Parenting Through Genetic Uncertainty: Themes in the Disclosure of Breast Cancer Risk Information to Children

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Aim: Among mothers undergoing *BRCA1/2* testing and their spouses/partners, this study sought to examine decision support needs and motivations for family communication of genetic risk information to asymptomatic children. **Methods:** This study gathered data from 213 tested mothers and 104 of their untested parenting partners 1 month after maternal receipt of genetic test results and upon making a decision about communicating genetic information to their child (ages 8–21 years). Data include parents' perceived needs for family communication decision support, decision motivations, and parent-child communication. **Results:** Parents reported high decision support needs (e.g., educational materials, professional counseling, peer assistance). Motivations for disclosure to children among mothers and partners focused on promoting the parent-child bond and maintaining family health (55.3% and 75%, respectively) and promoting positive child affect (44.7% and 25.5%, respectively). Motivations for nondisclosure to children among mothers and partners focused on the lack of appropriateness (69.6% and 51.3%, respectively) and relative importance of genetic test results (30.4% and 48.7%, respectively). Significant discrepancies in parental motivation for family communication were observed. Decision support needs were highest among disclosing mothers with affect-related motivations [$t(129) = 2.47$; $p = 0.01$]. Parent-child communication was poorest among nondisclosing mothers concerned about the appropriateness of genetic information for their child [$t(77) = -3.29$; $p = .002$]. **Conclusions:** Parents receiving information about hereditary cancer predisposition have unmet needs when making decisions about disclosing genetic risk information to their asymptomatic children. These data can guide the development of cancer risk communication decision support interventions for parents undergoing such testing.

Introduction

COMMUNICATING INFORMATION ABOUT GENETIC conditions to family members can be a complex and emotionally charged process (Tercyak *et al.*, 2001; Tercyak *et al.*, 2002; Forrest *et al.*, 2003; Gallo *et al.*, 2005). Decisions about communicating genetic risk information to children presents parents with special challenges, including whether, when, and how to disclose information to the child; what to disclose; and anticipation of how the child may react (Gallo *et al.*, 2005). This is especially true for asymptomatic children who may be at risk for adult-onset disease. Under these circumstances, the child's disease risk is not yet known and genetic testing of children is not recommended or considered to be appropriate (Malpas 2006). However, parents often feel compelled to

share genetic risk information with their children (Forrest *et al.*, 2003; Hallowell *et al.*, 2005; Metcalfe *et al.*, 2008) and face uncertainty when considering disclosure, including whether the child is adequately prepared to comprehend complex risk information, the consequences for the child's future, and the possible negative effect of disclosure on child adjustment and family functioning (Malpas 2006).

Hereditary breast cancer is one such genetic condition in which asymptomatic children within families with a known genetic mutation have a higher probability than the general population of carrying an increased genetic risk. Hereditary breast cancer, attributable to *BRCA1/2* genetic mutations, carries a 40–85% lifetime risk for breast cancer among those identified as carriers and up to a 25–65% risk for ovarian cancer (Chen and Parmigiani 2007; Amir *et al.*, 2010).

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Offspring of *BRCA1/2* mutation carriers have a 50% chance of inheritance, yet testing children is discouraged because of the lack of immediate medical implications and potential adverse psychological effects (American Society of Clinical Oncology 2003). However, learning about children's risk for inheriting a mutation is often a factor motivating parental genetic testing (Tercyak *et al.*, 2007), and parents frequently disclose genetic test results to young children (Tercyak *et al.*, 2001; Tercyak *et al.*, 2002; Cheung *et al.*, 2010) and demonstrate interest in pediatric *BRCA1/2* testing (Peshkin *et al.*, 2009; Bradbury *et al.*, 2010).

