



## Psychosocial outcomes and counselee satisfaction following genetic counseling for hereditary breast and ovarian cancer: A patient-reported outcome study



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### ABSTRACT

**Objective:** We investigated the psychosocial consequences of genetic counseling and testing (GCT) for hereditary breast and ovarian cancer (HBOC) at follow-up in a “real-life” sample of counselees at an Austrian tertiary care center.

**Methods:** The study cohort included counselees who had undergone genetic counseling for HBOC and completed a follow-up self-report questionnaire battery on psychosocial outcomes (quality of life, psychological distress, satisfaction with counseling and decisions). For comparison of distress, we recruited a reference sample of breast cancer survivors (BCS;  $n = 665$ ) who had not requested GCT in the same setting.

**Results:** Overall, counselees did not exhibit increased levels of anxiety and depression when compared to BCS. No specific follow-up deleterious psychosocial consequences were detected among the former group. Of the 137 counselees, 22.6% and 9.8% experienced clinically relevant levels of anxiety and depression, respectively, at an average follow-up time of 1.8 years. However, both anxiety and depression significantly decreased with time and were alike between counselees with and without cancer diagnosis. Follow-up cancer worry seems to be significantly higher among counselees who had not undergone genetic testing or were undecided about it than among counselees who had been tested.

**Conclusion:** Our results strongly support GCT as part of routine care for patients with HBOC. The risk factors of increased distress in specific subgroups of counselees, such as recent cancer diagnosis or uncertainty about testing, warrant further exploration and specific attention in clinical routines. Particularly, the psychological needs of undecided counselees warrant ongoing attention and potential follow-ups.

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### 1. Introduction

Genetic counseling and testing (GCT), including psychological counseling, for hereditary breast and ovarian cancer (HBOC) has become an integral part of care, not only for patients but also their healthy relatives. Approximately 30% of all patients with breast and ovarian cancer (BOC) report familial clustering, with around 5–10% of cases being based on a genetic predisposition due to a highly penetrant genetic alteration (i.e. in *BRCA1* or *BRCA2*) [1–3]. Such autosomal-dominant

inherited mutations cause significantly elevated individual lifetime and recurrence risks for affected individuals [1–3], and at the same time confront relatives with the knowledge of their own potential risk for HBOC. As BOC patients and their healthy relatives with a history of GCT have become a large and heterogeneous group in BOC care, health care providers are finding it increasingly important to understand the specific health care needs of this group (and sub-groups), particularly for optimizing psychological counseling.

In the short-term, GCT has been shown to improve patient knowledge on hereditary cancer risk and support deliberate informed decision-making [4]. This increase in awareness, however, comes at the price of inducing specific psychosocial care needs related to the knowledge of increased cancer risk in about three-fourths of patients [5].

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These specific needs concern topics such as cancer worry, decisional conflicts, feelings of guilt or shame, family communication problems, and concern for other family members [5]. Previous studies have predominantly focused on counselees who have undergone genetic testing; however, counselees who decide against doing so or are undecided are largely underrepresented. To further expand our understanding of the psychosocial consequences of GCT for HBOC, it is crucial to represent the various subgroups of counselees who opt for counseling without pre-selection. Hence, we aimed to recruit a real-life sample of counselees including those who ultimately decided not to be tested or who are unsure about their decision, both those with and those without a previous cancer diagnosis. This approach helps to reduce selection bias and generate a heterogeneous study population with characteristics representing the “typical” setting for genetic counseling.

A heterogeneous group of predominantly Anglo-American and Dutch studies have evaluated aspects of counselees' psychological adjustment over a follow-up period of above or equal to 2 years [6–12]. In this follow-up period, factors such as previous cancer diagnosis, decision uncertainty, and sociodemographic variables might contribute to counselees' psychosocial adjustment. Specifically, as a cancer diagnosis and related treatments can increase patients' distress levels during the follow-up period, comparing counselees for HBOC and breast cancer survivors (BCS) who did not request GCT could provide additional insight into the unique effects of GCT on counselees' distress levels. We therefore included a group of BCS who had not requested GCT to allow for such comparison. To our knowledge, this is the first study directly comparing psychological distress levels between BOC patients who have and those who have not undergone GCT.

