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Women’s perceptions of familial aspects of breast cancer

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Abstract

Women’s understanding of familial aspects of breast cancer was examined using both focus groups and interviews. The studies covered issues related to perceptions of breast cancer risk factors, perceived breast cancer risk, understanding of risk information, and family history of breast cancer as a risk factor. Study 1 consisted of four focus group discussions with women from the general community. Study 2 comprised ten face-to-face interviews with women who had a family history of breast cancer. The results in combination indicate a fairly high level of awareness of family history as a risk factor for breast cancer. However, the definition of a familial history of breast cancer differed between the groups, with those without a family history being more inclusive than those with such a history. The paper concludes with suggestions for use by those developing resources materials for those with a familial history of breast cancer.

Introduction

Family history and breast cancer risk

Breast cancer is the most common form of cancer among Australian women (McCreddie et al., 1995). It is estimated that 1 in 13 Australian women will develop breast cancer by the age of 75 (Karlik et al., 1996), while in the UK it is estimated that 1 in 11 women will develop breast cancer at some time in their lives (CRC, 2000). Having a family history of breast cancer is recognized as one of the strongest risk factors for developing the disease. A recent review of the literature (Thompson, 1994) suggests that having any first-degree relative with breast cancer may increase a woman’s risk, having multiple first-degree relatives affected is associated with particularly elevated risks, and having a second-degree relative affected with breast cancer also appears to increase the risk of breast cancer. The risks associated with affected members on the paternal and maternal sides of the family appear to be equal (Thompson, 1994), and the risks of breast cancer are particularly elevated for women whose
relatives were diagnosed with breast cancer at an early age (Claus et al., 1994, 1996; Evans et al., 1994; Peto et al., 1996). Although the literature demonstrates conclusive evidence of an increased risk of breast cancer due to having a family history of breast cancer, it must be stressed that the associated risks are not extremely high, and that only a very small subset of the population would be considered to be at exceptionally high risk (McCredie et al., 1995).

**Perceptions of familial breast cancer risk**

Qualitative studies demonstrate that women recognize family history of breast cancer as a risk factor (Savage and Clarke, 1998; Zapka and Berkowitz, 1992). However, little is known about women’s understanding of the familial risks associated with the disease (Evans et al., 1994). Inaccuracies in personal perceptions of risk are concerning for two reasons. First, some women may perceive their risk of breast cancer as much higher than is actually the case, which may cause these women unnecessary anxiety and possible overuse of medical services. Second, other women may underestimate their personal risk of breast cancer, and thus fail to engage in early detection measures such as mammography screening, breast self-examination (BSE), and clinical breast examination (CBE).

**Perceived risk and early detection behaviours**

In Australia, free screening mammograms are available to all women aged over 40, with women aged 50-69 actively encouraged to have a screening mammogram every two years. All Australian women are also recommended to practice monthly BSE, and have a yearly CBE if over the age of 40 years (Genetic Testing Working Group of the NH and MRC National Breast Cancer Centre, 1996). Women who have several close relatives who have had breast cancer, or have relatives who have been diagnosed with breast cancer at an early age, are advised to consider more regular mammograms and six monthly CBEs, depending on the strength of the family history of breast cancer (Genetic Testing Working Group of the NH and MRC National Breast Cancer Centre, 1996).

Perceived susceptibility to breast cancer has been associated with screening mammography (Champion, 1991; Cockburn et al., 1991; Stein et al., 1992) and BSE (Champion, 1991; Wyper, 1990) behaviours. Studies which have focussed on women with a family history of breast cancer show that, for these women, having a higher perception of the risk of breast cancer appears to motivate mammography screening behaviour (Bondy et al., 1992; Costanza et al., 1992; Vernon et al., 1993; Vogel et al., 1990).

