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### ► To cite this version:

F. Gauna, S. Carof, E Mouret-fourme, I. Coupier, V. Mari, et al.. Links between gender norms and the intergenerational transmission of health information in parents carrying BRCA1/2 pathogenic variants. *Journal of Genetic Counseling*, 2023, Online ahead of print. 10.1002/jgc4.1734. inserm-04302095

**HAL Id: inserm-04302095**

**<https://inserm.hal.science/inserm-04302095>**

Submitted on 23 Nov 2023

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## ORIGINAL ARTICLE

# Links between gender norms and the intergenerational transmission of health information in parents carrying BRCA1/2 pathogenic variants

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## Funding information

institut national du cancer, Grant/Award Number: INCa, grant number 2018-119

## Abstract

Understanding how gender norms affect parents' communication of genetic and cancer risk information to their children can enable healthcare professionals to better facilitate cascade genetic testing. We conducted a qualitative study with semi-structured interviews to determine social factors associated with parents carrying the BRCA1/2 pathogenic variants who communicated cancer prevention practices to their children. Thirty adult carriers (23 women, 7 men) participated in the interviews. All had at least one child aged over 8 years old. Interview topics included their discovery of the variants, their relationship to their body and to the risk of cancer, as well as disclosure to and subsequent communication with their children after testing positive for BRCA1/2. The interviews were analyzed qualitatively, and the major themes identified were identified and compared. We described the roles played by the BRCA1/2 carriers and their partners in communicating cancer prevention practices to their children, from how they managed their own risk of cancer after testing positive, to how they disclosed the risks linked to these pathogenic variants to their children. We also described their involvement in the process of their children going for professional genetic consultation. Gender norms lead women to be more attentive than men to their own health and that of their loved ones. In the context of the transmission of genetic information to children, gender differences in behavior are reinforced by perceptions of the risks of BRCA1/2 variants and women's related health management practices. Cancer prevention is shaped by complex links between gender norms and health management practices.

## KEYWORDS

cancer, family history, gender, genetics, risk perception

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## 1 | INTRODUCTION

Identification of *BRCA1* and *BRCA2* as high-risk cancer predisposition genes has increased the identification of high-risk families. A positive genetic test can reveal serious health risks for individuals and families, and genetic consultation is strongly recommended. Analyzing psychosocial dimensions of the transmission of genetic information helps to improve the genetic consultation process in families. These dimensions have been widely documented (D'Agincourt-Canning, 2001; Julian-Reynier et al., 2011; Patenaude et al., 2013; Young et al., 2019). Many studies have considered the method, content, motivations, and barriers involved when family members discuss the deleterious consequences of these pathogenic variants (Clarke et al., 2008; Daly et al., 2003). Some studies have examined the issue of gender as an explanatory variable for health-related behaviors (Hallowell, 1999, 2000). In this context, it is essential to explore the influence of gender norms on parents who are pathogenic variant carriers. The present study follows on from previous studies, which often found contradictory results about the role of gender in managing cancer-related genetic pathogenic variants (D'Agincourt-Canning, 2001; Hallowell, 1999).

Health psychologists have suggested the relevance of conceptualizing health behaviors as practices, which are contextualized, gendered, and embodied. In this context, gender is defined as a situated social practice, which reflects what is expected of a person depending on the situation. Gender is a two-part process. First, it involves *gendering practices* recommended by society and institutions; in this study's context, one example of this is how *BRCA1/2* pathogenic variant carriers should behave depending on their gender (Martin, 2003). Second, it involves *practicing gender*, which is co-constructed during interactions. More specifically, people interpret the same interaction differently according to whether the behaviors are those ascribed to a gender (Poggio, 2006).

The main objective of genetic testing is to optimize monitoring (both pre- and post-testing) and cancer screening recommendations for individuals categorized at risk of cancer (Cohen-Haguenauer, 2019). In the presence of a *BRCA1* pathogenic variant, the risk of female and male breast cancer is 65%–79%, and 1.2%, respectively; and with *BRCA2*, the risk of female and male breast cancer is 61%–77% and 6.8%, respectively. The risk of ovarian cancer is 36%–53% and 11%–25% for *BRCA1* and *BRCA2* pathogenic variant carriers, respectively (Antoniou et al., 2003; Metcalfe et al., 2008; Troian et al., 2020), while the risk of prostate cancer in *BRCA2* pathogenic variant carriers is 15%–25% (Moynihan et al., 2017).

To understand health behaviors from a more contextualized perspective, these practices must engage people's bodies in such a way as to take into account the fact that our vision of our body is dependent on socially rooted values. For example, most studies on genetic testing show that families with a history of pathogenic variants often give more specific information and support (medical, psychological, moral, etc.) to women than to men. Furthermore, women are expected to give support to other family members

### What is known about this topic

Studies have found that children of *BRCA1* and *BRCA2* pathogenic variant carriers have low rates of genetic consultation uptake. Female sex, advanced age, mutation in the father, diagnosis of cancer in the mutation-carrying parent, and good family relationships all affect genetic consultation uptake. Moreover, young adults are influenced by their parents' views and values, particularly about their parents' perceived gendered differences between women and men in terms of health and behaviors.

