Cancer genetic health communication in families tested for hereditary breast/ovarian cancer risk: a qualitative investigation of impact on children's genetic health literacy and psychosocial adjustment

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Abstract

Children's literacy about the genetics of late-onset hereditary breast/ovarian cancer (HBOC) often develops through conversations with parents about *BRCA* gene testing and adults' cancer diagnoses. These conversations may promote early understanding of HBOC, but the long-term impact on children's psychosocial adjustment remains unclear. We investigated cancer genetic health communication in *BRCA*-tested families to consider benefits, risks, and moderating influences on children's understanding and well-being. Adolescent and young adult children (ages 12–24) of mothers who underwent *BRCA* testing 1+ years previously completed qualitative interviews that were transcribed, coded (intercoder $K \geq .70$), and content-analyzed ($N = 34$). Children readily recalled conversations about *BRCA* testing and HBOC (100%) that they considered important (94%), but implications for children were ambiguous and obfuscated their concerns. Psychosocial impacts were muted, multifaceted, and displayed a range of favorable (82%), neutral (71%), and unfavorable (59%) response—frequently co-occurring within the same child over different aspects (e.g., medical, concern for self and others). Children verbalized active (50%) and avoidant (38%) coping strategies: about 1:5 endorsed transient thoughts about vulnerability to HBOC, 1:3 had not further considered it, and all reported specific actions they had or would undertake to remain healthy (e.g., diet/exercise). A majority (94%) of children had or would consider genetic testing for themselves, usually later in life (59%). Long-term outcomes highlighted benefits (awareness of HBOC, psychological hardiness, healthier lifestyle behaviors), as well as some psychosocial concerns that could be managed through interventions promoting genetic health literacy.

Keywords

Breast cancer, Genetic counseling, Genetic testing, Health communication, Children, Families

INTRODUCTION

Genetic counseling and testing for hereditary breast/ovarian cancer (HBOC) risk, primarily identified by mutations in *BRCA* genes, is generally not recommended until adulthood when cancer screening and prevention strategies exist for high-risk individuals [1, 2]. For breast cancer, these strategies include clinical

Implications

Practice: Parents and providers can support children's genetic health literacy and psychosocial adjustment to hereditary breast/ovarian cancer (HBOC) risk information through open family communication.

Policy: Public health benefits from genetic testing for HBOC mutations may only be realized when all high-risk relatives of individual mutation carriers are informed of their family's status, including children, so that appropriate risk-reducing steps can be considered at different life stages.

Research: Future research is needed to examine the integration of family communication and psychosocial support tools into cancer genetic counseling and testing protocols.

breast examination, mammography, MRI, prophylactic surgery, and chemoprevention [3]. Oncology clinical practice guidelines endorse communicating known information about HBOC and *BRCA* to adult biological relatives who may be at increased risk owing to shared genes and familial susceptibilities [1, 4]. However, there are no guidelines about the age at which children should be informed about HBOC risk in their kindreds or parental *BRCA* gene status in particular [5]. On the one hand, early disclosure of hereditary cancer risk information to children affords families more opportunities to educate themselves about avoiding environmental exposures of cancer risk (e.g., tobacco, high body mass index) [6], promote more open dialogs about HBOC, and alleviate cancer worries [7]. On the other hand, early disclosure could engender feelings of uncertainty in some children of parents carrying a deleterious *BRCA* alteration, depending on the nature of the information

being shared, when and how it is presented, and the manner in which it is communicated [7].

Prior work clearly demonstrates that parents commonly disclose their *BRCA* test results to their children [8], including *BRCA* positivity (*BRCA*+), and soon after parents' genetic counseling [9]. The long-term consequences of such disclosure on children's knowledge and psychosocial development remain poorly characterized [10], making it difficult to directly assess the risks and benefits of family communication to children. More broadly, the issue of how children respond to genetic information and develop a knowledge base about hereditary diseases remains elusive [11]. A recent study found that girls with breast cancer family histories reported elevated levels of breast cancer-specific distress and perceived risks of breast cancer in relation to those without breast cancer in the family history [12]. However, that study failed to examine outcomes among boys or children older than age 13—a key time in psychosocial development and the onset of cancer risk behaviors [12, 13].

As a clinical domain of inquiry in behavioral cancer prevention and control research, factors influencing patterns of family communication about HBOC and *BRCA* risks have been examined at the individual, dyadic, and social levels [14]; and see [15] for a comprehensive review of genetics professional issues in family communication. When taken together, this ecological framework underscores the complexity of health communication decisions both within and across generational lines about genetics [16, 17], and the importance of cultivating genetic health literacy skills for all involved [18]. Genetic health literacy has been referred to as an individual's capacity to acquire and use genetic information for health choices [19]. Herein, it is viewed as a specialized subset of children's overall health literacy, or the more general set of skills needed to understand and maintain one's own health from a disease prevention and health promotion standpoint [20]. Unfortunately, most children's genetic health literacy skills are neither instructed nor well-understood—contributing to a general dearth of insight into this topic [19]. A thin state of knowledge is particularly troublesome given the burgeoning expansion of precision medicine [21] and the unrealized potential impact of genetics education on health and society [22]. As such, cancer genetic health communication in families tested for *BRCA* offers behavioral medicine researchers, clinicians, and policymakers a potentially powerful lens and model framework through which to view how individuals and families navigate this nascent issue together. Included are conversations between parents and children about HBOC, inherited cancer risk, *BRCA* genetic counseling and testing, and disclosure of parents' genetic test results to their children, to name a few. Doing so could reveal strengths, weaknesses, and intervention

targets in genetic health literacy to promote more favorable outcomes of genetic testing within high-risk families and healthcare.