It is women’s perceived risk of breast cancer, not their objective risk, which influences their early detection behaviour. Therefore, it is important to understand how women themselves perceive their risk of breast cancer. Little information is available on such perceptions, or how they are altered when there is a family history of breast cancer (Evans et al., 1994). There is also a general lack of research on communication of breast cancer risk, and of practical efforts to communicate risk information to women who are at an increased risk of breast cancer (Stefanek and Wilcox, 1991; Vernon et al., 1993).

**Overall methodology**
The present research formed part of a project which developed and evaluated a brochure on the topic of breast cancer risk and family history. Two qualitative studies were conducted to examine women’s perceptions of familial aspects associated with breast cancer. In the first study, focus groups were conducted with women from the general public. Focus groups were selected as an efficient way of obtaining information from many women in the general community simultaneously. This methodology is appropriate for examining public understandings of health-related issues (Kitzinger, 1995). The second study employed face-to-face interviews with women who had had either a mother or a sister diagnosed with breast cancer. For this second study, it was felt more appropriate to interview women individually. Given that the women all had at least one family member with breast cancer, the topic of the interview was potentially distressing to these women. Individual interviews enabled a more sensitive approach, and also a more detailed examination of how having a family member with breast cancer affected these women’s understanding of their breast cancer risk. The use of two methodologies was intended to provide both a breadth of information, and an opportunity to validate some findings across the two methods.

The aims of this research were:

- to examine perceptions of issues regarding breast cancer and the role of family history as a risk factor, amongst women who have a family history of breast cancer, and women who do not have a family history of breast cancer, and
- to identify possible misconceptions and information needs as information that can be used to guide the development of a brochure about familial aspects of breast cancer.

As different methodologies and samples were utilized for the two studies, the method and results of each study will be presented separately, followed by a discussion of the overall results of both studies.

**Study 1: focus groups**

**Method**

**Sample**

A total of 38 women participated in four separate group discussions. The focus group participants were recruited by contacting organizations randomly selected from the telephone directory. Each organization contacted was offered a donation of $150 for the provision of a group. One focus group comprised women from a bowling club, two groups comprised women from two separate community centers, and one group comprised women from a neighborhood house. The sampling plan comprised two groups of women aged 35-49 years, and two groups aged 50-69 years. These ages were chosen to include women who are both within and outside the recommended age group for screening mammography (50-69 years). However, one of the older groups included five women aged 70-83 years. One older and one younger group were selected from lower socioeconomic suburbs (Groups 1 and 2), and the second older and younger groups were selected from higher socioeconomic suburbs (Groups 3 and 4). None of the focus group participants had a family history of breast cancer.
Procedure

A female facilitator conducted the discussions with help from a female assistant. A list of semi-structured discussion questions was used to guide the groups. Questions included:

- Whether participants thought some women are more likely to get breast cancer and why.
- What participants thought were factors that increase or decrease a woman’s risk of getting breast cancer.
- Whether participants saw family history as an important factor affecting their risk of breast cancer.
- Which family members participants thought we need to talk about when talking about a family history of breast cancer.
- How much breast cancer thought there would have to be in the family to have an increased risk.

Participants were also presented with different formats of risk information and asked what each one meant to them, and how useful they found the information.

The duration of the discussions ranged from 45 to 75 minutes. At the conclusion of each focus group, debriefing was provided, during which the facilitator answered participants’ questions and gave accurate information about breast cancer risk factors. The discussions were audio taped with the consent of the participants. The tapes were transcribed.

Analysis

The responses made within each focus group were sorted into topics based on the issue being addressed, and then divided into categories and sub-categories, until all responses could be classified. Summaries of each category and sub-category were made separately for each focus group. Analysis involved comparing individual participants’ discussions of similar themes, both across and within the groups. This strategy was chosen as the purpose of the analysis was descriptive rather than theoretical or interpretative.

