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Family Caring, Culture, and Communication: Barriers to *BRCA*-Related Risk Disclosure in Korea—A Qualitative Study

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ABSTRACT

Objectives: Despite the importance of disclosing a pathogenic/likely pathogenic (P/LP) variant related to hereditary cancer, fewer than half of index cases share their genetic test results with at-risk, biological relatives. Given this missed opportunity for cancer prevention, this study explored the barriers to family communication in Korea, from the perspective of women with hereditary breast and ovarian cancer syndrome.
Methods: In-depth interviews were conducted with 22 women (17 affected, 5 unaffected) carrying P/LP variants in one the *BRCA* genes in Korea. Individual face-to-face and small-group interviews were conducted between August 2020 and November 2021. Narrative data were analyzed using inductive content analysis to identify how participants experienced and interpreted barriers to family communication.
Results: Participants expressed a need for more information and guidance before initiating conversations with relatives. Emotional burden was especially heightened for affected carriers, who had to manage their own cancer diagnosis while assuming the responsibility of informing relatives. Four key barriers to family communication were identified: (1) Blurry understanding of *BRCA* in social and health context; (2) emotional turmoil in clinical communication; (3) disrupted expectations in family risk communication; and (4) culturally shaped disclosure decisions.
Conclusions: Women with P/LP variants in *BRCA* genes face multifaceted barriers in communicating hereditary cancer risk to their relatives. Disclosure should be framed not as delivering bad news but as conveying actionable and preventive information. Culturally sensitive, stepwise communication support, delivered consistently by healthcare professionals, is needed to help carriers navigate this process and avoid isolation and emotional distress.
Implications for Nursing Practice: Nurses are critical mediators in the physician-patient-family nexus, playing a role that extends beyond clinical support to include emotional guidance, risk communication, and cultural sensitivity in facilitating family communication.

Hereditary breast and ovarian cancer (HBOC) accounts for 5% to 10% of breast cancer cases and up to 20% of ovarian cancer cases.[1] Pathogenic/likely pathogenic (P/LP) variants in the *BRCA1* and *BRCA2* genes (hereafter *BRCA*) account for most cases. Persons with HBOC-related P/LP variants have up to 20 times higher risk of developing breast, ovarian, prostate, and pancreatic cancer compared to the general population.[2] Biological relatives of carriers of P/LP variants have 12.5% to 50% of carrying the familial cancer predisposition due to the autosomal dominant pattern of inheritance of *BRCA* genes. Screening unaffected relatives for the familial pathogenic variant offers the greatest health benefits, particularly to younger individuals, by enabling the timely management of cancer risk.[3] However, genetic information worldwide is characterized as private, requiring that the tested individual disseminates information about the familial genetic predisposition to at-risk relatives.[4,5] Consequently, healthcare providers cannot directly contact biological relatives, with exceptions made in very rare cases.[6,7]

Disclosing genetic testing results allows biological relatives to become aware of their potential risk for the genetic predisposition and the option to seek cascade genetic testing and risk-reducing measures. However, disclosing the familial cancer predisposition to biological relatives and advocating for the use of genetic services varies significantly from family to family, and can be influenced by

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Layperson Summary

What we investigated and why

Individuals at inherited risk for cancer often hesitate to share this information with blood-related relatives, who may also have the same likelihood due to genes. This can lead to missed opportunities for cancer prevention in relatives who may not know about their potentially elevated cancer risk. While there are many barriers to family communication about cancer genetic risks, little is known about Korean families.

How we did our research

We interviewed 22 Korean women with genetic predisposition in *BRCA* genes (17 with cancer and 5 without).

What we have found

We identified four main barriers to sharing *BRCA*-related cancer risk with relatives: Blurry understanding of *BRCA* in social and health context; emotional turmoil in clinical communication; disrupted expectations in family communication; and culturally shaped disclosure decisions.

What it means

Communication regarding cancer risk is embedded in notions of family caring in the Korean culture. Healthcare providers could offer clear explanations and emotional guidance to help carriers share genetic information with relatives. Such information may enable relatives to take preventive actions.

genetic literacy,[8-11] emotional[9-10,12-14] and geographical closeness[9,13] among family members, and prior experiences with cancer.[13,14] Prior studies exploring experiences when disclosing genetic testing results to biological relatives reported some negative outcomes, such as emotional distress[15] and lack of confidence.[13] Structural contexts such as gender scripting effects,[16] where the family communication about genetic risk is often shaped by gender roles, not just biology are important, as is how genetic information relayed from healthcare provider to index case, can cause confusion in the process communicating with family, especially when relatives react negatively.[17] Decisional empowerment (ie, having the knowledge, confidence, and support to actively and independently choose health options) and support were also reported as being important structural factors facilitating family communication.[13,18] However, most studies examining family communication of genetic cancer risk have been largely conducted with samples from North America with a few from Europe and Southwestern/eastern Asia. Studies on underserved populations[19] and comparisons across different health systems[20] highlight how structural issues may influence gaps in accurate risk communication. Furthermore, prior studies in Turkey[11] and Malaysia[21] have underscored the importance of cultural context in family communication. Despite this previous work, cultural variations in societal values and norms have not been fully explored regarding family communication of *BRCA* genetic testing results.

