

## PSYCHOLOGICAL CARE OF WOMEN WITH A FAMILY HISTORY OF BREAST CANCER

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### Resumen

De forma paralela al desarrollo de los aspectos clínicos del asesoramiento en mujeres con historia familiar de cáncer de mama, ha habido una creciente necesidad de identificar las secuelas psicológicas de averiguar el riesgo, el examen genético y la cirugía profiláctica mamaria. La organización y la estructura de las Unidades de Consejo Genético varían ampliamente dentro del ámbito nacional y alrededor de Europa, así como la integración en ellas de la atención psicológica. La investigación disponible muestra poca variación en resultados psicosociales pero factores culturales afectan a las actitudes, la realización del test genético y la cirugía preventiva. Existe un acuerdo general en que el consejo acerca del riesgo puede ser beneficioso, sin que induzca o aumente la morbilidad psicológica. Los profesionales de la Salud de los servicios de manejo de riesgo y test en consejo genético oncológico usan cada vez más protocolos clínicos y pautas profesionales. El apoyo psicológico habitual no es necesario para la mayoría de mujeres con una historia familiar de cáncer de mama, pero el acceso a los servicios psicológicos debe estar disponible para aquellas mujeres que presenten un malestar elevado debido a su historia familiar, o para aquellas que van a llevar a cabo un test genético o cirugía preventiva. El personal de la Unidad de consejo genético debe ser consciente de las consecuencias psicológicas adversas potenciales de la evaluación del riesgo y de las intervenciones para manejar el riesgo, y estar adecuadamente entrenado para elicitación de las preocupaciones de las mujeres e implicar a los colegas psicosociales cuando sea apropiado.

**Palabras clave:** Cáncer de mama, atención psicológica, consejo genético, malestar.

### Abstract

In parallel to the development of clinical cancer genetics services for women with a significant history of breast cancer, there has been a growing need to identify the psychological sequelae to risk ascertainment, predictive genetic testing and preventive breast surgery. The organisation and structure of cancer genetics clinics vary widely both nationally and across Europe, as does the level of integration of psychological care: available research shows little variation in psychosocial outcomes but cultural factors affect attitudes to and uptake of predictive testing and preventive surgery. There is general agreement that risk counselling can be beneficial without inducing or increasing psychological morbidity. Health professionals in cancer genetic counselling, testing and risk management services increasingly use clinical protocols and professional guidelines. Routine psychological support is not required for the majority of women with a family history of breast cancer, but access to psychological services should be in place for women with high distress relating to the family history or those undergoing predictive testing or preventive surgery. Genetics staff should be aware of potential adverse psychological consequences of risk assessment and risk management interventions, and be adequately trained to elicit women's concerns and involve psychosocial colleagues where appropriate.

**Key words:** Breast cancer, psychological care, genetic counselling, distress.

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## INTRODUCTION

The field of breast cancer genetics has been a rapidly growing one, and across Europe this has prompted the development of clinical cancer genetics services<sup>(1-3)</sup>. Much of the demand for information and advice about familial breast cancer has come from women themselves, wanting to find out about the implications of their family history and ways to manage the risk. Given the limited options for preventing breast cancer, concern was expressed about the potential for negative psychological effects of providing detailed risk information, especially if the actual risk was much higher than the woman expected. This motivated psychosocial research to evaluate the impact of risk communication, and studies in the UK drew on the experiences of women attending family history clinic services<sup>(4-6)</sup>.

With the availability of testing for breast cancer predisposing genes *BRCA1* and *BRCA2*, research has determined the uptake, psychological benefits and morbidity consequent on predictive genetic testing<sup>(7)</sup>, highlighting issues for affected and unaffected women. Results from large prospective clinically based studies are now available<sup>(8,9)</sup>, providing longer-term outcomes<sup>(9)</sup>. The outcomes of decision-making about preventive mastectomies became a focus for investigation, given the significant controversies around the potential for benefit or harm with this procedure<sup>(10-12)</sup>.

Psychological care for women at increased risk of breast cancer has evolved as evidence of need has accumulated, but there has been wide variation in service provision and therefore in the structure and organisation of psychological aspects of cancer genetics services. National guidelines and clinical protocols have now been produced in a number of European countries<sup>(1,13,14)</sup> and so it is timely to review the indications for psychological care in the cancer genetics setting.

