# Which factors predict proposal and uptake of psychological counselling after BRCA1/2 test result disclosure?

Christine Maheu<sup>1,2,3,4</sup>, Anne-Deborah Bouhnik<sup>1,2,3</sup>, Catherine Nogues<sup>5,6</sup>, Emmanuelle Mouret-Fourme<sup>5,6</sup>, Dominique Stoppa-Lyonnet<sup>6,7</sup>, Christine Lasset<sup>8</sup>, Pascaline Berthet<sup>9</sup>, Jean-Pierre Fricker<sup>10</sup>, Olivier Caron<sup>11</sup>, Elizabeth Luporsi<sup>12</sup>, Laurence Gladieff<sup>13</sup> and Claire Julian-Reynier<sup>1,2,3,14</sup>\*

\*Correspondence to: UMR912, Institut Paoli-Calmettes, 232 Bd Sainte Marguerite, 13273 Marseille Cedex 09, France. E-mail: claire.julian-reynier@inserm.fr

#### **Abstract**

*Objective*: The aim of this study is to prospectively determine the factors contributing to whether unaffected women from BRCA1/2 families reported that clinicians proposed psychological consultations and that they had attended these consultations during the genetic testing process.

*Methods*: A prospective study was performed on a national cohort, using self-administered questionnaires to determine the rates of proposal and use of psychological services at the time of BRCA1/2 test result disclosure (N=533) and during the first year after disclosure (N=478) among unaffected French women from BRCA1/2 families who had undergone genetic testing for BRCA1/2. Multivariate adjustment was carried out using logistic regression models fitted using generalized estimation equations, with the genetic testing centre as the clustering variable.

Results: At the time of BRCA1/2 test result disclosure, a psychological consultation was proposed by cancer geneticists to 72% and 32% of the carriers (N=232) and noncarriers (N=301), respectively (p < 0.001). One year after disclosure, 21% of the carriers had consulted a psychologist, versus 9% of the noncarriers (p < 0.001). Both the proposal and the uptake depended on the women's BRCA1/2 mutation carrier status (proposal adjusted odds ratio (AOR): 4.9; 95% confidence interval (CI) 3.4–7.2; uptake AOR: 2.2; 95% CI 1.2–4.0), their level of education (proposal AOR: 1.7; 95% CI 1.1–2.7; uptake AOR: 4.5; 95% CI 1.7–12.1) and the distress they experienced about their genetic test results (proposal AOR: 1.02; 95% CI 1.01–1.03; uptake AOR: 1.04; 95% CI 1.02–1.06)

Conclusions: Determinants of the proposal/uptake of psychological consultations in the BRCA1/2 testing process highlight the need for inventive strategies to reach the different types of women's profiles. Copyright © 2013 John Wiley & Sons, Ltd.

Received: 5 February 2013 Revised: 19 September 2013 Accepted: 22 September 2013

#### Introduction

Several factors are known to be associated with greater use of psychological support among cancer populations, such as younger age, being female and having high cancer-related distress or less social support [1,2]. However, these factors contributing to the uptake of psychological services do not hold true at all times, and previous studies on this topic have been mostly restricted to patients who

actually have cancer. As far as we know, no evidence-based guidelines have been published to assist cancer geneticists dealing with cancer-free members of hereditary breast—ovarian cancer (HBOC) families. International recommendations for genetic counselling and psychosocial support have been published, however, in the context of genetic testing [3].

High anxiety levels have been found to occur and to persist for some time after testing, especially in a

<sup>&</sup>lt;sup>1</sup>INSERM, UMR912, Marseille, France

<sup>&</sup>lt;sup>2</sup>Aix-Marseille Université, UMR912, Marseille, France

<sup>&</sup>lt;sup>3</sup>IRD, UMR9 I 2, Marseille, France

<sup>&</sup>lt;sup>4</sup>McGill University, Montreal, Canada

<sup>&</sup>lt;sup>5</sup>Hô pital René Huguenin, Saint Cloud, France

<sup>&</sup>lt;sup>6</sup>Institut Curie, Paris, France

<sup>&</sup>lt;sup>7</sup>Université Paris Descartes, Sorbonne Paris Cité, France