To further the study of early literacy skills and communication about genetics in families, we conducted a qualitative investigation of adolescent and young adult children's psychosocial adjustment following disclosure of their mother's *BRCA* test results. Our primary interest was to learn directly from these families about their specific cancer genetic health communications, including association with these children's understanding and long-term psychosocial outcomes.

METHODS

Design

Data for this study were drawn from a larger cross-sectional, mixed-methods investigation of English-speaking mothers ($N = 300$) who had undergone genetic counseling and testing for *BRCA* at least 1 year previously (and less than 5 years) and their adolescent and young adult children (12–24 years old). Study participants independently completed, and following informed consent/assent, structured telephone surveys about parents' and children's health attitudes, beliefs, and behaviors subsequent to maternal cancer genetic testing and ensuing cancer-related events.

At the close of this survey, a randomly selected subset of approximately 20% of mothers who had previously disclosed their own genetic status to their children were asked for their permission to be re-contacted for the qualitative sub-study focused on children's genetic health literacy and psychosocial adjustment to cancer risk information disclosure. Predefined sampling quotas were established in four stratified categories to adequately represent the subpopulations of greatest interest: (a) child gender ("M" = male, "F" = female); (b) child age (12–17 years, 18+ years); (c) maternal breast/ovarian cancer history ("A" = previously affected [survivor], "U" = unaffected); and (d) maternal *BRCA* test result ("+" = deleterious gene alterations conferring increased HBOC risk found, "-" = known deleterious gene alterations not found, not at increased HBOC risk, "?" = uninformative negative gene alterations found, HBOC risk cannot be determined with certainty). Mothers were approached first, prior to inviting their children.

All mothers invited into the sub-study agreed to participate and were re-screened by telephone. Those in the qualitative sub-study received a \$10 gift certificate for their time. Human subjects approval was obtained from Institutional Review Boards at each of the study sites (regional cancer centers in Washington, DC; Boston, MA; Scarborough, ME; and Houston, TX) where mothers had originally been counseled, tested, and recruited through.

Measures

Child interview

The semi-structured, qualitative interview for children was designed by the investigative team based on prior research literature and theories of communication and psychosocial development [5, 23]. The child interview covered four main areas within the broad realm of genetic health literacy and psychosocial well-being, with interview probes intended to elicit thick descriptions from children's perspectives about their: (a) recall of conversations with parents about HBOC and disclosure of their mothers' *BRCA* test results (i.e., cognitions, emotional reactions, and behaviors related to learning information about HBOC, maternal and hereditary breast cancer risk, and genetic testing); (b) psychosocial identity formation and future orientation (i.e., intentions and expectations for the future educational, social, and family goals in light of cancer genetic health communication); (c) current and future health behaviors and cancer prevention actions (i.e., cancer risk behavior tolerance, general health and cancer awareness, personal beliefs about one's own cancer susceptibility, advantages of cancer and communication of medical information, and voiced adoption of preventive or health-promoting behaviors), and; (d) viewpoints on informed conversations about HBOC in the family (i.e., suggestions for mothers and health care providers about cancer genetic health communication in families tested for *BRCA* and its impact on children's psychosocial status).

The interview was administered over the telephone by a trained interviewer with master's-level expertise in social and behavioral science research and clinical psychosocial oncology. Interviews (ranging in length from 33 to 73 min; $M = 55.6$, $SD = 11.7$ min) were conducted in private, without the parent present, and audio recorded. The interviewer was instructed to adhere to the interview domains of inquiry: all-time variation is attributed to the amount of detail (productivity) that children vocalized. Upon completion, interviews were verbatim transcribed by professional transcriptionists unaffiliated with the research team. Names were omitted from transcripts to ensure confidentiality, and children's ages were aggregated for additional masking.

Data analysis

Transcribed text files were uploaded into ATLAS.ti (Scientific Software Development GmbH), a commonly used qualitative data analysis system. ATLAS.ti computer software allows researchers to associate user-defined codes or labels with chunks of acquired text, search these codes for patterns, and construct classification codes that reflect testable models of the conceptual structure of the underlying data. Each document was coded for demographic features and the study site (to account for potential

differences in maternal information receipt and provision via genetic counseling), child gender, age, and race/ethnicity, and maternal cancer status and genetic test result to facilitate linking similar categories in analyses.