### What this paper adds to the topic

Parents' gendered social roles, perceptions of *BRCA1/2* pathogenic variants, and health management practices influenced the type and quantity of information transmitted to their children and the way they supported their children in their health management.

(Bradbury et al., 2007; Eismann et al., 2016; Wham et al., 2010; Wiseman et al., 2010). This contrasts with what is expected of men. Consequently, the latter group is rarely involved by their parents in family conversations regarding their genetic risk. As a result, they receive little information about the implications of genetic testing for their health (Clarke et al., 2008; Daly et al., 2016).

Recent studies conducted in young adults aware of their parents' positive *BRCA1/2* pathogenic variant status while growing up have underlined the role of the parents, family culture, and familial bonds in helping them cope with their inherited genetic risk (Young et al., 2019). In the French context, the GENEPSO-PS study (*Gene Étude Prospective Sein Ovaire Psycho-Social*) showed a high rate ( $\approx 90\%$ ) of genetic risk disclosure by parents to their children. However, only 38% of adult children subsequently went for genetic consultation (Gauna Cristaldo et al., 2019; Troian et al., 2020). In line with previous studies, GENEPSO-PS also found that genetic consultation uptake was higher in women, older adults, and people who received social support from their family members. Surprisingly, consultation uptake rates were higher in adult children of male *BRCA1/2* pathogenic variant carriers. This finding calls into question previous work (D'Agincourt-Canning, 2001; Daly, 2009) that showed that women were the main communicators on genetic issues, which might suggest that it is the children of female not male *BRCA1/2* pathogenic variant carriers who go for genetic counseling more often. It is, therefore, important to investigate gender differences in genetic communication when exploring differences in children's health behaviors.

The purpose of this study was to examine the gender experiences of *BRCA1/2* carriers by analyzing parental roles. To do so, we explored two questions: (i) how study participants navigated social norms about

the role of "care" and gender in the context of cancer prevention practices, and (ii) how they reconciled these social norms with their roles as parents in the genetic risk disclosure process to their children.

## 2 | METHOD

This study was approved by the Ethics Committee of the French National Institute of Health and Medical Research (Comité Consultatif sur le Traitement de l'Information en Matière de Recherche dans le Domaine de la Santé) (CCTIRS) and is registered as study number 17-359.

### 2.1 | Participants

Participants in our qualitative study were recruited in 2018 from the ongoing national cohort study GENEPSO, which follows individuals with BRCA1/2 pathogenic variants (Lecarpentier et al., 2015). Created in 1999, the cohort's participants receive regular questionnaires aimed at identifying genetic factors, which make people more susceptible to the risk of breast and ovarian cancer, and at understanding how people live with knowledge of their pathogenic variant. Individuals were eligible to participate if (i) they had at least one child over 8 years old [as we assumed that this was the minimum age that parents could realistically share information about their status and the risk to their children (Mackenzie et al., 2009), and (ii) had tested positive for a BRCA1/2 pathogenic variant at least 2 years previous to the present study. Persons with a history of breast cancer were eligible if they had been diagnosed at least 2 years previously so as not to interfere with their treatment.

### 2.2 | Instrumentation

The interview guide was developed and pilot-tested by the second author (a sociologist and gender specialist), with the help of the last author (genetic cancer epidemiologist). The pilot test was conducted with three initial respondents, which allowed for modification and improvement of the interview guide. The interview guide was designed to ask questions about the experience of genetic consultation, including family history of diagnosed BRCA1/2 pathogenic variants, receiving positive test results, cancer risk management decisions which the respondents made for themselves, and disclosure to and subsequent communication with their children about the latter's inherited risk.

### 2.3 | Procedure

Purposive sampling was used to recruit the study sample. Using the principle of diversification (Corbin & Strauss, 2014), potential

participants from four Comprehensive Cancer Centers participating in GENEPSO (*Institut Paoli-Calmettes, Institut Curie, Centre Antoine Lacassagne, Centre Hospitalier Universitaire de Montpellier*) with different socioeconomic profiles and children of different ages (toddlers, adolescents, and young adults) were identified. The investigating physicians at the participating cohort centers introduced the study to individuals who met inclusion criteria. Once identified, eligible candidates were informed by postal mail about the main objectives of the present study and were invited to contact the research team for a face-to-face interview. The majority of respondents were women. The rest were men. No transgender or non-binary person replied. All participants provided written informed consent.

Thirty pathogenic variants carriers (23 women, 7 men) were interviewed, including the three respondents in the pilot study. All semi-structured interviews were conducted by the second author. Interviews were held in 2018. Reported data were anonymized (names and interviews) and there was no prior relationship between the interviewer and the participants. Twenty-eight interviews were performed face-to-face, either at the respondent's home or in their care center; two interviews were conducted by phone. Each lasted between 40 and 120 min. All interviews were audio-recorded and transcribed verbatim. Data on participants' sociodemographic characteristics (i.e., age, education level, and occupation) were also collected in the interview. The saturation principle was employed, whereby no new interview was performed once no new theme emerged (Morse, 1995).

### 2.4 | Data analysis

After transcription, a content analysis of the data was conducted (Denzin, 2017). In accordance with standardized methods of sociological content analysis, we used Grounded Theory (Corbin & Strauss, 2014). Specifically, we conducted semi-structured interviews to explore complex links between gender norms and parental roles (care and transmission of information to children) in France in a population of diagnosed adult BRCA1/2 pathogenic variants carriers.