<sup>&</sup>lt;sup>8</sup>Centre Léon Bérard, Lyon, France

<sup>&</sup>lt;sup>9</sup>Centre François Baclesse, Caen, France

<sup>&</sup>lt;sup>10</sup>Centre Paul Strauss, Strasbourg, France

<sup>&</sup>lt;sup>11</sup>Institut Gustave Roussy, Paris, France

<sup>&</sup>lt;sup>12</sup>Centre Alexis Vautrin, Nancy, France

<sup>&</sup>lt;sup>13</sup>Institut Claudius Regaud, Toulouse, France

<sup>&</sup>lt;sup>14</sup>Institut Paoli-Calmettes, UMR912, Marseille, France

subgroup of carriers [4–6], whereas less clear-cut results have been obtained on noncarriers [7]. Some authors have observed no differences in distress depending on carrier status, whereas others have reported that genetic testing can have beneficial psychological effects on noncarriers [8–10]. Carriers' anxiety tends to linger for years [11,12] and has been found to last anything between 6 months [13] and 5 years [4,6] after BRCA testing. In the context of genetic testing for the risk of life threatening diseases, providing psychological support before, during and after testing might therefore constitute a useful preventive distress management strategy. There exists a growing consensus that all women undergoing BRCA1/ 2 testing should be provided with minimum psychosocial support at the pretest genetic counselling sessions [14,15]. The authors of a detailed study on the psychosocial needs reported by people who had undergone BRCA1/2 tests concluded that apart from some very marginal psychopathological issues, there exist specific emotional and existential needs that require to be met by arranging discussions and consultations, in particular, when risk reducing surgery is envisaged [16–18].

Although it is generally agreed that HBOC and high risk families undergoing BRCA1/2 testing should be provided with minimum psychosocial support [15], opinions still diverge as to whether services of this kind should be widely recommended and provided [18], especially because of funding limitations. Identifying the personal and psychosocial factors contributing to the uptake of psychological consultations before and after BRCA testing could help practitioners target those individuals who are most likely to seek and to use psychological services.

There is too little evidence available at present to be able to conclude whether psychological support should be systematically provided before, during and after BRCA1/2 testing. It is therefore proposed here to fill this gap by examining the personal and psychosocial factors associated with the proposal of psychological assistance and its use by both unaffected carriers and noncarriers during the BRCA1/2 genetic testing process in France, where the National Cancer Plan has made psychological support available at cancer genetic clinics free of charge.

#### Material and methods

#### Study group

Participants were identified on the basis of a companion psychosocial study on the GENEPSO cohort (GENe Etude Prospective Sein Ovaire) [19]. The GENEPSO cohort included *BRCA1/2* carriers and noncarriers from BRCA-mutation-positive families (hence, HBOC families) recruited in a routine consultation context from 2000 to 2006 at 26 cancer genetic clinics belonging to the Unicancer Cancer Genetic Network. The companion

psychosocial study included both unaffected carriers identified in the GENEPSO cohort (carriers in whom no cancer had been diagnosed) and noncarriers from BRCA1/2 mutated families. Eligible subjects were women at least 18 years of age who were cancer-free, belonged to a family where a deleterious mutation predisposing them to breast/ovarian cancer (a BRCA1/2 mutation) had been identified and had attended one of the participating cancer genetic clinics for BRCA1/2 testing.

#### Procedures of counselling

In France, the BRCA1/2 genetic test result delivery procedures applied at cancer genetic clinics has always included optional consultations with a psychologist/psychiatrist before and/or after genetic testing to help patients' decision-making about cancer genetic testing or preventive options. These consultations, which are available at the cancer genetic centres free of charge at the doctor's and patient's request, are given by professionals who are aware of both the cancer issues and the testing procedures involved.

#### Data collected

Women included in the cohort completed a self-administered questionnaire before disclosure of the test results (M0) and again 15 days (D15) after disclosure. The follow-up procedure also included self-administered questionnaires, which were completed 6, 12, 24 and 60 months after disclosure. Only the results obtained prior to the tests, 15 days and 12 months after disclosure, will be presented here. The medical data collected in parallel at the cancer genetic consultations included the test results, the type of mutation (BRCA1 or BRCA2), the familial history of breast and/or ovarian cancer and the uptake of prophylactic surgery (risk-reducing mastectomy (RRM) and/or risk reducing salpingo-oophorectomy (RRSO)) during the years following disclosure by all the women in the cohort. Overall, 533 unaffected women from HBOC families participated in the companion psychosocial study. These women were all undergoing genetic testing in order to determine whether or not they carried the known familial BRCA1/2 mutation.

#### Self-administered questionnaires

The first questionnaire, which was completed before test result disclosure (M0), included questions about the participants' sociodemographic characteristics (age, marital status, education, employment and number of children), perceived lifetime risk of breast and ovarian cancer and whether or not they intended to undergo prophylactic surgery if the results turned out to be positive.

422 C. Maheu et al.

#### Outcome measures

#### Psychological care

In the questionnaire administered prior to test result disclosure (M0), the women were asked whether they had consulted a psychologist at the centre. In the second questionnaire, administered 15 days after disclosure (D15), they were asked whether a psychologist had been present at the time of the disclosure and whether a consultation with a psychologist had been proposed on that occasion. In the subsequent questionnaires, the women were asked whether they had attended any psychological consultations since they received their results.

#### Other psychological variables

Depression: Depression was measured at M0 using the French version of the Center for Epidemiologic Studies Depression (CES-D) Scale [20], a 20-item scale that is widely used in population-based studies [21] and in studies on cancer patients [22]. The threshold score of 23 has been found to be indicative of significant depressive symptoms in French women [20]. In the present sample, the CES-D showed a high level of reliability (Cronbach's  $\alpha$ =0.93). Depression was assessed using the continuous score and a dichotomous variable with 23 as the cut-off point.

