

# The impact of information given to patients' families: Breast cancer risk notification

*ESTRELLA DURÁ FERRANDIS (\*)*  
*YOLANDA ANDREU (\*)*  
*M. JOSÉ GALDÓN (\*)*

## INTRODUCTION

A family history of breast cancer is a clear risk factor for developing the disease. In effect, women who have a first degree relative with breast cancer have a 2- to 3-fold higher risk of developing the disease, while women who have both the mother and a sister with breast cancer are 14 times more likely to develop the disease than patients without a family history of breast cancer (Sattin et al., 1985). Therefore, when a woman is diagnosed of breast cancer, all her female first degree relatives become individuals at risk. This implies a number of important aspects to be taken into account by psycho-oncology professionals. Four of these aspects will be dealt with here: (a) Knowledge of the increased risk of developing breast cancer can generate much psychological distress; (b) These women become the main target of secondary breast can-

cer prevention strategies, where periodic breast controls are essential; (c) These women may either over- or underestimate their true risk status; and (d) these women may request genetic testing to determine whether they carry genetic mutations that cause some types of breast cancer.

## PSYCHOLOGICAL DISTRESS IN WOMEN WITH A FAMILY HISTORY OF BREAST CANCER

A number of studies have shown that women with a family history of breast cancer can develop a broad range of psychopathological symptoms, including anxiety, intrusive and persistent concern over breast cancer, fear and uncertainty, feelings of guilt, helplessness against the disease, despair, isolation and loneliness (Gagnon et al., 1996; Kash et al., 1992; Kash et al., 1995; Lerman et al., 1993; Valdimarsdottir et al., 1995; Wellisch et al., 1992; Zakowski et al., 1997). Two different studies (Gagnon et al., 1996; Kash et al., 1992) found women with a family history of breast cancer to yield Brief Symptom Inventory global scores similar to those of women who had survived Hodgkin's lymphoma or leu-

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(\*) Departamento de Personalidad, Evaluación y Tratamientos Psicológicos, Facultad de Psicología, Universidad de Valencia.

kemia. Other data also suggest that women with a family history of breast cancer may suffer mood disturbances comparable to those seen in patients recently diagnosed of breast cancer (Lerman & Schwartz, 1993).

A number of factors may evidently cause psychological distress in this population (Gagnon et al., 1996), including the awareness of being a high risk individual for a life-threatening and potentially disfiguring illness; anticipation of the disease in oneself; the caring for relatives suffering from the disease; or personal identification with the traumatic experiences of such affected relatives.

In sum, in addition to the stress associated with the diagnosis and treatment of breast cancer in a close relative, female first-degree relatives of breast cancer patients suffer the added stress of learning that they are at risk of this same disease. Psychological screening of these subjects is therefore indicated, with attention to the psychological problems they may present. In this sense, some recent studies have proposed the development of specific intervention programs for the relatives of recently diagnosed breast cancer patients (Schwartz et al., 1998).

On the other hand, research suggests that one consequence of psychological distress in this population may be decreased adherence to breast-self examination and mammography (Kash et al., 1992; Lerman et al., 1993).

#### SECONDARY BREAST CANCER PREVENTION IN WOMEN WITH A FAMILY HISTORY OF BREAST CANCER

The early detection of breast cancer is presently the most effective way to reduce mortality associated with the disease. Therefore, as risk individuals, women with a family history of breast cancer become the central target of secondary breast cancer prevention measures (Chart & Franssen, 1997). However, studies show that a substantial proportion of women with such a family history do not adhere to recommended mammographic screening. When considering concrete statistics, the non-adherence percentages are seen to vary considerably from one study to another: in the case of mammography, from 45% to 85% (Lerman & Schwartz, 1993). Simi-

lar considerations apply to clinical exploration - though percentage adherence in this case seems to be better than for mammographic screening - and self-examination. Attempts have been made to explain such diverging results in terms of certain psychological variables that seem to modulate the relation between a family history of breast cancer and screening behavior (Lerman et al., 1993). In this sense, emphasis has been placed on the important role play by (a) patient self-perception of the level of risk; and (b) the psychological distress or anxiety suffered by women with a family history of the disease.