The Republic of Korea (hereafter, Korea) is an early starter to provide national health insurance coverage for *BRCA* genetic testing to patients with breast cancer at high risk for genetic predisposition since December 2012.[22] Research on the prevalence of P/LP variants in *BRCA* genes in Korea has primarily focused on specific at-risk groups,[23,24] yet, the estimated prevalence in the Korean population was reported as 15.8% out of 5,433 Koreans tested in a population-based analysis,[25] which is consistent with findings from western countries. Interpretation of genetic test results to patients is a role legally restricted to physicians, and genetic counseling by nonphysicians is still limited.[26] Yet, and consistent with the global legal framework that addresses privacy of genetic information, the Korean legal framework dictates that dissemination of genetic testing results to at-risk relatives is delegated solely to the tested individual.[27]

In our prior work, we examined how Korean and Swiss carriers of P/LP variants in *BRCA* genes understand and interpret their responsibility to share genetic testing results with at-risk relatives.[28] By juxtaposing narrative data from both countries, we developed a typology of family communication that, while shaped by each country's cultural context, revealed themes with broader, cross-cultural relevance. In other words, the previous study[28] focused on identifying shared patterns across both Korean and Swiss accounts. However, the Korean narratives also pointed to distinct structural and cultural aspects of Korea's healthcare system and society that strongly influenced decisions about follow-up treatment and family communication, often framing these actions as "acts of family caring." In light of this, the present study explores how Korean women with a P/LP variant in a *BRCA* gene communicate their genetic testing results with family members, within a context shaped by structural barriers and cultural expectations. This approach makes it possible to situate family communication in a non-Western setting and to examine how broader social expectations around caring for one's kin interact with personal experiences of hereditary cancer risk.

Materials and Methods

Study Design

This exploratory qualitative study was a substudy of CASCADE, a multinational, observational cohort of families harboring P/LP variants associated with HBOC (NCT04214210; CRIS: KCT0005643).[29,30] An exploratory qualitative study component is included in the design of CASCADE. This article reports on narrative data from Korean carriers of P/LP variants in *BRCA* genes, focusing on the disclosure of genetic testing results to relatives and communicating the need for cascade genetic testing. The study adhered to the COREQ guideline in reporting.[31]

Participants

Korean index cases (ie, first person in the family to be identified with P/LP variants) with *BRCA* were recruited in person during their follow-up surveillance appointments. Eligibility criteria were 19 years or older and having at least one alive biological relative. Exclusion criteria were having no living biological relatives and conditions that may interfere with participation (eg, severely ill per self-report). The study was advertised through breast and gynecological cancer clinics in 5 hospitals in the Seoul metropolitan and the surrounding Gyeonggi-do area, in which roughly half of Korea's population reside.[32] It was also announced in an online community of breast cancer patients. Of the 26 potential participants identified, ultimately 22 consented and participated in the interviews. Narrative data were collected until information saturation was achieved through purposive and snowball sampling.

Data Collection

The study was approved by the Institutional Review Board of Severance Hospital (4-2020-0520), and informed consent was obtained from the participants. Data were collected from August 2020 to August 2021, via individual face-to-face or phone interviews (n = 19) according to participants' preference; and two small group interviews (3 persons each) focusing on the experiences of unmarried women with cancer *v* married women with cancer and with children, to add interpretive depth through juxtaposition of possibly different experiences. All interviews were conducted in Korean. Three

participants took part in individual follow-up interviews to allow the research team to more fully capture their detailed experiences.

Individual interviews averaged 60 minutes (range 40-90 minutes), while small group interviews lasted approximately 90 minutes. The interview guide (Appendix 1) included questions such as "*What do you think is the most pressing issue when communicating with a relative about BRCA genes?*" "*Can you describe a time when you found it particularly difficult to talk to a relative about BRCA? What made it challenging?*", and "*How did you or your family react in that situation?*" Probes were used for clarification and exploring potential cultural interpretations. Data collection and analysis were performed simultaneously to identify saturation while verifying the conceptualization of the data being collected.