Distress: Distress specifically because of cancer risk information and genetic test results was measured using the 15-item Impact of Event Scale (IES) [23]. The IES includes two subscales measuring intrusive and avoidance ideations. In this study, both the Global IES score (Cronbach's  $\alpha$ =0.91) and the two subscales (intrusive ideation: Cronbach's  $\alpha$ =0.88 and avoidance ideation: Cronbach's  $\alpha$ =0.82) were measured. Specific BRCA1/2 distress was measured at D15 and at M12.

Family support: Women were asked on D15 whether they felt supported by their family (not at all/ a little/ average/ strongly/ no family). Those 'strongly supported' were opposed to the other categories for the analysis.

#### Statistical analysis

The women who reported that a psychological consultation had been proposed at the disclosure of their results were compared with the others in terms of BRCA1/2 results, sociodemographics (age, level of education, marital status, having children and employment status) and baseline psychosocial characteristics (baseline CES-D score, the IES measured at D15, family support, previous use of psychological services and the presence

of a psychologist or a psychiatrist at disclosure) by making group comparisons using chi-squared tests and Student's *t*-tests.

The women who reported at M12 that they had consulted a psychologist since the disclosure of their test results were compared in the same way. In addition to the characteristics listed in the preceding texts, the uptake of prophylactic surgery during the year following disclosure was also included in these comparisons.

Logistic regression models fitted using generalized estimation equations were also used to identify the factors independently associated with the proposal and uptake of psychological consultations. The generalized estimation equations models take into account the clustering of observations within genetic clinics in which women consulted. In all the multivariate analyses, a stepwise procedure was used to select statistically significant factors in a multivariate model (entry threshold p < 0.20). First order interactions were systematically checked. Only variables that were still significantly associated with the outcome variable with a p-value <0.05 were kept in the final model. Statistical analyses were performed using the SPSS version 12.0.1 software programme (SPSS, Inc., Chicago, IL, USA) and the STATA software programme, version 9 (StataCorp., TX, USA).

#### Results

#### Description of the cohort

Five hundred and thirty-three women were included in the cohort. Carriers (N=232) were significantly younger than noncarriers (N=301) ((39.0 years (standard deviation (SD)=10.9) versus 42.1 (SD=11.9), p=0.002). None of the other sociodemographic characteristics tested were found to differ between the two groups: 75.0% had an educational level above secondary school level, 78.0% were living with a partner, 74.5% had children and 77.3% had an occupational activity at inclusion in the cohort.

Before disclosure of the test results, 22.8% of carriers and 16.6% of noncarriers (p = 0.071) reported that they had consulted a psychologist at the centre. A psychologist was present at the disclosure in 11.3% of cases, and no significant differences were observed in this respect between carriers and noncarriers.

### Women to whom psychological consultations were proposed and the contributing factors (Table 1)

During the consultation at which the BRCA1/2 test results were disclosed, 263 of the 533 women (49.3%) were invited to consult a psychologist: the rates of proposal were higher among carriers than noncarriers (71.6% versus 32.2%; p < 0.001).

**Table 1.** Characteristics of women to whom a psychological consultation was proposed at disclosure of BRCA1/2 results—univariate analyses and multiple adjustment by generalized estimation equations regression with the centre as clustering variable—the GENEPSO cohort study—n = 533

