Patient Education and Counseling 123 (2024) 108202

Contents lists available at ScienceDirect

Patient Education and Counseling

journal homepage: www.journals.elsevier.com/patient-education-and-counseling

Modes of responsibility in disclosing cancer genetic test results to relatives: An analysis of Swiss and Korean narrative data

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ARTICLE INFO

Keywords:
Cascade genetic testing
Confidentiality
Family communication
HBOC
Management of hereditary cancer risk

ABSTRACT

Objective: We examined how responsibility (the "duty to inform relatives about genetic testing results") is understood and enacted among Swiss and Korean women carrying *BRCA1* or *BRCA2* pathogenic variants.
Methods: In-depth interviews and/or focus groups with 46 Swiss and 22 Korean carriers were conducted, using an identical interview guide. Data were analyzed inductively and translated into English for cross-country comparisons.
Results: We identified five modes of responsibility in both samples: Persuader, Enabler, Relayer, Delayer, and Decliner. The Enabler and Relayer modes were the most common in both countries. They followed the rational imperative of health and norms of competence and self-determination, respectively. The Relayer mode transmitted information without trying to influence relatives' decisions. The Delayer and Decliner modes withheld information, deeming it the best way to safeguard the family during that specific moment of its trajectory. Responsibility to disclose testing results was influenced by culturally diverging conceptions of the family unit and socio-contextual norms.
Conclusion: Responsibility primarily reflects the imperative of health prevention; findings demonstrate various interpretations, including the sense of family caring achieved through controlled disclosure of genetic information.
Practice implications: Findings offer healthcare providers socio-anthropological insights to assist probands navigate the disclosure of genetic information within their families.
Trial registration number: NCT 04214210 (registered Nov 2, 2020), KCT 0005643 (registered Nov 23, 2020)

1. Introduction

Communicating genetic testing results is vital for cascade screening of biological relatives in hereditary breast and ovarian cancer (HBOC) syndrome. Many countries, including Switzerland and Korea, restrict healthcare providers from directly informing at-risk relatives about genetic testing results of a family member, leaving the sole responsibility to the individual identified as the carrier of the cancer predisposing gene [1–3]. Evidence suggests that sharing genetic test results tends to be limited to close family members [4,5]. Up to 50% of at-risk relatives are unaware of relevant genetic information, suggesting that the potential benefits of genetic testing are often not communicated effectively within

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https://doi.org/10.1016/j.pec.2024.108202
Received 12 August 2023; Received in revised form 31 January 2024; Accepted 8 February 2024
Available online 16 February 2024
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families [6]. Receiving genetic information about HBOC has implications regarding the duty to warn and protect relatives and has often been linked to the concept of responsibility to share genetic testing results [7–9]. However, this undertaking is not without potential drawbacks, as the implementation of preventive and risk-reducing measures has also raised questions regarding their necessity, efficacy and expediency [10]. Responsibility may be perceived as a dilemma, accompanied by feelings of guilt, fear, and frustration, thereby, heightening the burden potentially associated with a cancer diagnosis [11]. Communicating genetic risk to relatives is an intricate process influenced by various factors, which can act as facilitators or barriers. Individual aspects, such as perceived responsibility and genetic literacy, interpersonal dynamics (closeness and frequency of interactions), experiences with cancer, and social characteristics (social class, gender, and ethnicity) can all impact the acceptability of the disclosure process [12–18].

All the more, responsibility linked to sharing genetic test results is an intriguing phenomenon. This is because responsibility towards one's family can have different conceptual, cultural, and historical meanings [19,20]. A systematic review regarding the concept of genetic responsibility revealed vagueness and multiple meanings among different studies, underlining "the rarity of reflection on cultural variance" [19]. Lay individuals consider family conceptions, social roles, religion, socio-economic factors, and societal trends when deciding on the utility of genetic screening [21–25]. However, little is known on how responsibility to disclose genetic test results is interpreted and enacted. Existing studies that examine motivators and challenges regarding family communication of genetic testing results focus on relatively homogeneous samples in North America [25] or Australia [23]. There is a paucity of information regarding possible cultural variations in the interpretation of the duty to inform relatives and the sense of responsibility to share genetic test results, and likely other health-related personal information, with at-risk relatives. Thus, the purpose of the present study is to explore and comprehensively consider various perspectives on the meaning of responsibility to share genetic testing results, exploring the extent to which medical norms that link responsibility to the disclosure of information to relatives are variably applied in different cultural contexts and stages of life. Conducting comparative research in two countries with distinct cultures can bring out differences in the concept of responsibility. The study explored how Swiss and Korean women with pathogenic variants in the *BRCA1* and *BRCA2* genes (hereafter *BRCA*) interpret and act on their responsibility to disclose genetic information and cancer predisposition to at-risk relatives.

The study is based on the hypothesis that lay individuals' thinking differs from health professionals and public health authorities due to culturally diverging conceptions of family, cancer, genetics, and privacy. Drawing from Boudon's concept of subjective rationality [26], individuals are characterized as "motivated actors", whose behavior is driven by reasons that, while not always objectively rational or in line with established norms, are subjectively justified. These reasons may be considered "good" from the individual's subjective standpoint, as they provide internal consistency and valid motivations given the individual's specific characteristics and situations. Boudon underscores that these reasons possess the "curious property of being both invalid and good", and argues that it is more appropriate to view them as rational rather than irrational to deeply comprehend the individual's actions. The concept of the motivated actor appears particularly relevant for exploring the intrinsic motivations behind an individual's communication behavior, even when their choices, from a clinical or public health perspective, may appear questionable [26]. By understanding different interpretations of responsibility to share genetic testing results, healthcare professionals can better support family disclosure of genetic information in diverse cultural contexts with varying family relationships and resources.