As the analysis progressed, relevant themes were identified; this allowed the interviewer to examine certain elements included in the interview guide in greater detail in subsequent interviews. After defining the relevant themes, data were analyzed again using content analysis in order to capture explicit accounts and details of lived experiences. The first and second authors read all the transcripts to identify descriptive codes. The transcripts were then independently coded line-by-line according to the themes discussed by each coder. An inter-rater reliability test was conducted between the two coders, and based on a comparison of all transcripts, the inter-rater reliability was 80%. Themes were categorized and subsequently aggregated until the primary categories were identified. These primary categories reflected the principal themes extracted from excerpts of the participants' discourses (Smith, 2012), and were subsequently structured to build a thematic analysis structure, which represented

the participants' discourses (see Table 2). We first identified a set of 30 sub-themes. After discussion and redundancy (i.e., overlapping sub-themes) the remaining sub-themes were grouped under 10 high-level themes (Table 3). The latter were in turn grouped to construct the following three categories for in-depth analysis. This analysis enabled us to compare the experiences and representations of the respondents, based on their gender, age, social background, family, and medical trajectory. Data analysis was conducted in the source language (French). The quotes in the Results section were translated into English by a professional translator in the field of health studies.

### 3 | RESULTS

#### 3.1 | Participants' characteristics

Participants were aged between 40 and 60 years old. The thirty participants had 72 children (31 minors including 16 girls, and 41 adults, including 24 women). The study sample's main characteristics are listed in Tables 1 and 2. One woman had prophylactic mastectomy, and nine had prophylactic oophorectomy, while six had both. Two other women had both breast and ovary surgery after being diagnosed with breast cancer. Finally, one woman had prophylactic fallopian tube surgery. In Table 2, we describe participants' characteristics. For reasons of anonymity, non-biological and deceased children were removed from the tables and the analyses when not substantively relevant.

#### 3.2 | Main themes

Results are summarized in the three sub-sections below: [See Table 3].

##### 3.2.1 | Gendered embodiment of genetic information

In terms BRCA1/2 pathogenic variants, the risk of breast and ovarian cancer in individuals assigned female at birth is higher than the risk of prostate cancer in individuals assigned male at birth. As a result, there are more women than men with breast cancer, and therefore, more family histories of women with cancer. Family histories influence the experiences of women when they discover they realize they are BRCA1/2 pathogenic variants carriers. H el ene, 52 years old, 3 children, came from a family where a majority of women had had breast cancer and survived. "Actually, we have a pattern in the family where we say 'A mother's life [first] and after we'll think about our cancer', because it's always been like that ... So we live our life [first] as a mother, and afterwards we'll take care ...". This inherited risk which all the women in our study had, led them to identify their own body with those of their loved ones affected by their pathogenic variant or by breast cancer. On the contrary, even in the families of male

TABLE 1 Participants' Characteristics.

	Women: n = 23	Men: n = 7
Age (at time of the interview) (years)		
Median	50	52
Range	42–59	43–60
Occupation <sup>a</sup>		
Farmer	0	0
Craftsman, merchant, entrepreneur	0	2
Executive and Senior Professional	12	3
Intermediate Professional	6	1
Employee	4	0
Blue-collar worker	0	0
Retired/Housewife	1	1
Total	23	7
Combined number of children (by gender)		
Daughters	28	12
Sons	26	6
Total	54	18
Age of Children (years)		
Under 11	4	3
Between 11 and 17	21	3
Between 18 and 30	27	12
Over 30	2	0
Total	54	18

<sup>a</sup>This socioprofessional classification is used in France; occupations are classified into eight different categories (we combined the 7th and 8th categories for retired and inactive people).

participants whose fathers, uncles, etc. had been affected by cancers potentially related to being a BRCA1/2 pathogenic variant carrier (e.g., breast cancer and prostate cancer), the process of identification with these men had not taken place. Accordingly, these participants' discourses about cancer were disconnected from their family histories. This lack of family history discourse regarding cancer in men is also linked to the lack of communication between men on health and on the body in general. Male and female participants' discourses, therefore, focused on female bodies and pregnancy, as in their opinion, the BRCA1/2 pathogenic variants jeopardize, femininity and fecundity, not masculinity.

Another dimension which reinforced women's embodiment of genetic risks concerns risk management. In our study, a majority of women (17/23) chose to undergo prophylactic surgery to avoid cancer related to BRCA1/2 pathogenic variants. Unlike these women, those who declined to have this surgery decided that the potential negative consequences on their lives outweighed the potential benefits in terms of reducing cancer risk: "I'm very apprehensive about sudden menopause and its consequences, and in terms of personal comfort, weight gain, skin quality, consequences on my intimate life, so I'm no hurry whatsoever" said Sara, 47 year old, 2 children. Women's embodiment of genetic risk was,

TABLE 2 Participants' characteristics.