Thus, on one hand, it has been postulated that the impact of a family history upon adherence to screening may be mediated by *perceived vulnerability* to the disease. In this sense, the presence of a given risk factor (in this case a family history of breast cancer) may be thought to likely predispose to adherence only if the women are aware of the importance of that factor for the development of the disease (Costanza et al., 1992; Taplin, Anderman & Grothaus, 1989). According to Costanza et al. (1992), although the existence of a family history of breast cancer is not associated with mammographic screening, personal awareness of the fact that such a history constitutes a risk factor is indeed related to screening adherence. These observations suggest that knowledge or information concerning the risk factors, and thus personal risk (perceived vulnerability), is the variable predicting the adoption of preventive measures, rather than objective risk as such. In the study by Lipkus, Rimer and Strigo (1996), both objective and subjective breast cancer risk was seen to be individually associated with the use of mammography; however, when objective and subjective risk were included in a multivariate model, only subjective risk predicted adherence to mammography. However, as in the case of the general population, the role of this variable is complex. In effect, while some studies have reported a positive relation between perceived vulnerability and adherence to screening others have found that intense perceived vulnerability to breast cancer may inhibit the use of screening among high risk women (Hailey, 1991).

On the other hand, on assessing perceived risk among women with a family history of breast cancer, these individuals have been observed to

systematically overestimate the true risk of the disease (Bondy et al., 1992; Evans et al., 1993; Gagnon et al., 1996; Stefanek, 1990). Specifically, the study of Evans et al. (1993) found only 11% of the women in the series to be able to correctly estimate risk, while 45% overestimated it. In the more recent study by Gagnon et al. (1996), mean perceived risk among the participating women was 55%, while the true mean risk (derived from empirical tables) was only 18%; in turn, 75% of these women subjectively estimated risk to be more than double the true risk. A number of authors have pointed out that such incorrect perception and overestimation of risk could contribute to increase psychological distress in a population subgroup that – as has already been pointed out – often exhibits a broad range of psychopathological symptoms. Empirical research has shown the relation between a family history of breast cancer, psychological distress and screening behavior to be complex. While some authors consider that the probability of adherence to screening recommendations decreases with increasing psychological distress symptoms (Kash et al., 1992; Lerman et al., 1990, 1993), others describe a positive association between the two variables (Stefanek & Wilcox, 1991).

These conflicting results were initially interpreted in terms of the classical «Fear-arousing Communications» Theory (Janis & Feshbach, 1953). According to this theory, a nonlinear relation exists between anxiety and preventive behavior, where moderate psychological distress would be optimum for activating preventive behavior, while low distress levels could fail to generate sufficient motivation for behavioral change, and excessively intense distress could lead to avoidance of information relating to the threat (Hailey, 1991; Lerman & Schwartz, 1993). Those authors, whose own empirical results proved contradictory, subsequently agreed that their observed differences in anxiety level justified the results obtained, and that in both cases the findings point to a nonlinear relation between anxiety and preventive behavior (Kash, 1992; Lerman, Kash & Stefanek, 1994; Stefanek, 1992).

More recently, Leventhal's «Self-regulation Theory» (Leventhal, 1970; Leventhal, Meyer & Nerenz, 1980) was proposed with the principal aim of understanding the process by which peo-

ple define and represent disease threats and how they cope with such threats. As such, the theory may constitute a more adequate reference in the specific context of women with a family history of breast cancer. In effect, according to Leventhal, and considering that the individual reacts both cognitively and emotionally to health communications, two parallel channels or independent systems would exist for the processing of information, and both could occasionally interfere with each other. One of the systems or channels would give rise to the elaboration of an objective representation of the health threat and to the development of coping responses for controlling the threat (i.e., threat control), while the second system or channel would involve processing of the emotional reactions to the threat and the implementation of coping strategies to control such reactions (fear control). As pointed out by Shiloh, Vinter and Barak (1997), screening behaviors are a good candidate for the development of interference between both channels or systems, since occasionally screening avoidance may be a more effective strategy for controlling fear – thereby preventing the implementation of coping strategies to deal with the objective threat.