2. Methods

This analysis is part of the CASCADE and K-CASCADE cohorts conducted in Switzerland (NCT03124212) [27] and in Korea (KCT0005643) [28]. The cohorts target individuals from HBOC families to facilitate cascade testing and access to cancer genetic services. Eligible participants are adults (≥18 years old in Switzerland and ≥19 in Korea) currently living in Switzerland or Korea, are able to provide written consent, and communicate in one of the local languages. CASCADE and K-CASCADE have been approved by appropriate Ethics Committees (BASEC 2016–02052 and YUHS 4–2020-0520, respectively). Individuals carrying pathogenic variants in the *BRCA* genes are recruited from diverse oncology and genetic testing centers to ensure representativeness.

All women who consented to provide narrative data within the quantitative cohorts had received genetic counseling and were subsequently contacted. Swiss participants had genetic testing a median of 4 years (1–6 years) prior to enrollment in the study and providing narrative data. Korean participants had genetic testing a median of 3 years (<1 year – 8 years) at the time of interviews. The final sample was deliberatively diversified across various factors, including age, linguistic region, marital status, and residence in either rural or urban areas. Data collection was ongoing until data saturation was achieved [29]. Data were collected between April 2019 and November 2021 in situ, or via phone and videoconferences during the COVID-19 pandemic. Two experts in qualitative methodology were attentive in addressing the switch to online videoconferencing for sensitive topics and/or with vulnerable participants [30]. The interviews (n = 40) and focus groups (n = 13) were conducted by six team members in their native language, i.e., German, French, Italian, and Korean. Participants were asked to provide a biographical description of their experience [31] related to hereditary cancer risk, genetic testing, risk management, and family communication. Audio recordings of interviews and focus groups were transcribed verbatim, using pseudonyms for confidentiality, and translated into English for comparative analysis.

Qualitative content analysis was done using MAXQDA [32] to identify inductively preliminary themes and compare different meanings of responsibility. Inductive thematic analysis aims at identifying, analyzing and reporting patterns within raw data through six iterative steps: familiarizing with the data by re-reading the transcripts, coding the data, identifying themes, reviewing themes, creating relationships between themes, and writing the report [33,34]. The research team used a comparative method to identify patterns of cultural divergence, i.e., after analyzing data from their own country, the Swiss and the Korean researchers analyzed each other's transcripts to identify common themes and to compare unusual or unexpected findings linked to different cultural contexts. Emerging codes were subsequently discussed with the entire research team (six experts with backgrounds in nursing, psychology, and sociology) with an emphasis on identifying ethnocentric bias of different viewpoints. The research team was aware that some responses could lead to judging the *"other"* culture, or making assumptions of stereotypical cultural customs based on their own norms, values, or beliefs. To minimize this bias a *cultural relativism* approach was used, i.e., understanding cultural practices in their own cultural context while avoiding judging what may seem strange based on binary right and wrong assumptions. In order to explore the social and cultural reasons for transmitting, delaying, or withholding genetic information from relatives, the analysis considered cultural factors linked to family customs, gender, and disease representations. First, modes of responsibility were identified in a systematic way and were shared using mind maps. Second, classifying modes of responsibility enabled developing the coding process in a hypothetic-deductive method for the entire sample. Each researcher recoded their own subsample of narratives and conducted a systematic sorting of data, which was shared in English to compare Swiss and Korean similarities and differences. The result is a panoramic view of Swiss and Korean tendencies in terms of sharing

genetic testing results. The study adhered to the Standards for reporting Qualitative Research (https://www.equator-network.org/reporting-guidelines/srqr/).

3. Results

The final sample included narrative data from 46 Swiss and 22 Korean women carrying pathogenic variants in the *BRCA* genes. Korean participants were on average younger (average 42; range: 27–68 years) compared to Swiss participants (average 50; range: 32–72 years). Most participants from Switzerland and Korea were married or partnered (76% and 68%, respectively), and had at least one previous cancer diagnoses (63% and 77%, respectively). One noted difference was that a higher proportion of Swiss women had one or more adult children compared to Korean women (52% and 23%, respectively). Other characteristics are presented in Table 1.

We identified five different modes of responsibility to inform relatives about genetic test results, each one leading to different outcomes (Table 2). These five modes of responsibility are to be considered as ideal types, that is, as conceptual constructs that capture the essential elements of the phenomenon and serve as analytical and illustrative tools. Some participants behaved with all relatives in the same way based on their values and their personal experiences and were classified in one mode. Other participants embraced different modes of responsibility depending on the characteristics of relatives or their own circumstances. Following the variety of disclosure manners, they were classified in more than one mode. Finally, Swiss and Korean women's modes of responsibility were represented in all five categories although with varying levels of distribution.

Table 1
Characteristics of the participants.