Nickname	Gender	Family composition	Number of children	
			Boys	Girls
1 Gabrielle	Woman	Married to the father of her children	2	0
2 Arlette	Woman	Married to the father of her children	2	1
3 Nathalie	Woman	Married to the father of her children	2	0
4 Isabelle	Woman	Married to the father of her children	0	3
5 Charlotte	Woman	Divorced from the father of her children. In charge of her children	1	1
6 Judith	Woman	Married to the father of her children	1	2
7 Maylis	Woman	Married to the father of her children	1	3
8 Véronique	Woman	Married to the father of her children	2	2
9 Stéphanie	Woman	Married to the father of her children	2	1
10 Monique	Woman	Married to the father of her children	0	2
11 Isabelle	Woman	In a couple. Divorced from the father of her child	1	0
12 Daphnée	Woman	Married to the father of her child	1	0
13 Vivienne	Woman	Married to the father of her child	1	0
14 Anais	Woman	Married to the father of her children	2	2
15 Sara	Woman	Married to the father of her children	0	2
16 Hélène	Woman	In a couple. Divorced from the father of her children. In charge of her children	1	2
17 Pierrette	Woman	Married to the father of her children	1	2
18 Renate	Woman	In a couple. Divorced. In charge of her daughter	0	1
19 Christiane	Woman	Separated from the father of her children. In charge of her children	2	1
20 Carla	Woman	In a couple with the father of one of her daughters; In charge of her other child.	0	2
21 Carole	Woman	Married to the father of her children	2	0
22 Chloé	Woman	Married to the father of her children	1	1
23 Laure	Woman	In a couple. Separated from the father of her child. In charge of her child	1	0
24 Héctor	Man	Married to the mother of his children	0	2
25 Jean-Pierre	Man	Separated. In charge of the children	1	2
26 Pierrot	Man	Divorced. Alternating custody of the children	1	1
27 Victor	Man	Married to the mother of his children	0	2
28 Jérôme	Man	In a couple with the mother of his children	1	2
29 Louis	Man	Married to the mother of his children	1	2
30 Mathieu	Man	Divorced. In charge of his children	2	1

therefore, situated at three levels: the family level (identifying themselves in the “female” cancers of their family members), the personal level (the associated risk of cancer concerned parts of the body perceived or represented as feminine), and the temporal level (prophylactic measures had important bodily consequences on their femininity, such as menopause, which leads to accelerated aging).

Male participants reported having few discussions about cancer risks and prevention practices with family because this topic did not fit gender stereotypes that associate, for example, breasts with female bodies. Mathieu, 51 years old, 3 children, discussed

the possibility of having breast cancer with his children: “*And my kids laughed when I told them that this could happen to me [Light laughter]*”. This perception is also reflected in sons' beliefs—as perceived by their parents—that men do not have breasts. Hélène explained for example that for her eldest son “*It's the sexual dimension of the breast which makes it that ... for him, a man does not have breasts*”. This difficulty for male participants to establish a link between carrying a BRCA1/2 pathogenic variant and the possible risk of breast cancer for themselves was accentuated by their perception that, in general, research study protocols and information

TABLE 3 High-level themes.

Themes/number of transcripts N = 30	Examples of verbatim discourses
<b>1. Gender norms and female body issues</b>	
Description of the family history of females with breast cancer? <i>n</i> = 30	Well, the beginning yes; it started with my mother in the 1980s who had breast cancer, knowing that ... the whole family on the maternal side, all the women died of breast cancer ... so in a way, when my mother learned that she had cancer uh ... it didn't surprise her all that much ... Carla, 50years old, 2 children
BRCA1/2 pathogenic variant and gendered bodies/ <i>n</i> = 28	Once, Lise went to see her gynecologist and she came back, I don't fully remember, but almost in tears because of her gynecologist. She told her she could be a carrier of the pathogenic variant. And the gynecologist was very radical and said, "You have to have kids soon, etc." She didn't even know if Lise was a carrier or not. Lise only said, "My father's sister, etc." ... and I think that freaked Lise out a bit [to discover her genetic status]. Jean-Pierre, 60years old, 3 children
Cancer prevention practices and femininity/ <i>n</i> = 28	Yes. I accepted them [her breasts after reconstruction]; it's because I saw that I accepted the right one that made me have the left one (slight laughter), and then I said to myself ... And then it's true that when you're supported ... my partner, he ... he accepted and he validated, and actually, I don't look at my breasts with a magnifying glass, and it is nice to be able to have reconstruction because ... you're happy to be saved, that's the first thing you want of course, but it's true that afterwards, you have a life .... Renate, 50years old, 1 daughter
Absence of information about risk of cancer for men/ <i>n</i> = 17	Yeah, yeah, it's ... I got the information. But then again, that was 3–5 years ago; things have certainly changed ... since then. But, but that's because back then we said that the risk for men was prostate cancer and ... at the time no one really knew much; she [the doctor] wasn't able to tell me. Now, maybe ... but ... I don't know, I think that ... I'll be informed if there are any developments, or if there's something that I ... I don't know. Pierrot, 47years old, 2 children
<b>2. The distribution of health care tasks in the family</b>	
Responsibility towards family members/ <i>n</i> = 25	"The decision to do it [to have a mastectomy] was twofold. There was the aspect of "I'm going to take all the risks, now that I know what level it's at. And second, 'I'm going to show my daughters and my sisters that it's possible'. Now it's ... it's possible." Pierrette, 59 years old, 3 children
Family as a means of support/ <i>n</i> = 16	Actually, we are so much like a family where ... let's say 'the cancer generation'; I don't know if you can call it that. For us, cancer was never a taboo ... even in my grandmother's time, we talked about it openly. And for us, it's not ... you know there are people who say about cancer that you shouldn't talk about it, or you shouldn't tell other people. For us, it was not really a taboo subject ... on the contrary, it was a subject that we could ask a lot of questions about ... Laure, 53years old, 2 children
Family relationship as a constraint to communication/ <i>n</i> = 12	And then, it's also the fear that the child will blame ... for example, my daughter has back pain, so she says to me 'ah well, it's your fault that I've got back pain, it's because you hurt me' ... sometimes she says things like that, laughing, but I react quickly ... Arlette, 55 years old, 2 children
<b>3. Communication of information to children according to their gender and the implications of this communication on genetic testing of the children</b>	
Disclosure to children described as a process/ <i>n</i> = 26	For me and for us, because it's a decision of ... of parents ... (sighs) it's not part of the world of childhood in our view; they know ... Isabelle, 45 years old, 3 children
Gendered expectations about children's behavior after being told about their parent's pathogenic variant diagnosis/ <i>n</i> = 28	Well, my eldest son, he'll be ... he's 28 years old, but it's only for his kids so ... he's got time before his kids are 30, he has time to watch and then ... even if I won't forget ... and then I think he'll do it. Right now, I'm trying to convince my eldest daughter, who is 26, so that she thinks about it. Lise, 59 years old, 3 children
Description of children with stereotypical health behaviors according to gender/ <i>n</i> = 24	So, my son did the screening, but he still hasn't found the time ... to go and get the results. So, that's unbelievable all the same, because he was the one who pushed everyone else to get the results. Véronique, 53 years old, 4 children

