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Prevalence and correlates of mothers and fathers attending pretest cancer genetic counseling together

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Abstract

Objective—To determine the prevalence of fathers' attendance at pretest cancer genetic counseling sessions with mothers undergoing *BRCA1/2* genetic testing for hereditary breast/ovarian cancer (HBOC) risk, and to identify psychosocial and other correlates of fathers' attendance.

Methods—One hundred twenty-one fathers of minor-age children who were spouses/partners of women (mothers) undergoing such counseling and testing were recruited, completed a behavioral self-report survey, and provided data about their sociodemographic backgrounds, father-child cancer communication histories, parenting relationship quality, and information-seeking and perceived knowledge.

Results—A total of 27.3% of fathers attended pretest cancer genetic counseling with mothers. Compared to fathers who did not attend pretest cancer genetic counseling, those who did had stronger parenting alliances with mothers, were more likely to have sought out information about *BRCA1/2* testing, and felt more informed about testing. In an adjusted logistic regression model of session attendance, the strength of the parenting alliance was associated with a 6% increase in the likelihood of attending genetic counseling (Odds Ratio [OR] = 1.06, 95% Confidence Interval [CI] = 1.01, 1.12, $p < .05$) and greater perceived knowledge about *BRCA1/2* testing was associated a four-fold increase in the likelihood of session attendance (OR = 4.03, CI = 1.77, 9.37, $p < .001$).

Conclusion—One in three fathers attend pretest cancer genetic counseling with mothers undergoing *BRCA1/2* testing; those who do have closer parenting relationships and are more informed about *BRCA1/2* testing.

Practice implications—When possible, providers should discuss mothers including fathers in cancer genetic counseling sessions as this may affect outcomes of HBOC genetic counseling and testing.

Keywords

Cancer; Breast cancer; Genetic counseling; *BRCA1/2* testing; Parents

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1. Introduction

Mutations in the two major hereditary breast/ovarian cancer (HBOC) susceptibility genes, *BRCA1* and *BRCA2* (*BRCA1/2*), account for nearly 5%–10% of all breast cancer cases and are associated with up to an 85% lifetime risk of cancer [1]. The process of genetic counseling affords individuals opportunities to discuss and anticipate possible genetic test results, the medical and psychosocial implications of those results, the pros and cons of testing for themselves and for their potentially at-risk relatives, and to facilitate cascade testing for at-risk relatives [2,3]. In many ways, this process is a family-centered experience [4,5]. Central for some women are their thoughts and feelings about passing along risk-conferring mutations to their offspring [6–8], and the ways in which the marital or parenting relationship affects and/or is influenced by HBOC risks [9–11].

The literature has shown a high rate of disclosure of *BRCA1/2* test results to adult relatives [12–14]. Communication to minor-age children, however, is lower, with 50% or more of mothers disclosing their *BRCA1/2* test results to their minor-age children, regardless of what the results are [15,16]. This raises questions about potential psychosocial impacts of learning such news on minor children's quality of life and long-term adaptation to familial cancer risk information [17,18].

Though mothers assume a primary responsibility in parenting young children [19], decisions about communicating with children is made in a family context in which a spouse or partner may play a significant role. Psychological research on husbands'/fathers' roles within a hereditary cancer context suggests the importance of open communication lines between spouses to promote healthy family adaptation [20–22]. Relatively little is known about the impact on fathers of being both support persons to cancer genetic testing participants, and fathers of potentially at-risk children [23,24].

Given the potential impact and outcomes of genetic testing for both of the members of a mother-father parenting dyad, providers of genetic services sometimes encourage joint attendance at genetic counseling, though not uniformly so [25–27]. Questions remain about how often mothers and fathers attend such counseling together, factors associated with father attendance, if fathers' attendance makes significant differences in the counseling process and outcome, and in later communication with offspring. Most data on parenting dyads have been collected in the prenatal genetic testing setting, indicating that fathers often attend genetic counseling sessions with mothers, and accompanied mothers may have a greater need for social support [26,28,29].

For women undergoing *BRCA1/2* genetic counseling, greater perceived support from a spouse and encouragement during counseling and testing are associated with lower levels of posttest stress [10,11]. However, over 50% of women attend pre- and posttest genetic counseling for *BRCA1/2* mutations without the benefit of a support person, and many of these women are also mothers of minor-age children [23,25]. There is a need to more closely examine how often fathers attend genetic counseling sessions for *BRCA1/2* with mothers, and to identify sociodemographic, clinical, and psychosocial factors associated with attendance. In our study, these factors were selected based on literature reviewed, as well as health information-seeking models [30] and models of family functioning in a cancer genetic context [31]. We hypothesized that a majority of mothers would be accompanied to counseling by fathers, and that fathers who attended genetic counseling sessions could be distinguishable from those who did not by having closer family relationships and greater access to genetic information.