Characteristics	Swiss sample n = 46 (%)	Korean sample n = 22 (%)
Linguistic region		
German-speaking	14 (31%)	
French-speaking	25 (54%)	
Italian-speaking	7 (15%)	
Korean-speaking		22 (100%)
Education		
≤ High school/Technical school	28 (61%)	7 (32%)
University/Post-graduate degree	18 (39%)	15 (68%)
Employment		
Full or part time	36 (78%)	8 (36%)
Retired/ housewife/ student	10 (22%)	14 (64%)
Marital status		
Married/Partnered	35 (76%)	15 (68%)
Divorced/Separated	6 (13%)	0 (0%)
Single	4 (9%)	6 (27%)
Widowed	1 (2%)	1 (5%)
Adult child(ren)	24 (52%)	5 (23%)
Previous cancer diagnoses		
Breast cancer	24 (52%)	11 (50%)
Ovarian cancer	3 (7%)	4 (18%)
Other	2 (4%)	2 (9%)
No cancer	17 (37%)	5 (23%)

Table 2
Social norms, action, and challenges of each mode of responsibility.

Modes of responsibility	Social Norms and Reasoning	Action	Implications and Challenges
1. Persuader	The imperative of biomedical health: *"I am responsible for the other person's decision until they take action. I will convince them to make the right decision and ensure that they get genetic testing."*	CONVINCING until the relative undergoes genetic testing	Risks of overriding the relative's autonomy; breakdown in family relationships; proband' s exhaustion
2. Enabler	Autonomy linked to relative's informed decision: *"I am responsible for the other person making an informed decision. I will do my best to provide all information, helping them understand the issue and make an informed decision."*	ENLIGHTENING until the relative can make an informed decision	Risk of proband' s exhaustion until the relative can make an autonomous choice
3. Relayer	Relatives' self-determination and individual choice: *"I am responsible that relatives receive the information. I will transmit the basic information that a gene is running in the family. The rest is up to them."*	RELAYING genetic information	Risk of relatives' misunderstanding and indifference; lack of urgency
4. Delayer	Individual and family general wellbeing: *"I am responsible to take care of the wellbeing of the family system, not only of health. I am waiting for a better opportunity to disclose the information. This sense of protection justifies that I delay the information."*	DELAYING transmitting information until there is a better moment	Risk of relatives losing opportune time for prevention; risk of proband' s loneliness and sense of guilt
5. Decliner	Norm of proband's autonomy: *"I am not responsible because I feel there is no need to tell."*	OMITTING transmitting information	Risk of relative's exclusion from information

3.1. The Persuader mode

In the Persuader mode, participants openly disclosed information about their pathogenic variant, based on the reasoning that they are responsible for ensuring that relatives make the "right" decision, which is in their view to undergo genetic testing. There were nearly the same number of Swiss and Korean participants referring to this category. In the Persuader mode, individuals sought to enhance action through convincing and adopted different strategies until relatives decided to undergo genetic testing. They claimed the norms of prevention and their reasoning integrated the imperative of health for themselves and their

relatives. They used a convincing tone and insistent recommendations, especially towards adult children but also towards their parents and more distant relatives (quotes 1.1 - 1.3; Table 3). They expressed high levels of responsibility and a strong sense of duty towards relatives, generally because they wished to prevent relatives from having harmful experiences. This mode is centered on the belief of the *duty to inform* in order for relatives to commit to prevention and management of hereditary cancer risk. This cancer prevention awareness leads individuals who embrace the Persuader mode to accept relatives' *right to know* in order to have genetic testing and the chance to engage in cancer risk management. However, this may also conflict with relatives' *right not to know*. This overwhelming sense of responsibility may on one hand burden the individual with the pathogenic variant herself, and, on the other hand, it may contravene with relatives' decision-making autonomy. Participants embracing the Persuader mode used terms like "being obsessed" (quote 1.4) and "taking on a job" (quote 1.5) to describe their attitude towards their relatives. As one participant explained, her responsibility was to convince others to get tested and urged all relatives to do so in an insistent manner, using dramatic words to persuade hesitant relatives.

3.2. The Enabler mode

Behind the Enabler mode, there was a high sense of duty to "*break the chain*" through enhancing relatives' reflection and enlightening them. Participants considered that it is important to provide information to relatives, enable them to understand the implications of genetic information, and ideally, increase their genetic literacy, in order for them to

Table 3
Supporting quotes for the modes of responsibility.

1. Persuader

1.1. "When I heard that it [genetic test result] *was positive, I just had to tell my mother to get tested quickly. If I am positive, there is a very high probability that she will be positive. With that thought, I often told my mother to take the test. (…) So I think my mom probably accepted it because I kept recommending it."* (Lina, Korean, rectal cancer, 33 y-o)

1.2. "I recommended my son [about age 40 years.] *to get tested, and he said he wouldn't. But I just forced him to get it. But fortunately, it's a relief that there's no problem with him".* (Somi, Korean, ovarian cancer, 68 y-o)

1.3. "Because if you are not sharing this information, it's irresponsible. Because it affects them as well… I can't see any reason … to not share this information with family members. (…) There is a huge passion that this shouldn't happen to anybody else. That I can fix this. That this is not gonna happen to another woman. I think every woman who's been diagnosed with breast cancer just feels … just goes on a mission to save every other woman." (Pam, Swiss, French-speaking, breast cancer, 61 y-o)

1.4. "I tried hard to let other brothers and family members know about it. Everyone probably knows about it because I talked about it. (…) It seems that there are a lot of people like that, those who do not think it's that important. My personality isn't like that, so I've been so obsessed with it that there isn't a day that I haven't thought about it since I found out that the gene existed." (Peach, Korean, renal cancer, 45 y-o)