campaigns take little interest in men with these variants. For example, Mathieu had participated in a symposium about these variants with his daughter: "Yeah, but they only talked about women. So it's always ... There's no equality in this area [Laughs]". The lack of information received by men from the medical sphere was also revealed by the fact that most of the study's male participants were unable to say with certainty the extent to which they were at risk

of getting cancer—despite several of them knowing that prostate cancer could be related to the BRCA1/2 pathogenic variants—and whether they needed tailored follow-up.

The gendered dimension of the BRCA1/2 pathogenic variants was, therefore, underpinned by representations of body, risks, and cancers, but was also shaped by the social norms around healthcare and health management in the family.

### 3.2.2 | Gendered distribution of healthcare tasks in the family

From the interviews it emerged all the respondents took on, to varying degrees, a gendered division of parental roles. While men expressed a sense of responsibility to warn their children about genetic risks, their discourses suggested they are little engaged in the process of managing their children's risk of cancer (e.g., when to disclose the risk to them, etc.). More specifically, their discourses highlighted that they frequently relied on a woman in their family who was the pivotal person in communicating information with other key members of the family, to manage their children's cancer risk. This person was also indispensable in encouraging them to bring their children for genetic consultation. Victor, 52 years old, 2 children said: "My sister made me aware of this by saying to me: 'Victor, don't forget that you have two daughters; you have two daughters; there's still a lot of breast cancer ... so if ever they were to have the gene ... BRCA2 that's it ...'"

Hector, 59 years old, 2 children, explained that his daughter did not discuss genetic risk with him but with her mother because "it's more convenient for her". He saw this as something "normal" since the risk concerns problems, which are related to the female body. All the men we interviewed declared that they relied on their wives for the management of the children. However, divorced men and those who had to take care of children for domestic organizational reasons were more likely to report playing an important role in sharing genetic risk information with their children.

Female participants often asked for their partner's agreement before talking about genetic risk with their children; however, they independently chose the appropriate moment and the themes to be discussed. Although the female participants interviewed all declared that informing their children about genetic risk was a burden, none had left this responsibility to their non-carrier male partners or to other relatives.

The men interviewed recognized the value of both pre-test genetic consultations and early testing for their children. They were more likely to have made their children aware of their (i.e., the children's) responsibilities for their own health care management than having had the extended "care" role, which women had (whether the study's interviewed female carriers, the male participants' female partners, or another woman present in the male participants' lives). As a result, the main difference between women and men lay in the monitoring of their children's genetic risk, the latter being performed by women. Monitoring involved, among other things, accompanying children to genetic consultation and discussing the consequences of genetic testing with them.

The participants repeatedly mentioned the roles of men and women. Women described themselves as having a "care" role (Cresson, 2006). In their opinion, this role was not only an element of what was expected of them but also of how they evaluated themselves. Several women mentioned that health information needs to go through women—even when they are not the pathogenic variant carrier—so that children are better informed and monitored. This was the case, for example, for Monique, 58 years old, 2 daughters, when

she mentioned that she wished to help warn her nephews' children about the genetic risks linked to the BRCA1/2 pathogenic variant. She explained she would go to see her nephews' female spouses: "Because I think they would be better able to listen and hear, to hear that ... well, men are always a little in denial ...". For Monique, women were better "guardians" of family health, especially because she felt they communicated more than men: "It's not a problem, it's that he [her husband] doesn't really know how to talk about it, like, I don't know, men of this generation, maybe they find it hard to talk about these things too ...". Gender role stereotypes were, therefore, shared by both men and women in the study, with some women finding satisfaction in caring for the health of their families.