2. Methods

2.1. Participants

Adult parenting dyads were ascertained as part of a larger study of mothers participating in pretest cancer genetic counseling and testing for *BRCA1/2* mutations at three East coast cancer centers. In addition to being able to read/speak English, women had to be age 18 or older, to have a personal and/or family history suggestive of HBOC, and be mothers of one or more children ages 8–21. Co-parents (adult spouses and partners sharing in the upbringing of the child/ren with the mothers) were also eligible to participate in the behavioral aspects of the study; they did not undergo *BRCA1/2* genetic testing but could attend genetic counseling as a support person. A total of 121 mothers and their male co-parents (fathers) serve as the focus of this report.

2.2. Procedure

Genetic counselors determined eligibility and obtained informed consent from mothers at the conclusion of pretest counseling session and following women's stated intention to provide a blood sample for *BRCA1/2* mutation analysis: 81% of mothers consented and subsequently completed a telephone survey. Mothers with eligible co-parents were informed that study invitations could be extended to co-parents to yield more complete, dyadic perspectives on the outcomes of interest. The study's consent rate among co-parents was 60% [32]. Co-parent telephone surveys coincided with those of mothers' but were conducted independently. All participants were assessed after pretest genetic counseling, but prior to mothers' receipt of test results. A modest incentive was offered for completing study-related telephone calls; procedures were approved by the institutional review boards at each of the three participating sites.

2.3. Measures

2.3.1. Sociodemographics and medical information—Sociodemographic information was collected from mothers and fathers; medical information about personal and family history of cancer was collected about mothers only. The latter are important because they have been shown to affect testing decisions [33]. Permission was also received to access maternal *BRCA1/2* test results.

2.3.2. Family relationships—In prior work [16], we developed/validated a scale assessing the frequency of parent-child communication about cancer, hereditary cancer risks, and children's cancer worry. Five items were rated on a 4 point Likert scale (1 = Not at all, 4 = Often; range = 5–20) and summed to an overall score (Cronbach's coefficient $\alpha = 0.68$); higher scores indicate a more open father-child cancer communication history. Mother-father parenting relationship quality was assessed via a reliable and valid self-report scale, the Parenting Alliance Measure (PAM) [34]. The PAM is a 20-item measure of the strength of the child-rearing alliance between parents. Items are rated on a 5 point Likert scale (1 = Strongly disagree, 5 = Strongly agree; range = 20–100) and summed to yield a total score; higher scores are associated with stronger and more positive parenting alliance. The PAM is reliable and stable over time (Cronbach's coefficient $\alpha = 0.97$, test-retest reliability $r = 0.80$) [35] and measures the same dimensions for mothers and fathers alike [34]. The internal consistency of the father-reported PAM was high (Cronbach's coefficient $\alpha = 0.90$).

2.3.3. Information-seeking and perceived knowledge—Guided by health information-seeking models [30], we developed and administered two face-valid items regarding whether or not fathers had sought-out medical information (i.e., from literature, Internet, health care professional sources) about *BRCA1/2* testing (Yes/No), and assessed how well-informed they felt about such testing (1 = Not at all, 4 = Extremely). These items served

as indicators of fathers' *BRCA1/2*-related information-seeking and perceived knowledge, respectively.

2.3.4. Attendance—Based upon prior method [36], fathers' attendance at mothers' pretest cancer genetic counseling sessions was initially obtained via self-report, and subsequently verified by mothers' genetic counselors. In the event of any discrepancies ($N=8$ cases), the genetic counseling record was used as the data source.

2.3.5. Statistical analyses—Descriptive statistics were used to characterize the study population (Table 1). Factors potentially associated with fathers' attendance were first analyzed in a bivariate fashion using X^2 tests and t -tests (Table 2), and then in a multivariate logistic regression model (Table 3). Only those variables with significant relationships ($p < .05$) with session attendance were included in the model.

3. Results

3.1 Participant characteristics

Of the 121 fathers participating in this study, 57 (47.1%) were obtained at Site 1, 35 (28.9%) were obtained at Site 2, and 29 (24.0%) were obtained at Site 3 (see Table 1 for a full description of the sample).