Data Analysis

Data were analyzed using inductive content analysis as described by Elo and Kyngäs.[33] The process followed three key phases: preparation, organization, and reporting. During the preparation phase, all interview recordings were transcribed verbatim in Korean and read multiple times to ensure immersion in the data and sensitivity to the context. Transcripts were checked against the audio recordings by the interviewer and a research team member (SYK). In the organization phase, open coding was conducted independently by four researchers (JHJ, JHH, SYK, SK) who derived codes directly from the data. These codes were iteratively reviewed and grouped through over 25 in-person and online meetings, during which analytic decisions were made collaboratively. The resulting categories were structured around three key actors—physicians, patients (index cases), and relatives—reflecting the clinical and communicative flow of disclosing genetic testing results. In the final reporting phase, abstraction was applied to refine categories and subcategories through constant comparison across interviews, enhancing conceptual clarity and internal consistency. This phase allowed for the systematic structuring of findings into a coherent and transparent representation of the data. As a concluding step, the research team revisited uncategorized segments—including unclassified codes, ambiguous statements, and overlooked contextual cues—to verify the completeness of the analysis. To ensure analytical rigor, each code and its categorization had to be independently confirmed by at least three of the four researchers before it was considered for inclusion. Final decisions were made through collaborative discussion to reach full consensus, particularly in cases of ambiguity or disagreement. Microsoft Excel facilitated the organization and tracking of codes and categories, while analytical memos were recorded separately to support interpretive reflections during analysis. Key analytic labels and selected exemplar quotations were translated into English at the manuscript-writing stage by two bilingual authors fluent in Korean and English, and cross-checked against the original Korean excerpts. Coding discrepancies were resolved by multiple team discussions to reach agreement on codes and ensure conceptual equivalence of the translation.

Trustworthiness

To enhance the trustworthiness of the study, we followed the criteria proposed by Lincoln and Guba.[34] For credibility, various data collection strategies were employed, including individual and group interviews, and data analysis was conducted over a prolonged period of more than a year. The coding process involved four researchers (JHJ, JHH, SYK, SK) with qualitative research experience, including three with expertise in HBOC (JHH, SYK, SK), who met regularly to review, refine, and reach consensus on codes and categories. Preliminary interpretations were also discussed with a subset of participants to check whether our analyses resonated with their experiences.

To enhance transferability, an independent non-Korean researcher (MCK) reviewed the analytic categories and interpretations to check for potential cultural bias, highlight clarity of cultural nuances, and help identify meanings that could extend beyond the immediate context. Thick description of participants' demographic and familial contexts was also provided. Dependability and confirmability were addressed by maintaining reflexive journals and analytic memos throughout the process, and by documenting analytic decisions from data collection to interpretation. Audit trail of coding decisions and revisions were done in the form of qualitative data analysis notes. This iterative and transparent process helped ensure that the findings reflected participants' voices while remaining grounded in the data and sensitive to the social context of the study.

Results

This study included 22 *BRCA* carriers (17 affected, 5 unaffected), whose demographic and clinical characteristics are summarized in Table. Participants ranged in age from 27 to 68 years; most were married and had children. Among the affected carriers, most had been diagnosed with breast or ovarian cancer and had a family history of the disease.

Four categories captured key barriers participants encountered when communicating *BRCA*-related information within their families, spanning both clinical encounters and family dynamics. Some barriers were rooted in health system processes and provider communication, while others emerged in the interpersonal and emotional demands of sharing genetic risk within families.

Category 1. Blurry Understanding of BRCA *in Social and Health Context*

Participants' engagement with *BRCA* testing was shaped by limited awareness and restricted access within the healthcare system.

1-1. BRCA *as an Unfamiliar Concept*

Participants described the term "*BRCA*" as not immediately understandable, even among those already diagnosed with breast or ovarian cancer. Most had not heard of *BRCA* genes unless they had an affected close family member or learned about it through public figures such as Angelina Jolie, rather than health policies. Consequently, participants struggled to grasp the meaning of having a P/LP variant, particularly regarding decisions about preventive care and family communication.