Following the data analytic methods outlined by Hsieh and Shannon [24] and Weiss [25], the Master Coder (K.P.K.) developed the codes used by first completing line-by-line coding of child responses for interviews purposefully sampled to each represent the three *BRCA* test results of interest (+, −, ?). The coding process continued by grouping children's responses into conceptually distinct units of analysis. These units were named by key phrases that represented underlying content domains of genetic health literacy and psychosocial aspects of family communication about *BRCA*, HBOC, and genetic testing using children's own words, whenever possible, to preserve their voices in examination. Next, these first-level codes were grouped into conceptually similar second-level codes. Codebook definitions were created and used to content-code the remainder of the interviews in an iterative fashion following established methods. The Master Coder and another Senior Coder (S.M.B.) then applied the codes to a random selection of protocols, discussed discrepancies, and reconciled differences in code usage and further defined the codebook, codes, and code use. Afterward, protocols were independently coded (S.M.B., H.R.S.). A set of 10% of the coded statements was randomly chosen for quality control checking. Intercoader agreement in this set attained the sub-study's prescribed threshold ($K \geq .70$) and discrepancies were resolved by consensus and with the Senior Coder. Stratified frequency tables derived the numbers of children to whom each code was applied and of the codes themselves.

RESULTS

The sub-study approached 60 children to participate in qualitative interviews: 1 child declined (2%), 1 child agreed but subsequently withdrew (2%), 11 additional children agreed but could not be reached by telephone despite multiple attempts (18%), and 47 children agreed and were successfully interviewed (78%). Among the 47 child interviews completed, 34 (72% of those interviewed) were utilized for the analytic sample as thematic saturation of the data were sufficiently achieved (i.e., no additional data were identified that further developed the properties within each category) [26]. These interviews (Table 1) were obtained from 10 boys and 24 girls (M age = 17.7), most of whom were Caucasian and Non-Hispanic. They were part of well-resourced families of 34 mothers (M age = 48.7) who were racially/ethnically similar to their children, college-educated, and predominantly living in married/partnered relationships. A majority of mothers had survived a prior breast/ovarian cancer episode, were the first person in their kindred to participate in

Table 1 | Sample characteristics (*N* = 34)

	<i>M (SD) or N (%)</i>
<i>Child</i>	
Gender	
Male	10 (29.4)
Female	24 (70.6)
Age, in years	17.68 (3.2)
Race	
Caucasian	31 (91.2)
Non-Caucasian	3 (8.8)
Ethnicity	
Hispanic	1 (2.9)
Non-Hispanic	33 (97.1)
<i>Maternal</i>	
Age, in years	48.65 (5.0)
Race	
Caucasian	32 (94.1)
Non-Caucasian	2 (5.9)
Ethnicity	
Hispanic	1 (2.9)
Non-Hispanic	33 (97.1)
Marital status	
Married/living as married	30 (88.3)
Single/never married	1 (2.9)
Divorced/separated	3 (8.8)
Education level	
≥College	27 (79.4)
<College	7 (20.6)
Annual household income	
>\$75k	26 (76.5)
≤\$75k	7 (20.6)
Not reported	1 (2.9)
Breast/ovarian cancer history	
Previously affected (survivor)	22 (64.7)
Unaffected	12 (35.3)
Proband status	
Proband	28 (82.4)
Relative	6 (17.6)
<i>BRCA1/2</i> genetic test result	
Positive “+” (carrier)	11 (32.4)
Negative “-” (noncarrier) or Uninformative negative “?”	23 (67.6)

cancer genetic testing, and received either negative or uninformative negative *BRCA* test results. [Table 2](#) presents stratified characteristics of the analytic sample.

Examination of child interview response codes (>1,900 coded segments in total) was undertaken across three themes: (a) initial disclosure and the experience of learning information about familial cancer and *BRCA* testing, including how this

information was shared, what children inferred or understood about its meaning for them, and their reactions to receiving the information; (b) socio-emotional impact of the communication, children’s current feelings and their thoughts about the future; and (c) influence of the communication on children’s health behaviors (past, present, and future). Each theme is detailed below, and illustrative quotations are provided and denoted by the participant’s gender (M, F), age band (12–17, 18+), maternal breast/ovarian cancer history (A, U), and maternal genetic test result (+, –, ?), as defined previously, to describe the contexts in which they occurred. Where possible, trends indicative of potential developmental (i.e., age-based) differences in younger children’s, adolescents’, and young adults’ responses are noted, although the term “children” is used throughout when citing most exemplars in aggregate.

Disclosure, literacy, and the experience of learning genetic information

As shown in [Table 3](#), 100% of the children shared their recollections of the disclosure experience and this contributed to the majority of coded statements within this domain. Many children had only vague remembrances of the very first discussion and a few conflated learning about *BRCA* testing with learning about their mothers’ diagnosis of breast/ovarian cancer if she was a survivor. Children who were under age 18 at the time of receiving the information had relatively less well-developed genetic health literacy and were more likely to describe being confused or unsure about what they were being told. By contrast, literacy skills were more well-developed among older adolescents and young adults: one participant commented that her family’s conversations with her about the topic still “hadn’t sunk in” and that she “hadn’t really absorbed the information.” (F, 18+, A, +) Although cancer genetic health communication in families about HBOC and *BRCA* testing was relatively succinct and to the point, nearly all children (94%) affirmed the importance of these conversations both initially and with the passage of time. For those with mothers who were previously affected by breast/ovarian cancer and/or *BRCA*+, the content of communication focused more on supportive messaging and providing psychosocial reassurances so as to not transmit worry to family members. Another recalled she “*didn’t know what most of it [HBOC and *BRCA* testing] meant*” at the time, but was pleased that her mother “*was not overreacting because that made [the child] feel a lot better...so that really comforted [the child].*” (F, 18+, A, +) Similarly, children reported that their mothers attempted to balance sharing factual information without raising alarm and this was common across ages.

