

Commentary

Breast cancer risk perception: what do we know and understand?

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Abstract

Women's perceptions of breast cancer risk are largely inaccurate and are often associated with high levels of anxiety about cancer. There are interesting cultural differences that are not well researched. Genetic risk counselling significantly improves accuracy of women's perceptions of risk, but not necessarily to the correct level. Reasons for this are unclear, but may relate to personal beliefs about susceptibility and to problems or variations in risk communication. Research into the impact of demographic and psychological factors on risk perception has been inconclusive. An understanding of the process of developing a perception of risk would help to inform risk counselling strategies. This is important, because knowledge of risk is needed both for appropriate health care decision making and to reassure women who are not at increased risk.

Keywords: breast cancer, familial, genetic, psychosocial, risk perception

Introduction

Identification of breast and ovarian cancer predisposing genes [1,2] has created a demand for personalized risk information in families with a cancer family history. Services have developed to respond to this new need, and genetic risk counselling for women with histories of familial breast or ovarian cancer is widely advocated [3–5]. Guidelines for clinicians have been published [4,6,7], and the need to tailor information to the individual's affective state and to consider pre-existing perceptions has been recognized [8]. Psychosocial research has explored women's knowledge of personal risk before and after genetic counselling, and has begun to determine the emotional costs and benefits of acquiring risk information. It is evident that a wide range of methods have been used to

examine risk perceptions, resulting in apparently contradictory results. It is therefore timely to review the state of our knowledge about risk perception and to consider whether an accurate understanding of risk matters.

Accuracy of risk perceptions

Studies in the UK and USA have shown that women's perceptions of the population risk of cancer and their personal vulnerability are at variance with medical perspectives. Before genetic risk counselling, a minority of women have an accurate view of the chances of developing breast cancer, and the majority either over- or underestimate [9,10]. There are interesting differences between findings, with the extent of risk overestimation appearing to be much greater in studies conducted in the USA [11,12] and

Canada [13] than in UK studies [9,10], which have sometimes identified a larger proportion of underestimators. These differences may be due to true cultural differences, although access to risk information and methodological differences (such as sample derivation and the measurement of risk perception) also contribute. Genetic risk counselling has been shown to improve significantly the accuracy of risk perception [10–12,14–16], but up to 30% of UK women and two-thirds of US women continue to report exaggerated risks of cancer. This raises two broad questions. First, why is this happening? Second, does it matter? Both of these issues have serious implications for the practice of future cancer risk counselling.

Why do women continue to have inaccurate perceptions of the risk of cancer?

It is unclear whether failure to modify inaccurate risk perceptions after risk counselling reflects inadequacy of the communication process itself, and/or difficulties on the part of counselled persons in comprehending or remembering the information given. The ability to grasp complex information about inheritance, gene expression and the use of numeric probability terms, such as the odds ratio, has been questioned. However, within a given country, variations in methods of risk presentation have resulted in broadly similar levels of risk inaccuracy [10,14–16]. This suggests that, although all of the above factors may have some relevance, more subtle underlying factors are also involved.

It has been shown that both younger [17] and older [18] women often overestimate the risk of death from breast cancer, irrespective of their actual risk level. In contrast, responses to questions about the comparative risk of dying from breast cancer or from heart disease were broadly accurate [18], suggesting that women had a realistic idea of the relative risks, but that the way risk information is framed or elicited can affect perceived risk accuracy. Interestingly, women who were actually in the 'high-risk' group underestimated their risk compared with the average woman, raising the possibility of an 'optimistic bias' in risk perception, although Woloshin *et al* [18] state that their own data do not support this explanation. The tendency for counselled persons to translate a numerical value into a broader relative risk category (eg 'higher' or 'average') has been shown in other genetics settings and, although a relationship between the medical risk value and use of a lay 'high' or 'low' category is maintained, much information about risk is lost in the process [19].

Studies that are based on the use of precise numerical risk values are more likely to result in high levels of misclassified risk perceptions (despite genetic counselling) compared with those that use broader categories of risk such as 'lower than average', 'average' or 'high risk', perhaps because they are more cognitively demanding. Some confirmatory evidence for this rests in the finding

that women with less education and less numeracy had less accurate numerical perceptions of risk [18]. It is also concerning to find that the concept of 'lifetime risk', implicit in the 1:10 or 1:12 population risk figures quoted frequently by both health professionals and the media, is often misunderstood [15].

