoring make a difference? *Genet Test*. 2002; 6:93–105. [PubMed: 12215248]
- Smith, ACM. Patient education. In: Baker, DL.; Schuette, JL.; Uhlmann, WR., editors. *A guide to genetic counseling*. Wiley-Liss; New York: 1998. p. 99-121.
- Susan G. Komen Breast Cancer Foundation. What's happening to the woman we love? Families coping with breast cancer. 2003a Item No. 806-416.
- Susan G. Komen Breast Cancer Foundation. What's happening to mom? Helping children cope with breast cancer. 2003b Item No. 806-418.
- Tercyak KP, Hughes C, Main D, Snyder C, Lynch JF, Lynch HT, Lerman C. Parental communication of BRCA1/2 genetic test results to children. *Patient Educ Couns*. 2001; 42:213–224. [PubMed: 11164320]
- Tercyak KP, Peshkin BN, Streisand R, Lerman C. Psychological issues among children of hereditary breast cancer gene (BRCA1/2) testing participants. *Psycho-Oncology*. 2001; 10:336–346. [PubMed: 11462232]
- Tercyak KP, Peshkin BN, DeMarco TA, Brogan BM, Lerman C. Parent-child factors and their effect on communicating BRCA1/2 test results to children. *Patient Educ Couns*. 2002; 47:145–153. [PubMed: 12191538]
- Tercyak, KP. Genetic disorders and genetic testing. In: Roberts, MC., editor. *Handbook of pediatric psychology*. 3rd. New York: Guilford Press; 2003. p. 719-734.
- Tercyak KP, Streisand RM, Peshkin BN, Lerman C. Psychosocial impact of predictive testing for illness on children and families: Challenges for a new millennium. *J Clin Psychol Medical Settings*. 2000; 7:55–68.
- Trepanier A, Ahrens M, McKinnon W, Peters J, Stopfer J, Grumet SC, Manley S, Culver JO, Acton R, Larsen-Haidle J, Correia LA, Bennett R, Pettersen B, Ferlita TD, Costalas JW, Hunt K, Donlon S, Skrzynia C, Farrell C, Callif-Daley F, Vockley CW. Genetic cancer risk assessment and counseling: Recommendations of the National Society of Genetic Counselors. *J Genet Couns*. 2004; 13:83–114. [PubMed: 15604628]
- van Oostrom I, Meijers-Heijboer H, Duivenvoorden HJ, Brocker-Vriends AH, van Asperen CJ, Sijmons RH, Seynaeve C, Van Gool AR, Klijn JG, Tibben A. Comparison of individuals opting for BRCA1/2 or HNPCC genetic susceptibility testing with regard to coping, illness perceptions, illness experiences, family system characteristics and hereditary cancer distress. *Patient Educ Couns*. 2007; 65:58–68. [PubMed: 16872788]
- Yale Cancer Center. Cancer Genetic Counseling Program Newsletter (Spring 2004) BRCA documentary. November 16, 2006 info.med.yale.edu/ycc/genetics/newsletters/pdf/spring_2004_patient.pdf Last accessed

Figure 1. Mothers' Resource Needs

Table 1
Participant Demographic Characteristics (N=187)

	<i>m</i>	<i>sd</i>	<i>n</i>	%
Maternal age	45.6	5.9		
Race				
White			152	81.3
Other			35	18.7
Ethnicity				
Jewish			67	35.8
Other			120	64.2
Education				
< College			47	25.1
College			140	74.9
Household income				
< 75k			45	24.1
75k			142	75.9
Married or living as married				
Yes			150	80.2
Personal history of breast/ovarian cancer				
Yes			109	58.3
Family history of breast/ovarian cancer				
Yes			94	50.3
Proband status				
Yes			142	75.9
Child age	12.9	3.8		
Child female gender				
Yes	95	50.8		

Table 2
Mothers' Reasons Why Learning About Children's Risks is a motivation for *BRCA1/2* Testing (*N*=143)

Reason	<i>n</i>	%
Direct benefit to the mother (e.g., her health to raise the child)	19	13.3
Indirect benefit to the mother (e.g., cascade testing)	53	37.1
Potential benefit of this information to the child (e.g., prevention)	63	44.1
Psychological benefit (e.g., open family communication)	5	3.5
Other	3	2.1

Table 3
Hierarchical Multiple Regression Model of Need Frequency

Variable	β	$SE(\beta)$	t	p
Race (0 - Other, 1 - White)	-0.39	0.23	-1.65	0.10
Education (0 < College, 1 - College)	-0.45	0.23	-1.96	0.05
Household income (0 - < 75k, 1 - 75k)	-0.02	0.24	-0.07	0.94
Motivations	0.35	0.16	2.22	0.03
Vigilance	0.16	0.05	3.42	0.00
Conflict	0.10	0.04	2.76	0.00