|   |                    |                            | ere offered a psyc<br>at test result disc |         |                  |         |
|---|--------------------|----------------------------|---|---------|------------------|---------|
|   | Total n (column %) | No 270 (50.7)<br>n (row %) | Yes 263 (49.3)<br>n (row %)               | p-value | AOR* CI (95%)    | p-value |
| Age (mean (SE))   | 40.7 (11.6)        | 42.6 (12.0)                | 38.8 (10.7)                               | < 0.00  |                  |         |
| Level of education  |                    |                            |   |         |                  |         |
| Secondary and lower   | 133 (25.0)         | 78 (58.6)                  | 55 (41.4)                                 | 0.033   | I                |         |
| Higher than secondary   | 400 (75.0)         | 192 (48.0)                 | 208 (52.0)                                |         | 1.71 [1.09–2.68] | 0.019   |
| Marital status  |                    |                            |   | 0.955   |                  |         |
| Single/widow  | 117 (22.0)         | 59 (50.4)                  | 58 (49.6)                                 |         |                  |         |
| Married/living maritally  | 416 (78.0)         | 211 (50.7)                 | 205 (49.3)                                |         |                  |         |
| Having children   |                    |                            |   |         |                  |         |
| No  | 136 (25.5)         | 62 (45.6)                  | 74 (54.4)                                 | 0.171   |                  |         |
| Yes   | 397 (74.5)         | 208 (52.4)                 | 189 (47.6)                                |         |                  |         |
| Employment status   |                    |                            |   |         |                  |         |
| Not employed  | 121 (22.7)         | 69 (57.0)                  | 52 (43.0)                                 | 0.111   |                  |         |
| Employed  | 412 (77.3)         | 201 (48.8)                 | 211 (51.2)                                |         |                  |         |
| BRCA1/2 Mutation  |                    |                            |   |         |                  |         |
| Noncarriers   | 301 (56.5)         | 204 (67.8)                 | 97 (32.2)                                 | < 0.00  | 1                |         |
| Carriers  | 232 (43.5)         | 66 (28.4)                  | 166 (71.6)                                |         | 4.93 [3.37-7.22] | < 0.001 |
| Presence of a psychologist or a psychiatrist at disclosure of results |                    |                            |   |         |                  |         |
| No  | 473 (88.7)         | 250 (52.9)                 | 223 (47.1)                                | 0.004   | 1                | 0.004   |
| Yes   | 60 (11.3)          | 20 (33.3)                  | 40 (66.7)                                 |         | 2.61 [1.36-5.02] |         |
| Previous use of psychological services at the centre before disclosi  | ure                |                            |   |         |                  |         |
| No  | 430 (80.7)         | 227 (52.8)                 | 203 (47.2)                                | 0.044   |                  |         |
| Yes   | 103 (19.3)         | 43 (41.7)                  | 60 (58.3)                                 |         |                  |         |
| Presence of family support  |                    |                            |   |         |                  |         |
| Yes   | 364 (68.3)         | 178 (48.9)                 | 186 (51.1)                                | 0.234   |                  |         |
| No  | 169 (31.7)         | 92 (54.4)                  | 77 (45.6)                                 |         |                  |         |
| Intended to undergo RRM in case of positive test at M0                |                    |                            |   |         |                  |         |
| Certainly yes/ probably yes   | 143 (26.8)         | 73 (51.0)                  | 70 (49.0)                                 | 0.985   |                  |         |
| Did not know  | 163 (30.6)         | 83 (50.9)                  | 80 (49.1)                                 |         |                  |         |
| Certainly no/ probably no   | 227 (42.6)         | 114 (50.2)                 | 113 (49.8)                                |         |                  |         |
| Intended to undergo RRSO in case of positive test at M0               |                    |                            |   |         |                  |         |
| Certainly yes/ probably yes   | 286 (53.7)         | 142 (49.7)                 | 144 (50.3)                                | 0.553   |                  |         |
| Did not know  | 155 (29.1)         | 84 (54.2)                  | 71 (45.8)                                 |         |                  |         |
| Certainly not/ probably not   | 92 (17.3)          | 44 (47.8)                  | 48 (52.2)                                 |         |                  |         |
| IES score at Day 15 (mean (SE))                                       | 15.5 (17.7)        | 14.3 (14.6)                | 23.2 (17.7)                               | < 0.001 | 1.02 [1.01-1.03] | < 0.001 |
| CES-D score at M0 (mean (SE))   | 11.5 (9.2)         | 11.1 (9.0)                 | 14.1 (10.3)                               | 0.015   |                  |         |

RRM, risk-reducing mastectomy; RRSO, risk reducing salpingo-oophorectomy; IES, Impact of Event Scale; CES-D, Center for Epidemiologic Studies Depression.

The factors found in the univariate and multivariate comparisons to be associated with the proposal of psychological consultations are presented in Table 1. After multivariate adjustment, women to whom a psychological consultation was proposed were significantly and independently associated with being BRCA1/2 carriers (adjusted odds ratio (AOR) 4.93), having a higher educational level (AOR 1.71), having a psychologist present at disclosure (AOR 2.61) and having a high IES score 15 days after disclosure (AOR 1.02 for one point of the IES score increase). Younger age and

having consulted a psychologist prior to disclosure were significantly associated with being invited to attend a psychological consultation in the univariate analyses, but this was no longer the case after multivariate adjustment.

Being invited to attend a psychological consultation was not found to be associated with any of the following sociodemographic and personal factors: marital status, having children, employment status, family support, depression level or the *a priori* intention to have prophylactic surgery. No significant interactions were observed between any of

<sup>\*</sup>Adjusted odds ratio; only variables that were still significantly associated with the outcome variable with a p-value < 0.05 were kept in the multivariate model using a stepwise procedure.

424 С. Маheu et *al*.

the factors, such as BRCA status and the IES score in particular, and being invited to attend a psychological consultation.

## Uptake of psychological consultations during the first year after disclosure and the contributing factors (Table 2)

Six of the 533 women who were included at baseline in the study were excluded from the 12-month follow-up analyses. Five of them had developed breast/ovarian cancer and one had died of causes other than cancer. All six women were BRCA1/2 carriers. Among the remaining cancer-free women 12 months after disclosure (n = 527), 478 (90.7%) completed the M12 questionnaire and were included in this analysis. Those who completed M12 had lower IES scores at D15 (mean score = 15.5 versus 22.3 in the case of nonrespondents; p = 0.003). Respondents and nonrespondents did not differ significantly in terms of any of the other baseline sociodemographic or psychological characteristics tested.