It remains largely unknown why parents elect to share information about a mother's *BRCA1/2* mutation status with children. Preliminary evidence suggests that the decision to disclose may be influenced by positive attributes of parent-child communication and perceptions of the child's developmental status (Hallowell *et al.*, 2005; Bradbury *et al.*, 2007; Tercyak *et al.*, 2007; Metcalfe *et al.*, 2008). Formative research on parents' disclosure decisions surrounding hereditary breast cancer and Huntington disease (a genetic disorder in which asymptomatic children's risk status is also uncertain) suggests that disclosure typically occurs when parents determine children to be developmentally prepared to process risk information and deem information to be relevant to their child (Forrest *et al.*, 2003; Hamilton *et al.*, 2005; Forrest Keenan *et al.*, 2009). These data also suggest that parents' disclosure decisions are motivated by a desire for balance between honoring children's right to know about genetic risk and protecting children from worry or uncertainty, as well as promoting trust and open communication within the family (Forrest *et al.*, 2003; Wilson *et al.*, 2004; Hallowell *et al.*, 2005; Metcalfe *et al.*, 2008).

Decisions to disclose information about genetic risk to asymptomatic children may also be related to parents' needs for support (Forrest *et al.*, 2003; Tercyak *et al.*, 2007). For example, mothers considering disclosure of *BRCA1/2* genetic information require multiple resources to support their decision-making (Tercyak *et al.*, 2007), including literature, counseling, and speaking with other parents. Carriers of *BRCA1/2* mutations maintain strong interest in similar resources to aid in their decision-making and disclosure process (Segal *et al.*, 2004). A recent meta-synthesis on parent-child communication of inherited genetic risk found consistent need among parents for more support in family communication about genetic conditions (Metcalfe *et al.*, 2008).

Disclosure of genetic risk information for hereditary breast cancer to asymptomatic children is a process that has important implications for families, including mothers, their child-rearing partners, and offspring (Tercyak *et al.*, 2002; Wilson *et al.*, 2004; Tercyak *et al.*, 2007; Cheung *et al.*, 2010). Research suggests that when *BRCA1/2* status is disclosed to minor children, disclosure is usually performed by mothers alone acting as information gate-keepers (Tercyak *et al.*, 2001; Segal *et al.*, 2004). Yet, when child-rearing partners participate in genetic counseling together, they report a closer parenting relationship, which may facilitate shared decisions about disclosure (DeMarco *et al.*, 2010). Unfortunately, less than one third of partners attend cancer genetic counseling sessions, promoting a standard of care as individual-focused rather than family-focused (DeMarco *et al.*, 2010). To fully understand the experience of parenting through the uncertainty of genetic risk information as it relates to familial coping and

support, it is therefore necessary to examine the needs and motivations of both tested mothers and their untested partners, regardless of prior exposure to genetic counseling.

Our study sought to do so in a sample of parents who had experienced *BRCA1/2* testing in order to identify major themes in parental motivations toward disclosing medical information to children. We sought to determine whether and how parental motivations were associated with child-related factors and parents' needs for decision support surrounding family communication. The outcomes of this research could help inform the development of interventions for parents rearing children in the context of genetic uncertainty (Mackenzie *et al.*, 2009; Peshkin *et al.*, 2010).

Methods

Setting

Institutional review boards at 3 participating sites approved this work, and all participants provided informed consent. All sites were cancer centers hosting well-established clinical research programs focusing on adult hereditary breast and ovarian cancer.

Sample

Participants were 213 mothers who underwent genetic counseling and testing for *BRCA1/2* and 104 of their untested spouses or partners (herein, "partners"). There were 102 mother-partner dyads (47.9% of study total). Women had to be older than age 18 years, be participating in *BRCA1/2* testing and provide a DNA sample, and be mother to more than 1 child age 8–21 years. The lower-bound age was selected because previous work has determined that children of that age may learn about their mothers' genetic risk (Tercyak *et al.*, 2001; Tercyak *et al.*, 2002); the upper-bound age was selected because children of that age might also be considered eligible for genetic testing under some circumstances (American Society of Clinical Oncology 2003). Partners were eligible to participate in the survey but did not undergo *BRCA1/2* testing.