1.5. "To make the receiver feel concerned is an unpleasant and difficult process. And when you are not successful, then there is no further check. And this is an unsolvable problem. It is somebody from the family who has to make the other 'verbally sick' [persuasive talking about their possibility of becoming ill]*, so that he/she feels concerned and goes for checking."* (Mrs. D., Swiss, German-speaking, unaffected, 52 y-o)

2. Enabler

2.1. "But it's important to give this information so that everyone can decide what to do next. In a certain sense it's not pleasant, it's not easy, it's not nice, but it's useful information to know in order to make informed choices and not to say 'if we had known about it before'…" (Sonia, Swiss, Italian-speaking, unaffected, 35 y-o)

2.2. "But my family avoids talking about it. Instead of seeing it as a learning opportunity… They don't want to think or hear about it. (…) I definitely think that there's a certain cultural aspect that plays a role… I want to change how they perceive those mutated genes. BRCA mutations are not well known or clearly understood. And even a lot of cancer patients are not familiar with them, needless to mention the general public. So when people think that carrying the variant increases your risk of developing cancer, it's impossible for them to see how being a carrier can help them or others take preventive measures. So, it makes sense that our parents associate those mutations with something merely unpleasant." (Shiny, Korean, breast cancer, 33 y-o)

2.3. "He [the geneticist] *told me that he had prepared a letter* [with medical information] *for the relatives, that I had to distribute. It explained what to do and that they had to approach the* [hospital name] *or his office. (…) I thought it was good, because barging into people's homes and saying: 'Well, I have such and such a gene'. Whereas here, the letter was really helpful. And it gave importance, credit, I thought, to what was happening."* (Christine, Swiss, French-speaking, unaffected, 47 y-o)

3. Relayer

3.1. "With my extended family I just gave the information and if they have questions that I can answer, I answer them. If I can't, I say: 'Look, you need to talk to your doctor and find out more'. I actually gave them copies of my report. So that they could show it to their doctors. So whether they did or not [genetic testing] *I don't know. (…) I bucked off and said 'do with this information as you wish, but here's the situation'."* (Pam, Swiss, French-speaking, breast cancer, 61 y-o)

3.2. "I thought it was better to know than not to know, so I just said the same thing. I have the gene, so my mother and my sisters might carry it too. So, I told them to take care of their health from now on, to get tested if they can. But I don't think it's an area where I can actively do anything. There may be people who can live to be 100 years old in good health, right? Even people who don't have it can get cancer. So, we just talked like that, and I let them make their own choices (…)" (Grace, Korean, breast cancer, 39 y-o)

3.3 "But I don't think my aunts will go get tested. They are more athletic than me [laughs] *so I figured they are probably healthier than me, so I didn't push them further."* (Peach, Korean, renal cancer, 45 y-o)

3.4. "I also have a younger brother, so I told him to get this test, early on when I found out. But I don't think he fully knows that I have BRCA or anything about this. So, I just don't [talk about it] *anymore."* (Jeong, Korean, breast cancer, 43 y-o)

3.5. "Well, in my opinion, you have to talk about it without dramatizing it (…) Well, I'm a carrier of this, but now I'll have the chance to be controlled, and to avoid something happening". Well, I'm a positive person, so I'm not going to upset him [her 17-year-old son]" (Federica, Swiss, French-speaking, unaffected, 46 y-o)

4. Delayer

4.1. "After my chemo (I wrote to my relatives). It was not possible before, I was so weak that it was not possible. But I did it maybe a year and a half after the cancer was discovered… When I started to get better…" (Anna, Swiss, French-speaking, breast cancer, 48 y-o).

4.2. "I purposely didn't talk to my children about it, because unfortunately we had a bereavement in 2014, a death [of her husband] *due to a tumor, and I didn't want to give my children another negative thought or another sorrow. (…) Then there was this* [son's] *marriage in the way. I did it* [delayed the disclosure] *out of an act of love for them. Which costed me… It costed me effort, a lot, it costed me some tears, not being able to share it with anyone, of course…"* (Bruna, Swiss, Italian-speaking, breast cancer, 67 y-o).

4.3. "I haven't told him [son] *about that stuff yet. He's 24 now. So, I might talk to him when he's finished his military duty and when it's time for him to get married. But until then, I don't think he would take it seriously even if I tell him now."* (Jeong, Korean, breast cancer, 43 y-o).

4.4. "I'm going to tell her [daughter, aged 19 years] *about it after she gets married, not now. […] Or, at the age when she can be stable. I think it's good to talk to her when she can hear things like that and not be shaken too much. I'll tell her then, and I'm waiting for that time right now. But I think it's good to tell her when she is married, has a husband* [who can offer support]*, and has children".* (Nara, Korean, unaffected, 49 y-o)

4.5. "Um… I feel a little guilty. I think I should inform my [cousins] *of breast cancer and help them take preventive measures, including getting tested. But I also need to think about how my parents feel about it … um… But I do need to tell* [other relatives] *about the disease at some point".* (Young, Korean, breast cancer, 29 y-o)

5. Decliner

5.1. I decided to inform only my cousins and not my uncles or aunts because of their age. I felt it would be "too much" for them" (Gaia, Italian-speaking, breast cancer, 42 y-o)

*5.2. "There is a big age gap. [*between her and older cousin*] (…) Oh, even if I did* [try to tell] *she'd probably go 'what's that.' Besides, we haven't been in touch."* (Kira, Korean, breast cancer, 38 y-o)

5.3. "So, it's difficult to talk to someone who you do not have any kind of contact with, because I know I had some distant relatives in Italy somewhere. And we didn't want to call them, since they are too far away." (Gisela, Swiss, German-speaking, unaffected, 46 y-o).