Results

Risk factors

Having a family history of breast cancer was the first risk factor to be mentioned in each of the four groups, and was also the risk factor which generated the most discussion. Most of the women agreed that there is a link between family history and breast cancer, with comments such as “It could be heredity”, “It’s in the family”, and “Often you notice it in families”. In expressing agreement that family history is a risk factor, several women provided examples of people they knew who had breast cancer running in their families.

The association between not having children and having an increased risk of breast cancer was mentioned only in one of the groups (Group 4). Diet as a risk factor for breast cancer was mentioned in both of the lower SES groups. Psychological risk factors such as stress and depression were mentioned in the two older groups. Receiving knocks to the breast was mentioned in one group as a possible cause of breast cancer, as was an injury in another
group. In two of the groups, the contraceptive pill and smoking were both mentioned briefly as risk factors for breast cancer. Other risk factors mentioned included not wearing a bra, hormone therapy, silicone, exposure to radiation at unnecessary levels, and the pesticide DDT.

Understanding of prevalence data

The focus groups provided an opportunity to examine responses to different forms of presentation of quantitative risk information, and thus produced valuable information concerning women’s comprehension of statistical risk information. They were presented with three different ways of presenting risk information: a gambling odds statement “Women have a 1 in 13 chance of developing breast cancer by the age of 74”; a percentage statement “There is a 7.5 per cent chance of developing breast cancer by the age of 74”; and a table presenting the 5, 10, 15 and 20 year risk of developing breast cancer for women of different age groups.

Gambling odds. All of the women in Groups 1, 2, and 3 found the 1 in 13 figure to be quite alarming, with comments such as “a hell of a lot of breast cancer”, “very scary”, and “a very real threat”. Whilst half of the Group 4 women shared these perceptions, the other half had thought that the figure would be higher. An interesting finding was that in each of the four groups, at least one participant counted around the room and made a comment along the lines of “If we had two more women, one of those women would develop breast cancer.”

Percentages. Across the four groups, the women generally did not find the percentage estimate useful. Comments included “Well, my percentages are not very good!” and “I have to stop and think about, and can’t be bothered working it out.”

Table. The participants’ reactions to the table were varied, with Group 4 in particular giving different responses to those of the other three groups. The presentation of this table was met with horrified reactions by most of the women in the first three groups, with comments such as “Oh God!”, “Oh my goodness!”, “It’s overwhelming”, “Too complicated”, and “Very computer!” With instruction, most of the women were able to use the table to find their own risk estimate, however, among these three groups there was a general misinterpretation of the meaning of the risk information contained in the table. The information presented in the table had more of an impact on women in Group 4, who commented on the increase in breast cancer risk with age presented in the table.

Comparison of formats

In discussing the relative usefulness of the various risk statements, Groups 1 to 3 agreed that the “1 in 13” statement was the most useful, with some members of Group 4 expressing a preference for the table. All of the women across the groups favored the “1 in 13” statement over the “7.5 per cent”. Across the groups, the women gave similar reasons for this preference. First, several of the women indicated difficulties in understanding percentages. Second, the women felt that the “1 in 13” as compared with the “7.5 per cent”, was easier to understand because it is a more personalized statement, and is therefore easier to visualize:
What is it that makes the 1 in 13 more easy to understand? It’s actual people. Yeah, people, actual people. It’s not a statistic. Like if you were into statistics and percentages you’d probably understand it better but it’s not going to impact on everybody, which is ... It’s more personal when it’s you know, you’re saying 1 in 13 Australian women ... . The number, not the percentage. (Group3)

Understanding of family history and risk of breast cancer

When asked how important family history is compared to other risk factors for breast cancer, all of the participants across the groups agreed that having a family history of breast cancer is a very important risk factor. One group replied:

I think it’s very important. Very. Yeah, very important, mmm ... Really important. Why do you say that? Because there’s a bigger risk of running it if it’s in the family. You see how they suffer. I guess if they’ve all got it then there’s a good chance that you’ll get it as well, but if only one or two have it, then it’s not such a risk factor. (Group 2)

Only one woman, from Group 4, pointed out that although family history can increase the risk of breast cancer, it does not mean that if you have got a family history of breast cancer then you definitely will get it, or that you will not get it if you do not have it in your family.