To summarize, the gendered dimension of the BRCA1/2 pathogenic variant was expressed by the participants according to existing social norms of health care, women being considered as responsible for transmitting information and for monitoring, even when they are not pathogenic variant carriers. Male carriers communicated information about genetic risk, but had a less extensive "care" role.

### 3.2.3 | Gendered transmission of cancer risk information

The majority of the participants' children (52/72) had been informed by their parents about the BRCA1/2 pathogenic variants and the associated risk of cancer. This information was transmitted differently to sons and daughters. Participants expressed greater anxiety and specific expectations for their daughters in terms of when the latter should test to see if they too were carriers, and when to begin cancer prevention practices. Parents considered their daughters to be vulnerable and believed they needed to supervise them to ensure they were protected.

*"And that it wasn't the same as discovering it [when you're young] and to have to live your whole life as a young woman with it. Now ... and I said to myself, you ... you're discovering it when you're already ... you're mature, you have ... lived, and you've had your life as a woman, you've had your children. It's not the same thing. But my grandmother died [from cancer] when she was 29 years old; she fell ill very young; so I thought to myself, I don't want to leave her [respondent's own daughter] in the .... I want to be able to protect her because 29 years old, you know, is [young]". Charlotte, 52 years old, 2 children*

Participants' discourses highlighted stereotypes of female vulnerability and male self-sufficiency. Nancy (48 years old, 3 daughters, 1 son) said "I think. Then again, it's true that ... boys always seem very distant from it all. Everything that's medical, for boys, in general, is distant and left to one side. I think it's more delicate for a girl, because there's the problem of having children and all that ...". Sons were not perceived to be as directly concerned by the genetic risk as daughters. Furthermore, sons were seen as autonomous. With this perception, Louis, 59 years old, 3



children, explained why in his opinion his son refused to be tested: "I think it's a mix of everything that we just talked about, his assertion ... as a young man, and of responsibility, and then opposition, and then today he decided on that, and he doesn't want to go back on his decision ...".

The communication of genetic risk based on a binary conception of gender had implications for how boys and girls perceived the risks of the BRCA1/2 pathogenic variants. For example, in Carole's family, 49 years old, 2 children, "They're [her sons] boys and boys don't care so much about breast cancer, they think it's girls who risk getting sick". She explained: "it goes a bit over their heads, they listen to me for ... because I'm their mother and they want to please me ... As long as they don't have children, they won't feel concerned about the problem, because they're boys. A girl wouldn't be the same. I think my niece, when she's 18 years old, will get a blood test right away, that's it."

Parents in our study argued that for boys genetic consultation can wait until they plan to have children, while girls must start monitoring at approximately 25 years old independently of their plans to have children. In the parents' discourses, their daughters had incorporated the norm that it is their own responsibility to avoid getting cancer, and accordingly, were more likely to go for genetic consultation. Instead, sons were described as being less interested in discovering their genetic status. Furthermore, sons who agreed to go for genetic consultation were described as being more likely to forget medical appointments. Among the participants' adult children (aged between 18 and 33 years old), 35 had been notified by their parents that they (i.e., the parents) were BRCA1/2 pathogenic variants carriers (3 men and 3 women were not notified) and that the children were at risk. Of these, 11 women had gone for genetic testing; only one man had told his parents that he had testing (Table 4). Moreover, this person did not return to obtain the results, which were available for several months.

To summarize, the difference in communication from parents to children according to the child's gender, linked in particular to representations of the BRCA1/2 pathogenic variants as well as to gendered norms of parenting, had consequences on the management of health risks for children.

## 4 | DISCUSSION

In this study of the roles played by BRCA1/2 pathogenic variants carriers and their partners in communicating cancer prevention practices to their children, gender differences were manifested in interviews in complex ways. Gender differences were linked to the body, cancer risk management, self-identification in discussions with

TABLE 4 Access to genetic testing by adult children who were notified by their parents (i.e., the study sample) of their genetic risk.

Adult children	Tested	Not-tested	Total
Women	11	10	21
Men	1	13	14
Total	12	23	35

family members, gender roles in the distribution of health care tasks in the family, and differing gender-based expectations of adolescents' behaviors upon learning of their parent's pathogenic variant. Several issues, which ran across these themes were highlighted during the analysis and we discuss them in more in detail in the subsections below.

### 4.1 | The "health" value and its associated practices

The relationship between gender and health is complex in terms of the timing of specific health diagnoses and associated health behaviors (Bancroft et al., 2019; Happe, 2013). Our results suggest that in our participants this relationship was largely based on healthism. According to this belief system, individuals are morally accountable for failing to act appropriately to avoid illness (Crawford, 1980). This moral responsibility comprises two imperatives: to take care of one's own health, and that of one's loved ones.

Risk self-management practices were influenced in our investigation by gendered representations of the BRCA1/2 pathogenic variant and bodily experiences of BRCA1/2 pathogenic variant carriers. Patients who carry a pathogenic variant make sense of BRCA1/2 test results through ongoing clinical risk assessments (Pender, 2018). Our data suggest that these assessments are gender-based, partly because of objective risks of developing cancers, which are associated with certain organs and the decisions patients have to face once a pathogenic variant is confirmed. The consequences of the BRCA1/2 pathogenic variants differed between participants in our study, and were much more visible in women who developed breast cancer and in those who took prophylactic surgical measures. In a different context, Del Río Carral and Lyons (2020) showed that in female senior managers, activities related to health and wellbeing were inseparable from the influence of social contexts, gender, and embodiment. For our participants, intimate personal decisions they made to manage their cancer risk (e.g., having an annual mammogram) and how they managed their health, interacted with their bodily representations of themselves and—in the case of women—their "femininity" (in terms of their physical appearance and their capacity for seduction, their ability to have children, etc.) and their wellbeing.