## PSYCHOLOGICAL IMPACT OF RISK COMMUNICATION: IMPLICATIONS FOR CARE

A large literature now exists describing the psychological impact of risk communication, in terms of levels of risk accuracy, mental health and satisfaction, and results have been further evaluated in systematic reviews and meta-analyses<sup>(15-17)</sup>. There is still, however, a lack of information about health behavioural consequences or lifestyle changes. Risk knowledge and inaccuracies in women's perceptions became a focus for research when it was realised that women had a hazy knowledge of their own risks and of those in the general population. Risks could be exaggerated or minimised, and only 10% were accurate pre-counselling. This improved to a sustained level of 66% post-counselling in our own service<sup>(18)</sup>. Provision of personalised risk information in a letter summarising the genetic consultation increased the accuracy of risk perceptions following counselling<sup>(19)</sup>. However, women who overestimated their risks appear to be more refractory to accurate risk information and continued to hold inaccurate risk perceptions. In turn, these were found to be strongly associated with increased cancer specific distress<sup>(20)</sup>. Findings are contradictory as to whether genetic counselling reduces cancer worry<sup>(20,21)</sup>, but women with a dysfunctional level of cancer worry may require psychological support or intervention.

In order to better understand the nature and aetiology of psychological morbidity in women attending a family history clinic, we carried out a longitudinal prospective study, which involved in depth interviews and serial questionnaire assessments. This gave rich information about the psychological support needs of these women<sup>(4)</sup>. Results in this clinical setting confirmed that the majority of women experienced no increase in psychological morbidity over the longer term, so that routine psychological support was not required. Prevalence of psychological morbidity was equivalent to popula-

tion rates and only about half of women found to have psychiatric diagnoses at interview needed or wanted psychological help. Some women had unresolved grief relating to the family history and disrupted family life including sexual abuse in the family following the death of a mother in childhood. Other vulnerability factors are guilt because of the chance of passing on the risk to daughters and fear of the personal threat of cancer, after witnessing the illness in a close relative. Referral to psychological care may be needed in these cases. Although research studies have often been in agreement about the prevalence of distress identified with questionnaires, caution is needed in extrapolating these results, as an indicator of support needs, as questionnaires are not diagnostic and rates of distress may be inflated. Threshold scores on scales used may need to be re-calibrated to provide more accurate results<sup>(4)</sup>.

Facing the reality of the family history and reviewing cancers in the generations brought personal risk into focus for the first time for some women, which was anxiety provoking and upsetting, but usually only transiently so<sup>(4)</sup>. For those who experience more acute distress at this time, prompt access to psychological support is needed. Psychological intervention may be required for a prolonged period for a small number of women for whom previously un conscious losses and fears are evoked by risk counselling.

## IMPLICATIONS FOR GENETIC COUNSELLING

Although it is assumed that the majority of women attending cancer genetics services want personal risk information, some women feel the information is delivered unsympathetically, and others received it even if it was unwanted. It is important to ensure that women's reasons for attending a cancer genetics clinic are elucidated routinely, so that information and advice is appropriately tailored<sup>(18,22)</sup>. Issues of loss and grief may be

underestimated and psychological concerns are often missed<sup>(23)</sup> in this setting. Genetic counsellors need to be aware of the potential to uncover such feelings during routine consultations and to feel confident in discussing them, and the importance of providing psychosocial support around the process of genetic testing has been well expressed in the context of the genetic nursing role<sup>(24)</sup>. Moreover a communication skills training was one of the most valued components of genetics nurse training programme<sup>(25)</sup> and this could be made more routinely available.

To date, surprisingly little research has focussed on the process of risk communication itself, although an Australian group have addressed this<sup>(23,26)</sup>. The need for a consensus for the definition of genetic counselling and its goals has been eloquently argued in a recent review, and strategies proposed for approaching this complex area<sup>(27,28)</sup>. These authors promote presentation of tailored information and a more psychological focus. The need for standardised information in a variety of formats has also been highlighted.