5.4. "It is not necessary for them [her parents] *to know, because it just makes them sad without any solution.* (June, Korean, breast cancer, 38 y-o)

5.5. 'The physician said "Boys should not take the test. For the moment, we don't do it with the boys, only with the girls". "(Ana-Lisa, Swiss, French-speaking, breast cancer, 65 y-o)

become autonomous decision-makers and make an informed health-related decision. Their reasoning embraced the social norm of competence to make an informed decision and relatives' decision-making autonomy is ultimately respected. The enabler mode was slightly more prominent (i.e., greatest frequency) among Swiss participants as compared to Korean participants (i.e., similar frequency of Enabler and Relayer modes). In the Enabler mode, individuals embraced the benefits of the *right to know* and focused on providing enough information so that relatives can make an informed decision, while they also respected private choice (quote 2.1) linked to sociocultural barriers (quote 2.2.). Therefore, they took time to enhance relatives' genetic literacy, while also respecting their *right not to know*. They focused on making relatives sufficiently aware to make an informed decision, and were interested in the process, not necessarily in the outcome of relatives' decision. Genetic information was presented as providing new choices for managing health. This message framing appeared to be more widely shared among Swiss participants, illustrating the process of transforming the *"bad news"* into *"useful news"* and an opportunity for preventive action.

Many Swiss participants mentioned the usefulness of communication decision aids, e.g., a formal document from healthcare providers that would help them share genetic test results with relatives (quote 2.3). According to them, such a document demonstrates medical authority and solemnity, the seriousness and precision of the genetic information, and probes relatives to give due consideration to the matter. None of the Korean women mentioned the use of such a document, as this is not common practice in Korea. Although women did the best they could, the disclosure process in the Enabler mode was sometimes unsuccessful, either due to relatives ignoring the information, or a tension in family relationships. Thus, some participants may have felt uncertainty and exhaustion with this task, especially when empowering relatives with information was failing and their reluctance or resistance was becoming a burden for the woman transmitting this information.

3.3. The Relayer mode

In the Relayer mode, individuals demonstrated feeling the need to convey information about the pathogenic variant, without necessarily paying attention to the outcomes of this transmission. This does not mean that they were not concerned about relatives, but rather reflects a belief that relatives' decision to undergo genetic testing is beyond their influence, once the basic information, i.e., *"gene is running in the family"*, has been transmitted. Their reasoning embraced the social norms of self-determination for relatives (quote 3.1). They considered relatives as independent actors. The belief in relatives' individual responsibility was often supported by lay notions, such as being particularly athletic and thus less susceptible to cancer risk (quotes 3.2, 3.3). Analysis of the narratives did not reveal strong differences between Swiss and Korean participants. In the Relayer mode information was transmitted with less emotional implications, sometimes in a more disengaged manner or with lightness and positivity to avoid creating fear, particularly among younger relatives and their own children (quotes 3.4, 3.5). This disengaged manner can be misunderstood and generate indifference among relatives.

3.4. The Delayer mode

The number of interactions referring to the Delayer mode was small and quite similar in both countries. Participants in this mode embraced the social norms of individual or family wellbeing, where preserving the physical health of one or more individuals was not the only aspect to be considered. Rather, preserving the wellbeing of relatives and the family-at-large was more valued. Choosing to delay the disclosure of genetic information for a "*good reason"* was mainly related to their own (quote 4.1) or the relatives' life trajectory. Delaying the transmission of genetic information was often due to the desire to protect relatives who were in vulnerable periods in their lives or were facing significant life events (quotes 4.2, 4.3). Events associated with important life transitions or social milestones were weighted more than the responsibility to disclose genetic information, thus, delayed the disclosure. For these women, the *"duty to warn"* was often confronted with perceptions of *"bad timing"* for the disclosure. Some participants were also seeking relational support to protect the family unit. This was mainly common among Korean women, who expressed a high sense of wanting to protect family members and the belief that there will be a better time to disclose genetic information. Support from a future family system, projected to provide more stability and more resources compared to parental support, would enable offspring to better cope with hereditary cancer risk and have more options for risk management (quote 4.4). Living *"linked lives"*, meaning respecting the wishes of others in the family unit to keep genetic test results a secret, was also prominent in Korean women embracing the Delayer mode of responsibility (quote 4.5). Similar to other modes of responsibility, the Delayer mode also has drawbacks. In this case, relatives remain ignorant about their increased cancer risk, potentially losing an opportune time for prevention and early detection from a medical point of view, and they may have to face a cancer diagnosis later. However, the cost of withholding information is also high for these participants, who may often experience loneliness and guilt, secretly carrying the weight of responsibility.

