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Information needs on breast cancer genetic and non-genetic risk factors in relatives of women with a *BRCA1/2* or *PALB2* pathogenic variant

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ABSTRACT

Objectives: Comprehensive breast cancer (BC) risk models integrating effects of genetic (GRF) and non-genetic risk factors (NGRF) may refine BC prevention recommendations. We explored the perceived information received on BC risk factors, and related characteristics, in female relatives of women with a *BRCA1/2* or *PALB2* pathogenic variant, undergoing BC risk assessment using the CanRisk© prediction tool.
Methods: Of 200 consecutive cancer-free women approached after the initial genetic consultation, 161 (80.5%) filled in questionnaires on their perception of information received and wished further information on BC risk factors (e.g., being a carrier of a moderate risk altered gene, personal genetic profile, lifestyles). Multilevel multivariate linear models were performed accounting for the clinician who met the counselee and exploring the effect of counselees' socio-demographic, familial and psychological characteristics on the perceived extent of information received.
Results: Perceived no/little information received and wish for further information were more frequent for NGRF (>50%) than for GRF, especially high-risk genes (<20%). Perceived amount of information received and desire for further information were inversely correlated (p=<0.0001). Higher education level related to lower perceived levels of information received on GRF. Younger counselees' age ($\beta = 0.13$, $p = 0.02$) and less frequent engagement coping (e.g., inclination to solicit information) ($\beta = 0.24$, $p = 0.02$) related to lower perceived information received about NGRF. Other assessed counselees' features were not found to be associated to GRF and NGRF information perception.
Conclusions: Awareness of counselees' perceived lack of information on BC risk factors indicates a need to enhance evidence-based information on BC NGRF especially.
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1. Introduction

Breast cancer (BC) risk assessment commonly takes into account the family history and the presence of a genetic susceptibility as major BC risk factors [1]. Carriers of a pathogenic variant (PV) in

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BRCA1, BRCA2, and PALB2, or in ATM, BARD1, CHEK2, RAD51C, and RAD51D have a high- or moderate-risk of developing BC, respectively [2]. Recently, additional genetic (GRF) as well as non-genetic risk factors (NGRF) have been integrated in predictive models of breast cancer (BC) risk [3].

Indeed, additional GRF and NGRF have been shown to modify BC risk. Firstly, common genetic variants known as Single Nucleotide Polymorphisms (SNPs) have been identified. Individually, these SNPs confer a very small increase in BC risk but jointly they may lead to a substantial increase of the risk. They are combined in a polygenic risk score (PRS) that stratifies BC risk in women both with and without a family history of BC [4]. Secondly, breast density [5], hormonal, reproductive and lifestyle factors [6] also affect BC risk. Among these factors, some are 'modifiable' such as alcohol intake and physical activity and these modifiable factors seem to impact on the number of BRCA-associated BC cases [6–10].

Statistical models such as the Tyrer-Cuzick [11] and the 'Breast and Ovarian Analysis of Disease Incidence and Carrier Estimation Algorithm (BOADICEA)' [12] integrate the PRS and NGRF and can now provide a more precise and accurate BC risk prediction than family history or monogenic testing alone. Based on this estimation, more personalized recommendations, such as increased breast surveillance at a younger age than standard recommendation, can be delivered for BC risk management. Accounting for NGRF also offers the opportunity to discuss health prevention through lifestyle changes [13].

Many women at high BC risk show an interest in moderate risk BC gene testing [14] and in receiving refined BC risk estimations based on common genetic variants (PRS) [15,16]. However, the adequacy of counselees' understanding of multiple gene testing, their subsequent interpretation of results and adequate communication to family members has been questioned [14]. Many counselees at high hereditary BC risk reveal unmet needs about hereditary predisposition concerns [17]. Moreover, an identified genetic predisposition to cancer is not always shared among all family members [18–23], and when shared, it is generally incomplete or incorrect [24]. Thus, relatives of tested women may feel insufficiently informed.

