

Decisional Outcomes of Maternal Disclosure of *BRCA1/2* Genetic Test Results to Children

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Abstract

Background: Although *BRCA1/2* genetic testing is discouraged in minors, mothers may disclose their own results to their children. Factors affecting patients' disclosure decisions and patient outcomes of disclosure are largely unknown.

Methods: Mothers ($N = 221$) of children aged 8 to 21 years enrolled in this prospective study of family communication about cancer genetic testing. Patients underwent *BRCA1/2* genetic counseling and testing, and completed standardized behavioral assessments before and 1-month following receipt of their results.

Results: Most patients (62.4%) disclosed *BRCA1/2* test results to their child. Patients were more likely to disclose if they received negative or uninformative versus positive results [OR = 3.11; 95% confidence interval (CI), 1.11–8.71; $P = .03$], their child was 13 years of age or more versus younger (OR = 5.43; 95% CI, 2.18–13.53; $P < .001$), and as the ratio of patients' perceived benefits of disclosure outweighed potential risks (OR = 2.40; 95% CI, 1.63–3.54; $P < .001$). Postdecision satisfaction about disclosure was lowest among nondisclosing patients ($P < .001$) and those reporting greater decisional conflict ($P < .001$).

Conclusions: Patients commonly discuss their *BRCA1/2* results with their teenage and young adult children, especially if the information is perceived as beneficial. Satisfaction with disclosure decision making remains lowest among nondisclosing and conflicted patients. Family communication decision support adjuncts to genetic counseling are needed to help ameliorate these effects.

Impact: This study describes the prevalence of family communication about maternal *BRCA1/2* genetic testing with minor children, and decisions and outcomes of disclosure. *Cancer Epidemiol Biomarkers Prev*; 22(7); 1260–6. ©2013 AACR.

Introduction

Observational studies suggest that a majority of patients tested for *BRCA1/2* mutations who are raising children will disclose their test results to these children (1–5). However, our understanding of the predictors of disclosure to children and its outcomes remains extremely limited. Early evidence suggests that disclosure decisions may be influenced by patient demographic (e.g., child age) and clinical factors (e.g., family history; refs. 2, 5), but decision-making and psychologic factors are poorly characterized and impede intervention.

Disclosure has important implications for patients, their partners, and offspring (3, 5, 6). A better understand-

ing of psychologic factors associated with the decision to disclose, and patient outcomes of disclosure, could facilitate the development of targeted and tailored decision support interventions to better assist patients in making disclosure choices and improve cancer genetic testing outcomes (6, 7).

Given the scant research in this area, our study sought to investigate the prevalence of patient disclosure of *BRCA1/2* genetic test results to children and to identify demographic, clinical, decision-making, and psychologic predictors of this outcome. A second objective was to assess patients' satisfaction with their disclosure choice, ascertaining predictors of higher satisfaction in this important context. These variables were guided by behavioral decision-making theory (8, 9) and Baum's model of stress and genetic testing (10).

Materials and Methods

Study design and patients

Methods for this prospective, observational study have been described previously (6, 11). Patients were 221 mothers to one or more children aged 8 to 21 years. All patients underwent pretest *BRCA1/2* genetic counseling, provided a DNA sample for genetic testing at one of the

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three cancer centers in DC, MA, or NY participating in this research, and received their cancer genetic test results: no child was genetically tested through this research program. The study sites host well-established hereditary breast/ovarian cancer clinical research programs, and all procedures were approved by the Institutional Review Boards at each site.

Study procedures

Patients were screened and approached for participation by their cancer genetic counselor at the conclusion of their pretest genetic counseling appointment and after providing a DNA sample. Study eligibility included self-identification as a mother to 1 child or more aged 8 to 21 years old. At enrollment, patients enumerated their children including ages, dates of birth, genders, birth order, and birth relationship (e.g., biologic child). For those with more than 1 child, a computerized random selection algorithm designated a target child of interest within the study age range to alleviate parental selection, reduce bias, and maintain 1:1 parent-child dyads for statistical analysis (12–14).