3.5. The Decliner mode

The frequency of interactions referring to the Decliner mode was also small in both samples. These women did not appear to feel a sense of responsibility towards relatives; thus, they were not informing them, at least for the time being. Their reasoning appears to center on their own autonomy, conceived as a lack of connection to others or an emotional detachment, rather than the autonomy of relatives. These participants exercised an autonomous choice regarding not wanting to share genetic information and their reasoning mitigated the sense of accountability. Their reasoning relied on relatives' old age (quote 5.1), weak familial contact (quotes 5.2, 5.3), or sense of uselessness (quote 5.4). Another reason for omitting the sharing of genetic information was related to gender misconceptions or trivialization related to male transmission. Lack of or inaccurate genetic information about the probability of male transmission sometimes appeared to stem from the healthcare provider, and subsequently, impeded genetic information disclosure (quote 5.5). However, participants appeared to make usually a conscious decision not to inform relatives about genetic testing results, as they feel there is no need to share this information, and also after considering relatives' characteristics.

4. Discussion and conclusion

4.1. Discussion

The five modes of responsibility identified in the data show that the sense of responsibility to disclose genetic information is dynamic, has multiple layers, is guided by various social norms, is supported by reasoning, and is associated with relational and contextual factors leading to different actions. The disclosure of genetic risk follows a "communication chain", which is initiated by healthcare providers, reaches relatives through individuals with a pathogenic variant who had genetic consultation, and is governed by family dynamics and often contradictory *"logics of action"*, which compel carriers to engage in complex arbitrating processes [22]. According to genetic consultation protocols implemented in Switzerland and in Korea, individuals receive information regarding the implications of genetic risk for relatives and who needs to be informed. However, this information is conveyed in various ways and covers a small portion towards the end of the consultation process [22,35]. This variability likely introduces additional challenges, particularly in navigating the delicate balance between the *duty to warn* and the *right not to know*.

4.1.1. Adaptive disclosure to different relatives

While the literature has shown that distinctions are often made between informing first- and second-degree relatives [36], this study reveals that a deeper, more complex layer of reasoning may affect the sense of responsibility to disclose genetic test results. Even within first-degree relatives, the nature of the relationship appears to be important, e.g., one may adopt a Persuader mode with their offspring whereas take on a Delayer mode with their siblings. Some participants were unique in presenting only one mode of responsibility. Persuaders tended to communicate with all relatives in the same way, aiming to convince them to have genetic testing. However, most participants embraced various modes of responsibility based on characteristics of relatives. Participants would often embrace the Persuader mode with their offspring, the Enabler mode with siblings, the Relayer mode with cousins, the Delayer mode with relatives living far away, or the Decliner mode with relatives with whom there has been no contact for a long time. Timing and contextual reasons, such as closeness of relationships, were factors impeding disclosure of genetic information, as reported in the literature [37].

When developing their own interpretation of responsibility to disclose genetic testing results, individuals with a pathogenic variant configure their own and their relatives' significant life events and social transitions as *"linked lives"* [38–40]. Personal, professional, or familial affairs, such as a new partner or family events, appeared to play a significant role in the embraced responsibility mode. Balancing these aspects within one's social network was perceived by some participants as a "good reason" to delay or omit disclosing genetic information. Consequently, a holistic approach to assisting with family disclosure of genetic test results should also consider social events and life transitions, both of tested individuals and of untested relatives, to grasp how individual decisions for family communication evolve over time. Following Hamilton [41], who linked the genetic testing process to the life course perspective, the aim is to capture all aspects of the person's experience and focus on the timing and social aspects involved in healthcare decisions.

4.1.2. The influence of lay theories and genetic literacy

Both Swiss and Korean women with pathogenic variants in *BRCA* genes embraced most often the Enabler and Relayer modes of responsibility, especially for siblings and second-degree relatives. While disclosing genetic information has often been seen as a dilemma [42], enacting the Relayer mode is one solution that costs less energy. Behind the Delayer mode, participants were inclined to formulate lay theories, i.e., lay people's explanations or metaphors that guide their perceptions of what puts someone at risk for developing cancer and about the optimal timing for sharing information [43,44]. They frequently justified their decision to postpone the disclosure of genetic testing results by referencing significant life events, especially during specific periods and personal or social transitions. Low genetic literacy and gendered misconceptions about transmission of HBOC-associated variants were also associated with the Delayer and the Decliner mode, especially when omitting disclosure to male relatives. This common misconception stems from the perception that males are less likely to develop an HBOC-associated cancer, although the probability of developing *BRCA2*-associated prostate cancer can be as high as 60% [45], and the probability of passing on the pathogenic variant to offspring is 50% for both parents. Our findings are consistent with other studies that reported low levels of attention given to the risk of male transmission of HBOC-associated variants [46–49]. Also, some of *the "good reasons"* mentioned by women omitting to disclose genetic information in this study, such as a relative's older age, geographic distance, and/or superficial contact, have also been reported in the literature [42,50–52]. Narratives from some participants demonstrated confusion around the genetics of HBOC, which is consistent with the literature [53]. Low genetic literacy and low socio-economic background are frequently mentioned as barriers to informed decision-making for genetic testing [54]. However, it is also possible that lack of clarity in health communication contributes to negative iatrogenic consequences that can lead to potentially worse healthcare decisions. Some studies reported that cancer-free individuals identified with an HBOC-associated variant have to navigate an ambiguous state, between being sick and being healthy, and that contradictory messages from different healthcare providers can contribute to difficulties in making informed decisions [10,55]. Since approximately one in three of our participants was cancer-free at the time they provided narrative data, we cannot exclude the possibility that lack of clarity in health messages contributed to embracing a particular mode of responsibility.