Surprisingly, the process involved in developing a personal perception of the risk of breast cancer, the events that influence it and the relative contribution of affective or cognitive factors are largely unknown. Genetic counselling is framed around the probability of cancer occurrence, but the woman's notion of risk is infrequently explored. Psychosocial research has largely assessed women's risk knowledge in the same terms as used by health professionals in genetics consultations, assuming that the lay construction of risk is comparable with objective estimates by health professionals. There has been little qualitative research focused on the meaning of risk, and it may be difficult to know what exactly is being considered when women formulate their personal risks. This could include the likelihood of developing cancer, the perceived lethality of the disease, or its controllability.

Factors associated with the perception of risk

Individuals with strong family histories may acknowledge an increase in risk, but frequently think in non-Mendelian terms and are more influenced by their particular familial experience of the condition [5,20]. Their perceived vulnerability may be based on the burden of cancer in the family rather than on the hereditary nature of a faulty gene. This will help to explain why some women do not adjust their risk to the value given by the genetic counsellor. A number of other factors have been explored for their possible association with risk perception, including demographic and psychological factors [10,13–15], coping and cognitive factors [21] and heuristic factors [22]. The impact on risk perception of anxiety proneness, 'state' anxiety (ie anxiety at a particular moment, such as when attending for risk counselling), prior mental health, age, the number of affected relatives and the individual doctor who is communicating risk information have been evaluated, but no conclusive associations have been identified.

In a study from Scotland [10], older age, higher anxiety proneness and a tendency to 'externalize' control over health were found to be linked with risk overestimation before counselling, but only age was linked to any significant degree. Higher levels of worry about cancer have been significantly associated with a tendency to overestimate risk before risk counselling [23], but the cause/effect nature of this relationship is uncertain. A quantitative survey of 330 women [23] showed that those who had lost a mother (from breast cancer) in adolescence were more likely to overestimate and to have higher levels of cancer worry. This may be linked to the observations that

a cohort of adolescent daughters of women with breast cancer had difficulties in resolving the illness experience [24], and these findings need confirmation. The theory of parent/child attachment is interesting in this context, because it suggests that disruption to this relationship because of separation, illness or death can have an influence on relationships and behaviour in adult life, depending on the security of the original attachment [25]. This could help explain differences in the resolution of early bereavement from cancer and subsequent risk perception, but these ideas are as yet largely unexplored. The theory could also help to explain variations (as yet unquantified) in ability to communicate about risk: feeling free to talk openly about the loss or risk would be associated with secure attachment/realistic risk; whereas being preoccupied and communicating negatively would be associated with insecure attachment/overestimating risk. These hypotheses warrant further exploration.

The experience of cancer in the family

The timing of illness events and deaths in cancer-prone families is often an important triggering factor in consideration of personal risk and in seeking risk assessment and advice on risk management or cancer prevention. Women's perceptions of vulnerability may be developed from this 'lived experience' of cancer and through strong identification with an affected or deceased mother or sister [26]. This is congruent with findings in other genetic conditions, in which the 'availability heuristic' has been found to influence risk perception. This means that people judge an experience that is cognitively 'available' (ie can be remembered) as more likely to occur, and beliefs about the frequency of lethal events may lead to overestimation of risk of disease occurrence or of the seriousness of the risk. Moreover, the perception of the severity of the disorder tends to be included in the interpretation of the risk, irrespective of the risk value given at genetic counselling. Thus, both cognitive and emotional factors interplay in the formulation of risk perception. Another example of this interaction in the cancer risk setting was described by Schwartz *et al* [21], who studied women at increased risk for ovarian cancer. They found a relationship between the tendency to overestimate risk, increased distress and a form of coping in which the threat of the disease is actively confronted, as opposed to trying to avoid such information. Results such as these, if confirmed, would help in the design of interventions to reduce intrusive worries and foster more accurate risk perceptions.

Qualitative research methods have started to improve our understanding of the development of risk perception. Canadian researchers interviewed women who had a primary relative with breast cancer, but who were not attending family risk clinics [26]. Those investigators suggested the importance of three key stages in the development of risk perception, in which the emotional impact of

the family member's cancer and the woman's sense of vulnerability played major roles in determining the degree of threat. The more difficult the illness experience and the more unresolved the emotional impact of the breast cancer, the less women felt in control of their risk. The importance of clear information, open communication within the family, and personal support were all deemed to be important in facilitating the development of an accurate estimation of risk [27].