Patients completed telephone interviews at baseline, following pretest genetic counseling, and again at follow-up 1-month posttest counseling. The timing of the follow-up was based on prior research indicating that most disclosures to relatives (including children) occur shortly after posttest counseling (5, 15). A modest incentive (\$5 gift card) was offered to acknowledge each patient interview completed. In total, 79% of eligible patients consented to participate ($n = 262$) and 84% of consented patients ($n = 221$) completed both assessments and were included in our analyses. Compared with patients with incomplete assessments ($n = 41$), patients included in the analysis were significantly more likely to have a college education (78% vs. 60%; $P < 0.001$). No other differences were evident based on demographic or clinical characteristics.

Survey measures

Outcome variables. Two outcomes were analyzed for this study. First, a dichotomous variable indicating patient self-disclosure of *BRCA1/2* test results to the target child, based on a single item with established face validity and reliability (4, 5). Second, satisfaction with the disclosure decision, as measured at follow-up using the 4-item Effective Decision subscale of the Decision Conflict Scale (DCS; Cronbach $\alpha = 0.76$; ref. 16). This addressed making an informed choice, consistency of the decision with patient values, and overall satisfaction. Higher scores indicate less decision satisfaction (16).

Demographic and clinical information. Patient and child demographics, and information about the patient's personal and family history of breast/ovarian cancer, were self-reported at baseline. *BRCA1/2* genetic test results were obtained from clinical records before follow-up.

Disclosure decision-making process. The pros (5-items) and cons (5-items) of patients disclosing *BRCA1/2*

test results to their child were assessed at baseline and again follow-up (Cronbach $\alpha > 0.80$; ref. 5). All items were specifically worded to reflect this choice. Pros/cons ratios were computed and used for analyses. Decisional conflict surrounding the disclosure choice was measured with a separate 10-item version of the DCS at baseline and follow-up (Cronbach $\alpha > 0.75$; ref. 17). Items captured decision uncertainty, understanding potential pros/cons of decision outcomes, and decision support: higher values indicate greater decisional conflict.

Psychologic distress. The 15-item Impact of Events Scale-Revised (18) and a modified 12-item version of the Brief Symptom Inventory (BSI; refs. 19–21) measured cancer-specific and general psychologic distress, respectively, at baseline and follow-up (all Cronbach $\alpha > 0.80$). Higher values correspond to greater distress. Our BSI included items comprising the Anxiety and Depression subscales, with a 4-point Likert response ("not at all" to "extremely") that has been used extensively in genetic testing outcomes research (20, 22). Psychologic distress observed in our sample was comparable with that reported in other *BRCA1/2* testing studies (20).

Statistical analysis

Descriptive statistics and bivariate tests (χ^2 tests, t tests) described the sample and identified baseline predictor variables associated with the maternal disclosure outcome at follow-up. Predictors of disclosure at $P < 0.10$ were then regressed onto the outcome in a multivariable logistic regression model. We used a similar approach to identify predictors associated with postdecision satisfaction ($P \leq .10$), applying nonparametric bivariate tests (Wilcoxon rank-sum test, Spearman ρ) due to the non-normal distribution of the satisfaction variable. Multivariable linear regression then examined predictors of satisfaction with the disclosure decision. To obtain robust estimates, follow-up decision conflict and satisfaction variables were log transformed (23). As predictors and outcomes were measured on different scales, both unstandardized and standardized coefficients are reported.

A total of 12 patients in our sample (5.4% of study total) were members of the same kindred. Thus, we examined the extent to which study data were correlated within kindreds to determine the need for adjustment due to familial clustering. The intraclass correlation (ρ) for both outcomes approached 0.08, which is smaller than what has previously been reported in kindred studies of behavioral outcomes of *BRCA1/2* testing (24). To assess the potential impact of familial clustering, we ran our final regression models as both generalized (PROC GENMOD) and mixed-linear models (PROC MIXED), respectively, accounting for nonindependent data. These parameter estimates and interpretations were essentially unchanged. Therefore, we report our findings from the standard logistic and linear models described above.