These information gaps may also apply to NGRF. In the general population, women seem aware of the GRF influence on BC risk but less so of the influence of NGRF [25–27]. For example, in a French survey, only 6% and 3% spontaneously evoked alcohol consumption or physical inactivity respectively, when asked about BC risk factors [27]. Moreover, it seems that belonging to a high-risk, multiple case family, or being a carrier of a BRCA1/2 altered gene does not lead to adopting a healthier lifestyle compared to the general population [7,28,29]. According to the Health Belief Model, adopting a specific behavior is related to the belief that it may be effective in reducing the health risk [30], so women at high BC risk may not be aware of the role of health behaviors on BC risk.

The CanRisk application (https://canrisk.org) [31] is based on the BOADICEA V5 algorithm [12], and now integrates BC risk GRF and NGRF. It is currently being implemented in clinical practice, making it timely and important to assess counselees' baseline expectations of overall information on BC risk factors. Cancer genetic counseling is primarily meant to respond to information needs about the risk of hereditary cancer and of passing this risk on to offspring [32]. In the near future, women from families at genetic risk for developing BC are likely to receive BC risk estimates that integrate the PRS as well as NGRF. Thus their baseline level of information about these BC risk factors is important to investigate. To our knowledge, no study has investigated the perceived amount of information received on BC GRF as well as NGRF and their wish for additional information in that respect. Thus, we enquired about information needs after the initial genetic counseling regarding overall BC risk factors. We hypothesize greater unmet needs regarding NGRF [27–29] than GRF.

Moreover, as information needs may be related to counselees' characteristics such as their age [17], level of education [33–35], parental status [17], exposure to familial experience with BC [28], cancer risk perceptions [36], distress [19] and coping modalities [37,38], these aspects were further explored to identify subgroups of counselees particularly in need for enhanced communication and additional information on BC GRF and NGRF.

2. Materials and methods

The study received ethical approval by the Committee of the Person Protection (CPP) of Ile-de-France V (ID RCB 2018-A03355-50) in November 2019. Women were required to provide their written informed consent for BRIDGES 8-gene panel and 306 SNPs testing, and breast and ovarian cancer risk estimation using the CanRisk© tool [31] based on the BOADICEA model [12].

2.1. Design

A cross-sectional observational psychosocial study was performed within the 'Breast Cancer Risk after Diagnostic Gene Sequencing' (BRIDGES) program (https://bridges-research.eu) which is aimed to further develop the BOADICEA BC risk estimation model [12]. Women were approached at their initial genetic consultation (pre-test) and invited to complete a set of questionnaires at home, online or on paper within one month after the consultation.

2.2. Study participants and inclusion criteria

Accrual took place from November 2019 to December 2020 after the initial genetic counseling at Institute Curie (France).

Two-hundred women aged above 18 years, free of cancer and blood relatives (whatever the degree of kinship) of women with a BRCA1, BRCA2 or PALB2 PV, and who accepted BRIDGES panel testing and BC risk estimation based on BOADICEA [12] were consecutively approached.

2.3. Clinical setting

Women eligible for study participation were approached at their initial (pre-test) genetic consultation. During the initial genetic consultation, genetic counseling was first provided for "standard" BC targeted testing, which is aimed at determining whether the woman is a carrier of a PV in one of the three high-risk BC genes (BRCA1, BRCA2 or PALB2) that are routinely tested at Institut Curie.

Secondly, they were informed on the possibility to receive a more personalized BC risk estimate within the BRIDGES study, computed by the BOADICEA V5 algorithm [12] and so integrating: 1) the results of sequencing a panel of BC predisposing genes (TruRisk®-Panel), 2) family cancer history 3), a PRS computed from 306 SNPs [39], and 4) breast density, reproductive, hormonal, and lifestyle factors.