Recruitment and data collection

Mothers were screened and approached for inclusion by their cancer genetic counselor at the conclusion of their pretest appointment and after giving a DNA sample. Mothers sharing the responsibility of raising a child with a partner were informed of the opportunity for him or her to participate. All were informed that the study focused on family communication: 81% of eligible mothers and 60% of partners consented to participate (DeMarco *et al.*, 2008).

On enrollment, mothers provided data for each of their children (age, date of birth, sex, birth order, and birth relationship [i.e., biological child, stepchild, or other]). A computerized random selection algorithm designated a "target child" of interest within the study age range for mothers with more than 1 child to alleviate parental selection and reduce bias (Peshkin *et al.*, 2009). Enrolled participants completed 3 telephone interviews: immediately following pretest counseling, and 1 and 6 months after post-test counseling. A modest incentive was offered to acknowledge interview completion. Data analyzed in this study were collected 1 month after counseling, and all mothers participated in both pre- and post-test counseling sessions.

Measures

Demographic and maternal clinical information. Demographic information was obtained from parents about themselves (sex, age, race, education, household income, marital status) and their target child (age, sex). Maternal clinical information about personal and family history of breast and ovarian cancer was collected from mothers only. Test results were recorded directly.

Need for resources on decision support for family communication. Parents were presented with a list of 4 types of resources that could support decision-making about communicating genetic information to their child or children: 1) speaking with a peer/experienced parent, 2) accessing print materials, 3) speaking with a family counselor, and 4) attending a support group. An additional item permitted parent-nominated resources. For each resource type, parents indicated whether it was needed in the context of decision-making about family communication (0=no, 1=yes). Affirmative endorsements were summed to create a measure of decision support need (range, 0–5) (Tercyak *et al.*, 2007). (Note that no resources were actually made available to parents as part of this study, other than genetic counseling. Parents may have independently sought additional resources, but assessment of that was beyond the scope of this work.)

Motivations for family communication decisions. A majority of parent decision-making regarding disclosure to children has been observed to take place shortly after post-test counseling (Tercyak *et al.*, 2001; Tercyak *et al.*, 2002). Parents were independently asked whether they made a communication choice (disclosed or nondisclosed to their child) and subsequently responded to an open-ended item assessing disclosure motivations. Responses were recorded verbatim and qualitatively coded using an empirically derived scheme (Tercyak *et al.*, 2002). Participants' responses were independently coded by 2 raters (T.A.D. and M.E.S.). High inter-rater agreement was obtained for both mothers and partners who disclosed (Cohen κ =0.82–0.83) and did not disclose (Cohen κ =0.81–0.91). Coding discrepancies (32 total; 11%) were discussed with an expert coder (K.P.T.) and resolved by consensus. For statistical analyses, codes were collapsed into 4 categories, reflecting 2 major themes for disclosure and 2 major themes for nondisclosure. Criteria for the categories was based on 7 members of the research team (T.A.D., D.M., A.F.P., B.N.P., K.A.S., M.E.S., and K.P.T.) engaging in a rationally derived, inductive process to consolidate subordinate categories into major themes (Walker and Myrick 2006).

Parent-child communication. To measure the quality of parents' general communication styles with their child, we administered the Parent-Adolescent Communication Scale (PAC) (Barnes and Olson 1982). The PAC is a reliable and valid 20-item behavioral self-report measure. Higher scores indicate more open/less conflicted communication with the child. Internal consistency for mothers and partners was solid (Cronbach α =0.85 and 0.83, respectively). The PAC has successfully been used with preadolescents in research on family communication and genetic testing (Tercyak *et al.*, 2002).