Role of genetic risk counselling

The positive impact of genetic risk counselling on risk accuracy has been shown repeatedly [10,12,14–16], and additional information in the form of a personal letter [10] or audiotape of the consultation [28], or a more general video presentation [29] have all been shown to confer additional small benefits in accuracy of risk perception. They may help to reduce factual inaccuracies and reinforce retention of correct information. It remains to be seen whether new forms of risk presentation using innovative computer graphics can improve on these results. The most effective methods of presenting risk information to women who continue to overestimate or underestimate are still to be determined, but an important initiative has recently been taken by the American Cancer Society [30] to try to develop a consensus communications model that provides guidance for breast cancer risk communication. The recommendations include the avoidance of the concept of lifetime risk; use of absolute risk in preference to relative risk; an agreed definition of 'high risk', which is based on the need to take different action from the average woman and the use of comparison risks for other diseases. These recommendations follow logically from published research in the field, and will have implications for the delivery of risk information both in educating the general population and in personalized genetic risk counselling.

Is accuracy in risk perception important?

Generating a risk value is extremely useful for the clinician, because it will indicate which risk management options are available and facilitate discussion of screening and prevention strategies [7,18]. Frequently, only women in the highest risk categories (lifetime risk >1:4) have access to genetic testing or are eligible to consider risk-reducing bilateral mastectomy or oophorectomy. Women need appropriate information with which to appraise their options for risk management, make informed decisions and to understand why some services are not available to them. Arguably, it is as important to understand why a counselled person's perception of risk is inaccurate, so that this can be explored and any obvious misperceptions (such as belief that similarity in appearance indicates similarity in risk) addressed. Some women may not want a precise risk figure, and sensitive interviewing is required to avoid giving unwanted details, which cannot be eradicated. A recent bereavement or an impending death may

increase the fear of cancer and influence feelings of vulnerability. Some women are unable to cope with their worries or grief and need referral for psychological assessment and appropriate intervention, based on an awareness of both the actual and perceived risks.

Logically, it is important to prevent women who overestimate risk from undergoing excessive screening and preventive strategies, and to encourage those who underestimate to take appropriate health care behaviour. The impact of risk knowledge on breast checking and adherence to screening mammography has been investigated, and appears to be complex. Although risk awareness may enhance screening adherence, the effect is moderated by anxiety and education ([12] and Smith RA, unpublished data, 2000). Thus, highly anxious women and less educated women may have suboptimal levels of compliance, suggesting that both education and tailored information are needed.

Implications for clinical practice

An understanding of a woman's risk perception, which is grounded in a knowledge of her true risk, is a necessary basis for risk management and decision making. The processes through which women develop a perception of risk have been described as complex and multifaceted, and there is little doubt that the lived experience of breast cancer can interfere with the development of accurate perception of risk and can cause ongoing cancer worry. A better understanding of the development and maintenance of beliefs about breast cancer and personal risk is needed, together with an assessment of cancer-related anxiety in order to help health professionals to provide optimal risk counselling and discussion of risk management. The impact of guidelines on risk communication needs to be evaluated in terms of improved risk knowledge in the population at large, as well as in women with a family history of breast cancer.

Women's concerns need to be more systematically elicited and explored in the genetics clinic, as has been advocated in the breast cancer clinic. The use of a more emotionally focused approach to genetic risk counselling has implications for the training and support of genetic counsellors. At-risk women are likely to vary in the type and amount of information they need, as well as in their preferences for involvement in decision-making processes. Risk counselling that relies only on measuring probability will remain a necessary, but insufficient basis for dealing with the sensitive issue of a personal risk of breast cancer.

Conclusion

The rapid response to the new breast cancer genetics has led to the development of specialist services to provide risk assessment and genetic counselling. Psychosocial research has shown that these services have a positive

impact on risk knowledge, albeit with some interesting cultural differences. Intriguingly, however, a significant proportion of women continue to hold misperceptions which are not explained by a range of demographic or psychological factors. To explore women's perceived vulnerability to cancer, we need a better understanding of the effect of growing up in a cancer-prone family, together with insights into family relationships. Improved methods of risk communication will also be important, to ensure that women have appropriate risk information with which to make informed choices about risk management options and preventative interventions.

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