## IMPACT OF SERVICE ORGANISATION ON PSYCHOLOGICAL OUTCOMES

Referral rates, staffing level and composition of the multidisciplinary team within cancer genetics services vary widely both within countries<sup>(2)</sup> and across Europe<sup>(1)</sup>. Therefore psychological expertise, or involvement of psychosocial staff in cancer genetics clinics, is not routine or standardised. In addition, there is considerable variation in the design of service provision nationally<sup>(2,29,30)</sup> and internationally<sup>(1)</sup>: comparisons of different models of service provision services have attempted to determine the psychological consequences of different approaches and infer best practice for psychological care.

Findings are interesting and perhaps counterintuitive. In the UK, it was anticipated that a model for service provision

would be identified that could be used to develop or refine other services, but no single model has emerged. In a comparison of risk counselling in S.E Scotland, existing genetics services were compared with community genetics clinics<sup>(29)</sup> whilst in Wales, they were compared with surgical clinics<sup>(30)</sup>; results of both studies showed no significant difference in psychosocial outcomes. Moreover, in an evaluation of psychosocial outcomes in randomly selected UK cancer genetics centres, differences in satisfaction with various aspects of service provision were found, but these could not be linked to any particular type of clinical service<sup>(31)</sup>, and no preferred model could be identified. Centres differed in the reduction of cancer worry reported by counselees, but these differences were not clinically significant. In Europe, our recent survey of seven centres found an interesting balance between convergence of aspects of clinical activity despite wide divergence in national systems of medical care and maturity of cancer genetics services, indicating some standardisation of aims and intentions, but psychosocial outcomes were not available.

## SPECIAL SITUATIONS

Genetic testing and preventive breast surgery are two situations where the potential for psychological harm is arguably greater because of the irreversible nature of the information received or intervention undertaken. Surgery in particular has been a controversial issue both amongst medical professionals as well as the lay public.

### Genetic testing

Availability and attitudes towards genetic testing and preventive surgery vary cross-culturally<sup>(32)</sup> but the psychological consequences of predictive testing for *BRCA1/2* gene mutations has now been the subject of some valuable research<sup>(8,9,33-35)</sup>, so that psychological support needs can be more accurately estimated in this context

(see 7, and 36 for reviews). These studies show psychological benefits in emotional well being for women found to be non-carriers and transient increases in distress in carriers. In the longer term, women with gene mutations may have somewhat elevated levels of cancer worry compared to non-carriers, but these are not necessarily increased over baseline levels. Younger women may be more vulnerable to distress and warrant closer monitoring. Where women's pre-test levels of distress are elevated, monitoring is also advisable, as this predicts post-test levels. However, raised levels of general distress have not been confirmed for the majority of women tested and carriers may feel more confident making subsequent risk management decisions. They value ensured access to breast surveillance programmes, and relief of long held uncertainty about their risk. All women undertaking genetic testing should be counselled about these costs and benefits of the procedure; they should be made aware of the potential for distress and of the need for adaptation to carrier status. Some may be unexpectedly distressed in reaction to their results and warrant further professional support.

Whilst seeking genetic information for family members may be a strong motivation for predictive genetic testing, other women are distressed by the thought of transferring a risk to their daughters. It has become evident from recent literature that disclosing such information in the family may be upsetting and difficult. Apart from the obvious problems of having to contact estranged or little seen relatives, quite subtle factors may influence reactions to disclosure, such as the order in which results were obtained amongst siblings, and the woman's own expectations and level of personal support. Genetic counselling can address particular hurdles in transferring information through the family, including the fact that some relatives may wish to avoid such information, and that disclosure can change family relationships.

## Preventive surgery

Evidence exists for the reduction of risk from preventive mastectomies and of the potential for reduction in anxiety about cancer, but surgery has elicited very mixed reactions across Europe, in terms of attitudes and uptake, again based largely on cultural differences. The stage of service development and national funding for health services also play a part. There are low uptake rates in France, for example, whereas the UK and The Netherlands have been active in providing surgical intervention and evaluating its impact. A recent systematic review<sup>(37)</sup> concluded that there were high levels of satisfaction with the decision to undergo preventive mastectomies, but of the psychosocial outcomes measured, body image and feelings of femininity were the most likely to cause dissatisfaction, especially if surgical complications occurred. Emotional recovery was generally good and reduced cancer worry was frequently recorded. Despite the expected levels of risk reduction, uptake of preventive mastectomy remains lower than for preventive oophorectomy in most countries.