This consultation lasting up to 1 h was provided face-to-face by one of twelve genetic clinicians. Information systematically provided at that time comprised the woman's estimated probability of carrying a PV and her projected cancer risks (breast or ovarian) depending on the genetic test result. Information on gene panel testing mainly included the possible identification of other risk-increasing variants, e.g. moderate BC risk genes. The BRIDGES study was presented at the end of the consultation and hardly any of the counselees asked for information on the PRS score and NGRF.

2.4. Questionnaire and data collection

Perceived amount of information received and further information wish on BC GRF and NGRF were assessed from a list of factors reflecting the BOADICEA V5 model [12], excluding NGRF that are non-modifiable (i.e., age, height, breast density). This list was supplemented by factors that are harmful to health in general (e.g., smoking, physical inactivity [40]), to BC specifically (e.g., menopausal hormone replacement [41]), or factors that are commonly believed to affect BC risk in spite of no proven association (e.g., stress related to difficult experienced events, personality such as a pessimistic attitude [42,43]). Quantifying information needs in this regard was intended to evaluate common misconceptions on the link between stress or personality traits and BC occurrence.

The resulting 14-item list (provided in supplementary material) comprised being a carrier of a high- or moderate-risk PV, the personal genetic profile (reflected in the PRS [44]), reproductive (e.g., breast-feeding), hormonal (e.g., menopausal hormone therapy), body mass index, diet, physical exercise, smoking, alcohol consumption, environmental (sun, solar lamps, pesticides), stress and personality factors.

For each BC risk factor, counselees were asked to assess the perceived information received on GRF and NGRF using the validated 4-level response options “none” (score 1), “little” [2], “quite” [3], “much” [4,45], and to express their wish (yes = 1) or not (no = 2) for further information.

Among factors tested in relation to the perceived information received, **perceived BC risk** was assessed by a 6-level categorical scale with responses expressed as words, “low”, “low to moderate”, “moderate”, “high”, “very high” and “major” and allowing “not concerned” or “don't know” response options.

Anxiety and depression were measured by the Hospital Anxiety and Depression Scale (HADS), comprising the HADS-Anxiety and HADS-Depression subscales [46]. The total HADS score ranges from 0 to 21, with a higher score indicative of a greater distress.

Coping was measured using the French-version of the Brief-COPE inventory of coping responses [47,48]. This 28-item measure presents fourteen 2-item scales. To allow a more parsimonious assessment, referring to conceptual frameworks [49], these scales were aggregated into two dimensions: 1) Engagement coping (e.g., direct action, acceptance, use of instrumental support) (Cronbach's alpha = 0.82) and 2) Disengagement coping (e.g., self-distraction, avoidance) (Cronbach's alpha = 0.63). The Brief COPE engagement and disengagement scale scores range from 16 to 64, and 12 to 48 respectively, with a higher score indicative of a higher frequency of the coping strategy use.

Additional data was gathered on age, education level, marital and parental status, having a first-degree relative carrying a BRCA1/2 or PALB2 PV and having lost a family member due to breast or ovarian cancer.

3. Data analysis

Respondents were defined as having responded to at least one item of the socio-demographic and perceived information questionnaire. We used Student's t-test for continuous data and Chi-square test for categorical data to compare respondents and non-respondents on age, having children and having a first-degree relative carrying a BRCA1/2 or PALB2 PV.

Principal component analysis identified two sets of items within the questionnaire on BC risk factors, corresponding to GRF (Cronbach's alpha = 0.79) and NGRF (Cronbach's alpha = 0.95). This allowed deriving two multi-item scale scores by summing response scores to items in each of the GRF and NGRF set.

For all multi-item questionnaire scales, missing data were replaced by the mean per counselee if at least 50% of the items per domain were answered.

Multilevel multivariate linear models were tested on two outcomes: 1) Perceived information received on GRF and 2) Perceived information received on NGRF. A random effect was introduced in the model on the intercept in order to account for the fact that a given clinician could encounter several counselees. Tested associations in bivariate analyses included age, education level, marital status, having children, BC risk perception, anxiety, depression, engagement and disengagement coping, having a first-degree relative carrier of PV and having lost a family member due to cancer. Significant bivariate associations at p-value < 0.10 were retained in multilevel multivariate linear models.