In sum, while a moderate level of breast cancer fear or distress may contribute to the development of preventive behavior, intense distress associated with marked perceived vulnerability to breast cancer may lead to the avoidance of screening as a way to cope with fear of the threat of disease. Mammographic screening may pose a threat particularly to women with a high risk of developing breast cancer, since the technique is unable to reduce the probability of developing the disease. This may cause such women to try to control their fear by avoiding anxiety-generating actions – of which mammographic screening may constitute an example.

#### BREAST CANCER RISK COUNSELING

The existence of such complex relationships between perceived vulnerability, psychological distress and adherence to screening in women with a family history of breast cancer has produced the need for specific intervention programs for this high risk population. Most such

programs have adopted the traditional medical model of genetic counseling – their central aim being empirical assessment of the true or statistical risk of breast cancer, with risk notification to the woman in order to adjust her perceived vulnerability to the true risk, and to promote early breast cancer detection behavior. In general, these programs include a few sessions (sometimes only one) in which risk quantification, patient notification and the recommendation and instruction of preventive behavior is conducted by a health professional on an individualized basis.

As regards the quantification of statistical risk, the two most commonly used systems have been recently developed by Gail et al. (1989) and Clauss et al. (1990, 1994). Both are statistical estimates of breast cancer risk based on a series of factors. The first approach constitutes a multifactor system involving five variables: the number of first degree relatives with breast cancer, the current age of the woman, her age at menarche, age at term of first pregnancy, and the number of previous breast biopsies performed. The system developed by Clauss et al. in turn contemplates only the number of first or second degree relatives with breast cancer, the age of the affected relative/s at the time of diagnosis of the disease, and the age of the woman at the time of risk assessment.

A number of authors have published results suggesting that individualized breast cancer risk counseling improves understanding of the risk of breast cancer, thereby improving agreement between real and perceived risk (Evans et al., 1994; Gagnon et al., 1996; Lerman et al., 1995). However, such programs also have limitations. In effect, a number of studies have found that risk counseling does not increase adherence to breast cancer screening (Evans et al., 1994; Gagnon et al., 1996), while others report that although perceived risk is better adjusted to true risk as a result of counseling, many women continue to have mistaken perceptions of breast cancer risk and have difficulties remembering the notified risk level (Cull et al., 1999; Hallowell et al., 1997; Lloyd et al., 1996; Watson et al., 1999). Such limitations point to the need for taking into account the psychological aspects implicated in risk counseling programs – particularly when considering the results obtained by Lerman et al.

(1995), who found that the subgroup of women who before counseling already exhibited high levels of concern and anxiety over breast cancer were the only patients who failed to benefit from counseling. The authors suggest that the high distress levels in these women may have interfered with their capacity to assimilate the information provided, and point to the need for developing and assessing strategies to deal with the psychological challenges posed by risk counseling.

In this sense, the most recent approaches to breast cancer risk counseling emphasize the need to combine risk counseling and psychological counseling, in a continuous process over time and involving long-term assessments (Bennett, Gattas & Teh, 1999; Hopwood et al., 1998; Watson et al., 1998). Of the programs for women with a high risk of developing breast cancer that combine risk and psychological counseling, emphasis should be placed on the Strang Cancer Prevention Center (New York) protocol, since a first assessment of this program has already been published (Kash et al., 1995). The program, based on six consecutive weekly sessions, sets the following objectives: reduced emotional stress and anxiety, lessened perceived vulnerability to breast cancer, modification of health beliefs, and increased adherence to screening.