Manchester has an active programme of cancer prevention, and our approach to risk reducing breast surgery has been to intervene on the basis of a strict clinical protocol<sup>(38)</sup>, which requires extensive pre-operative counselling by a multidisciplinary team. Specialist onco-plastic surgeons undertake surgery and long-term follow-up is a requirement. Psychological counselling and assessment involves the partner wherever possible, and involves both a discussion of the woman's own motivation, expectations, and concerns about surgery, as well as her perceived capacity to cope with complications or disappointment, should they arise. Past and present mental health status and coping resources are discussed and intervention provided where appropriate. Consultations are tailored to individual circumstances to deal with personal concerns or vulnerability factors. The protocol is flexible so that women may defer

surgery to deal with illness in the family, to have further pregnancies or resolve relationship problems or cope with other priorities. Postoperative consultations review progress at an early stage in order to provide further advice and support if appropriate.

Clinical follow up data has now accumulated in respect of psychosocial outcomes<sup>(12,39)</sup> showing low levels of cancer worry and body image concerns post operatively for the majority of women. A mean reduction of cancer worry scores of 30%-40% is observed over time, which is of clinical value. Surgical complications can have short and long term effects on psychological well being and cosmesis, and psychological support and intervention may be required. Both general psychological support strategies, and pharmacological intervention may be required for distressed women. Where body image concerns result in avoidance behaviour, cognitive behaviour therapy or use of guided imagery may be very beneficial. Women may need weeks or months to accommodate the changes in their breasts following reconstruction, and some say that the breasts never quite feel like their natural breasts. This does not cause regret but is seen as an anticipated consequence of risk reduction, which in itself can bring substantial relief.

Couples often need time to adapt to the change in breast sensation and appearance in the context of physical intimacy but significant difficulties in sexual functioning evoked by the procedure are not common. In our experience, where there have been pre-existing difficulties in a couple's sex life or the relationship itself, preventive surgery can add an additional strain and may be blamed for the problems.

Data from other European centres have reported the psychosocial outcomes of surgery as well as the frequency and types of complications associated with breast reconstruction<sup>(40-42)</sup>. Results emphasise the need to adequately inform and discuss all aspects of surgery realistically with women who are



considering this approach. Only then can they balance the advantages and disadvantages in the context of their own priorities and personal circumstances.

A specific concern that has arisen in our preventive programme is the presentation of women requesting mastectomies who have factitious family histories of breast cancer<sup>(43)</sup>, which could lead to inappropriate surgery being undertaken. Although this is uncommon, it is essential for clinical teams to be alert to inconsistent family histories, and to verify the family history of cancers before agreeing to proceed.

Finally, it is important to mention psychological care needs for women affected with cancer who carry a genetic mutation or have a strong family history. It is beyond the remit of this paper to discuss this in detail, but it is important to highlight the need for good prospective studies, both qualitative and quantitative, to tease out the interplay of complex decisions<sup>(44)</sup> and psychological issues<sup>(45-48)</sup> pertaining to their predicament.

## SUMMARY

An extensive evidence base now exists in which there are consistent findings in key areas, so that psychosocial services within cancer genetics can be developed according to local resources and priorities. Psychosocial counselling and information prior to predictive testing and preventive surgery, delivered by a trained health professional, should be available in cancer genetics services. However, routine psychological support for women at increased risk is not necessary for the majority. There may be a need for psychological assessment and/or intervention for women with psychological morbidity or unresolved grief, arising from the family history, and for those women who have an unexpectedly difficult reaction to predictive testing or preventive surgery. Difficulties in adapting to surgical outcomes or changes in sexual functioning may affect a minority of couples and warrant further help.

New areas of need for psychological support are emerging as other aspects of cancer genetics are researched, such as difficulties in disclosing risk information to family members and problems concerning complex decision-making for affected women. Therefore cancer genetics service staff should be aware of the potential for distress and aim to build a multidisciplinary team skilled to provide optimal care, guided by clinical guidelines and protocols to support their interventions, together with standard information sources for their counselees.

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