Table 2 | Interview stratification

Child characteristics	Maternal characteristics			
	Breast/ovarian cancer history <i>BRCA</i> test result			
	Previously affected (survivor) (<i>n</i> = 22)		Unaffected (<i>n</i> = 12)	
	Positive (<i>n</i> = 9)	Negative/uninformative ^a (<i>n</i> = 13)	Positive (<i>n</i> = 2)	Negative/uninformative (<i>n</i> = 10)
Gender Age				
Male (<i>n</i> = 10)				
12–17 (<i>n</i> = 5)	0	3	0	2
18–24 (<i>n</i> = 5)	2	2	0	1
Female (<i>n</i> = 24)				
12–17 (<i>n</i> = 12)	4	5	0	3
18–24 (<i>n</i> = 12)	3	3	2	4

^aFor analytic purposes, the categories of negative and uninformative negative were combined.

Umm, she wanted us to understand, like this [the results] she didn't want it to, like scare us. Like, she didn't want to scare us, like to think, like we have to think about this our whole lives because we could have it, too. And she didn't want us to think about, like how she could maybe get it again. She just wanted us to, like focus on living our lives and not be scared about the thought of having cancer. (F, 12–17, A, +)

There were 68% of interviewed children with questions that were unanswered, or more frequently, were unanswerable at the time of the disclosure: some wanted more facts and information about the test itself, its reliability, and general statistics about HBOC (i.e., medical information typically encountered during genetic counseling consultations).

It's a lot of big questions that aren't possible to answer, but I want to know, like how they did that. And, "Why could they do that?" And, "What was, like, the process?" And, like just, "What happened?" And, "How do they know this?" And, "Are they sure?" Like, "Are they positive?" 'Cause, I don't wanna get misled. (F, 12–17, A, ?)

Of those, several sought-out information on their own on the Internet or from science teachers at school. Another subset, however, were concerned that they could not obtain definitive or quantitative information about their own cancer risks in specific and accurate numbers. These children wanted to understand if they themselves were at greater or lesser risk for cancer in numerical and more absolute terms, especially in light of practices deferring such testing until adulthood. As one child whose affected mother received uninformative negative results noted, *"Why can't they find out how if I'm definitely gonna get cancer or not? Like, why won't they do it [genetic testing]?"* [F, 12–17, A, ?]

A substantial percentage of children (88%) referenced their understanding of what *BRCA* is, and some made statements suggesting they incorrectly recalled medical genetic facts, had misheard or

misconstrued the meaning of their families' HBOC risk, and/or when mothers attempted to reassure their children they miscommunicated the meaning of the results. All were children (many of them male and 12–17 years) whose mothers had received uninformative negative result, which has a nuanced and more complex interpretation. Typically, these children misinterpreted its meaning: many believed they were not at risk for any cancer or, if they were, it was not due to genetic factors despite an awareness of multiple family members affected by or surviving with cancer. This tended to be evidence across the age spectrum of children, both younger and older.

Well, it was me, my mom, and my sister and we were, umm, walking I think to a store, and I asked her if it was genetics, and she said no. And I was excited (laughs) because it wasn't, even though my grandma and my mom had it. Yeah, she told me that it wasn't genetic. (F, 18+, A, ?)

Others believed the results indicated a more favorable prognosis for their mothers than may have been true.

Yeah. Umm, let's see. I think my understanding was that it [genetic test result] was a very good thing and that it made it less likely that it [cancer] would return. Uh, and that was m-m-more of kind of, you know, a-a random fluke thing, umm, but it was not quite as serious for her even, umm, because it wasn't the, the type of cancer that was genetic. (M, 18+, A, ?).

Children reported a range of reactions to disclosure, with mixed feelings about what they learned. That is, children reported a multiplicity of positive, neutral, and negative responses to family communication. For example, 80% of children reported some positive/favorable reaction to the information communicated to them. The nature of those responses differed depending on the nature of the results and not necessarily due to developmental level. Children whose mothers had received negative or