All analyses were performed using the statistical software SAS version 9.4 (SAS Institute, Inc., Cary, NC, USA).

4. Results

4.1. Sample characteristics

Table 1 displays the sample sociodemographic, familial and psychological characteristics. The overall sample mean age (standard deviation) was 39.3 (13.3) years; 97 (48.5%) had children and 122 (61.6%) had a first-degree relative carrier of a BRCA1/2 or PALB2 PV.

Among the 161 (80.5%) respondents, 118 (74.7%) had a higher degree of education, 98 (61.3%) were married/partnered and 78 (49.1%) had lost a family member due to breast or ovarian cancer. Low, moderate and high perceived BC risk were reported by 7 (4.4%), 53 (33.3%) and 78 (49.1%) counselees, respectively. The mean (standard deviation) levels of anxiety and depression, and of engagement and disengagement coping were 7.7 (4.1) and 3.0 (3.2), and 37.1 (7.8) and 21.6 (4.2), respectively.

Respondents were older than non-respondents (T-test, p = 0.05) but did not differ in other available characteristics (parental status, number of counselees with a first-degree relative carrier of a PV).

4.2. Perceived amount of information received on BC risk factors and further information wish

Table 2 provides item response frequencies of perceived information received and further information wish on GRF and NGRF.

Women were more likely to feel sufficiently or much informed about high- (82%) and moderate-risk (73%) genetic risk than about all NGRF (<50%). Wishes for information about GRF and NGRF were reported by 18% and 22% women, respectively.

The perceived amount of information received on the individual genetic profile (PRS) (56% sufficiently/much informed) was moderate, as was the wish for further information on this factor (36%).

The perception of sufficient/much information received was least frequent and further information wish was most frequent on factors relating to personality (15%; 62%), stress (18%; 64%), light exposure (18%; 60%), as well as reproductive (20%; 63%) and hormonal factors (20%; 58%).

Thirty-one percent of counselees felt at least sufficiently informed about diet and 62% still wanted further information.

For the body mass index, 27% felt at least sufficiently informed and 37% wished further information. Almost half of the women felt at least sufficiently informed about alcohol consumption (45%) and about smoking (49%) and with for further information was relatively less frequent on these matters (32%; 23%).

Table 1
Sample socio-demographic, familial and psychological characteristics.[a].

Eligible counselees (N = 200)	
Age Median [Range] - Mean (SD)[b]	36.3 [21–80] - 39.3 (13.3)
Age by category n (%)	
21–29	65 (32.5)
30–39	51 (25.5)
40–49	38 (19.0)
50–59	25 (12.5)
60–69	18 (9.0)
>70	3 (1.5)
Having children Yes n (%)	97 (48.5)
Counselees with a 1st degree relative BRCA1/2 or PALB2 carrier n (%)	114 (57.9)
Respondents *(N = 161)*[c]	
Education level n (%)	
Compulsory education or below	4 (2.5)
Secondary or technical/vocational education	36 (22.8)
Higher education or above	118 (74.7)
Marital status n (%)	
Married/partnered	98 (61.3)
Others (widowed, separated/divorced, single/never married)	62 (38.8)
Having lost of family member due to breast/ovarian cancer Yes n (%)	78 (49.1)
Perceived breast cancer risk n (%)	
Not concerned/Don't know	21 (13.2)
Low	7 (4.4)
Moderate	53 (33.3)
High	78 (49.1)
HADS Anxiety[d] - Mean (SD)	7.7 (4.1)
HADS Depression - Mean (SD)	3.0 (3.2)
Brief COPE Engagement coping[e] - Mean (SD)	37.1 (7.8)
Brief COPE Disengagement coping[f] - Mean (SD)	21.6 (4.2)

[a] Missing data range = [1–3].
[b] Non-respondents are younger (P = 0.05).
[c] Respondents (N = 161) are defined as having responded to at least one item on socio-demographic or information on breast cancer risk factors questionnaire.
[d] HADS=Hospital Anxiety and Depression Scales, score range = [0–21].
[e] Engagement coping score range = [16–64].
[f] Disengagement coping score range = [12–48].