In order to achieve these aims, the program combines individual psychotherapy with group psychoeducational intervention based on Leventhal's «Self-regulation Theory» (Leventhal, Diefenbach & Leventhal, 1992), involving three components: education, cognitive restructuring and emotional support. The educational component provides the woman with information concerning her relative risk, clarifying her knowledge of the disease and other risk factors, detailing healthy life styles and modifying eating habits; instruction on self-exploration techniques, and emphasis on the importance of adherence to the recommended screening regimens. Cognitive restructuring in term aims to reduce anxiety and the feeling of helplessness, and to help women solve problems, encouraging them to use active coping strategies instead of avoiding or denying risk status. Finally, emotional support attempts to reduce the feeling of isolation, encouraging the patient to share her feelings and thoughts with others, and to establish

communicative and supportive relations with other women.

A pilot study applying this program was able to reduce perceived vulnerability, adjusting it to the true statistical risk, correcting false perceptions regarding breast cancer, and boosting adherence to screening techniques over the following three-year period. At present, the authors are evaluating the program based on a control group randomization design, with promising preliminary results.

#### GENETIC TESTING IN WOMEN WITH A FAMILY HISTORY OF BREAST CANCER

Lastly, considering that recent advances in molecular biology have shown that some breast cancers may develop as a result of mutations of several specific gene loci, many women with a family history of breast cancer could request genetic testing to determine whether they carry such mutations. However, only a small proportion of breast cancers (between 5% and 10%) are attributable to genetic mutations. In addition, the tests developed to date for evaluating mutation carrier status are complicated, expensive and not available in all oncological centers. Consequently, it is necessary to determine who should undergo genetic testing, and particularly the conditions under which testing should occur.

A number of authors have proposed assigning genetic testing on two basic context (Lynch & Lynch, 1996): (1) families thought to most likely present a hereditary syndrome predisposing to cancer; and (2) family members who have given informed consent before testing and before disclosure of the test results. The chance of carrying a genetic mutation varies markedly from woman to woman, depending on the family history of breast cancer and related cancers. In this context, risk-prediction algorithms that fully reflect our knowledge of the nature of the inheritance mechanism may contribute in an important way to decide genetic testing. Models for estimating the individual probability of carrying a BRCA1 or BRCA2 mutation are being developed (Parmigiani, Berry & Aguilar, 1998); in view of the expense of testing and the possibility of uninformative results, such estimates may be quite useful. On the other hand, genetic testing should be

performed in centers where physicians are highly experienced in oncology and genetics and have worked intensively with cancer-prone families. Ideally, such groups should have consultants who are skilled genetic counselors, social workers, and psychologists who are knowledgeable about how this genetic information might affect insurability, employability, intrafamily conflicts, and emotions.

In recent years, many countries have seen the emergence of Cancer Family Clinics, usually run jointly by an oncological surgeon, oncologist and a geneticist. The purpose of such clinics (Bennett, Gattas & Teh, 1999) is to: provide individuals with information about familial aspects of cancer; assess their statistical risk of developing breast cancer; offer genetic testing where appropriate; make recommendations regarding the need for either ongoing surveillance (screening) or more active interventional therapies (prophylactic surgery or chemoprevention); and alleviate anxiety, since many women may have an inappropriately high expectation of their degree of risk – and most such women can be greatly reassured as a result of counseling in the clinic.

Although such centers have proliferated in many countries in recent years, no studies have yet been made to assess their results. The psychological aspects of cancer genetics practices remain to be addressed. Prospective studies with an adequate duration of follow-up will be required to assess outcomes, and to help define vulnerable subgroups that may exhibit poor adjustment to risk counseling and/or genetic testing and intervention (Beckmann et al., 1996; Lerman & Croyle, 1994; Hopwood, 1997).