3.2. Genetic counseling session attendance

Among the 121 fathers participating in this study, 33 (27.3%) attended pretest cancer genetic counseling with mothers and 88 (72.7%) did not. Significantly fewer fathers attended than did not attend genetic counseling (see Table 2). Differences in session attendance were not due to site effects (Site 1 vs. Sites 2 + 3), $X^2(1) = 1.01$, $p = .32$.

3.3. Differences between session attenders and nonattenders

As shown in Table 2, there were few significant differences between fathers who did and did not attend counseling, except in the areas of parenting relationship quality, information-seeking, and perceived knowledge. Compared to fathers who did not attend pretest cancer genetic counseling, those who did had stronger parenting alliances, were more likely to have sought out information about *BRCA1/2* testing, and with greater perceived knowledge about *BRCA1/2* testing.

3.4. Adjusted model of session attendance

Logistic regression was used to assess the likelihood of fathers' attendance at genetic counseling, based on significant predictors identified at the bivariate level (parenting, information, knowledge). The results displayed in Table 3 indicate that strength of the parenting alliance was associated with a 6% increase in the likelihood of attending genetic counseling (Odds Ratio [OR] = 1.06, 95% Confidence Interval [CI] = 1.01, 1.12, $p < .05$), and that greater perceived knowledge about *BRCA1/2* testing was associated with a fourfold increase in the likelihood of session attendance (OR = 4.03, CI = 1.77, 9.37, $p < .001$).

4. Discussion

The purpose of this study was to determine how often mothers of minor-age children participating in *BRCA1/2* genetic counseling and testing jointly attend a pretest session with their spouses/partners (i.e., their children's fathers), and to identify psychosocial factors distinguishing fathers who attend sessions vs. those who do not. Data indicate 27.3% of mothers and fathers attend pretest counseling together. Mother-father dyads attending sessions together

have stronger working alliances as parents, and these fathers also have greater perceived knowledge about *BRCA1/2* testing. Whether this latter finding is a cause or consequence of paternal participation in counseling cannot be determined here, but is an area ripe for future exploration.

That nearly one-third of mothers and fathers attend pretest *BRCA1/2* genetic counseling sessions together has not been well-documented previously. Moreover, that they function more effectively together as parents vs. those families where mothers attend alone is consistent with the parenting literature on the benefits of stronger parenting alliances on family functioning [37–39]. It is also consistent with prior reporting on the role of parenting alliance in the context of genetic counseling [32]. In light of the recommendation for women to attend cancer genetic counseling with a support person [27], additional research on barriers and facilitators of fathers' session attendance seems warranted.

4.1. Limitations

The study is limited by a lack of representation of racial and ethnic minorities and little socioeconomic diversity. It also did not assess women and their partners who ultimately did not opt for *BRCA1/2* testing. Further, 40% of fathers who were potentially eligible to be in the study did not participate and were part of more parentally stressed dyads [32]. It is unknown if (or how many) fathers who were invited to attend sessions by mothers failed to do so. The study did not directly assess fathers' motivations for session participation or nonparticipation, nor did it examine father's attendance at posttest counseling (though the literature suggests pretest and posttest support systems are similar [25]). Lastly, the cross-sectional design of the study does not permit causal modeling of fathers' session attendance.

4.2. Conclusions

Roughly 1 in 3 fathers attend pretest cancer genetic counseling with mothers undergoing *BRCA1/2* testing. Those who do have closer parenting relationships and greater perceived knowledge about *BRCA1/2* testing. These fathers may, in turn, be better equipped to support mothers about making key decisions later on, including medical decisions and family communication decisions.

With respect to practice implications, providers should recognize fathers as collateral counseling participants who might be beneficial to the counseling process. Helping fathers to become involved in cancer genetic counseling may encourage their ongoing support of mothers. Further understanding of mother-father relationships in the context of cancer genetic counseling could lead to parent-focused interventions and improve HBOC counseling and testing outcomes.