> *Nobody really knows about BRCA, and even breast cancer patients don't recognize it at first. So how would regular people know? That's why it's hard for them to understand that having this gene means a higher risk of cancer. . . and even harder to see it as something positive in terms of prevention. (P11, 32 years, breast cancer)*

> *Some people may know about BRCA now because of Angelina Jolie's famous prophylactic resection, but before that, most people didn't know and neither did I. (P21, 35 years, unaffected)*

1-2. Perceived Inaccessibility of BRCA *Testing*

Participants noted that even when biological relatives came to understand the significance of hereditary cancer, genetic testing still felt out of reach, due to a combination of financial and geographical constraints. Although national health insurance in Korea began to cover genetic testing for patients under certain conditions since December 2012,[22] coverage for biological relatives was limited and often involved high out-of-pocket costs. In addition to these financial constraints, testing was typically available only in large hospitals located in urban areas, requiring long-distance travel for those in rural regions. These combined challenges made the testing process not only burdensome but also confusing. Participants and their family were often uncertain about how much it would cost, where they needed to go, and under what conditions they could actually receive the test.

TABLE
General Characteristics of Participants (N = 22)

Characteristics		*n* (%)
Age (y)	**Mean ± SD (range)** 43.00 ± 10.32 (27-68)	
	20-29	2 (9.1)
	30-39	8 (36.3)
	40-49	6 (27.3)
	50-59	4 (18.2)
	60-69	2 (9.1)
Marital status	Married	16 (72.7)
	Unmarried	6 (27.3)
Children (n = 16)	Yes	15 (93.7)
	Daughter only	7 (43.7)
	Son only	3 (18.7)
	Both	5 (31.3)
	No	1 (6.3)
Cancer diagnosis	Breast cancer	11 (50.0)
	Ovarian cancer	4 (18.2)
	Other cancers (renal, rectal)	2 (9.1)
	No	5 (22.7)
Family history of breast and/or ovarian cancer	Yes	18 (81.8)
	No	4 (18.2)
Risk-reducing surgery	Yes	8 (36.3)
	Risk-reducing salpingo-oophorectomy	5 (22.7)
	Risk-reducing mastectomy	2 (9.1)
	Contralateral prophylactic mastectomy	1 (4.5)
	No	14 (63.6)

It is not easy for a person who does not have cancer to get a genetic test. Because of the cost, a significant number of people do not actively take the test. Wouldn't people get more tests if the tests were cheaper? (P20, 51 years, ovarian cancer)

Since I live in a rural area, I didn't feel inclined to go all the way to Seoul to get the genetic test. (P8, 38 years, breast cancer)

These findings point to both informational and institutional barriers to engaging with *BRCA* testing. While many were unfamiliar with hereditary cancer and the term "*BRCA*" itself, even those who understood its significance often faced financial and logistical obstacles. These interconnected challenges limited their ability to act on genetic risk information meaningfully. Data suggest that without shared social familiarity and feasible access, genetic risk information may remain difficult to translate into concrete action and family communication, even when medical relevance is recognized.

Category 2. Emotional Turmoil in Clinical Communication

Early clinical conversations often left participants feeling confused, overwhelmed, or emotionally unprepared to act.

2-1. Confusion from Conflicting Information

Participants described receiving conflicting explanations from physicians across various specialties and hospitals. Preventive treatment recommendations varied greatly, depending on the provider, leaving many uncertain about which guidance to follow. This inconsistency caused confusion and anxiety, making it difficult for participants to interpret their genetic testing results or feel confident about next steps. In trying to resolve the uncertainty, some sought additional information from online communities or relatives, but efforts often deepened their confusion rather than provide clarity.

They (initial HCP) said don't worry too much about it (HBOC) and just have regular health checkups on time and have surgery later; because at a young age, cancer doesn't develop often. (. . .) I passed this on to my mom, and she said that what I heard was completely different from a meeting she attended, where doctors recommended preventive treatments as soon as possible. (P19, 39 years, ovarian cancer)

The OB-GYN told me that my genetic results were "really bad" and that I'd probably need to have my ovaries removed, too. But then another professor said I didn't necessarily have to go that far. I guess they had a different perspective on it. (P9, 52 years, breast cancer)

2-2. Pressure from Forceful Messaging

Some participants described being spoken to in ways that felt abrupt or "heavy-handed" when discussing risk-reducing options were relayed by healthcare providers in the process of being informed of their genetic test result. Rather than feeling supported, participants felt overwhelmed and unable to fully process the information. This emotional pressure left some hesitant or resistant to act, even when they understood the medical reasoning behind the recommendation.