Among the 478 women who completed the M12 questionnaire, 206 were BRCA1/2 carriers and the remaining 272 were noncarriers. By the 12th month after disclosure, 14.0% of the women had consulted a psychologist or a psychiatrist (Table 2). This percentage was higher among BRCA1/2 mutation carriers (20.9%) than noncarriers (8.8%) (p < 0.001). After multivariate adjustment taking into account the clusters of data corresponding to the genetic clinics at which the women consulted, the details of which are presented in Table 2, being a BRCA1/2 mutation carrier was still significantly associated with higher rates of psychological consultation during the first year after disclosure (AOR 2.23), as was a higher educational background (AOR 4.55), higher distress scores (AOR 1.04 for one point of the IES score increase), having consulted a psychologist prior to disclosure (AOR 3.19) and having no children (AOR 0.47). No significant interactions were observed between any of the factors involved and attending psychological consultations.

Younger age, being single/widowed, having an occupation, little or no family support, higher depression scores, having undergone RRM since BRCA1/2 test result disclosure and/or having been invited to attend a psychological consultation at disclosure of the results were significantly associated in the univariate analyses with actually consulting a psychologist, but this was no longer the case after multivariate adjustment (Table 2).

Other factors tested, such as support from partners and RRSO, were not found in the univariate comparisons to be significantly associated with attendance of psychological consultations.

A similar multivariate model was obtained upon restricting the population to the 229 women who had been

given the possibility of consulting a psychologist at the time of their test result disclosure.

Among the 143 BRCA1/2 mutation carriers who had been given the possibility of consulting a psychologist at disclosure, 25.2% (n=36) actually saw a psychologist versus 10.5% (9 out of 86) in the case of noncarriers (p=0.007). Among the BRCA1/2 mutation carriers, seven reported having undergone RRM since disclosure of their BRCA1/2 test results and 58 had undergone RRSO.

#### **Discussion**

As far as we know, this is one of the first prospective national surveys on the psychological services available to cancer-free BRCA1/2 carriers/noncarriers during the first year after disclosure of their BRCA1/2 test results. This study sheds new light on the factors associated with the provision and uptake of psychological services before, during and after the disclosure of BRCA1/2 test results. The important finding that educational background affects both the rates of proposal and especially the uptake of psychologists' services should henceforth be mentioned in educational programmes for providers, patients or both in order to improve the patients' care. Cancer geneticists more frequently proposed psychological consultations to the most highly educated counselees, and the most highly educated women were also found to use psychologists' services more frequently than women with a lower educational background. The effect of educational background on the uptake of psychologists' services was still observed in the subgroup of women to whom a psychological consultation was proposed by the cancer geneticist. This may be due to the social belief held by the providers that more highly educated people will express their difficulties and emotions more easily at psychological consultations and to the stigma frequently attached to psychologists' services by both the providers and the patients themselves, which may constitute a barrier to help-seeking by patients with mental disorders [24,25]. However, because similar psychosocial needs are surely liable to arise regardless of women's rank on the socioeconomic ladder, the accessibility of these services to all counselees whatever their educational background should be regarded as a priority. On these lines, several models for psychosocial support involving other trained professionals such as genetic counsellors, genetic nurses, social workers or other specialists may provide useful means of reaching people with lower educational backgrounds [26]. Other more accessible kinds of psychosocial intervention could also be promoted in the context of routine care [27]. The second noteworthy finding obtained here was that the rate of uptake of psychological consultations was lower in women with children than in childless women. Because these results were adjusted on age, this finding may be attributable to the fact that these women had less time available than the others; women who

Copyright © 2013 John Wiley & Sons, Ltd.

Psycho-Oncology 23: 420-427 (2014)

**Table 2.** Characteristics of women who consulted a psychiatrist or a psychologist during the first year after disclosure of BRCA1/2 results—univariate analyses and multiple adjustment by stepwise generalized estimation equations regression with the centre as clustering variable—GENEPSO cohort study—n = 478