Table 3 | Codebook, by frequency

Thematic domain	Code	Definition	N of children (%)	N of code
Disclosure	Disclosure to child.	Child recalls how he/she was informed about maternal test result, including others present, location, reasoning behind why was informed at that time.	34 (100)	233
	Meaning of genetic testing to child.	Child's affirmation of the importance of knowing about <i>BRCA</i> , including what child thinks <i>BRCA</i> means for him/her (including beyond the results).	32 (94)	146
	Understanding HBOC risk.	Child describes what he/she knows and understands about <i>BRCA</i> /genetic testing/HBOC, states medical implications, reports confusion, misunderstanding.	30 (88)	133
	Favorable responses to <i>BRCA</i> .	Child describes favorable responses to <i>BRCA</i> disclosure, appraisals of result.	28 (82)	97
	Neutral responses to <i>BRCA</i> .	Child describes neutral responses to <i>BRCA</i> disclosure, appraisals of result.	24 (71)	70
	Having both unanswered and unanswerable questions.	Child expresses uncertainty about HBOC and other (future) cancer risks.	23 (68)	75
	Unfavorable responses to <i>BRCA</i> .	Child describes unfavorable responses to <i>BRCA</i> disclosure, appraisals of result.	20 (59)	67
	Approach/avoid others about <i>BRCA</i> and HBOC.	Child reports others with whom he/she did or did not want to discuss <i>BRCA</i> and/or HBOC.	34 (100)	193
	Thoughts/feelings about open communication.	Child describes preferences for how he/she wants parent(s) to communicate with him/her about maternal HBOC and health.	31 (91)	127
	Something to be concerned about.	Child reports uncertainties and/or emotional concerns about <i>BRCA</i> and/or HBOC.	17 (50)	46
	Active coping.	Child reports positive actions he/she has, can, or will take to maintain a healthy outlook into adulthood (e.g., resist cancer).	17 (50)	34
	Avoidant coping.	Child reports distracting and/or avoidant actions about his/her own and/or family's cancer (risk).	13 (38)	29
	Cancer fatalism.	Child anticipates developing cancer in the future.	12 (35)	28
	Have not thought about it.	Child describes not having thought about <i>BRCA</i> and/or HBOC and what it/they meant(s).	13 (38)	21
	Revisiting feelings/emotions about <i>BRCA</i> and/or HBOC.	Child reports renewed/emerging interest in <i>BRCA</i> and/or HBOC over time.	13 (38)	20
Health information and behavior	Intrusive thoughts about <i>BRCA</i> and/or HBOC.	Child perceives vulnerability to cancer and/or need to be genetically tested someday.	7 (21)	11
	Health promotion.	Child reports specific actions to take to remain healthy, lead a healthy lifestyle, and live cancer-free.	34 (100)	271
	Information preferences.	Child describes preferred ways to learn more about genetics and health.	34 (100)	166
	<i>BRCA</i> testing for child.	Child reports family discussions and/or child deliberations about him-/herself pursuing <i>BRCA</i> testing at some point.	32 (94)	116
	Deferring thinking about <i>BRCA</i> testing for child.	Child references waiting until older/adulthood to consider <i>BRCA</i> testing.	20 (59)	32
	Awareness.	Child reports being more aware of genetic testing and health.	6 (18)	13
	HBOC hereditary breast/ovarian cancer. %'s rounded to the nearest whole number.			

uninformative negative results almost uniformly reported feeling “relief” and being “glad” about the information, both in terms of their own health and the health of their mothers. Strikingly, children whose mothers received *BRCA*+ results also had favorable reactions that centered around the importance of having answers and information for and about their mothers’ health, treatment decisions, and for their own future plans and opportunities for cancer prevention. Again, this was evidenced across the age gradient of children.

Umm, yeah. I mean, I’m definitely glad that it is possible to know this type of stuff. I mean, I feel really grateful for technology because I think if you know something, you’re more likely to, I guess, take action on it. (F, 18+, A +)

A relatively smaller proportion (59%) also and, in some cases, simultaneously reported having some negative/unfavorable responses to disclosure as well. Depending on their mothers’ test result, the nature of those concerns varied: children whose mothers’ were *BRCA*+ expressed feeling apprehensive about their own future health and their mothers’.

And then when she told me, then I guess I was, umm, it was kind of unsettling because that means that I might be at greater risk for it, and it also might put my mom at greater risk for other types of cancer like ovarian cancer. (F, 12–17, A, +)

Children whose mothers’ results were not *BRCA*+ noted that even though they were relieved by the news, it also raised the issue of familial cancer for themselves and for their mothers.

And, umm, like I knew it ran in the family, so but my mom had always been really healthy. So, for some reason I wasn’t that concerned about her. Like, and then when she mentioned it, it kinda freaked me out because I hadn’t really thought about it happening to my mom yet. (F, 18+, U,?)

Despite reporting some initially favorable and unfavorable responses, a substantial proportion of children at younger and older ages (71%), also or uniquely endorsed dispassionate and neutral responses to the disclosure process. That is, there was neither a discernibly favorable nor unfavorable tenor to their stated affect. In some cases, given their awareness of the family history of cancer, children were simply “not surprised by the news.” As one young man (18+, A, +) noted, “we kind of suspected it was coming since she had already been diagnosed and treated for breast cancer.” In other children whose mothers’ had results other than *BRCA*+, the children did not identify personal implications for themselves at that time. For those children whose mothers were breast/ovarian cancer survivors, they spoke more about the impact of that event rather

than on the specifics of learning about *BRCA*. This, too, was consistent across ages.