I wish the doctor had told me many good things, but he said mostly bad things. (. . .) It was too explicit to say that my nipples could be rotten and have to be removed. (. . .) The doctor spoke so strongly that I was even more intimidated. (P12, 42 years, unaffected)

[When I hesitated] she (the doctor) said, "Do you have great faith about your own womb?" (P3, 45 years, renal cancer)

These challenges highlight how the delivery of genetic information by physicians often led to emotional distress and hesitation among carriers. Participants identified two common patterns in how this information was communicated: explanations that were unclear or incomplete, and conversations that felt overly directive or one-sided. Although differing in tone, both forms contributed to a sense of uncertainty and reduced participants' confidence in making informed choices. In context, early clinical communication appears to set the emotional and cognitive conditions for later family discussions, shaping whether participants feel equipped to disclose and act.

Category 3. Disrupted Expectations in Family Risk Communication

Sharing *BRCA*-related information within families was shaped by two challenges: the emotional weight of initiating disclosure and the disappointment that followed when support was not forthcoming.

3-1. Burden of Disclosure

Participants described the emotional weight of having to convey *BRCA*-related genetic test results to their relatives. Being the first to receive this information and recognizing that they would need to inform family members felt like placing a genetic "stigma" on the family, which many feared would cause distress or an unwanted sense of responsibility. They felt conflicted about initiating such conversations, recalling their own shock and anxiety when first learning the results and hesitating to elicit similar feelings in others. This hesitation was reinforced by implicit expectations to keep distressing topics unspoken and to minimize emotional burden on family members. Consequently, participants weighed whether, when, and how to share the information; some delayed disclosure or avoided direct conversations altogether.

The reason I couldn't speak directly to my younger sister is that, if she has the BRCA gene, she should consider prevention and have her uterus removed. Honestly speaking, I feel like I'm just putting another big burden on her. (P2, 43 years, breast cancer)

I'm thinking about a more stable period when my child (19 y-o) won't be shaken up too much, even after hearing such a thing. I'll tell her, but I'm still considering the timing. (P17, 49 years, unaffected)

Just the fact that I have cancer is already keeping everyone up all night, there's no need to agitate them more… (P4, 46 years, breast cancer)

3-2. Relatives' Indifference and Lack of Perceived Immediacy

Participants described feeling disheartened when relatives reacted with indifference and little concern after learning about the P/LP variant. Some questioned the need for action in the absence of symptoms or dismissed the relevance of knowing such information in advance. Such responses reflected a difficulty in acknowledging potential future risk and made it difficult to continue the conversation. When relatives showed reluctance to engage, participants felt discouraged and often gave up trying to explain further, experiencing a disconnect from the support they had hoped to receive.

Unless people fully understand my problem, the usual response of those who are healthy right now is that they don't know why I'm worried about whether the cancer comes. (P3, 45 years, renal cancer)

If they haven't actually gotten cancer, the whole BRCA thing… no matter how much I try to explain, they don't really take it seriously unless it happens to them. (P20, 51 years, ovarian cancer)

(My cousin responded) "If I get (cancer), I'll just get treated. It's not like there's some special medicine for it, so what's the point of knowing in advance? What could I even do to prevent it? Knowing would just make me upset." So I guess that's why she hasn't told her daughter about it either. (P9, 52 years, breast cancer)

These findings reveal how participants' efforts to communicate *BRCA*-related risk within their families were shaped by unmet expectations of support and emotional closeness. Although families were seen as natural spaces for sharing sensitive health information, many participants hesitated to disclose their results due to fears of upsetting loved ones, being misunderstood, or being blamed for causing distress. When relatives responded with indifference, disbelief, or emotional distance, participants were often left feeling isolated and discouraged, exposing a disconnect between the support they had anticipated and the responses they actually received. Thus, participants' burden of disclosure is not merely an interpersonal dimension but was also structurally reinforced, given that dissemination of the genetic predisposition to at-risk relatives is delegated to the tested individual. This helps explain why responses that prioritized immediate concerns over future-oriented prevention could stall collective follow-up, leaving index cases to carry much of the emotional burden alone.

Category 4. Culturally Shaped Disclosure Decisions

Decisions about disclosure were shaped by concerns about stigma, social roles, and the emotional well-being of family members.

4-1. Stigma Tied to Family Reputation

Participants shared that their *BRCA* status was often regarded not simply as a medical matter but as something that could cast a shadow over the family's image. Some referred to the P/LP variant as a "family flaw," especially when discussing how relatives or in-laws might perceive the news. Parents, in particular, struggled with the belief that they had passed down something harmful, and younger participants sensed the weight of this feeling within the family. Such perceptions made open discussion difficult, leading many to limit what they shared or to speak about it only in cautious terms.