4.1.3. Cultural framing of the sense of responsibility

Our comparative analyses suggest some differences between Swiss and Korean participants and contribute to the literature that has largely focused on perspectives from North America, Australia, and the UK [8,23–25]. Korean women in the Delayer mode demonstrated the desire to protect relatives perceived as vulnerable and their life prospects related to marriage or maternity, or to guard the social status of the family and maintain its integrity. These narratives may reflect a cultural collectivism, with the family unit taking priority over individual rights, or guiding the decision of *who needs to know*. Family harmony, a common value in East Asia [56], may shape a fierce notion of becoming the protector of the family unit. If this fuels delay, however, family-centered communication may potentially become a double-edged sword, with family sense of caring and protecting outweighing the *duty to warn*. This is consistent with Dimond's notion of family gatekeeping, and provides a lens to examine family entanglement, which helps explain the complex mechanisms through which family and genetics are intimately entwined [57]. The attention given by Korean participants to the family unit suggests a deep consideration not to disturb fate, harmony, or reputation. Our results mirror the findings of British-Pakistani families being unwilling to share genetic information with the wider family, due to the perceived stigma, the potentially emotional and social disruptive effects for themselves and their children, and limiting marriage prospects of children and relatives [58].

In contrast, Swiss participants were more committed to the Enabler mode, having integrated a rational and medical sense of responsibility, both for their own health and the health of relatives, and their narratives were more likely to demonstrate individual free choice and agency. Actor-centered health decisions appeared to take priority over family reputation and solidarity, with greater transparency and initiative to protect one's health and overall wellbeing. Swiss participants generally considered that their relatives needed to receive genetic information. The western medical perspective relies on a rational processing of the *duty to warn* and a proactive disclosure of genetic information, expressing the cultural value of *"actionability"*. Under this value, management of genetic cancer risk depends on activated and engaged patients who take control over their health. As emphasized by Angelina Jolie in the New York Times in 2013, being proactive may minimize cancer risk, *"It is possible to take control and tackle head-on any health issues. (…) Knowledge is power."* (Diary of surgery, The NYT, March 24, 2015). While Korean women also mentioned the positive effect of Angelina Jolie at raising awareness at the societal level, in many instances their family did not recognize the news could be helpful information. In contrast, Korean participants noted that information about the pathogenic variant was generally viewed negatively, the available options for cancer prevention were viewed as intrusive and drastic, and it was difficult to frame the information as helpful for health management options. These cultural differences show resonance with studies analyzing notable differences between Israeli and German individuals concerned with adult-onset genetic conditions [59,60]. While both the Swiss and the Korean participants expressed that potential health benefits have to be balanced against concerns for relatives' emotional responses and challenges of the family system, findings on culturally nuanced interpretations offer a deeper understanding of the multiple

layers of the *"sense of responsibility"* towards oneself and the family system.

4.1.4. Limitations

Some limitations stem from differences between the Swiss and Korean women providing narrative data. Korean women in the sample were younger, with a higher proportion being single, and fewer having at least one adult child compared to Swiss women. This may mean they had fewer relatives to convey genetic testing results and were at different points in their life trajectories than Swiss women. Considering the importance of timing and social aspects in healthcare decisions, these differences may have impacted the sample's data. Furthermore, the time between having genetic testing and providing narrative data for the study spans from as little as one year, primarily among Korean women, to as long as 20 years for some Swiss women. Consequently, some women may have had a limited time or fewer opportunities to convey genetic information to at-risk relatives. Additionally, we cannot exclude the possibility that people who are more averse to family communication of genetic testing results may be under-represented in the study. Finally, the study only considered the viewpoint of the communicator, but could not examine the content of the conversation with the receiver, nor did it explore the point of view of the receivers themselves. As a potential avenue for new research, eliciting the perspectives of at-risk relatives would offer valuable insights from the receivers' standpoint. Further research with men, using a gendered perspective, is needed to understand the logic behind men's sense of responsibility towards family communication and their attitudes towards receiving information about being potentially at risk for a genetic syndrome that has been associated primarily with female sex. Furthermore, exploring data from individuals who opt not to undergo genetic counseling could offer insights into the reasons behind their decision, and provide crucial insight for a more comprehensive and nuanced understanding of the broader implications of genetic information dissemination. Bas du formulaire.

4.2. Conclusion

While the *duty to warn* is the current public health imperative in the field of medical genetics, narrative data from participants recruited through the CASCADE study in Switzerland and Korea identified five modes of responsibility to disclosing genetic test results. These modes of responsibility emerged from individual and situational factors. While the Enabler and Relayer modes were prevalent in both countries with minimal differences among participants, variations among the Delayer and Decliner modes centered around culturally diverging conceptions of the family unit and autonomy in decision making for cancer prevention and early detection. Korean participants notably elaborated on the need to protect vulnerable relatives and/or to keep the integrity of the family. Findings enable understanding the important reasons that underlie delaying or declining the disclosure of genetic information and provide socio-anthropological insights, specifically culturally embedded relational and family practices, to better understand the rationale behind the communication behaviors in the Delayer and Decliner modes. Indeed, the *making sense* of responsibility can deviate from the conventional medical perspectives that emphasizes transparent communication for preventive measures. Our comparative analyses between Swiss and Korean women have broadened the perspective on responsibility, which is typically associated with a medical-centered approach of the compliant patient. While responsibility primarily reflects the imperative of health prevention, our analyses demonstrate the need to consider various interpretations of *making sense* of responsibility, such as the sense of family caring achieved through controlled disclosure of genetic information. Our analyses also demonstrate the need to consider various interpretations of making sense of responsibility, such as the sense of family caring achieved through controlled disclosure of genetic information.