Analysis

Descriptive statistics were used to summarize all variables for mothers and partners separately. Differences in proportions for mothers' and partners' motivations for disclosure or nondisclosure of test results were examined separately by using chi-square tests: agreement within the subsample of intact parenting dyads was assessed by using the Cohen κ statistic, a robust statistical measure of agreement for categorical items. Bivariate associations between child-related variables and parents' perceived resource needs with reasons for disclosure/nondisclosure were then analyzed by using chi-square tests and *t*-tests. (using SAS 9.2)

Results

Sample characteristics

Characteristics of the study sample are displayed in Table 1.

Need for resources on decision support for family communication

On average, mothers designated a mean $\pm$ standard deviation of 3.2 ± 1.4 resources as potentially beneficial in supporting their disclosure decisions. The most commonly endorsed resources were needing access to print materials (86.9%), speaking with a counselor (79.8%), speaking with a peer or experienced parent (75.1%), and attending a support group (57.8%). Partners also designated an average of 3.2 ± 1.3 resources for this purpose, needing guidance by print materials (92.3%), counseling (78.9%), peers (76.0%), and group support (51.9%). Resource need among mothers and their partners was weakly correlated ($r=0.22$; $p=0.03$), suggesting intrafamilial variability.

TABLE 1. PARTICIPANT CHARACTERISTICS (N=317)

Characteristic	Mothers (n=213)	Partners (n=104)
Age (y)	46.2 $\pm$ 6.1	47.8 $\pm$ 7.1
Race		
White	172 (80.8)	90 (86.5)
Nonwhite	41 (19.2)	14 (13.5)
Education		
Less than college degree	47 (22.1)	22 (21.2)
College degree or greater	166 (77.9)	82 (78.8)
Household income		
<\$75,000	43 (20.2)	23 (22.1)
$\geq$ \$75,000	170 (79.8)	81 (77.9)
Married/living as married	177 (83.1)	94 (90.4)
Personal cancer history (yes) ^a	121 (56.8)	
Family cancer history (yes) ^a	111 (52.1)	
Proband status (yes) ^a	162 (76.1)	
BRCA1/2 carrier status ^a		
True negative	23 (10.8)	14 (13.5)
Uninformative	161 (75.6)	80 (76.9)
Positive	29 (13.6)	10 (9.6)
Child age (y)	13.0 $\pm$ 3.8	12.3 $\pm$ 3.3
Female child	106 (49.8)	58 (55.8)

Unless otherwise noted, values are the number (percentage) of participants.

^aApplies to mothers only.

Motivations for family communication decisions

Parents' self-reported motivations for disclosure and non-disclosure are displayed in Tables 2 and 3, respectively.

Disclosure. All but 1 mother provided a response that could be coded ($n = 132$). Maternal motivations for disclosure were to promote the parent-child bond and for family health maintenance purposes (55.3%), followed by promoting positive feelings or affect in the child (44.7%) [chi-square (1) = 1.48; $p = 0.22$]. Among partners ($n = 44$), all but 2 provided a coded response. Unlike mothers, partners who had informed their child about a *BRCA1/2* result were more likely to have done so for family health maintenance purposes than out of concern for child affect (75.0% and 25.0%, respectively) [chi-square (1) = 11.00; $p = 0.0009$]. Among intact mother-partner dyads, motivations for disclosure converged less than 25% of the time (Cohen $\kappa = 0.22$; 95% confidence interval [CI], $-0.09, 0.53$).

Nondisclosure. Maternal motivations against disclosure included that the information was not considered appropriate for the child at that time (69.6%), and a genetic test result (in and of itself) did not warrant disclosure (30.4%) [chi-square

(1) = 12.16; $p = 0.0005$]. By contrast, no dominant trend was observed among partners (51.3% and 48.7%, respectively) [chi-square (1) = 0.03; $p = 0.87$]. There was poor agreement among intact parenting dyads about motivations for nondisclosure as well (Cohen $\kappa = 0.17$; 95% CI, $-0.15, 0.49$).