The specific variables that we investigated included follow-up psychosocial outcomes, including quality of life (QOL), psychological distress, cancer worry, and patient satisfaction with GCT and their decisions regarding it. Together with our comparison to BCS who had not undergone GCT, our study may help in meeting the follow-up health care demands of this particular patient group and in improving their QOL outcomes.

In detail, the following research questions were addressed:

- To what degree do counselees for HBOC experience psychological distress during the follow-up period?
- Are there differences in psychosocial outcomes between subgroups of counselees (tested vs. not tested vs. undecided; positive vs. negative test result; cancer patients vs. healthy individuals)?
- Do levels of psychological distress differ between counselees for HBOC and BCS who did not undergo GCT?
- Which counseling-related variables predict follow-up patient satisfaction with decisions?

## 2. Method

The work was carried out in accordance with The Code of Ethics of the World Medical Association (Declaration of Helsinki) for experiments involving humans. The study was approved by the Ethics Committee of the Medical University of Innsbruck (Nr: UN4518, 306/4.8, date 22.10.2013).

### 2.1. Study cohort

The target cohort was individuals who had undergone genetic counseling at the Medical University of Innsbruck, an Austrian tertiary care center, from January 2011 to February 2014. All study participants met the following inclusion criteria: requested genetic counseling for a possible HBOC predisposition (see section “referral to GC” below); with or without a previous cancer diagnosis; 18–85 years of age; fluency in German; and no overt cognitive impairments. Notably, we included

patients who decided to be tested after the counseling, those who decided to not be tested, and those who remained undecided.

### 2.2. Referral to GC

Patients were ascertained via two main routes. 80% of counselees were referred within the treatment setting for BOC at the Department of Obstetrics and Gynecology, Medical University of Innsbruck. Additionally, independent of socioeconomic status, all Austrian residents are free to request GC with referral from their primary care physician (20%). Both patient groups autonomously consented to GC, an interdisciplinary service of gynecologists, human geneticists and psychologists.

### 2.3. Reference group

We also recruited a reference group of BCS who had not undergone GCT and who were in the aftercare stage. These patients were not actively offered GCT during the treatment process by the treating physician because they did not meet the eligibility criteria for genetic testing based on their family history [13].

### 2.4. Procedure

We conducted a cross-sectional, patient-reported-outcome (PRO) assessment targeting psychosocial outcomes including QOL, psychological distress, cancer worry and patient satisfaction with genetic counseling and health care decisions via a mail survey. The assessment also obtained single self-report items directed at patients' decisions within the GCT process (see details in the Measures section). The assessment was completed anonymously.

Eligible counselees were identified by searching the medical counseling records of the Division of Human Genetics, Medical University of Innsbruck, and were sent an invitation letter explaining the study purpose and asking for study participation, accompanied by an informed consent form and the questionnaire battery. Participants anonymously returned the completed questionnaires and informed consent form via mail. A follow-up call (which had been announced in the invitation letter) was performed 8 weeks after the mail survey asking for the status of study participation. The major purpose of this call was to re-invite or remind counselees of their participation.

The reference data were independently collected at the outpatient unit of the Department of Gynecology and Obstetrics, Medical University of Innsbruck. In this patient group, only psychological distress was assessed (using the Hospital Anxiety and Depression Scale [HADS]).

### 2.5. Measures

The assessment was performed using a PRO assessment battery including the following sections.

#### 2.5.1. Self-reported sociodemographic variables and information on GCT

Sociodemographic variables and information on GCT were assessed by means of single self-report items developed for the purpose of this study. Sociodemographic variables included the following: gender, age, marital status, education, and employment status.

Items on GCT included the patient's decisions regarding genetic testing (for, against, undecided) and related management strategies (preventive or prophylactic) as well as test results (received or have not received test result; mutation positive or mutation negative); e.g. “After genetic counseling, did you decide to undergo genetic testing?” – response format: 0 = decided to undergo genetic testing, 1 = decided not to undergo genetic testing, 2 = undecided); “Did you decide to receive the genetic test result?” – response format: 0 = decided to receive test result, 1 = decided not to receive test result, 2 = undecided whether to receive test result; “Which management strategy (surveillance or prophylactic procedures) did you decide to undergo?” – response

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