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Editorial

Psychological Sequelae of Screening Women with a Family History of Breast Cancer

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At the crude but compelling level of a body count, mammographic screening reduces the mortality from breast cancer by one third in women aged over 50 years [1]. Opponents of screening will, however, argue that this saving of lives takes a disproportionate amount of resources from beleaguered health budgets. This debate could run for years and occupy the conference-going 'oncofolk' in countless hours of discussion as the number of angels on the head of a pin once did theologists. More telling is the potential harm that could be done to perfectly normal women who suffer false-positive screening recall leading to intense short-term anxiety [2]. In the U.S.A., approximately 11% of mammograms are reported as abnormal compared with only 2.5% in Sweden.

In a review of a cohort of 2,400 healthy American women screened over a 10 year period, 50% had a false-positive recall for assessment, particularly in the 40-49 year age group when compared with those aged 50-79 years. This does not bode well for women with a strong family history of breast cancer who might be invited for screening between the ages of 35 and 50 years. Kash and associates examined health beliefs in 217 participants in the Strang Cancer Prevention Center's Breast Surveillance Programme [3]. All screenees had either one first degree relative with premenopausal bilateral breast cancer, or a mother and maternal grandmother with breast cancer, or two or more first degree relatives with the disease. Validated instruments were used including the Impact of Event Scale, Brief Symptoms Inventory, Taylor Manifest Anxiety Scale and Cancer-Related Anxiety and Helplessness Scale. This group proved to have levels of psychological distress one standard deviation above the mean. More than one quarter had distress levels warranting therapy. Those with higher levels of distress were less likely to attend for clinical examination or to carry out breast self-examination.

Adherence to recommended mammographic screening and psychological distress of first degree relatives of breast cancer cases was determined by telephone interview in another US study [4]. The 140 interviewees were aged 35–79 years and the instruments used included the Depression Subscale of the Mental Health Inventory, the Intrusion Subscale of the Impact of Events Scale and a single 4 point Likert-style item on Breast Cancer Worries. Of those aged

35–39 years, 76% complied compared with 86% of those aged 40–49 years and only 63% of those aged 50 years or over. The major determinants of compliance were level of education, employment and time elapsed since diagnosis of the index relative. Significant factors inhibiting compliance were age, intrusive thoughts about breast cancer and breast cancer worries interfering with daily normal function. In a multivariate analysis, breast cancer worries and education were the only significant factors affecting compliance.

Part of the problem is the unrealistic estimate of risk carried by many women who deem themselves to be candidates for familial breast cancer. This was studied by Evans and associates who asked 517 women attending a Family History Clinic about their subjective risk assessment in relation to the general population, just prior to their appointment [5]. There was a range of 7 choices given for risk ranging from 1 in 3 to 1 in 12. Individuals then saw a clinical geneticist who constructed a pedigree and gave an individual lifetime estimate of breast cancer risk. Those returning to the clinic at least 1 year later were re-interviewed about their personal risk estimate. Only 16% of the women knew the general population risk prior to their first consultation. One year later, two thirds still did not know the general population risk. One in nine (11%) made a correct pre-consultation estimate of their risk and 1 year after counselling this rose to 41%. Possibly anxiety is blocking retention of information. Certainly there may be a need for revision of the manner in which risk estimates are conveyed to worried women.

In another study of 62 women attending a Genetic Counselling Clinic, their psychological morbidity, perception of risk and health behaviour was compared with 62 age-matched women without a family history who were attending a local primary care centre [6]. Using the Brief Symptoms Inventory, Impact of Event Scale and Risk Perception, 31% of cases had psychological morbidity consistent with need for counselling, as did 34% of the controls. Cancer specific anxiety was significantly more common in the higher risk cases (65% versus 16%). The high baseline levels of psychological morbidity might mask some of the harm resulting from screening.

To address this problem, Gilbert and colleagues studied the impact of recall for assessment in a cohort of women in whom psychological morbidity had been measured prior to the invitation for screening [7]. Participants were 2,357 women, aged between 50 and 64 years from three health 1992 I.S. Fentiman

centres in North-east Scotland. All were asked to complete the Hospital Anxiety and Depression Scale (HADS) [8], which was successfully carried out by 90%. Subsequently, when they attended for screening they were asked to compete a second HADS and 70% complied. At that time participants were also invited to complete The Health Questionnaire (HQ), a 7 point scale measuring perceived stress levels [9]. There were 133 recalled for assessment, of whom 9 proved to have breast cancer and were excluded from the study. Of the recalled screenees, 35 gave a first degree family history of breast cancer and 87 did not. The reasons for recall for the 35 with a family history were either a possible mammographic abnormality (n=18) or because of a family history alone (n=17). At the assessment clinic the HADS and HQ were repeated and subsequently these were sent by post for completion 5 weeks and 4 months later.

The baseline HADS scores showed significant anxiety in 24% and depression in 6%. At the time of screening, only 18% had significant anxiety which rose to 26% at the time of recall for assessment. By 5 weeks 18% had significant anxiety and 14% at 3 months. There was a significant rise in Health Questionnaire scores between screening and assessment visits. Those women with a family history were significantly more anxious at the time of recall. Despite this, by 3 months after false-positive recall the HADS scores of those with a family history were lower than at baseline.

This can be taken as source of comfort to screeners and high risk group collectors. It does appear that no permanent psychological harm results from false-positive recall. Of course, the instruments used, although well validated, are only a rough guide to temporal levels of anxiety, stress and depression. The ultimate test is whether false recall of those who are already worried will lead to denial behaviour and failure to return for subsequent rounds of screening.

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