Determinants of family communication

Disclosure. Among mothers who disclosed genetic information to their child, there were no differences by child age, sex, or parent-child communication functioning between those who disclosed for affective reasons and those who disclosed for family health maintenance reasons. However, disclosing mothers with primarily affective motivations had significantly greater needs for family communication decision support resources (mean = 3.6 ± 1.1) than did disclosing mothers with primarily family health maintenance motivations [mean = 3.1 ± 1.5 ; t (129) = 2.47; $p = 0.01$]. No differences were observed among partners.

Nondisclosure. Among mothers who did not disclose genetic information to their child, a significant effect was observed for parent-child communication: mothers expressing

TABLE 2. REASONS FOR PARENTAL DISCLOSURE OF *BRCA1/2* GENETIC TEST RESULTS TO CHILDREN

<i>Superordinate theme</i>	<i>Subordinate theme</i>	<i>Description</i>	<i>Mothers</i> ($n = 132$)	<i>Partners</i> ($n = 44$)
Affect: Promoting positive feelings or affect in the child by preventing worry or suspicion or sharing of good news			59 (44.7)	11 (25.0)
	Good news	Test result was negative, so parent shared the news (e.g., news was good and it would be a relief to the child to hear it)	26 (19.7)	8 (18.2)
	Avoid worry	To prevent or stop any further worry or suspicion, the parent informed the child about the test result	33 (25.0)	3 (6.8)
Maintenance: Promoting the parent-child bond and maintaining a healthy family			73 (55.3)	33 (75.0)
	Child rights	In general, the child has the right to know; the child has the right to know about health issues that may affect him/her now or in the future	31 (23.5)	11 (25.0)
	Parental responsibility	Parent felt a basic sense of responsibility or duty to tell the child, including an intent to maintain awareness of cancer prevention and health issues	15 (11.4)	9 (20.5)
	Trust	To maintain trust and open communication, including that the child was aware of the mother's genetic counseling appointment, cancer diagnosis and treatment, etc.: not talking about the result constituted withholding information.	27 (20.5)	13 (29.6)

Data are the number (percentage) of participants. Mother response not coded ($n = 1$), partner response not given ($n = 1$), partner response not coded ($n = 1$).

TABLE 3. REASONS FOR PARENTAL NONDISCLOSURE OF *BRCA1/2* GENETIC TEST RESULTS TO CHILDREN

<i>Superordinate theme</i>	<i>Subordinate theme</i>	<i>Description</i>	<i>Mothers (n = 79)</i>	<i>Partners (n = 39)</i>
Inappropriate: Child is too young or cognitively or emotionally immature, or the timing is not right			55 (69.6)	20 (51.3)
	Concern	Concerned that the child would become too worried, burdened, or anxious over the news.	13 (16.5)	4 (10.3)
	Age/maturity	Child is too young to understand the information; parent would prefer to wait to talk to the child about testing until the child is older; child is not mature enough to appreciate the information	33 (41.8)	14 (35.9)
Not compelling: Test result itself is not compelling enough to discuss	Timing	Just not the right time and/or place to disclose results; have intentions of disclosing when the timing is more appropriate	9 (11.4)	2 (5.1)
	Not an issue	Child has not asked about the result or does not seem interested	24 (30.4)	19 (48.7)
	Too vague	The test result itself does not seem compelling enough to warrant discussion with the child, especially in the absence of other medical (i.e., diagnostic, preventive) implications or events; <i>BRCA1/2</i> test results seem vague and irrelevant	7 (8.9)	3 (7.7)
			17 (21.5)	16 (41.0)

Data are the number (percentage) of participants. Mother response not given ($n=1$), partner response not given ($n=16$), partner response not coded ($n=1$).

that genetic information was inappropriate for their child to learn reported less openness in their parent-child communication patterns and more communication problems (mean = 75.7 ± 11.4) than did mothers who expressed that genetic information was not compelling [mean = 84.1 ± 8.1 ; $t(77) = -3.29$; $p = .002$]. No other differences were found.