Interrogating the socio-emotional impact of genetic health communication

On the whole, children did not report long-term, persistent, or adverse reactions to the communication of their mothers’ *BRCA* test results. In fact, almost 40% reported they had not really thought about the event since the initial disclosure, and regardless of test results obtained, their gender, or age. That same number noted they do not dwell on their own potential cancer risk, and again regardless of the results communicated and other demographic factors. Half of children (50%) reported during interview that developing cancer in the future was something that concerned them. The frequency of this sentiment, however, did not markedly differ by maternal genetic test result. That is, children of mothers with a *BRCA*+ result appeared no more or less likely to endorse this than did the others. Children’s concerns about cancer (more broadly) seemingly stemmed from the totality of the lived experiences of their families’ cancer histories rather than an episode of genetic testing per se.

Umm, what brings it up is just it’s so much a part of my life. So, it concerns me because I’ve just always got to worry about it ‘cause it was in my mom’s life. And it could be in me and my sisters. And it’s just all over the place pretty much. (F, 12–17, A, +)

Importantly, 50% of the children affirmed that they felt they could cope well with any future health issues that might arise, frequently citing their mothers’ own coping with cancer as a positive role model. There was a trend for children of *BRCA*+ mothers to endorse this sentiment more commonly than the others, and for this interpretation to be uniform across the ages and gender of children studied.

But I guess, if something did come up, I would just roll with it as it came and assess my situation as I got through each step and, like, figure things out from there. (M, 12–17, A, +)

As a result of disclosure, children were cognizant that cancer might be hereditary, and learning about their mother’s *BRCA* testing experience made this knowledge more salient: all children (100%) articulated with whom they wanted to discuss (or not discuss) this information. Some children reported feeling susceptible to cancer (21%). Among families with deleterious *BRCA* alterations, this was usually counterbalanced by their attempts to verbally reassure children about maternal health and well-being, children’s health and well-being, the importance of a healthy lifestyle (e.g., avoidance of tobacco use, consumption of a healthy diet, engagement in physical activity and exercise, maintaining a

healthy weight, and sun protection), and advanced medical research in cancer prevention and control (e.g., chemoprevention). In Layman's terms, they were "looking on the bright side," and it should be kept in mind that these discussions were unaided by healthcare professionals, occurred without the benefit of patient education materials, or the provision of psychosocial support families beyond mothers' genetic counseling. That younger children were able to verbalize this sentiment on par with that of adolescents and young adults speaks to their genetic literacy and understanding.

Honestly, like I feel that now that she [mother] has her genetic testing and that I'm already gonna have cancer. Like, I just feel like she probably has a likely chance of gettin' it [cancer] again. I will have a likely chance [of developing cancer]. I'm like, already planning for that—that stressful time on my life. I don't know when it's comin', but I feel like it will come sometime when I'm older. That I'm gonna have to face cancer. (F, 12–17, A, +)

Cancer genetic health communication prompted a few children to consider their own health and wonder what the future held for them (38%), but equally so regardless of test results or other assessed features.

Umm, it's [HBOC and genetic testing] definitely made me reflect more on what could happen to me, umm, because it was sort of—it was out of the blue for me. Umm, I never really experienced anything like that, and I definitely for a while—and currently still am—umm, I am concerned and wonder, umm, what sorts of things could come out of nowhere and happen to me? (M, 12–17, U, ?)

In 35% of cases, children expressed beliefs about the certainty that cancer would happen to them in the future and, again, this artifact was more driven by a maternal cancer history than genetics.

So, I guess just—I plan—I guess I plan for the next few years not for the next 20 years 'cause you don't know what's gonna happen. I guess it's just made me like a little bit more impulsive, but I'm just—I worry too much, so I can't be crazy impulsive. (F, 18+, U, -)

Another theme that emerged was cancer genetic health communication in families tested for *BRCA* alterations tending to make real for some children the fact that, regardless of behavior, there are elements that one cannot control but that affect one's future (i.e., genetics). This was especially poignant among older adolescents and young adults interviewed.

I mean, yeah, I definitely worry about it [cancer], but it's—it's seemingly, like out of my control. I mean, both my grandmas had breast cancer. And now my aunt. So, it's, I mean, it's

*definitely like in our family even if it's not the *BRCA* gene. It might be some, you know, some other genetic link.* (F, 18+, U, ?)

In a few cases, when mothers were previously affected with breast/ovarian cancer and had a *BRCA* test result, their children (and daughters in particular) reported that circumstances were beyond their control: these children conveyed that they would likely develop cancer in the future. In response to queries regarding the source of their worries about HBOC, one young woman responded: "Umm, I do not know. Just—I just do not wanna have cancer when I'm older. I just—I just think I'm going to." (F, 12–17, A, +) Another younger female child offered:

Like, I've always been scared of almost growing-up because I knew something was gonna happen to me. My dad had skin cancer, and she [mother] has breast cancer. And my grandmother had it [breast cancer]. And her gr—her mother had it [breast cancer]. So, I almost feel like, 'Okay, great. I'm doomed. I'm gonna have breast cancer.' (F, 12–17, A, ?)