|   | Total<br>n (column %)     | Consulted a psychiatrist or a<br>psychologist since disclosure of<br>their results |                               |                 |                        |         |
|---|---------------------------|--|-------------------------------|-----------------|------------------------|---------|
|   |                           | No<br>411 (86.0)<br>n (row %)  | Yes<br>67 (14.0)<br>n (row %) | p-value         | AOR* CI (95%)          | p-value |
| Age (mean (SE))<br>Level of education   | 40.8 (11.6)               | 41.4 (11.9)  | 37.3 (8.7)                    | 0.007           |                        |         |
| Secondary and lower<br>Higher than secondary  | 121 (25.3)<br>357 (74.7)  | 115 (95.0)<br>296 (82.9)   | 6 (5.0)<br>61 (17.1)          | 0.001           | l<br>4.55 [1.70–12.14] | 0.003   |
| Marital status Single/widow Married/living maritally                                | 103 (21.5)<br>375 (78.5)  | 80 (77.7)<br>331 (88.3)  | 23 (22.3)<br>44 (11.7)        | 0.006           |                        |         |
| Having children No Yes  | 122 (25.5)<br>356 (74.5)  | 94 (77.0)<br>317 (89.0)  | 28 (23.0)<br>39 (11.0)        | 0.001           | l<br>0.47 [0.26–0.85]  | 0.013   |
| Employment status Not employed Employed   | 111 (23.2)<br>367 (76.8)  | 103 (92.8)<br>308 (83.9)   | 8 (7.2)<br>59 (16.1)          | 0.018           |                        |         |
| BRCA1/2 carrier status Noncarrier Carrier   | 272 (56.9)<br>206 (43.1)  | 248 (91.2)<br>163 (79.1)   | 24 (8.8)<br>43 (20.9)         | <0.001          | l<br>2.23 [1.23–4.03]  | 0.008   |
| Presence of a psychologist or a psychiatrist at disclosure of results  No  Yes      | 423 (88.5)<br>55 (11.5)   | 365 (86.3)<br>46 (83.6)  | 58 (13.7)<br>9 (16.4)         | 0.594           |                        |         |
| Previous use of psychological services before disclosure No Yes                     | 386 (80.8)<br>92 (19.2)   | 344 (89.1)<br>67 (72.8)  | 42 (10.9)<br>25 (27.2)        | <0.001          | l<br>3.19 [1.70–6.00]  | <0.001  |
| A psychological consultation was recommended at disclosure of BRCA1/2 result No Yes | 249 (52.1)<br>229 (47.9)  | 227 (91.2)<br>184 (80.3)   | 22 (8.8)<br>45 (19.7)         | 0.001           |                        |         |
| Presence of family support Yes No   | 323 (67.6)<br>155 (32.4)  | 287 (88.9)<br>124 (80.0)   | 36 (II.I)<br>31 (20.0)        | 0.009           |                        |         |
| RRM during the year after disclosure of BRCA results  No Yes                        | 471 (98.5)<br>7 (1.5)     | 407 (86.4)<br>4 (57.1)   | 64 (13.6)<br>3 (42.9)         | 0.027           |                        |         |
| RRSO during the year after disclosure of BRCA results No Yes                        | 420 (87.9)<br>58 (12.1)   | 363 (86.4)<br>48 (82.8)  | 57 (13.6)<br>10 (17.2)        | 0.450           |                        |         |
| IES score at day I5 (mean (SE))<br>CES-D score at M0 (mean (SE))                    | 15.5 (17.7)<br>11.5 (9.2) | 14.3 (14.6)<br>11.1 (9.0)  | 23.2 (17.7)<br>14.1 (10.3)    | <0.001<br>0.015 | 1.04 [1.02–1.06]       | <0.001  |

RRM, risk-reducing mastectomy; RRSO, risk-reducing salpingo-oophorectomy; IES, Impact of Event Scale; CES-D, Center for Epidemiologic Studies Depression.

underwent tests because they were worried about their children's risk of cancer may also have been less concerned about themselves. This point would be worth investigating further using qualitative approaches, for example.

The present results show that only 21% of the 206 female BRCA1/2 mutation carriers in this French cohort (Table 2) actually consulted a psychologist. These women had a slightly higher baseline depressive profile

(CES-D>=23=17.8%) than the 10.8% observed in a comparable population of French women [28], but their test-related distress [6] appears to be comparable with that observed in other surveys [9]. Among the noncarriers, the rates of uptake of psychological services were found to be similar to those observed in a study on the general French population [29]. Although the option of preventive surgery is generally held to be a topic that should be

<sup>\*</sup>Adjusted odds ratio; only variables that were still significantly associated with the outcome variable with a p-value <0.05 were kept in the multivariate model using a stepwise procedure.

426 C. Maheu et *al*.

discussed with a psychologist [14,16–18], it emerged from the present study that consultations with psychologists were far from being arranged systematically prior to prophylactic mastectomy, because only three of the seven patients who had undergone this intervention (Table 2) had consulted a psychologist. French primary care providers and surgeons seem to be still more reluctant than their European colleagues to discuss prophylactic mastectomy with their patients [30]. Very few of the women in the GENEPSO cohort opted for prophylactic mastectomy [31].

In line with previous findings [1], the results of this study show that only a small subgroup of individuals (accounting for 25% of the 478 consultees) showed clinical distress levels during the first year after the genetic tests. However, it is possible that a higher proportion of individuals may actually have experienced high distress levels, because the nonrespondents to the 1-year questionnaire showed higher baseline distress levels than the respondents. This can be said to have constituted one of the limitations of this study; however, only 9% did not answer the 1-year follow-up questionnaire. The other limitations were the fact that the questionnaires were self-administered and the information about doctors' proposals and patients' attendance was not checked. There existed no means of collecting this information on this national cohort other than asking the participants themselves. Because the data were collected prospectively shortly after the proposal/uptake of psychological consultations had occurred, we were quite confident in their validity, especially as the questionnaires were analyzed anonymously: no individual data were transmitted to the practitioners responsible for the inclusion of the women in the cohort.