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Table 1Characteristics of Participating Fathers and Mothers ($N = 121$)

Variable	Total
	Fathers
Age, m (sd)	48.0 (6.5)
Race, n (%)	
White	102 (84.3)
Other	19 (15.7)
Marital status, n (%)	
Married	113 (93.4)
Other	8 (6.6)
Education, n (%)	
$\geq$ College	96 (79.3)
$<$ College	25 (20.7)
Fulltime employment, n (%)	
Yes	117 (96.7)
No	4 (3.3)
Family income, n (%)	
$> \$75k$	95 (79.2)
$\leq \$75k$	25 (20.8)
Biological father, n (%)	
Yes	110 (90.9)
No	11 (9.1)
	Mothers
Other relatives affected with breast/ovarian cancer, n (%)	
Yes	56 (46.3)
No	65 (53.7)
Personal breast/ovarian cancer history, n (%)	
Yes	79 (65.3)
No	42 (34.7)
Proband, n (%)	
Yes	96 (80.0)
No	24 (20.0)
	Psychosocial
Father-child communication history about cancer, m (sd)	9.3 (3.0)
Parenting alliance, m (sd)	89.4 (9.7)
Information-seeking about <i>BRCA1/2</i> , n (%)	
Yes	57 (47.1)
No	64 (52.9)
Perceived knowledge about <i>BRCA1/2</i> , m (sd)	2.4 (0.8)

Note. The mean score on the fathers' PAM was within the normal range [34], indicating a strong parenting alliance.

Table 2

Characteristics Associated with Participation in the Counseling Session Among Nontested Fathers

Variable	Attendance		Statistic	p-value
	Yes	No		
<i>n</i> (%)	33 (27.3)	88 (72.7)	χ^2 (1) = 25.00	<.0001
Age, <i>m</i> (<i>sd</i>)	47.3 (7.6)	48.3 (6.0)	<i>t</i> (119) = -0.73	.47
Race, <i>n</i> (%)				
White	30 (90.9)	72 (81.8)		
Other	3 (9.1)	16 (18.2)	χ^2 (1) = 1.50	.22
Marital status, <i>n</i> (%)				
Married	32 (97.0)	81 (92.1)		
Other	1 (3.0)	7 (7.9)	χ^2 (1) = 0.94	.33
Education, <i>n</i> (%)				
≥ College	24 (72.7)	72 (81.8)		
< College	9 (27.3)	16 (18.2)	χ^2 (1) = 1.21	.27
Fulltime employment, <i>n</i> (%)				
Yes	31 (93.9)	86 (97.7)		
No	2 (6.1)	2 (2.3)	χ^2 (1) = 1.08	.30
Family income, <i>n</i> (%)				
≥ \$75k	27 (81.8)	68 (78.2)		
< \$75k	6 (18.2)	19 (21.8)	χ^2 (1) = 0.19	.66
Biological father, <i>n</i> (%)				
Yes	32 (97.0)	78 (88.6)		
No	1 (3.0)	10 (11.4)	χ^2 (1) = 2.02	.16
Other maternal relatives affected with breast/ovarian cancer, <i>n</i> (%)				
Yes	14 (42.4)	42 (47.7)		
No	19 (57.6)	46 (52.3)	χ^2 (1) = 0.27	.60
Maternal breast/ovarian cancer history, <i>n</i> (%)				
Yes	24 (72.7)	55 (62.5)		
No	9 (27.3)	33 (37.5)	χ^2 (1) = 1.11	.29
Maternal proband, <i>n</i> (%)				
Yes	27 (81.8)	69 (79.3)		
No	6 (18.2)	18 (20.7)	χ^2 (1) = 0.09	.76
Father-child communication history about cancer, <i>m</i> (<i>sd</i>)	10.2 (3.2)	9.0 (2.8)	<i>t</i> (119) = 1.91	.06
Parenting alliance, <i>m</i> (<i>sd</i>)	92.9 (9.5)	88.1 (9.5)		
Information-seeking about <i>BRCA1/2</i> , <i>n</i> (%)				
Yes	22 (66.7)	35 (40.0)		
No	11 (33.3)	53 (60.2)	χ^2 (1) = 7.00	.008
Perceived knowledge about <i>BRCA1/2</i> , <i>m</i> (<i>sd</i>)	2.9 (0.5)	2.2 (0.8)	<i>t</i> (80) = 5.40	<.0001

Table 3

Logistic Regression Model with Odds Ratios (OR's) and 95% Confidence Intervals (CI's) of Counseling Session Attendance Among Nontested Fathers

Variable	Estimate	Standard Error	OR	95% CI	p-value
Parenting alliance	0.05	0.03	1.06	1.01, 1.12	.04
Information-seeking about <i>BRCA</i> 1/2	0.13	0.51	1.13	0.42, 3.10	.81
Perceived knowledge about <i>BRCA</i> 1/2	1.41	0.43	4.03	1.77, 9.37	.0009