Results

Participants

Table 1 displays the characteristics of patients and their children at baseline, stratified by child disclosure status. Demographically, minorities comprised 19% of the study total: 9% Black/African American, 4% Hispanic, and 6% multiple other racial/ethnic identifications. The breakdown of genetic test results was 11% true negative (noncarriers), 75% uninformative (no mutation identified in a member of a kindred without a known mutation), and 15% positive (carriers). In all, 62.4% of patients reported disclosing *BRCA1/2* test results to their child.

BRCA1/2 disclosure decision

Bivariate results. Bivariate associations with patients' *BRCA1/2* disclosure status are also displayed in Table 1. Disclosing patients were of older age and more likely to be non-White, unmarried, and to have received true negative or uninformative *BRCA1/2* test results. Disclosing patients were more likely to do so to teenagers and young adults versus younger children and, on average, reported that the pros of disclosure outweighed the cons by a factor of nearly 3:1.

Multivariable results. Results from the logistic regression analysis are displayed in Table 2. The adjusted odds of patients disclosing *BRCA1/2* test results to their

Table 1. Patient demographic and clinical characteristics by child disclosure status ($N = 221$)

Characteristic	All ($N = 221$)		Disclosed ($n = 138, 62.4\%$)		Not disclosed ($n = 83, 37.6\%$)		P
	Mean (SD)	N (%)	Mean (SD)	N (%)	Mean (SD)	N (%)	
Maternal demographics							
Age, y	46.2 (6.0)		47.4 (5.7)		44.2 (6.1)		<0.001
Race/ethnicity							0.05
Non-Hispanic White		180 (81.4)		107 (77.5)		73 (88.0)	
Non-White		41 (18.6)		31 (22.5)		10 (12.0)	
Education							0.18
< College		48 (21.7)		34 (24.6)		14 (16.9)	
≥ College		173 (78.3)		104 (75.4)		69 (83.1)	
Marital status							0.01
Married/living as married		185 (83.7)		109 (79.0)		76 (91.6)	
Unmarried		36 (16.3)		29 (21.0)		7 (8.4)	
Household income							0.15
< \$75,000/year		43 (19.5)		31 (22.5)		12 (14.5)	
≥ \$75,000/year		178 (80.5)		107 (77.5)		71 (85.5)	
Maternal clinical characteristics							
Family cancer history							0.62
≥ 1 affected relative		115 (52.0)		70 (50.7)		45 (54.2)	
0 affected relatives		106 (48.0)		68 (49.3)		38 (45.8)	
Personal cancer history							0.93
Yes		127 (57.5)		79 (57.3)		48 (57.8)	
No		94 (42.5)		59 (42.7)		35 (42.2)	
<i>BRCA1/2</i> Carrier status							0.05
True negative/uninformative		189 (85.5)		123 (89.1)		66 (79.5)	
Positive		32 (14.5)		15 (10.9)		17 (20.5)	
Child age							<0.001
< 13 years		108 (48.9)		39 (28.3)		69 (83.1)	
≥ 13 years		113 (51.1)		99 (71.7)		14 (16.9)	
Child gender							0.41
Female		109 (49.3)		71 (51.4)		38 (45.8)	
Male		112 (50.7)		67 (48.6)		45 (54.2)	
Disclosure decision making							<0.001
Decisional balance	2.1 (1.5)		2.7 (1.4)		1.1 (0.8)		
Decisional conflict	10.2 (16.3)		9.5 (15.8)		11.5 (17.2)		0.51
Distress							0.20
General distress	17.0 (5.8)		16.7 (5.5)		17.7 (6.3)		
Cancer-specific distress	20.9 (17.3)		19.4 (16.8)		23.3 (17.9)		0.10

Table 2. Multivariate logistic regression analysis of patients' disclosure to children at follow-up

	OR (95% CI)	P
Maternal demographics		
Age		
< 46 years	0.74 (0.32–1.68)	0.47
≥ 46 years	Reference	
Race		
Non-Hispanic White	0.68 (0.25–1.88)	0.46
Non-White	Reference	
Marital status		
Married/living as married	0.60 (0.20–1.79)	0.36
Not married	Reference	
Maternal clinical characteristics		
<i>BRCA1/2</i> Carrier result		
Negative/uninformative	3.11 (1.11–8.71)	0.03
Positive	Reference	
Child age		
≥ 13 years	5.43 (2.18–13.53)	<0.001
< 13 years	Reference	
Disclosure decisional balance	2.40 (1.63–3.54)	<0.001

NOTE: Model Wald χ^2 6 df = 55.9; $P < .001$.

