EUROPEAN JOURNAL OF CANCER 42 (2006) 2722–2728

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journal homepage: www.ejconline.com

Short term psychological distress in patients actively approached for genetic counselling after diagnosis of breast cancer

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ARTICLE INFO

Article history:
Received 11 March 2006
Received in revised form
16 May 2006
Accepted 16 May 2006
Available online 1 September 2006

Keywords:
Breast cancer
Genetic counselling
Psychological distress
Approach

ABSTRACT

This prospective study assessed anxiety, depression and breast cancer-specific distress in recently diagnosed breast cancer patients before and after an active approach for genetic counselling at the beginning of adjuvant radiotherapy (mean: 52 days after surgery). Patients completed the hospital anxiety and depression scale (HADS) and the impact of event scale (IES). Psychological distress did not increase after the approach. High anxiety decreased in the comparison group ($n = 182$), whereas breast cancer specific distress decreased in the approached group ($n = 220$). It is concluded that breast cancer patients can be approached for genetic counselling shortly after surgery without additional short-term psychological burden. Patients who are young, single with little social support, less optimistic, use an avoiding coping style, experience a lower quality of life or who are highly distressed prior to approach for genetic counselling, need extra attention. Medical history did not prove to be relevant.

1. Introduction

An estimated 5–10% of all breast cancers are probably due to an autosomal dominant inherited genetic default.[1] Genetic testing became available for breast cancer patients and their family members after the identification of two breast cancer susceptibility genes, *BRCA1* and *BRCA2*. Inherited *BRCA1* and *BRCA2* mutations are associated with an increased risk for breast and ovarian cancer.[2]

Psychological distress after diagnosis and surgery for breast cancer has been well recognised and widely investigated.[3] Psychological distress was found in 20–30% of breast cancer patients within the first year after diagnosis. Burgess *et al.*[4] identified anxiety and depression or both in nearly 50% of breast cancer patients in the year following the diagnosis. In addition, high levels of intrusive thoughts and avoidance were noted in 18% and 14%, respectively, of breast cancer patients six weeks after surgery.[5] The psychological impact of genetic counselling and testing on unaffected women with a family history of breast cancer has been widely investigated as well. Non-carriers derive psychological benefits from genetic testing, while no adverse effects are observed amongst carriers.[6]

Little is known, however, about the psychological impact of genetic testing on breast cancer patients who participate in DNA testing for themselves or at the request of a healthy

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doi:10.1016/j.ejca.2006.05.032

family member. A few studies concerning genetic testing in breast cancer patients found that patients diagnosed less than one year before testing demonstrated higher general anxiety and breast cancer-specific distress prior to genetic counselling and more depression after testing than patients diagnosed long ago.[7] Patients diagnosed less than one year before testing seemed as interested in genetic testing as patients diagnosed more than one year before testing and showed more interest in testing when advised by a physician.[8] So far, psychological distress during genetic counselling after a recent diagnosis with breast cancer in such an early stage of primary treatment has not yet been assessed.

We previously studied a hospital-based series of recently diagnosed breast cancer patients for predictive factors associated with *BRCA1* and *BRCA2* mutations.[9] After active approach for genetic testing, a substantial portion of participants dropped out during the genetic counselling protocol. The reasons for dropping out were not thoroughly studied, although the main reason given was patients' concern for the additional psychological burden imposed by genetic testing.

The present prospective study was initiated to: (1) investigate the possible additional psychological burden from an active approach for genetic counselling in recently diagnosed breast cancer patients at the beginning of adjuvant radiotherapy; and (2) to identify characteristics of patients with high anxiety, depression and breast cancer specific distress after the approach. The women who were eligible for genetic counselling (see below) and who were approached at the beginning of adjuvant radiotherapy were expected to demonstrate higher psychological distress after approach than the women who were not eligible and not approached. The patients with high psychological distress at baseline were expected to portray high psychological distress after approach.[5,10] The patients with a low perceived level of social support and a less optimistic outlook on life were expected to have more difficulty with psychological adjustment to the approach for genetic counselling.[3,11] Patients with more maladaptive coping strategies were expected to have more difficulty as well.[12] Finally, breast cancer patients who had received a more extensive treatment were expected to experience more psychological distress after approach for genetic counselling.[13]

2. Materials and methods

2.1. Participants

The participating patients were recruited from all consecutive breast cancer patients referred to the University Medical Centre Utrecht for adjuvant radiotherapy between January 2002 and March 2004. The inclusion criteria were a first diagnosis of breast cancer, age between 18 and 75 years, and a good command of the Dutch language.

2.2. Procedure

Referred breast cancer patients were sent an introductory letter, an informed consent form, and a baseline questionnaire by mail prior to their first visit to the Department of Radiotherapy (T0). Patients were asked to complete this questionnaire before their first visit. During this visit (7–8 weeks after surgery), the radiation oncologist filled out a checklist, adapted from our previous study,[9] on the following factors presumed predictive for hereditary breast cancer: (1) age at diagnosis <40 years; (2) bilateral breast cancer; (3) multi-centricity or multi-focality of infiltrating carcinoma; (4) a personal history of ovarian cancer; (5) family members with breast cancer; and (6) family members with ovarian cancer. If the patient was diagnosed as positive for one or more of these predictive factors, then the radiation oncologist would inform her about the possible risk for hereditary breast cancer and offer to have a family pedigree drawn up to identify eligibility for further genetic counselling at the Department of Medical Genetics. If none of the predictive factors were diagnosed as, then the radiation oncologist would not offer pedigree analysis. Together with the checklist, the treating physician prospectively registered each patient's medical history including time since surgery, type of surgery (mastectomy *versus* lumpectomy), chemotherapy prior to radiotherapy (in case of four or more axillary lymph node metastases) and TNM stage.

Four weeks after the first visit, a research nurse explained to each participant from the approached group and the comparative group what further participation in the psychological study would involve and gave the opportunity to ask questions about the study. In addition, the approached patients were provided general information on the procedure of genetic counselling. The research nurse requested further participation in the study and provided a second informed consent form and questionnaire (T1). This questionnaire was returned by mail within ten days. The study flow scheme is shown in Fig. 1. This study was approved by the Medical Ethical Committee of the University Medical Centre, Utrecht.

2.3. Measures

T0 included questions on socio-demographics (age, marital status, age and sex of children, level of education and employment), number of first- and second-degree relatives with breast cancer, and involvement with family members with cancer. The following psychological characteristics were assessed:

Coping strategy was measured using the Utrecht Coping List (UCL).[14] This 15-item Dutch adaptation of the Westbrook Coping Scale[15] evaluates active coping (considers all aspects of a problem), social support seeking (shares concerns with others), avoidance (avoids difficult situations as much as possible), and the so-called palliative reactions (seeks distraction) using a four-point frequency scale ranging from 'almost never' to 'nearly always' (Cronbach's alpha was 0.67–0.84 in a random selection of Dutch cancer patients[14]) with higher scores indicating a more often use of a particular coping style.

Optimism was assessed using an 8-item subscale of the self-assessment questionnaire-Nijmegen (SAQ-N).[16,17] This four-point frequency scale ranges from 'almost never' to 'nearly always', with higher scores indicating a more optimistic outlook on life.

Quality of life was measured using the 2-item subscale of the quality of life questionnaire (QLQ) for cancer patients in general, developed by the European organisation for research