



## Original article

# Effect on perceived control and psychological distress of genetic knowledge in women with breast cancer receiving a *BRCA1/2* test result



Anne Brédart <sup>a, b, \*</sup>, Jean-Luc Kop <sup>c</sup>, Antoine De Pauw <sup>d</sup>, Olivier Caron <sup>e</sup>, Anne Fajac <sup>f</sup>, Catherine Noguès <sup>g</sup>, Dominique Stoppa-Lyonnet <sup>d</sup>, Sylvie Dolbeault <sup>a, h</sup>

<sup>a</sup> Institut Curie, Supportive Care Department, Psycho-oncology Unit 26 rue d'Ulm, 75005 Paris Cedex 05, France

<sup>b</sup> University Paris Descartes, 71, Avenue Edouard Vaillant, 92774 Boulogne-Billancourt, France

<sup>c</sup> Université de Lorraine, Inter-Psy, Inter-Psy, 3 Place Godefroy de Bouillon, BP 33 97, 54 015 Nancy Cedex, France

<sup>d</sup> Institut Curie, Cancer Genetic Clinic, 26 rue d'Ulm, 75005 Paris Cedex 05, France

<sup>e</sup> Gustave Roussy Hôpital Universitaire, Cancer Genetic Clinic, 114 rue Ed Vaillant, 94 805 Villejuif, France

<sup>f</sup> Hôpital Tenon Service d'Histologie-Biologie Tumorale, AP-HP, ER2 UPMC Université Pierre et Marie Curie, 4 rue de la Chine, 75020, France

<sup>g</sup> Institut Paoli-Calmettes, 232, Boulevard Sainte Margueritte, Marseille, France

<sup>h</sup> CESP, Univ. Paris-Sud, UVSQ, INSERM, Université Paris-Saclay, Villejuif, France

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## ABSTRACT

Information provision during *BRCA1/2* genetic counseling is complex and expected to be increasingly so with gene panel testing. This prospective study evaluated whether genetic knowledge in counsees with breast cancer (BC) after a pre-test genetic counseling visit (T1) enhance their feeling of personal control while minimizing distress after the notification of *BRCA1/2* result (T2).

At T1, 243 (89% response rate) counsees completed questionnaires on genetic knowledge (BGKQ), perceived cancer genetic risk; of which, at T2, 180 (66%) completed the BGKQ again, scales of anxiety/depression, distress specific to genetic risk, and perceived control. Multilevel models were performed accounting for clinician, and testing an effect of knowledge on psychological outcomes according to the adequacy of counsees' perceived genetic predisposition to cancer.

The mean knowledge score was moderate at T1, decreased while not significantly differing by *BRCA1/2* test result at T2. Knowledge at T1 had no direct effect on psychological outcomes, but in counsees who over-estimated their cancer genetic risk, higher knowledge at T1 predicted higher specific distress at T2.

In BC affected counsees who over-estimate their cancer genetic risk, higher *BRCA1/2* pre-test genetic knowledge seem to lead to increased specific distress. Identifying these BC affected counsees who over-estimate their genetic cancer risk and helping them to interpret their genetic knowledge instead of providing them with exhaustive genetic information could minimize their distress after test result receipt.

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## 1. Introduction

A diagnosis of breast cancer (BC) at a young age or a significant family history of BC, are among criteria for cancer predisposition gene testing [1]. Among the hereditary cancer gene panels now available [2], the *BRCA1* or *BRCA2* genes are commonly tested.

Women with BC who carry a mutation in the *BRCA1* or *BRCA2* gene have, respectively, a cumulative of 44.1% and 33.5% risk to develop contralateral BC, 25 years post diagnosis [3], as well as a 12.7% and 6.8% risk to develop an ovarian cancer [4].

National guidelines recommend embedding cancer genetic testing within a framework of genetic counseling [1]. Its main function is to provide counsees with relevant information in order to increase personal control [5–8], to facilitate medical decision-making about cancer gene testing [9], about cancer risk management options [10–13] and sharing genetic information with concerned family relatives [14,15] and to minimize psychological

\* Corresponding author. Institut Curie, 26 rue d'Ulm, 75005 Paris Cedex 05, France.

E-mail address: [anne.bredart@curie.net](mailto:anne.bredart@curie.net) (A. Brédart).

distress [16].

Genetic counseling confronts to large quantities of information involving complex statistic and genetic concepts [17,18] coupled to perceptions of cancer risk and worry [19]. Intricacies also involve the communication of uninformative gene test results. Indeed in the context of *BRCA1/2* gene testing, in about 80% of index cases (first person tested in the family, usually BC affected), a mutation is not identified (i.e.: the result is negative uninformative (NU)), and in an additional 12.5% cases, an unclassified variant (UV) is found [20]. Such results do not significantly decrease the probability of cancer genetic predisposition in families with a high number of breast or ovarian cancer cases; but no clear consensual risk management recommendation can be proposed [21].