Although the vast majority (91%) of children articulated thoughts and feelings about how they wanted parents to communicate with them about HBOC and maternal health, some children reported that they did not address their own stress/anxiety over HBOC and *BRCA* testing, even when recognizing concerned others would support them. Younger children had difficulty articulating why this was the case, other than that they wished to avoid negative feelings.

And then when she [mother] got the testing, I was still, like I didn't like talking about it [BRCA] because I keep things to myself. I don't know whether it's, like, a sense of I need to not make people think that I'm scared of things. I don't know. I just don't, like, openly express my [fears]. (F, 12–17, A, ?)

Others were reluctant to reveal any negative thoughts and feelings to their mothers because they did not want to increase maternal stress. There, children appeared to protectively buffer their parents against undue concern about the child's emotional state and alleviate parental guilt about HBOC or the possibility of having transmitted an altered *BRCA* gene to their offspring. This, too, tended to be reported robustly across the ages studied.

Umm, just generally, like I don't wanna hurt her [mother] feelings if I say something, like, "Well, why'd it have to be her? And thanks to her, now it's gonna be my turn." And, like, "Why did she have to do this to me?" And I don't want her to feel like it's her fault...So, I just—I-I don't really, like I just don't feel very comfortable talking to her about it because just for, like, her safety. Well, not safety, but, like, I don't wanna hurt her feelings. (F, 12–17, A, ?)

Forming health behaviors and health behavior changes

All children (100%) interviewed noted that they followed or would seek to follow a more healthy lifestyle to influence the portion of cancer risk that may be under their control (i.e., behavior) by engaging in exercise and physical activity and/or consuming a more nutritious diet. That is because they perceived general health benefits to doing so, or perceived health risks for not doing so. These determinants seemingly assuaged children's concerns about the future ascribed to their families' overall experience with genetic testing, HBOC, and cancer in general, to date.

I think what I could do to stay healthy is just eat right, exercise, be aware, go to the doctor or whatever, have a regular check-up, a regular wellness-like woman's wellness plan or woman's wellness check-up. (F, 18+, U,?)

All children (100%) also articulated preferences for how they would like to learn more about genetics and health. Among 94% of children, this included discussion of children having genetic testing—and a slight majority (59%) reported deferring this topic for serious consideration until adulthood. In those instances, children reported they would learn more and actively consider that option in the future, when they were “old enough” to be tested. A very few noted they would not want to know if they carried a *BRCA* gene alteration, because then they might learn they were at increased risk. When asked from whom and how they preferred to receive more information about genetic testing for HBOC, the most frequently noted sources were their parents, medical professionals, and self-help materials. However, <20% of children reported being knowledgeable about the relationship between genetics and health, beyond what was typically encountered in a middle or high school science course. Thus, a keen interest in health behavior was taken by males and females, across the full age range, and maternal test results with some differentiation among interest in testing based on family history and risk.

DISCUSSION

Qualitative interviews with children concerning cancer genetic health communication in families tested for the possibility of carrying deleterious *BRCA* genes generated several consistent and somewhat universal observations about their genetic health literacy and psychosocial adjustment. The first is that parents sharing medical information about *BRCA* and HBOC risk with their children was considered a notable family milestone at the time, and often became overshadowed by a mother's breast/ovarian cancer diagnosis (if applicable), ensuing treatment, and/or strong family history of cancer present in most HBOC kindreds. Put another way,

children, adolescents, and young adults commonly grappled with the hazy foreground of genetic test results (both for themselves and their mothers), especially children of mutation carriers, against the clear background of cancer in the family. Not surprisingly, children endorsed a range of responses to the initial disclosure and were more likely to recall favorable and/or neutral responses in the ensuing period. This highlights the multifaceted nature of children's thoughts and feelings about *BRCA* and HBOC that cannot easily be summarized as being either “good” or “bad” reactions, but contain more nuance meanings in both their significance and interpretation. Relatedly, these children's coping prowess demonstrated psychological hardiness against HBOC-related potential stressors and threats, be that in the form of maintaining a healthy outlook about the future, distracting one's self to look at the bright side of the situation, or both. Indeed, children of mothers determined to be *BRCA* gene mutation carriers were especially adept at doing so, and often taking cues for their own behavior from that of their parents. As family communicators, mothers seemingly attempted to educate, counsel, and reassure their children about HBOC and genetic risk as best they could, although this was a challenging task without the benefit of well-developed patient education and counseling resources.

Cancer genetic health communication in these families was also associated with perceptions of control that children felt about their health and the surrounding circumstances. Controllability, defined as an individual's ability to influence and regulate outcomes and events encountered in the environment [27], is a hallmark feature of psychosocial growth and development. In understanding adjustment to health threats and diseases, the actual or perceived controllability of a stressor or anxiety-provoking event may be a crucial dimension in determining the level of strain and adjustment displayed [28]. Low perceived control is theorized to enhance psychological states of distress. Among children, the relationship between cancer genetic health communication and psychological adjustment is inarguably moderated by several factors, including the nature of the information being communicated.