4.3. Practice implications

Recognizing subtle cultural nuances of family sharing can help healthcare providers tailor decisional and informational support they provide to individuals with pathogenic variants in *BRCA* genes and enhance cascade testing of relatives within each family unit. Healthcare providers often emphasize the *duty to warn* as a binary outcome of either disclosing genetic information or withholding it. However, our findings demonstrate that genetic responsibility is neither linear nor fixed and is guided by multilayered reasoning. Essentially, none of our participants expressed a sense that they perceive themselves as irresponsible, i.e., defined as a failure to fulfill one's duty or commitment. Noting that cultural framing of the sense of responsibility was important and novel in this study, providers should cultivate cultural sensitivity and actively inquire about clients' understanding of family sharing. Recognizing that delaying is not solely based on denial but can also be based on subjectively *"good reasons"* can help healthcare providers address these reasons with practical strategies. Recognizing that life transitions and the desire to protect the family unit may impose delaying, actively scheduling follow-up visits can provide additional opportunities for *"teachable moments"* where patients' reasoning can be re-evaluated. In clinical encounters, providers can reframe the genetic message as a timely opportunity to protect against illness, as well as offer coaching for handling possible negative family reactions while reinforcing with patients' stories. Encouraging a Relayer mode can be the minimum starting point and offering correct information on gender, i.e., how *BRCA* impacts men, should take place on an ongoing basis. Furthermore, healthcare providers should recognize that the Persuader mode is not necessarily the best approach, neither is coercing the sharing of information [3].

Finally, findings suggest that healthcare providers may benefit from a three-step protocol for discussing family sharing with patients. First, they should explore how patients perceive the communication of genetic information within the family, both in general and with each family member. Family communication cannot be approached as a single process but as a nuanced procedure that may vary from one family member to another. Second, they should delve into the reasons behind patients' intentions regarding sharing genetic information. This includes exploring the dynamics of family relationships, cultural norms around family unity and privacy, and the consideration of significant life events. Third, while recognizing the value of the "good reasons" behind their decision, healthcare providers can play a pivotal role in helping patients to be aware of the motives behind their choices. This involves helping them make informed decisions and suggesting strategies to find the right moment and way to communicate aligned with their values and cultural contexts.

Disclaimer

I confirm all patients/personal identifiers have been removed or disguised so the patient/persons described are not identifiable and cannot be identified through the details of the story.

Ethics approval

The study was conducted according to the guidelines of the Declaration of Helsinki and approved by the Ethikkommission Nordwest und Zentralschweiz (BASEC 2016–02052, approved February 6, 2017) and Yonsei University Health System (4–2020-0520, approved June 26, 2020). Written consent was obtained from all participants involved in the study.

Funding

This research was funded by the University of Basel, Office of the Vice Rector for Research; the Swiss Cancer League - KLS-4294–08-2017; the Swiss Cancer Research Foundation - KFS-5293–02-2021; the Swiss

National Science Foundation - IZKSZ3_188408/1; and the Korean National Research Foundation - 2019K1A3A1A14063080.

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Schweighoffer Reka: Writing – review & editing, Formal analysis. **Pedrazzani Carla:** Writing – review & editing, Formal analysis. **Caiata-Zufferey Maria:** Writing – review & editing, Validation, Formal analysis, Conceptualization. **Aceti Monica:** Writing – review & editing, Writing – original draft, Validation, Methodology, Formal analysis, Conceptualization. **Baroutsou Vasiliki:** Writing – review & editing, Formal analysis. **Kim Soo Yeon:** Writing – review & editing, Formal analysis. **Katapodi Maria C:** Writing – review & editing, Validation, Funding acquisition, Formal analysis, Conceptualization. **Kim Sue:** Writing – review & editing, Writing – original draft, Methodology, Funding acquisition, Formal analysis, Conceptualization.

Declaration of Competing Interest

None

Acknowledgments

We greatly appreciate all participants who shared their experiences during the interviews. The authors acknowledge the contributions of Dr. Juhye Jin (Department of Nursing, Korean National University of Transportation) and Dr. Jeehee Han (Red Cross College of Nursing, Chung-Ang University) for sharing their expertise in analyses of narrative data and we acknowledge the contributions of all members of the Swiss and Korean CASCADE Consortia for recruiting study participants, helping secure funding for the study, implementing the study protocol, and data management.

We acknowledge the contributions of members of the Swiss CASCADE Consortium and individuals in helping running the Swiss CASCADE cohort: Souria Aissaoui[1,2], Mekdes Alemu[3], Fulvia Brugnoletti[4], Rachel Bunger[3], Nicole Bürki[5], Pierre O. Chappuis[4,6], Muriel Fluri[7], Rossella Graffeo[8], Karl Heinimann[9,10], Ashley Machen[2], Christian Monnerat[11], Olivia Pagani[8], Manuela Rabaglio[7], Ursina Zürrer-Härdi[12].

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