One explanation for the interesting finding that high IES scores were associated with an invitation to attend a psychological consultation but not with depression level might be that cancer geneticists might respond more easily to cancer-related distress than to depression, which might reflect a state condition. The need has been expressed for clinical recommendations to cancer geneticists for screening distress and other specific problems among both carriers and noncarriers [32,18]. The oncologists' inability to accurately assess distress in their patients has been reported for years [33] and constitutes one of the reasons why psychosocial

care should be integrated into oncological practices [27,34]. The need for systematic tools such as questionnaires for screening early distress has also emerged from reviews of the literature [8,12,35].

A better understanding of HBOC families' use of psychological consultations before, during and after genetic testing is likely to provide cancer geneticists with some guidance as to how psychological assistance should be proposed and to whom. Despite the wealth of information available on the psychological impact of preBRCA1/2 and postBRCA1/2 testings [4,8,12,9,10], further research is now required to determine which consultees should be encouraged to apply for psychological assistance and which ones are liable to benefit the most from these services. This issue could also be investigated further in qualitative interviews with both patients and cancer genetic clinic providers. While being a carrier was definitely found to be associated with higher rates of proposal and uptake of psychological services, carriers do not all require psychological support, although the disclosure of positive genetic test results can give rise to clinical distress in some cases [10]. On the basis of the findings made in this study, it might also be useful to investigate the effects on those to whom psychological services have not been proposed, such as individuals with lower educational levels. This raises more general questions about the most suitable models for psychosocial care, which should surely be made available and acceptable to all those undergoing cancer genetic testing, whatever their educational background.

#### Acknowledgements

We would like to thank all the members of the GENEPSO cohort investigators, including Claude Adenis, Yves-Jean Bignon, Valerie Bonadona, Véronique Byrde, Annie Chevrier, Agnès Chompret<sup>†</sup>, Odile Cohen-Haguenauer, Isabelle Coupier, Liliane Demange<sup>†</sup>, Capucine Delnatte, Helene Dreyfus, Catherine Dugast, Francois Eisinger, Roxane Fabre, Laurence Faivre, Marc Frenay, Paul Gesta, Marion Gauthier-Villars, Michel Longy, Tan Dat NGuyen, Isabelle Pellegrini, Claude Picard, Hagay Sobol, Laurence Venat-bouvet, Philippe Vennin and Helene Zattara-Cannoni. This study was supported financially by the Institut National du Cancer RPT08011AAA, the SIRIC (grant INCA-DGOS-Inserm 6038) and the GENEPSO cohort, by 'La Ligue Nationale Contre le Cancer'.

#### References

- Visser A, Prins JB, Hoogerbrugge N, et al. Group medical visits in the follow-up of women with a BRCA mutation: design of a randomized controlled trial. BMC Womens Health 2011;11:39.
- McDowell ME, Occhipinti S, Ferguson M, et al. Prospective predictors of psychosocial support service use after cancer. Psycho-Oncology 2011;20:788–791.
- 3. Kääriäinen H, Hietala M, Kristoffersson U, et al. Recommendations for genetic counselling
- related to genetic testing, 2010. Available from: http://www.eurogentest.org/professionals/ public\_health/info/public/unit3/ summaryofguidelinesMay06.xhtml
- van Oostrom I, Meijers-Heijboer H, Lodder LN, et al. Long-term psychological impact of carrying a BRCA1/2 mutation and prophylactic surgery: a 5-year follow-up study. J Clin Oncol 2003;21:3867–3874.
- Segal J, Esplen MJ, Toner B, et al. An investigation of the disclosure process and support needs of BRCA1 and BRCA2 carriers. Am J Med Genet A 2004;125A:267–272.
- Julian-Reynier C, Mancini J, Mouret-Fourme E, et al. Cancer risk management strategies and perceptions of unaffected women 5 years after predictive genetic testing for BRCA1/2 mutations. Eur J Hum Genet 2011;19:500–506.
- Lim J, Macluran M, Price M, et al. Short- and long-term impact of receiving genetic mutation results in women at increased risk for hereditary breast cancer. J Genet Couns 2004;13:115–133.
- Meiser B. Psychological impact of genetic testing for cancer susceptibility: an update of the literature. *Psycho-Oncology* 2005;14:1060–1074.