### 4.2 | The naturalization of care responsibilities assigned to women

Gender expectations are socially constructed. They are manifested in medical, media, and family discourses, and more broadly in the behaviors of individuals, which remind us of what women and men "must" do in order not to be criticized. Our study highlighted how participants had incorporated these gender norms in terms of health behaviors, in the context of communicating the potential genetic risk associated with BRCA1/2 pathogenic variants to their children.

Participants tended to associate the variants with femininity because of the threat to women's reproductive roles as mothers, and

the associated behaviors women who have the variants should adopt to deal with their inherited cancer risk. These representations were adopted and naturalized by the participants in our study without any great deal of questioning. Accordingly, representations were mainly based on binary conceptions of gender, more specifically about the roles of women and men. The framework of the heterosexual couple reinforced the division of gendered work, because it was taken for granted that the women were responsible for transmitting information and for monitoring, even when they were not BRCA1/2 pathogenic variants carriers. Women were, therefore, assigned “to care” (Hesse-Biber & An, 2017) for their family. This important lay health-care work comprises practical (accompanying the child to a medical appointment), cognitive (providing information to the child), and emotional (reassuring the child) dimensions. It also involves inner work on oneself, both to learn about this genetic problem (even for mothers who are not variant carriers) and to learn how to avoid openly showing their fears. This inner work is part of the “mental burden” described in analyses of domestic care in families, and demonstrates the extent of the associated responsibility for women. In the present study, the cancer risk associated with the BRCA1/2 pathogenic variants, whose representations were gendered (even when common to both sexes: e.g., breast cancer), resulted in men not always knowing what stance to take after testing positive. On the whole, male participants had little knowledge of the risks for themselves, reflecting findings from other studies (Arguedas et al., 2019). Indeed, for some men, despite the fact that they recognized the value of early screening for the variant and subsequent monitoring (if necessary) for both themselves and their daughters, they reported that they had to be persuaded by other women in their circle of family and friends to go for testing. However, most men interviewed did not have the extended role of “care,” which the women had. Instead, they made their children aware of their (i.e., the children's) own responsibilities for their health care management. This behavior of male carriers may explain why children of male carriers go to genetic counseling more often than those of female carriers, as we have shown in a previous study (Gauna Cristaldo et al., 2019). Furthermore, male carriers were happy to accept the support of their wives in the genetic consultation process for their children, and some of them valued this female-perceived care work.

### 4.3 | The family, vector of transmissions and norms

Having a family history of the BRCA1/2 pathogenic variants means that more objective information and beliefs about cancer risks will be transmitted; however, this family history also participates in increasing the gendered perception of these variants. The importance of family transmission of information was described by the interviewees when they talked about their families (parents, aunts and uncles, cousins, etc.), as well as in the description of their own activity as informers for their children.

Participants' perceptions about the inheritance of genetic risk reinforced the stereotype that women have good health behaviors

while men's behaviors are detrimental to their health. Parents socialize their children to differing expectations depending on their gender to self-manage their health (Courtenay, 2000; Daly, 2009; Strømsvik et al., 2009). For our study participants, this had consequences for the risk management of their children. Several studies have shown that parents of daughters are more anxious about the consequences of genetic risk than parents of sons (Strømsvik et al., 2009), which leads daughters to have genetic testing more frequently than boys. Faced with inaccurate information and less anxious parents, the latter are in little hurry to be tested. Sons' perceptions of themselves as invincible might lead them to minimize the need for protective behaviors (Cichy et al., 2007; Courtenay, 2000). In a previous study, we underlined differences in genetic testing in children of BRCA1/2 pathogenic variant carriers and found that daughters were more likely than sons to go for genetic consultation across all age groups, but the difference between both genders decreased with increasing age (Gauna Cristaldo et al., 2019).

Although some studies have analyzed the interactions between gender and decisions based on genetic risk (Hallowell et al., 2006; Keenan et al., 2005), they rarely highlight the complex dimensions of gender or the way it is socially built by each family. Understanding this complexity means examining feminine identity, sexuality, the at-risk body, and gender roles. Our work here supports the notion that BRCA1/2 pathogenic variants detection in both men and women reinforces stereotypical ideas about femininity, which are particularly linked to motherhood (Arguedas et al., 2019; Read & Gorman, 2010), and stereotypical ideas about masculinity, including the supposed invulnerability of men who refuse to go for genetic consultation (Hochschild, 1990; Peterson, 2005). The western family model encourages the differentiating of roles, functions, values and cultural orientations according to gender, which influence cancer prevention practices and the intergenerational transmission of genetic risk information (Cichy et al., 2007). Family values are still embedded in norms structured around a clearly differentiated line of what is considered masculine and feminine (Forrest et al., 2003). This is naturalized in the context of BRCA1/2 pathogenic variants by medical discourses, which emphasize these categories. These considerations should be taken into account in genetic consultations, by strengthening training for genetic counselors, and sensitizing them to gender stereotypes, which often limit genetic consultation uptake.