My parents weren't too keen on letting our relatives know that I had (hereditary) cancer. They said it was hard for them to openly talk about it, like… how I ended up with this genetic flaw and that my health wasn't great. They really thought this [positive BRCA result] was a big family flaw and an embarrassment for our family. (P1, 29 years, breast cancer)

I think my mom (who had breast cancer and BRCA) felt that it was like announcing she had passed this bad thing on to me. (P3, 45 years, renal cancer)

Well, I had a bad feeling about why I was the only one who inherited this. My brother tested negative, and I just kept thinking… I wish I had dodged it, too. (P19, 39 years, ovarian cancer)

4-2. Concerns About Daughters' Future

Participants reflected on how the genetic predisposition might affect their daughters' lives, especially in relation to marriage and childbearing. Although sons can also inherit the P/LP variant, participants often focused on daughters because they feared the information could influence how they would be viewed within future marital relationships, by prospective partners and in-laws. Some worried about possible rejection by a partner or in-laws and felt uneasy about the label their daughter might carry. These concerns extended beyond health risk to the anticipated social consequences for daughters' future prospects.

I have a daughter, so my biggest fear was that she might have inherited the gene, too. More than anything, that's what worried me the most. That's why I broke down and cried so much after hearing the test results. (P5, 39 years, breast cancer)

It bothered me that my daughter is currently single. What if she doesn't get married because of the BRCA gene? Or what if she can't have children? (P11, 32 years, breast cancer)

(My mom said) "What if this BRCA gene keeps my daughter from getting married? Or what if it means she can't have children?"—You know, older folks still say things like, "she might be abandoned because of it"—and (mom said) "I wonder, what if she gets married but can't be happy because of this (hereditary cancer)." (P11, 32 years, breast cancer)

So, I've been kind of worried about it. I mean, my daughter's (future) in-laws probably want someone who's in perfect health to marry into the family… knowing there's even a little something makes me feel a bit uneasy. (P16, 54 years, unaffected)

4-3. Protecting elders' Peace of Mind

Participants often chose not to share their genetic test results with elderly parents, fearing that the information would cause distress

without offering real benefit. In several cases, elderly parents expressed reluctance to be tested or questioned the need for action at their age. Faced with this response, participants felt there was little reason to initiate the conversation. Choosing not to share was less about avoidance than about easing emotional burden—guided by care and a sense of familial responsibility.

> *I didn't see the point in making [my mother] get tested and find out she passed the gene down to me. It would only upset her, what good would that do? (P8, 38 years, breast cancer)*

> *My mom [who had breast cancer at and later, lymphoma] is older now, so I didn't really see the need for her to get tested for BRCA. She had her uterus removed a long time ago, and her ovaries have never been an issue. So it just didn't seem necessary at her age. So I did not say anything. (P20, 51 years, ovarian cancer)*

> *I think older folks have more fear. If they're found to have a mutation, I mean they don't have a lot of years left—but they'll have to live under stress, bound to that worry about cancer. (P21, 35 years, unaffected)*

In summary, category 4 illustrates how participants made culturally inflected, context-sensitive decisions about sharing their *BRCA* results with family members. Disclosure often involved navigating emotional and social risks shaped by concerns about family reputation, implications for daughters' future marriage, and expectations of not burdening older parents. Rather than disclosing openly, participants adjusted their approach depending on the perceived vulnerability, role, or reaction of each relative. These choices reflected efforts to protect family relationships by minimizing anticipated distress or conflict while acknowledging genetic risk.

Overall, these findings show how index cases negotiated *BRCA*-related risk communication through the interplay of communicating clinical information, emotional labor, and family expectations. The first two categories, socio-structural blurriness of genetic information and emotional turmoil in clinical communication, capture challenges within healthcare encounters, including limited familiarity with genetic testing and fragmented or distressing delivery of test results. The latter two disrupted expectations in family risk communication and disclosure decisions are shaped by family and social concern, and reflect the interpersonal demands of informing relatives (Fig.). Across the categories, "family caring" was the stage for communication, with emotional tension and relational uncertainty playing central roles in this process. These findings underscore the layered complexity of sharing hereditary cancer risk in Korean families, as described by participants in this study.

Discussion

The study examined how Korean individuals with P/LP variants in *BRCA* genes navigate the process of sharing hereditary cancer risk within their families. The findings revealed that while some challenges reflected universal issues, such as confusion around medical information or limited awareness of available testing services, which are also mentioned in studies with samples from Western cultures,[8-9] other barriers were shaped by family-based considerations that reflect culturally specific communication dynamics. Rather than being a straightforward task, communication was shaped by a complex interplay of informational uncertainty, emotional strain, relational hesitation, and cultural expectations shaping the responsibility to "care for one's kin." The following sections discuss each barrier in light of existing literature and consider implications for clinical and public health practice.