Table 2
Perceived information received and need for further information on breast cancer risk factors (N = 161)[a].

		None	Little	Sufficient	Much	Further information need
Genetic factors n (%)						
1	Being a carrier of a high risk altered gene	5 (3.2)	23 (14.6)	68 (43.0)	62 (39.2)	27 (17.9)
2	Being a carrier of a moderate risk altered gene	13 (8.3)	29 (18.5)	65 (41.4)	50 (31.8)	33 (22.0)
3	The individual genetic makeup of the person	25 (16.0)	44 (28.2)	54 (34.6)	33 (21.2)	52 (35.6)
Environmental/hormonal/reproductive/lifestyle factors n (%)						
4	Reproductive factors	59 (38.1)	55 (35.5)	31 (20.0)	10 (6.5)	94 (62.7)
5	Body mass index (i.e., being overweight)	80 (51.3)	34 (21.8)	31 (19.9)	11 (7.1)	56 (37.1)
6	Lifestyle habits like diet	70 (44.6)	39 (24.8)	32 (20.4)	16 (10.2)	92 (61.7)
7	Lifestyle habits like physical activity	63 (40.1)	46 (29.3)	31 (19.7)	17 (10.8)	79 (52.7)
8	Lifestyle habits like smoking	43 (27.6)	37 (23.7)	42 (26.9)	34 (21.8)	34 (23.1)
9	Lifestyle habits like alcohol consumption	51 (32.5)	36 (22.9)	48 (30.6)	22 (14.0)	48 (32.4)
10	Environmental factors like sun, solar lamps exposure	99 (63.9)	29 (18.7)	17 (11.0)	10 (6.5)	90 (60.4)
11	Environmental factors such as pesticides	80 (51.3)	39 (25.0)	26 (16.7)	11 (7.1)	80 (53.3)
12	External hormonal factors (e.g., menopausal hormone therapy)	85 (54.5)	40 (25.6)	21 (13.5)	10 (6.4)	87 (57.6)
13	Stress related to difficult life events	79 (50.3)	50 (31.8)	21 (13.4)	7 (4.5)	97 (64.2)
14	Personality (e.g. a pessimistic attitude)	99 (63.1)	34 (21.7)	19 (12.1)	5 (3.2)	94 (62.3)

[a] Missing data range: 3-19.

4.3. Factors related to the perception of information received on BC GRF and NGRF

Perceived information received and wish for further information were highly correlated, whether for GRF ($r = -0.40$, $p < 0.0001$) or NGRF ($r = -0.54$, $p=<0.0001$).

As shown in Table 3, in bivariate analyses only educational level appeared significantly associated at the statistical threshold of $p < 0.1$ with the perception of information received on GRF, whereas age, education level, having children, depression and coping strategies related significantly to the perception of information received on NGRF (Table 3).

Due to multicollinearity, 'having children' was excluded in multivariate model as highly associated with education level (Chi2-test, $p = 0.0002$) and age (*t*-test, $p < 0.0001$).

In multivariate analyses (Table 4), younger age at counseling (Unstandardized ß coefficient = 0.13, Confidence Interval [0.02–0.24], $p = 0.02$) and less frequent engagement coping (Unstandardized ß coefficient = 0.24, Confidence Interval [0.06–0.42], $p = 0.01$) were associated with lower perceived information

Table 3
Bivariate analyses of factor associated to the perceived information received on genetic and non-genetic risk factors.[a].