Hosmer–Lemeshow goodness of fit χ^2 8 df = 9.5; $P = .30$.

child were significantly greater among those receiving true negative or uninformative results [OR = 3.11; 95% confidence interval (CI), 1.11–8.71; $P = 0.03$] and those whose child was aged 13 years or older (OR = 5.43; 95% CI, 2.18–13.53; $P < 0.001$). The adjusted odds of patient disclosure to their child increased significantly as the ratio of pros to cons of disclosure to children increased (OR = 2.40; 95% CI, 1.63–3.54; $P < 0.001$).

Postdecision satisfaction

Bivariate results. Patients reported modest levels of satisfaction about their disclosure decision at follow-up (mean = 5.7, SD = 13.0). Patients receiving positive

BRCA1/2 test results [mean = 10.5 (SD 16.4)] and those who did not disclose results to their child [mean = 10.4 (SD = 18.2)] were less satisfied than those receiving negative or uninformative results [mean = 4.8 (SD = 12.1); $z = 2.41$; $P = 0.016$] and those who disclosed [mean = 2.8 (SD = 7.1); $z = 3.26$; $P = 0.001$]. Patients with greater decisional conflict (Spearman $\rho = 0.39$; $P < 0.001$) and psychologic distress (Spearman $\rho = 0.15$; $P = 0.02$) were also less satisfied with their disclosure decision.

Multivariable results. Results from the linear regression analysis are displayed in Table 3. After adjusting for other model variables, disclosing patients reported significantly greater satisfaction with their disclosure decision compared with patients who did not disclose to their child (standardized $\beta = -0.27$; $P < 0.001$). As decisional conflict increased, patients were less satisfied with their disclosure decision (standardized $\beta = 0.41$; $P < 0.001$). Less satisfaction with the decision to disclose was further predicted by greater cancer-specific distress, although this finding only approached conventional statistical significance (standardized $\beta = 0.11$; $P = 0.069$). Although general distress was associated with decision satisfaction in bivariate analyses at follow-up ($P < 0.10$), it did not significantly predict satisfaction in regression analyses and was removed from the final model. Overall, the final model explained 26% of the outcome's variance.

Discussion

This study focused on predictors and outcomes of patient decisions about the disclosure of maternal *BRCA1/2* genetic test results to their children. Although the current ages of the children in these families largely precluded them from being candidates for *BRCA1/2* testing themselves (25), we observed that disclosure was common with 62.4% of children being informed of their mother's risk status. Disclosure was more likely to occur when patients received either true negative or uninformative *BRCA1/2* test results, and when children were aged 13 years and older. That patients were more likely to share the "good" news with their child that a risk-conferring mutation in *BRCA1/2* was not found upon

Table 3. Predictors of patients' satisfaction with the decision to disclose at follow-up

	B	SE B	Standardized β	P
Disclosed <i>BRCA1/2</i> test result				
Yes	-0.31	0.07	-0.27	<0.001
No	Reference			
<i>BRCA1/2</i> Status				
Negative/uninformative	-0.02	0.07	-0.01	0.816
Positive	Reference			
Decisional conflict	0.41	0.06	0.41	<0.001
Cancer-specific distress	0.004	0.002	0.11	0.069

NOTE: Model $R^2 = 0.26$.

genetic testing is consistent with other positive parenting practices (11), even though the clinical interpretation of these test results (i.e., true negative, uninformative) differs substantially. In an earlier study, we reported that patients' anecdotal motivations for disclosure to children centered on promoting the parent-child bond, maintaining family health, and promoting positive child affect (11). Our results underscore the importance of parents taking into account both cancer genetic test results and the age of the child to be informed when making disclosure decisions. The effect of child age was especially salient in our model. Here, patients likely heed risk communication messaging strategies advocated by oncologists and health care providers emphasizing that information be shared with potentially at-risk relatives who might benefit from such information, including their offspring (26). Toward that end, it is likely that disclosure to uninformed younger children will eventually take place over time, perhaps when the child is older and he/she is more ready and mature, and with need for the information.