The persistence of ambiguity in how genetic testing is understood has been noted,[35] and in Korea, cancer is commonly perceived as an age-related condition, and hereditary cancer is less familiar in everyday discourse.[36] Consistent with this, our participants described *BRCA* as a medically unfamiliar concept, often misunderstood. Despite Korea's active coverage of genetic testing through national health insurance, which was further expanded in 2020 to include persons with triple negative breast cancer diagnosed at ≤60 years,[37] many women were unaware of the availability of cancer genetic testing, echoing findings that individuals lacked adequate informational resources even after formal counseling.[38-40] Insurance coverage alone did not improve awareness or clarity, particularly when patients lacked access to consistent information or follow-up resources. Confusion was compounded by cost-related uncertainty and logistical barriers, such as the need to travel long distances to specialized hospitals. Similar patterns have been reported in other healthcare systems with pronounced urban–rural gaps.[14,41,42] These results highlight the need to improve access as well as to strengthen informational infrastructure, such as providing clear, family-facing educational tools.[43]

Beyond limited understanding of genetic risk, participants described emotional distress stemming from how genetic test results were communicated. Inconsistent or overly directive consultations often left them uncertain and hesitant about further action. This mirrors literature suggesting that biomedical authority, when delivered without sensitivity to family values, may hinder informed decision-making about family communication.[44,45] In the Korean context, where deference to medical authority is culturally reinforced, blunt or alarmist communication may unintentionally increase anxiety or delay cascade testing. These findings support prior calls for culturally

	Categories	Subcategories
HCP → Index case	1. Blurry understanding of *BRCA* in social and health context	1-1. *BRCA* as an unfamiliar concept 1-2. Perceived inaccessibility of *BRCA* testing
	2. Emotional turmoil in clinical communication	2-1. Confusion from conflicting information 2-2. Pressure from forceful messaging
Index case → Relatives	3. Disrupted expectations in family risk communication	3-1. Burden of disclosure 3-2. Relatives' indifference and lack of perceived immediacy
	4. Culturally shaped disclosure decisions	4-1. Stigma tied to family reputation 4-2. Concerns about daughter's future 4-3. Protecting elders' peace of mind

FIG. Categories of structural and cultural barriers to family communication among Korean *BRCA* index cases. HCP, healthcare provider.

attuned, collaborative counseling practices that consider patients' emotional readiness and family dynamics.[44]

Once results were received, participants faced complex relational negotiations. Even when motivated to share the information, many encountered disinterest, denial, or emotional withdrawal from relatives. Similar to findings in other Asian settings,[46,47] the absence of symptoms often led to dismissal of risk, especially among healthy relatives. This mismatch in perceived urgency disrupted participants' expectations of shared concern and support. Instead of encouraging collective action, disclosure sometimes strained relationships or led to avoidance, a pattern also observed in other collectivist contexts.[48,49] These dynamics illustrate a deeper tension between personal responsibility for health and the cultural emphasis on preserving relational harmony.

The final category revealed how decisions about if, when, and how to disclose were shaped by moral and cultural obligations. Participants described concerns about stigmatizing the family or burdening elderly parents with worry. In several cases, protective actions for elders were not merely about managing facts, but about negotiating relational and moral responsibilities in a society shaped by Confucian norms, such as Korea, where maintaining emotional peace for elders is viewed as an obligation.[50] This finding deserves further inquiry, particularly regarding how older generations interpret or internalize hereditary risk and how such beliefs affect intergenerational communication. These findings align with prior literature showing that inherited cancer risk is often reframed in terms of family duty and reputation in East Asian societies.[48] This study suggests that selective disclosure was often a pragmatic response aimed at minimizing disruption and preserving family cohesion within contexts marked by uncertainty and relational sensitivity. Importantly, disclosure decisions were not static but negotiated, often shifting across relationships and evolving with major life transitions. The intersection of gender, age, and caregiving roles played a particularly strong role in this process, with mothers often bearing a disproportionate sense of responsibility for managing both genetic and social risks.

While in our previous work we reported that the sense of responsibility and cancer risk communication varies by the index case's situated context and who the relative is,[17,28] it is notable that in the Korean context, the responsibility of family caring was not distributed evenly within all family members. Participants described a burden when considering whether, when, and how to inform their children, particularly daughters. These concerns extended beyond physical health to encompass broader social implications, including marriage and childbearing prospects. Such gender-specific worry reflects deeply rooted gendered expectations, especially related to maternal responsibility, given that current Korean social norms emphasize the need for women to fulfill their roles as wives, mothers, and family nurturers. Participants expressed a sense of compassionate burden to their daughters' future and social value, in addition to their concern about physical health and cancer risk. Unlike a prior study in China where disclosure was delayed primarily to protect a child's educational or emotional development,[15] concerns in the present study extended to the long-term life trajectory of daughters, paralleling other qualitative findings that mothers with breast cancer often experience particular challenges when communicating with adolescent daughters.[51] This highlights how the perceived meaning of genetic risk is shaped not only by individuals but also by gendered social contexts.