Counselees' genetic knowledge reflects the recall of information obtained from genetic counseling among different sources. If gain in breast genetic knowledge is highlighted after genetic counseling [14,22–24], it is not clear whether an increased level of breast genetic knowledge contributes to enhancing psychological outcomes such as perceived control over one's health or psychological well-being. In view of recent development in BC risk multi-gene testing and the cumulative information that may be offered to counselees [25], it seemed relevant to assess the specific psychological impact of genetic knowledge. Although high-risk women affected with BC may exhibit specific care needs [26,27], to our knowledge, only one study specifically addressed genetic knowledge in these women [13]. However it is not known whether and for which of these women genetic knowledge is beneficial.

A critical factor is the perception of hereditary cancer risk [28,29]. Discrepancies have been highlighted between counselees' and clinicians' evaluations of cancer risks [30].

Genetic counseling is expected to produce similar cognitive effects, i.e. improving knowledge as well as cancer risk perception accuracy. However, it has been shown that after genetic counseling, knowledge may increase while cancer risk perception remained

largely inaccurate [5,7,10]. Although distress may decrease after genetic counseling [5,7,10], an inadequate perceived probability of genetic predisposition to cancer has been associated with higher levels of distress [29,31].

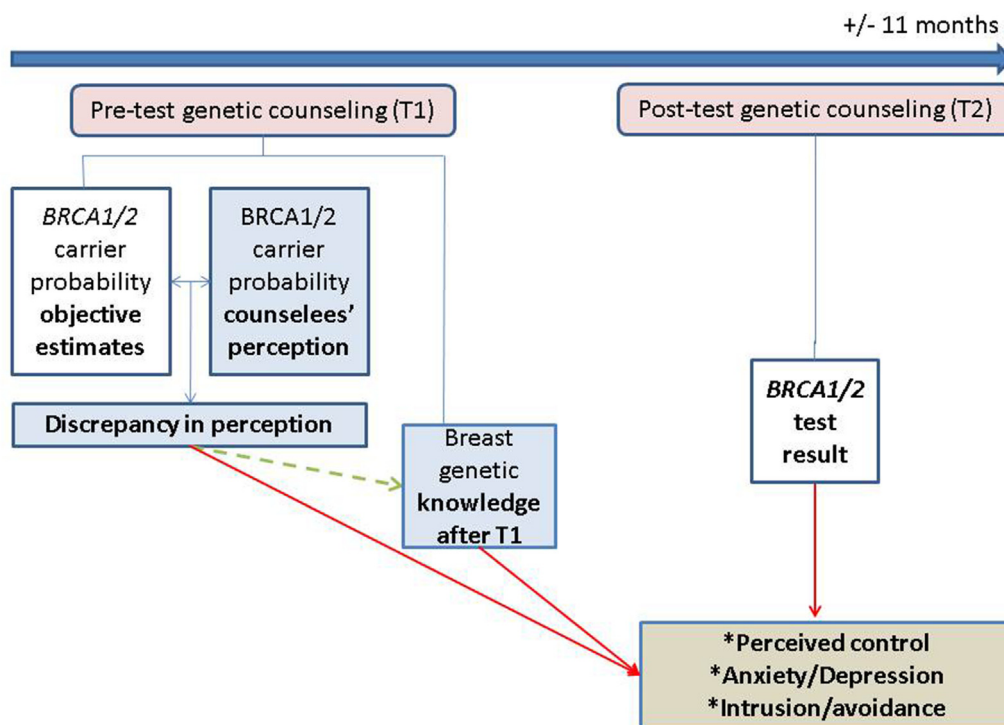
To the best of our search, no study simultaneously assessed the respective and interactive effect of knowledge and risk perception on psychological distress. So, as part of a prospective study exploring the psychological impact of the *BRCA1/2* test result in women affected with BC [31], we examined whether breast genetic knowledge after an initial genetic consultation improved counselees' perceived personal control while minimizing psychological distress after the *BRCA1/2* test disclosure. We also assessed whether the adequacy of counselees' perceived probability of genetic predisposition affected the psychological effect of knowledge. We hypothesized: 1) higher perceived personal control and lower distress after the communication of the *BRCA1/2* test result in women displaying higher genetic knowledge prior to testing; and 2) higher distress after the communication of the *BRCA1/2* test result in women overestimating their cancer genetic risk and evidencing higher knowledge prior to testing.

## 2. Methods

The protocol was approved by the *Comité consultatif sur le traitement de l'information en matière de recherche dans le domaine de la santé* (CCTIRS MG/CP°08.42) and by the *Commission Nationale Informatique et Libertés* (CNIL). All recruited women provided written informed consent.

### 2.1. Study design

The design of this multicenter study described elsewhere [31] is displayed in Fig. 1. The main effects tested are depicted as plain arrows. The modifying effect of the adequacy of counselees' perceived probability of genetic predisposition on the relationship



**Fig. 1.** Design of analyses testing the modifying effect of discrepancy between counselees' perceived probability of genetic predisposition to cancer and objective estimates, on the relationship between knowledge at T1 and psychological outcomes after notification of the *BRCA1/2* test result<sup>a</sup>. <sup>a</sup> Main effect tested depicted as plain arrows and interaction as dashed arrow.

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