Furthermore, breast cancer genetic counseling raises a series of ethical issues in which the questions presently outnumber the answers: Should a woman be informed of the risk of breast cancer if she cannot at the same time receive options for avoiding the disease? Is it an obligation to inform the relatives of breast cancer patients of their risk of developing the disease? To what extent should women with a genetic risk of developing breast cancer be subjected to chemoprevention or other procedures? In an article addressing these aspects, Lerman, Rimer and Engstrom (1991) suggested that application of the principles of informed consent theory to genetic counseling in cancer might

help clarify some of these ethical questions. Thus, the non-maleficence principle requires the notification of personal risk to imply no psychological sequelae, with the need to intervene upon such sequelae if they arise. In turn, the informed and autonomous decision-taking principle implies that the communication process must guarantee adequate comprehension of the information provided, while the principle of confidentiality obliges observance of the right to intimacy and non-discrimination.

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## ABSTRACT

A family history of breast cancer is a clear risk for developing the disease. Therefore, when a woman is diagnosed with breast cancer all her female first degree relatives become population at risk. This involve a number of important aspects to be taken into account by psychooncology professionals. (a) First, in addition to the stress associated with the diagnosis and treatment of breast cancer in a close relative, first degree relatives of breast cancer patients have the added stress of learning that they are at risk of this disease. (b) Second, these women become the main target of secondary breast cancer prevention strategies. However, various reports show that a considerable percentage of these women do not follow the recommended screening methods. For this reason, it is necessary to study the possible contribution of psychosocial factors, specially health beliefs, in the practice of preventive behavior aimed at preventing breast cancer in this population, and to design strategies to promote preventive practices. (c) Most of the research on health beliefs among women at risk for breast cancer has focused on risk perception. This research has found that some women with a family history of breast cancer have significantly overestimated their risk, while others have underestimated their risk. The need to provide risk counselling schemes for these women is therefore proposed, in order to estimate and advise them of their real risk. (d) Finally, these women may request genetic testing to determine whether they carry genetic mutations (BRCA1, BRCA2, or others) that cause some types of breast cancer. However, it must be remembered that, although many first degree relatives will have heard of and seek «the cancer gene test», currently testing is appropriate and available only for rare individuals. All these issues are reviewed in the present paper.

*Key words:* Breast cancer, psychology, risk counselling, genetic counselling.

## RESUMO

Uma história familiar de cancro da mama é um factor de risco para o desenvolvimento da doença. Assim, quando é diagnosticado um cancro da mama a uma mulher, todas as mulheres suas familiares em primeiro grau são uma população em risco. Isto implica aspectos importantes que devem ser tidos em conta pelos profissionais de psico-oncologia. (a) Juntamente com o stress associado ao diagnóstico e tratamento do cancro numa familiar próxima, estas mulheres experimentam também o stress de saberem que também têm risco de desenvolverem a doença. (b) Estas mulheres tornam-se, portanto, um grupo-alvo de estratégias de prevenção secundária do cancro da mama. Por esta razão, é necessário estudar a influência de factores psicossociais, especialmente das crenças de saúde, na prática de comportamentos especificamente direccionados para a prevenção do cancro da mama nessa população e, ao mesmo tempo, também é necessário delinear estratégias que promovam práticas preventivas. (c) A maior parte da investigação sobre as crenças de saúde de mulheres em risco de desenvolverem cancro da mama tem-se centrado na percepção de risco. Este estudo mostra que algumas mulheres com história familiar de cancro da mama sobrestimam significativamente o seu risco, enquanto outras o subestimam. Faz-se uma proposta de aconselhamento de risco, com a finalidade de avaliá-lo e aconselhar essas mulheres sobre o seu risco real. (d) Finalmente, estas mulheres podem necessitar de realizar testes genéticos para averiguar se são portadoras de marcadores relacionados com certos tipos de cancro da mama. Contudo, deve ser lembrado que, embora várias familiares em primeiro grau já tenham ouvido falar e solicitem fazer «o teste do gene do cancro», a sua realização só está indicada para algumas. Todos estes aspectos são revistos neste artigo.

*Palavras-chave:* Cancro da mama, psicologia, aconselhamento de risco, aconselhamento genético.