## 5 | LIMITATIONS AND FUTURE RESEARCH

Our study had several limitations. First, we only interviewed parents. This could have influenced our findings especially regarding the lived experience of gender norms through the participants' children. Second, although some participants had not yet shared their positive pathogenic variant status with their children, all affirmed the importance of doing so and the value of genetic consultation for the latter. The positive perception of genetic consultation and of communicating risk information may partly be linked to the fact that the majority of respondents in our study had middle to upper

socioeconomic status, which has been linked with greater attention to society-defined health injunctions.

The third limitation concerns gender; first, women responded more frequently. This is the case in many qualitative surveys on health or body, showing the influence of gender norms and social roles that assign women the duty to care more about these topics than men. Then, no transgender or non-binary person was interviewed. This may be related to the method of recruitment by physicians, as transgender people are often suspicious of the medical profession because of a long history of medical abuse. Another possible explanation is that transgender people in France had to be sterilized until 2017 in order to be eligible to change their identity cards, so the number of transgender people in France aged between 40 and 60 years old and who had children at the time of this study was very low (even though they were able to have children without administrative changes). Finally, all respondents had children with an opposite-sex partner. This necessarily influenced their perception of gender norms and the roles that society assigned them. More specifically, their gender norms were based on a heterosexual framework for couples as opposed to a non-heterosexual framework.

Further studies could compare the experiences of parents who are BRCA1/2 pathogenic variant carriers with those of their children, if possible at different stages in life. In addition, a comparison could be made between siblings interviewed together. We also recommend that surveys focus on LGBT+ families, which may shed additional light on gender issues associated with the BRCA1/2 pathogenic variants.

## 6 | CONCLUSIONS AND PRACTICAL IMPLICATIONS

This study describes the structuring dimension of gender in the socialization of parents and their children to genetic risk issues surrounding the BRCA1/2 pathogenic variants. Our results underline that parents play a role in teaching their children to self-manage their health, but that this socialization is strongly influenced by gender norms.

Since the genetic communication process is affected by gendered norms and by family values attributed and defended by the BRCA1/2 pathogenic variant carriers in the family, these same norms and family values must be taken into account by healthcare professionals in the support and follow-up care they offer. This attention to the embodied dimension of the pathogenic variant and to associated life experiences could help to fight against gendered stereotypes, which limit the transmission of information to children, and subsequent follow-up for the latter. More inclusive thinking about gender, through consideration of transgender and non-binary people, as well as non-heterosexual families, could also enable better monitoring of people, particularly LGBT+, who sometimes have different representations of gender and do not necessarily associate certain organs as being “feminine” or “masculine” for example.

## AUTHOR CONTRIBUTIONS

The authors confirm that they had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. All the authors gave final approval of this version to be published. All agreed to be accountable for all aspects of the work and to ensure that questions related to the accuracy or integrity of any part of the work were appropriately investigated and resolved. All authors read and approved the final manuscript. FBGC involved in conceptualization, formal analysis, writing the original draft. SC involved in conceptualization, interviewing process, support for analyses, writing, and proofreading. CN involved in investigation, review and editing, and funding acquisition. EMF, IC, VM, and JM involved in investigation and review and editing. ADB involved in conceptualization, investigation, review and editing, project administration, and funding acquisition.

## ACKNOWLEDGMENTS

We wish to warmly thank all the study participants. We are also grateful to the National Cancer Institute (INCa), which funded this study, and the Institut Paoli-Calmettes, the Institut Curie, the Centre Antoine Lacassagne, and the Centre Hospitalier Universitaire de Montpellier, which put us in contact with the respondents. Finally, our thanks to Jude Sweeney (Milan, Italy) for the English revision and copyediting of the manuscript.

## FUNDING INFORMATION

This study was funded by the French National Cancer Institute (INCa, grant number 2018-119). The sponsors had no role in the study design. Neither had they any role in the collection, analysis, or interpretation of data, in the writing of the report or the decision to submit the manuscript for publication.

## CONFLICT OF INTEREST STATEMENT

No conflict of interest declared.

## DATA AVAILABILITY STATEMENT

Data collected for this study are not available for ethical reasons.

## ETHICS STATEMENT

Human studies and informed consent: Approval to conduct this human subjects research was obtained from the Ethics Committee of the French National Institute of Health and Medical Research (Comité Consultatif sur le Traitement de l'Information en Matière de Recherche dans le Domaine de la Santé) (CCTIRS) and is registered as study number 17-359. Applicable guidelines were followed. All participants provided written informed consent.

Animal studies: No non-human studies were conducted for the work reported in this manuscript.

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**How to cite this article:** Gauna, F., Carof, S., Mouret-Fourme, E., Coupier, I., Mari, V., Moretta-Serra, J., Mancini, J., Noguès, C., & Bouhnik, A. D. (2023). Links between gender norms and the intergenerational transmission of health information in parents carrying BRCA1/2 pathogenic variants. *Journal of Genetic Counseling*, 00, 1–12. <https://doi.org/10.1002/jgc4.1734>