Discussion

Mothers tested for *BRCA1/2* and their childrearing partners face uncertain, difficult, and complicated decisions about disclosing genetic test results to their asymptomatic children (Tercyak *et al.*, 2001; Tercyak *et al.*, 2002). Although it is recommended that cancer genetic counseling sessions include discussions of family communication (Peterson 2005), this issue is often overlooked regarding asymptomatic children and their adult-onset disease risk. The lack of immediate medical implications on child health and the potential for genetic information to be misinterpreted by children make this understandable. However, it remains important to know how parents make decisions about family communication that include children so that decision supports can be enhanced through counseling or other means.

At the time of pretest genetic counseling, mothers anticipating decisions about whether and when to disclose their *BRCA1/2* test results to their child acknowledge needing additional assistance in doing so (Tercyak *et al.*, 2007). Our

findings extend these earlier results and that of previous research (Segal *et al.*, 2004; Metcalfe *et al.*, 2008) demonstrating mothers persistently need additional guidance. Parenting partners report similar levels of need for family communication support as counseled/tested mothers, although they infrequently attend genetic counseling themselves (DeMarco *et al.*, 2010). Thus, interventions focused on family communication appear warranted, especially interventions delivered as adjuncts to standard genetic counseling as currently practiced (Mackenzie *et al.*, 2009; Peshkin *et al.*, 2010).

Although mothers and partners endorse similar levels of need for family communication decision support resources, their choices and motivations about disclosure vary markedly. Among parents who disclosed genetic information to their child, mothers were almost equally likely to have done so out of the belief that disclosure maintains family health and positively influences child affect. Partners, on the other hand, were far more strongly motivated by the prospect of disclosure being a tool to help maintain family health. Among parents who did not disclose genetic information to their child, heterogeneity was evident there as well: mothers were more sensitive to the appropriateness of information to their child than were partners, whereas partners were more evenly influenced by this and whether the information was viewed as compelling.

Our findings build on previous research suggesting that parents are thoughtful about family communication and consider multiple factors when contemplating disclosure to

their child (e.g., family functioning, child development, relevance of genetic information, potential effect on child's psychological well-being) (Forrest *et al.*, 2003; Wilson *et al.*, 2004; Hallowell *et al.*, 2005; Hamilton *et al.*, 2005; Metcalfe *et al.*, 2008; Forrest Keenan *et al.*, 2009). This has implications for the development of family communication interventions, in that they include a focus on decision-making about disclosure to children. Toward that end, parenting communication tools addressing individual preferences and values toward disclosure, reflecting broad themes concerning risks and benefits of disclosure and nondisclosure on child affect, the maintenance of family health and balance, and the potential relevance of the information to the child at different stages of life, seem warranted. Because mothers and their parenting partners might view these issues differently and with different needs for resolving uncertainty, flexible and tailored approaches to patient education and counseling are also advised.

This study has several limitations, including the narrow diversity in the sample and the suboptimal rate of participation among eligible partners. Caution generalizing the findings to heterogeneous populations is advised, including to individuals who receive no or minimal genetic counseling in conjunction with *BRCA1/2* genetic testing.

Despite undergoing genetic counseling, mothers receiving information about their hereditary predisposition to breast or ovarian cancer have unmet needs for making well-informed decisions about family communication. In this case, the decision is whether to disclose genetic information to their asymptomatic minor-aged child. Childrearing partners also have unmet needs in this area. As a field, cancer control has embraced *BRCA1/2* genetic testing as a clinical tool for risk management, and genetic counseling is a recommended part of this process. However, our data would suggest that parents' needs for managing the uncertainty that stems from genetic information probably exceed the capacity of standard genetic counseling as practiced today with respect to professional guidance about family communication and disclosure to children. Our data indicate that parents base choices on a complex set of motivations for or against disclosure, often rooted in their perceived values of the medical information to be exchanged with the child. In the absence of evidence-based resources to better support parental decision-making, assistance should be offered to parents in exploring their disclosure-related motivations to make well-informed choices during genetic counseling.

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Disclosure Statement

The authors have reported no conflicts of interest.

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