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Risk perception and cancer worry: an exploratory study of the impact of genetic risk counselling in women with a family history of breast cancer

EDITOR—An important aim of genetic risk counselling is to confirm a level of cancer risk and offer risk management strategies.[1] By giving counsellees accurate information about their risk, in place of ignorance, uncertainty, or a false assumption of the inevitability of breast cancer, it is hoped that some of the associated worry about personal risk may be alleviated.

Earlier work by the authors showed that women frequently overestimate their risk of breast cancer,[2] creating the possibility of reassuring women by providing a more realistic risk value. Subsequent research showed that risk counselling significantly improved risk accuracy over a one year follow up period, both for women who overestimated and underestimated risk.[3] This improvement was more likely if women were sent a personal letter containing the risk information after their visit.[3] However, there was concern that accurate risk information may induce or increase anxiety in women referred for genetic counselling, especially in those who initially underestimated their risk.

This was not borne out by a study of first time attendees at the Family History Clinic, who were followed for a one year period after genetic risk counselling. Women were found to adopt a more accurate perception of their risk without an increase in scores on general measures of anxiety at any time point post-counselling.[4] There was a suggestion from questionnaire data that women with an accurate appraisal of risk after genetic counselling had the best levels of mental health and psychiatric diagnoses derived by interview were not caused by risk counselling. However, some women with psychiatric morbidity reported that the early loss of a mother was very difficult to resolve,[4] a problem also reported in adolescent daughters of breast cancer patients.[5] The relationship between early loss and cancer worry in high risk women has not been previously reported. Death of a mother in adolescence may be associated with a greater fear of cancer as an adult, because of exposure to the disease at this vulnerable age. Adolescent daughters of women with breast cancer find it difficult to put the illness behind them and report higher symptom scores for distress.[5]

Our previous study showed that genetic risk counselling did not adversely effect mental health, but the study lacked a specific measure of cancer worry. A previous UK study reported that specific cancer worry was not relieved by genetic risk counselling.[6] Perceived risk was the best predictor of cancer worry and intuitively one would expect women who overestimate to have more cancer worries but be amenable to reassurance from accurate risk knowledge. Thus, we considered it important to assess cancer worry prospectively and longitudinally in women at risk and, secondly, to find out whether the early loss of a mother had a bearing on the level of cancer worry.

It was hypothesised that (1) cancer worry scores would be greater in women who overestimated risk than in those who underestimated or had an accurate risk perception; (2) cancer worries would be greater in women whose mothers died from breast cancer before the daughters were aged 20, with those aged 10 to 20 (that is, adolescents) at the time of death being the most vulnerable; and (3) cancer worry scores would show no significant change following risk counselling.

At the time of study, the Family History Clinic service offered risk assessment to women with a family history of breast/ovarian cancer who had a minimum two-fold increased risk compared with the general population, but who were unaffected. The service was staffed by a consultant cancer geneticist, a consultant medical oncologist with expertise in risk assessment, and a Research Fellow in cancer genetics. Earlier research showed that women's risk perceptions post-counselling did not vary according to which clinician had provided risk counselling.[4] Referrals were received from general practitioners (>70%) and from surgeons/other clinicians but women could not self-refer. A detailed pedigree was first obtained by a mailed questionnaire which was then computed and risk level estimated using the Claus model.[7] Women reaching criterion risk were offered an appointment at which the family history was discussed and a personal risk level presented. Risk was given in two ways, including an odds ratio for lifetime risk. Clinical breast examination and mammography (where appropriate) were also provided. All women were sent a detailed letter after the consultation, summarising the discussion and including the lifetime risk value. Very few women attending the service would be able to consider genetic testing because many were not from obviously "dominant" breast cancer families, which is where most testing is focused.

An assessment of pre-counselling risk perception and cancer worry has formed part of the routine work up for new referrals to the Manchester Family History Clinic in recent years. The study population was formed by 500 newly referred women offered an appointment at the clinic, who had completed Lerman's Cancer Worry Scale (CWS)[8 9] and the Manchester Family History Clinic Questionnaire[4] (to assess risk perception) before their first attendance at the Family History Clinic.

A second pair of questionnaires was posted to 460 of these women in July 1998, a minimum of two and maximum of 21 months after genetic risk counselling with a letter requesting completion. Forty women who had already been approached to participate in another research study running concurrently were not recontacted. (These women were participating in the Tamoxifen Chemoprevention Trial, IBIS.) The CWS is a six item (originally four item) scale designed to measure worry about the risk of developing cancer and the impact of worry on daily functioning. Reference population norms are available,[8 9] but no clinical case threshold values are derived.The Family History Clinic Questionnaire provides information on source of referral, reason for attending, risk perception, and concern about risk. It has been used in several previous research studies[2–4] and showed consistency over time. Risk perception is assessed through selection of the appropriate