Factors	Perceived information received on genetic risk factors (N = 145)			Perceived information received on non-genetic risk factors (N = 140)		
	Unstandardized ß (95% Confidence Interval) p-value					
Age	−0.01	−0.04; 0.02	0.459	0.17	0.06; −0.27	<0.01
Education level						
Up to secondary or technical/vocational education	ref			ref		
Higher education or above	−0.95	−1.81; −0.09	0.031	−3.47	−6.72; −0.21	0.037
Marital status						
Married/partnered	ref			ref		
Others (widowed, separated/divorced, single/never married)	−0.39	−1.16; 0.38	0.316	−0.06	−3.02; 2.90	0.969
Children						
No	ref			ref		
Yes	0.25	−0.49; 0.99	0.508	2.81	−0.02; 5.64	0.052
HADS Anxiety	−0.04	−0.13; 0.05	0.380	0.25	−0.08; 0.59	0.136
HADS Depression	0.04	−0.07; −0.16	0.465	0.41	−0.02; −0.84	0.06
Brief COPE Engagement strategies	0.01	−0.04; 0.06	0.761	0.26	0.08; 0.44	0.005
Brief COPE Disengagement strategies	−0.03	−0.12; 0.06	0.492	0.38	0.04; 0.73	0.029
Perceived breast cancer risk						
Not concerned/Don't know	ref			ref		
Low	1.00	−1.04; 3.04	0.332	−0.88	−8.64; 6.89	0.823
Moderate	0.62	−0.55; 1.79	0.294	−4.11	−8.61; 0.39	0.073
High	0.82	−0.29; 1.93	0.145	0.53	−4.78; 3.72	0.805
Counselees with a 1st degree relative BRCA1/2 or PALB2 carrier						
No	ref			ref		
Yes	−0.20	−0.97; 0.57	0.610	−0.07	−3.02; 2.87	0.960
Having lost of family member due to breast/ovarian cancer						
No	ref			ref		
Yes	0.09	−0.67; 0.85	0.806	1.33	−1.57; 4.24	0.365

[a] Among counselees of clinicians who met at least 5 counselees.

Table 4
Multivariate analyses of factor associated to the perceived information received on non-genetic risk factors[a,b].

Factors		Perceived information received on non-genetic risk factors (N = 138)			
		Unstandardized ß	95% CI		p-value
			Lower	Upper	
Intercept		1.91	−9.93	13.75	0.71
Age		0.13	0.02	0.24	0.02
Education level	Up to secondary or technical/vocational education	ref			
	Higher education or above	−2.67	−6.06	0.71	0.12
Brief COPE Engagement strategies		0.24	0.06	0.42	0.01
Brief COPE Disengagement strategies		0.31	−0.03	0.66	0.07

[a] Among clinicians who met at least 5 counselees.
[b] Having children excluded as highly associated with education level (p-value Chi^2 = 0.0002) and with age (p-value *t*-test <.0001).

received on NGRF.

5. Discussion

This study invited women undergoing BRCA1/2 or PALB2 predictive testing to benefit from a comprehensive BC risk assessment integrating new genetic and non-genetic BC risk factors. These women reported feeling less informed on BC NGRF than on GRF and mostly wished further information on NGRF. Being younger and adopting engagement coping strategies less frequently were associated with the perception of having received little information on NGRF.

As the participating women were primarily attending a cancer genetic clinic to undergo targeted testing on a known PV identified in the family, it was expected that they would already be knowledgeable of hereditary BC predispositions and that they would less likely feel misinformed and express their wish for further information on GRF. Genetic counseling currently focuses mostly on GRF, especially autosomal dominant variants associated with high risk for developing breast cancer, as they have a much higher effect on BC risk compared to NGRF. Moreover, GRF are commonly already known as a BC risk factor in the general female population [27].