For example, reports from children whose mothers received uninformative negative *BRCA* test results contained elements of confusion over these findings and its HBOC risk implications, including younger and older children. This, too, has been observed among adult relatives [29] and the information can be dense. The heterogeneity in these children's responses, across the age range, to their mothers' genetic testing shares striking similarity to the experience of adults [30]. Interestingly, some children interpreted *BRCA* to indicate their mothers' cancer experience could not be genetic and that their family was not at risk to develop cancer. This false belief

was reinforced (inadvertently or otherwise) by mothers themselves in some cases, and presumably in an effort to reassure their children and allay worry. The impact of this interpretation on cancer risk and prevention behaviors in the long-term remains to be seen. In the short-term, it undermines these children's genetic health literacy and opportunity to adapt to a stressor over time and with the support of their parents and healthcare providers. Adults also interpret an uninformative negative *BRCA* test result as being akin to a true negative result [31], which is problematic whenever new information about genetic variants related to HBOC are later identified and require follow-up gene sequencing with families who lack *BRCA* mutations [32]. Although the majority of the studied children would become age-eligible for *BRCA* testing themselves within a few years' time, many parents express interest in pediatric *BRCA* testing and discuss this option with their children, pediatricians, and internists [33]. At the moment, health education, genetic health literacy skills, and preventive behavior in these children remain the only countermeasures. The data indicate both an awareness about and a desire to act in healthful ways that control cancer risk (e.g., diet and physical activity) [34, 35]. Along with fostering children's coping skills, these too could be capitalized upon in health promotion interventions. In young adulthood, work by Werner-Lin and colleagues suggest that preparations earlier in life can support subsequent adaptation and cancer risk management decision making and action steps among those young adults who are *BRCA*+ [36].

Limitations

This study has several limitations, including the narrow diversity in the sample and underrepresentation of males and certain *BRCA* genotypes that precluded some subgroup analyses and the ability to draw more definitive conclusions based on child demographic and maternal clinical variables. Moreover, it is possible that participation biases nonrandomly selected against families with less healthy overall adjustment to HBOC. Caution generalizing the findings to heterogeneous populations is advised, and to individuals from families who receive no or minimal genetic counseling in conjunction with *BRCA* testing. It is also important to keep in mind the descriptive nature of this work that precluded statistical testing of findings. Given the nascent state of the literature on this topic, qualitative research methods were chosen to explore the complexity of children's cognitive, psychosocial, and behavioral outcomes and generate deeper understanding of their interactions with genetic information.

CONCLUSIONS

An understanding of cancer genetic health communication in families tested for *BRCA* from the child's perspective is critical to planning when and how to communicate this information in an open, clear, and

timely manner. HBOC is an autosomal dominant disease passed down from parent to child, with a high likelihood of expression across generations and potentially with earlier onset. Some have suggested that this speaks in favor of screening and risk-reducing interventions on environmental and lifestyle contributors to *BRCA* expression earlier in life [37]. The current project lends critical insights into the genetic health literacy and psychosocial adjustment of 12- to 24-year-old children in relation to being informed about their family's HBOC risk status and hereditary genetic testing results: the literature previously suggested these were impactful characteristics and episodes in a cancer diagnosis on adult outcomes regarding genetic testing [38]. Those from *BRCA*+ families are on the cusp of becoming age-eligible for testing themselves in just a few years' time. Given their recall of disclosure conversations, (mis)understanding of HBOC risk, broad psychosocial impacts, and suggestive changes in health behavior, the field of behavioral medicine must consider how such experiences could influence their genetic health literacy and likelihood of genetic test uptake over time. Future research could lend a longitudinal focus with cohorts of children growing-up in families affected by HBOC, and who may have different understandings of their own genetic susceptibilities to cancer. That would include those at risk for cancers beyond HBOC, those with negative uninformative test results, and those with genetic variants of uncertain significance. This would inform the development of family support resources. It would also be useful to examine similarities among parents' experiences and children's experiences with family communication about cancer genetic testing, and to do so in samples of more diverse racial/ethnic and socioeconomic backgrounds.

Presently, there remains a need for developmentally informed and evidence-based interventions to help parents (and especially mothers) make decisions about communicating with their children about HBOC and *BRCA* testing and promote psychosocial adjustment [39, 40]—and among those harboring deleterious cancer-causing genes in particular. In the interim, genetic education and counseling for parents should continue to help prepare them to discuss hereditary cancer information with all at-risk relatives, including children.

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Compliance with Ethical Standards

Conflict of Interest: Kenneth P. Tercyak, Suzanne M. Bronheim, Nicole Kahn, Hillary A. Robertson, Bruno J. Anthony, Darren Mays, Suzanne C. O'Neill,

Susan K. Peterson, Susan Miesfeldt, Beth N. Peshkin, and Tiffani A. DeMarco declare that they have no conflicts of interest.

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Ethical Approval: All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. This work was reviewed and approved by the Georgetown University Institutional Review Board, as well as the human subjects committees at the participating medical institutions.

Informed Consent: Informed consent and assent were obtained from all individual participants included in the study.

Welfare of Animals: This manuscript does not contain any studies with animals performed by any of the authors.

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