Building on these insights, our findings suggest the need for tailored interventions across multiple levels. First, communication support tools, such as culturally appropriate letters that are tailored to the composition of each family, teach-back-informed scripts, or visual guides, should be developed to assist index cases in initiating conversations. Second, provider training must emphasize cultural competence, particularly in delivering results without coercion and facilitating shared decision-making. Specialized or advanced practice oncology nurses and genetic counselors can use findings to implement family-centered genetic care that actively considers the cultural implications underlying family dynamics. Third, national and institutional policies should be strengthened to promote cascade testing, including reimbursement strategies, standardized referral, and follow-up pathways for family outreach. Fourth, public education campaigns should aim to close the knowledge gap, especially in rural or underserved populations. Finally, efforts to engage community leaders and advocacy networks may help reduce stigma and foster open dialogue around hereditary cancer.

A key strength of this study lies in its focus on a non-Western population, offering contextual insight into how *BRCA* communication shaped by family expectations described by participants. Participants were recruited from multiple sites, several from Seoul and its surrounding areas where roughly half of Korea's population reside, supporting transferability of findings. However, the small number of unaffected carriers limits comparative insights across disease status. Although eligibility was not limited to women, study participants were all female, which requires caution in applying findings to males with HBOC-related P/LP variants. Future studies should include longitudinal approaches to capture how communication evolves over time and across generations. Additionally, examining the impact of emerging genomic services and direct-to-consumer testing on familial communication would be a valuable next step.

Conclusions

Women with P/LP variants in *BRCA* genes face the dual burden of managing their own genetic diagnosis, along with a possible cancer diagnosis and treatment, while struggling with how to communicate this genetic risk within their families. Beyond the emotional toll, they must work through structural and disclosure-relevant cultural expectations within families that shape their understanding of hereditary cancer risk and influence their decision-making. Given the substantial amount of information they must process, and in a short period of time, building trust and supportive interactions with healthcare providers is essential, particularly with the clinicians involved in disclosing genetic test results. Early interactions regarding the genetic testing results lay the foundation for how women process their own risk and approach family communication.

Nurses trained in genetics and genomics can serve as vital mediators within the physician–patient–family dynamic, especially by helping index cases interpret genetic information and providing clear, accessible information to bridge knowledge gaps. Offering emotional support for patients in family disclosure by helping index cases anticipate family reactions and utilizing decisional coaching and guidance is another key area. Extending tangible support in actively facilitating cascade testing, especially with informed decision-making, nurses can bridge critical gaps in accessing genetic care. Study findings also emphasize training nurses in culturally sensitive communication and engaging in advocacy for resources and community awareness.

Data Availability Statement

The data may be made available upon reasonable request to the corresponding author.

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Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this article.

CRediT authorship contribution statement

Juhye Jin: Writing – review & editing, Writing – original draft, Formal analysis, Conceptualization. **Jeehee Han:** Writing – review & editing, Formal analysis. **Soo Yeon Kim:** Writing – review & editing, Methodology, Formal analysis. **Maria C. Katapodi:** Writing – review & editing, Methodology, Funding acquisition. **Sue Kim:** Writing – review & editing, Writing – original draft, Methodology, Funding acquisition, Formal analysis, Conceptualization.

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Appendix 1. Interview Guide

Introductory Question

- To start, could you tell me a little about yourself (and your family)?

Transition Question

- Please share how you reacted when you were informed that you carried a genetic mutation for hereditary cancer.

Key Questions

Note: Probing questions were used as appropriate during interviews but are not included here for brevity.

- What do you think is the most pressing issue when communicating with a relative about BRCA genes?
- Can you describe a time when you found it particularly difficult to talk to a relative about BRCA? What made it challenging?
- How did you or your family react in that situation?
- What might be some general barriers to sharing genetic risk information with family members?
- How was family communication addressed in the genetic consultations you attended?
- Which healthcare professionals supported or hindered your communication efforts, and how?
- What do you think could help other families share genetic risk information more effectively?

Ending Question

- Is there anything else you would like to share about your experience or thoughts regarding family communication and genetic risk?

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