With respect to the decision outcomes, two findings are especially noteworthy. First, patients' decision to disclose to their child was more likely to occur as the perceived benefits of disclosure increasingly outweighed the risks. As measured in this study, benefits included the child's right to know the information, that the results conveyed "good news," to alleviate children's worry, and to promote greater trust and open communication between the parent and child. By contrast, risks included that the child was too young or immature to appreciate the information, disclosure might promote worry in the child, or the significance of the results to the child were uncertain. These complex themes surrounding familial disclosure of cancer genetic test results are encountered in clinical settings, and underscore the importance of oncologists and other health care providers attending to them to improve the outcomes of *BRCA1/2* testing (1). Interestingly, the group of children who might sooner and most directly benefit from the knowledge of their mothers' familial cancer risk are older adolescent and young adult children of *BRCA1/2* mutation carriers. However, mutation carriers were the least likely to inform offspring. Although it is possible that carrier mothers will eventually inform their children of hereditary cancer risks as children emerge into young adulthood, studies of cascade testing and second-generation testing among *BRCA1/2* mutation carrier families have not followed children longitudinally. Today, we know very little about the long-term outcomes of *BRCA1/2* testing as children grow up in these family environments. Work by van Oostrom and colleagues reports that having a parent with cancer during one's childhood places the individual at greater risk for psychologic distress during genetic testing (27). As cancer genetic testing proliferates, especially among members of affected kindreds (28), it is increasingly important for clinicians to attend

to the age at which the prospect of harboring a familial mutation was first recognized in the family, disclosed to the patient, and with what effect.

Second, when we examined patients' satisfaction with their disclosure decision, we found that satisfaction was lowest among those who did not disclose and those who were more conflicted about their decision. By contrast, satisfaction was highest among disclosing mothers with less conflict. Thus, patients who would like to disclose to their child but do not, and are uncomfortable with their choice, remain in a state of psychologic conflict. This combination portends the onset of disrupted parent-child communication surrounding hereditary cancer. If persistent and unabated, it runs counter to clinical practice guidelines promoting open family communication about hereditary risks. Here too, more data are needed about the long-term outcomes of patients' disclosure decisions and their impact on parent and child preventive health measures and well-being.

Limitations to this work include the predominantly non-Hispanic White patient sample with an above-average income, which limits generalizability. Race/ethnic differences in family communication within and across the socioeconomic gradient would be important to study in the future. Also, our project relied on brief, self-reported outcome measures, and a modified version of the BSI. Standardized, multidimensional/multimodal assessments could lend insight into patients' family communication processes and help to better characterize observed variations relative to population norms and other studies.

Despite these limitations, this work is important because it permits a fuller understanding of the clinical impact of the commonest form of genetic testing for adult-onset cancer (*BRCA1/2* testing) as a cancer control strategy for high-risk individuals and their potentially at-risk family members. Our work highlights decisions and decisional outcomes of disclosure to an overlooked subgroup of first-degree relatives, minor children of adult patients, in a more in-depth manner than studied previously. These new findings call for decision support interventions to better the testing process for patients with children. Prior work indicates that concern for children's (especially adolescents') future well-being is a salient motivation behind parents' decisions to participate in cancer genetic testing (4, 29, 30). Genetic information can shape both individual and collective (e.g., familial) identities about the burden of cancer and shared risks of inheritance, its likelihood of intergenerational transmission, and perceptions about the effectiveness of common risk-reduction methods (e.g., screening, nutrition, physical activity, tobacco avoidance; ref. 31). For some young offspring, information learned through a family member's genetic testing may be empowering and become part of health promotion efforts (32-34). Clinicians and public health specialists working with at-risk families should examine the psychologic, medical, and health behaviors of these children over time and develop adjuncts to genetic

counseling that improve patients' decision making about disclosure of their risk status to their children.

Disclosure of Potential Conflicts of Interest

J.E. Garber has commercial research support from Myriad Genetics. No potential conflicts of interest were disclosed by the other authors.

Disclaimer

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