Impact of genetic counselling for hereditary breast and ovarian cancer disposition on psychosocial outcomes and risk perception

A population-based follow-up study

Ellen M. Mikkelsen, RN, MPH

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Official opponents: Anders Bonde Jensen, Karin Nordin, MSc, PhD, Sweden and Jørgen Lous.

Tutors: Søren P. Johnsen, Lone Sunde and Christoffer Johansen.

Correspondance: Ellen M. Mikkelsen, Department of Clinical Epidemiology, Aarhus University Hospital, Ole Wormsallé 1150, 8000 Aarhus C. Denmark

E-mail: emM@dce.au.dk

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ABSTRACT

This PhD dissertation is based on studies carried out at Aarhus University Hospital, Copenhagen University Hospital, and the J.F. Kennedy Institute.

The aims of this dissertation were: 1) to compare the psychosocial conditions of women awaiting genetic counselling for hereditary breast and ovarian cancer (HBOC) with those of women from two reference groups; 2) to examine possible clinical and socioeconomic differences between study respondents and non-respondents and between participants with complete follow-up and drop-outs; 3) to assess the impact of genetic counselling over time on perceived personal lifetime risk of breast cancer and accuracy of risk perception; 4) to assess the impact of genetic counselling over time on anxiety, depression, cancer-specific distress and health related quality of life (HRQOL).

We conducted a population-based follow-up study of 431 women who received genetic counselling for HBOC, 417 women who underwent mammography (Reference Group I), and a random sample of 1315 women from the general population (Reference Group II). We obtained self-reported data using self-administered, standardized, mailed questionnaires and registry data from six nationwide registries.

Women, awaiting their first counselling session, experienced more cancer-specific distress, but did not suffer from more anxiety or depression than women in the reference groups.

The study showed no substantial differences between respondents and non-respondents and between participants with complete follow-up and drop-outs.

Women who received genetic counselling decreased their perceived risk by an average of 6.6 percentage points (95% CI: 3.0%; 10.2%) between baseline and 12 months of follow-up. In contrast, perceived risk remained relatively stable in the reference groups. The proportion of women who accurately perceived their risk increased by 16% in the group receiving genetic counselling, compared to a reduction of 5% (p=0.03) and 2% (p=0.01) in Reference Groups I and II, respectively.

52% of the women referred for genetic counselling experienced cancer-specific distress at a clinical level at baseline and this proportion decreased to 41% after 12 months of follow-up. This 10.8% (95% CI:1.4; 20.8) decrease observed in the Genetic Counselling Group exceeded the decrease observed in Reference Group I, 6.3% (95% CI:-1.3;13.8) and Reference Group II, 1.6% (95% CI:-2.3;5.5). In addition, genetic counselling did not lead to an increase in general anxiety and depression or a decrease in HRQOL among women in the Genetic Counselling Group compared to the women in the reference groups.

This population-based study indicates that genetic counselling can help Danish women with a family history of breast and ovarian cancer to alleviate their cancer-specific distress and improve their risk perception.