Women in our study expressed a moderate wish for further information on the influence of their personal genetic profile (PRS) on their BC risk. It was expected that women would lack knowledge on the role of the PRS on BC risk, as PRS testing is not yet implemented in clinical routine. Our results contrasts qualitative results of the “Variants in Practice Psychosocial Study” that reported broad knowledge and understanding of the PRS among women at high BC risk, possibly because of more in-depth information on PRS during the consultation [50]. Accounting for the PRS in BC risk estimation, women from the same family may prove to have different levels of risk even if they carry the same monogenic test result. This information may be confusing and therefore, clarification on this BC risk factor may be required. A specific communication leaflet may help ensuring adequate understanding of this information [51].

Most women felt insufficiently informed on the potential influence of specific BC NGRF. Excessive body weight, physical inactivity and alcohol consumption are well established BC risk factors, although the mechanisms of their impact on BC incidence

continues to be investigated [6].

Information provision on these BC risk factors can be achieved through social networks, media reports or community health services. In recent studies, women attending BC screening clinics seemed aware of the influence of the body mass index, physical activity or alcohol consumption on BC risk [52,53]. However, these BC risk factors were less frequently mentioned in a French survey involving women from the general population [27]; in the present study, women felt that they received little or modest information on the influence of body overweight, alcohol consumption or physical activity on BC risk and they wished further information on these aspects.

Currently, the focus of BC genetic counseling is the provision of information on GRF; however, raising attention to the additional BC risk factors may favor understanding of the value associated with different risks. Moreover, the clinical encounter during cancer genetic counseling in high-risk women may have a strong affective component and constitute a critical moment that may elicit behavioral change motivation, benefiting health generally [7]. Therefore, consultations along the cancer genetic journey are opportune to evoke health promotion through appropriate lifestyle changes [54]. Brief health messages, printed materials provided after the genetic consultation or referral to health education services may serve as an initial step for changing health-related behavior and would not interfere with the primary goal of the genetic consultation [7].

Among the BC NGRF assessed, women felt being under informed about reproductive and hormonal factors and their desires for information on these aspects were strong. A lack of information on BC NGRF was expressed particularly by younger women. Young women at high BC risk may face difficult decisions regarding BC risk management and their family planning. The need for adequate information on reproductive BC risk factors may be generated particularly in the BC high-risk context [55].

Factors like stress [42] or personality [43] have no proven association with the risk of developing BC. In our cohort, most women reported wishing further information on these aspects. This may hint at a potential need to correct misconceptions in this regard, especially in women facing stressful events linked to their familial cancer history, which they may believe, connect to their BC risk.

A higher education level was associated with the perception of being inadequately informed and the more frequent wish for further information on GRF. Conversely, information overload may be experienced by counselees with lower levels of education [32]. Since it may be the complexity rather than the amount of information that leads to a sense of information overload, this specific group of counselees may benefit from specific information material.

Qualitative data have shown that BC risk perception and familial cancer experience might motivate information-seeking [32]. We found that counselees who coped less frequently with engagement strategies (e.g., actively soliciting information) reported more often insufficient information received about NGRF. This suggests that these women facing BC risk do not adopt coping behaviors that allow them to meet their needs [37,56], indicating that this group may benefit from health education.

The generalizability of our study results is limited by the single-site survey, the study participants' high levels of education and low distress levels. Although comprehensive and designed with the input of clinicians, the questionnaire assessing information received on BC risk factors was study-specific and did not include breast density, which is recognized as an important BC risk factor, enabling individually targeted screening or prevention recommendation [5]. Strengths of this study are the robust response rate and the provision of useful quantitative data on counselees' information needs facing the emergence of refined BC risk estimations applied in clinical practice.

6. Conclusion

Women attending cancer genetic clinics for predictive testing of BRCA1/2 or PALB2 PV, especially those who were younger and adopting less frequent engagement coping, experienced a lack of information on BC NGRF. This suggests a need to enhance evidence based information on these BC risk factors, especially since these factors are now taken into account in BC risk prediction models and they may affect health prevention.

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Compliance with ethical standards

The authors declare no conflict of interest.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.breast.2021.08.011.

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