- Hamilton JG, Lobel M, Moyer A. Emotional distress following genetic testing for hereditary breast and ovarian cancer: a meta-analytic review. *Health Psychol* 2009;28:510–518.
- Heshka JT, Palleschi C, Howley H, et al. A systematic review of perceived risks, psychological and behavioral impacts of genetic testing. Genet Med 2008;10:19–32.
- Meiser B, Halliday JL. What is the impact of genetic counselling in women at increased risk of developing hereditary breast cancer?
   A meta-analytic review. Soc Sci Med 2002:54:1463–1470.
- Schwartz MD, Peshkin BN, Hughes C, et al. Impact of BRCA1/BRCA2 mutation testing on psychologic distress in a clinic-based sample. J Clin Oncol 2002;20:514–520.
- Beran TM, Stanton AL, Kwan L, et al. The trajectory of psychological impact in BRCA1/2 genetic testing: does time heal? Ann Behav Med 2008;36:107–116.
- Eisinger F, Bressac B, Castaigne D, et al. Identification and management of hereditary predisposition to cancer of the breast and the ovary (update 2004). Bull Cancer 2004;91:219–237.
- Dorval M, Bouchard K, Maunsell E, et al. Health behaviors and psychological distress in women initiating BRCA1/2 genetic testing: comparison with control population. J Genet Couns 2008;17:314–326.
- INCAInstitut National du Cancer. Chirurgie prophylactique des cancersavec prédisposition génétique: recommandations professionnelles, 2009.
- Patenaude AF, Orozco S, Li X, et al. Support needs and acceptability of psychological and peer consultation: attitudes of 108 women who had undergone or were considering prophylactic mastectomy. *Psycho-Oncology* 2008;17:831–843.
- 18. Vos J, van Asperen CJ, Oosterwijk JC, et al. The counselees' self-reported request for psychological help in genetic counseling for

- hereditary breast/ovarian cancer: not only psychopathology matters. *Psycho-Oncology* 2013;**22**(4):902–910.
- Andrieu N, Easton DF, Chang-Claude J, et al.
   Effect of chest X-rays on the risk of breast
   cancer among BRCA1/2 mutation carriers in
   the international BRCA1/2 carrier cohort
   study: a report from the EMBRACE,
   GENEPSO, GEO-HEBON, and IBCCS Collaborators' Group. J Clin Oncol
   2006;24:3361–3366.
- 20. Fuhrer R, Rouillon F. La version française de l'échelle CES-D (Center for Epidemiologic Studies-Depression Scale). Description et traduction de l'échelle d'autoévaluation. Psychiatr Psychobiol 1989;4:163–166.
- Radloff LS. The CES-D scale: a self-report depression scale for research in the general population. Appl Psychol Meas 1977;1:385–401.
- Hann D, Winter K, Jacobsen P. Measurement of depressive symptoms in cancer patients: evaluation of the Center for Epidemiological Studies Depression Scale (CES-D). J Psychosom Res 1999;46:437–443.
- Horowitz M, Wilner N, Alvarez W. Impact of event scale: a measure of subjective stress. *Psychosom Med* 1979;41:209.
- 24. Barney LJ, Griffiths KM, Christensen H, et al. Exploring the nature of stigmatising beliefs about depression and help-seeking: implications for reducing stigma. BMC Public Health 2009;9:61.
- Schomerus G, Angermeyer MC. Stigma and its impact on help-seeking for mental disorders: what do we know? *Epidemiol Psichiatr* Soc 2008;17:31–37.
- 26. McKinnon W, Naud S, Ashikaga T, et al. Results of an intervention for individuals and families with BRCA mutations: a model for providing medical updates and psychosocial support following genetic testing. J Genet Couns 2007;16:433–456.
- 27. Turner J, Kelly B, Clarke D, et al. A randomised trial of a psychosocial

- intervention for cancer patients integrated into routine care: the PROMPT study (promoting optimal outcomes in mood through tailored psychosocial therapies). *BMC Cancer* 2011;**11**:48
- 28. Cohidon C, Santin G. Santé mentale et activité professionnelle dans l'enquête décennale santé 2003 de l'Insee. InVS, 2007. Available from:
- Sapinho D, Chee CC. Recours aux soins pour raison de santé mentale. In La dépression en France: Enquête Anadep 2005, Inpes (ed.). Inpes: Paris, 2008, 85–117.
- Den Heijer M, van Asperen CJ, Harris H, et al. International variation in physicians' attitudes towards prophylactic mastectomy— Comparison between France, Germany, the Netherlands and the United Kingdom. Eur J Cancer 2013.
- Julian-Reynier C, Bouhnik AD, Mouret-Fourme E, et al. Time to prophylactic surgery in BRCA1/2 carriers depends on psychological and other characteristics. Genet Med 2010;12:801–807.
- 32. Evers-Kiebooms G, Welkenhuysen M, Claes E, et al. The psychological complexity of predictive testing for late onset neurogenetic diseases and hereditary cancers: implications for multidisciplinary counselling and for genetic education. Soc Sci Med 2000;51:831–841.
- 33. Newell S, Sanson-Fisher RW, Girgis A, et al. How well do medical oncologists' perceptions reflect their patients' reported physical and psychosocial problems? Data from a survey of five oncologists. Cancer 1998;83:1640–1651.
- Jacobsen PB, Holland JC, Steensma DP. Caring for the whole patient: the science of psychosocial care. *J Clin Oncol* 2012;30:1151– 1153.
- Condello C, Gesuita R, Pensabene M, et al.
   Distress and family functioning in oncogenetic counselling for hereditary and familial breast and/or ovarian cancers. J Genet Couns 2007;16:625–634.