Meaning of family history

When asked about the meaning of the term “family history”, a range of responses was given, such as “It means it’s hereditary”, “It’s in the genes”, “who develops it”, and “your closest relatives”. Across the groups, all women agreed that mothers, sisters and grandmothers must be considered when thinking about the risk of a family history of breast cancer, with several women also suggesting aunts and cousins as important. Most of the participants suggested they would not consider relatives past first cousins or grandparents as constituting a family history of breast cancer.

Maternal and/or paternal relatives

The focus groups were asked to comment on whether they thought a woman should consider her father’s relatives as well as her mother’s when thinking about a family history of breast cancer. Everyone agreed quite strongly that both sides of the family should be considered, as indicated by responses such as “Oh yes!” “Definitely”, “You inherit genes from both sides” and “I think equally”. The Group 4 respondents differed, however, in that, although they believed that both sides should be considered, they thought that relatives on the mother’s side had a stronger influence on breast cancer risk.

Number of relatives

Most of the participants believed that having just one family member diagnosed with breast cancer would be enough for them to consider themselves as having an increased risk of breast cancer. A few women suggested there would need to be two cases of breast cancer in their family for them to worry about it. When asked how much breast cancer they think there would be in the family to have an increased risk, one group replied:
To have it in one ... A couple of times. You think a couple of times? You think only one? I think two, mother perhaps and a sister, or your mother’s sister. It’d only have to happen once in my family for me to worry about it. For me to start thinking seriously. (Group 1)

**Study 2: one-to-one interviews**

**Method**

**Sample**

The sample comprised ten women who had either a mother or a sister who had previously been diagnosed with breast cancer. Their ages ranged from 32 to 69 years, with a mean age of 46.1 years. The interviewees were recruited from a variety of sources, including breast cancer support groups, researchers working in the area, and by word of mouth. Interviewees were paid $20 for their contribution. The women came from a range of occupations. None of the women had received genetic counseling prior to her interview.

**Procedure**

Semi-structured face-to-face interviews were conducted in locations chosen by the interviewees. Questions included:

- Whether participants thought some women are more likely to get breast cancer and why.
- What participants thought were factors that increase or decrease a woman’s risk of getting breast cancer.
- Information about relatives with breast cancer.
- How participants rated their own chance of getting breast cancer.
- How participants thought their chance compared with that of women in general.
- Whether participants thought that family history was an important factor affecting their risk of breast cancer.
- Which family members participants thought we need to talk about when talking about a family history of breast cancer.
- How much breast cancer participants thought there would have to be in the family to have an increased risk.

The interviews were audio taped with the interviewees’ consent, and ranged in length from 25 to 45 minutes.

**Analysis**

Individual responses were sorted into topics based on the issue being addressed, and then divided into categories and sub-categories, until all responses could be classified. The process of categorization was simplified by the structured nature of the interview schedule. Responses were compared within categories, and general themes emerging across categories were explored.

**Results**
**Risk factors**

Nine of the ten women mentioned family history of breast cancer as a potential risk factor for breast cancer. However, not all of these women agreed that having a family history of breast cancer increases the risk of getting it. Four women agreed that having a family history of breast cancer can increase the risk of developing it, with comments such as “If you’ve got a family history you’re likely to get breast cancer”, and “Oh definitely the ones whose mothers, or aunties or grandmothers have had breast cancer”. While an additional two women agreed that having a family history of breast cancer can increase the risk of breast cancer, they gave specific qualifications to the suggestion. One of these women stated that it is a risk factor specifically for women whose mother had been diagnosed with breast cancer pre-menopausal, while another referred to the type of family history.

Another two women stated that they had heard that family history may be a risk factor, but were not sure themselves whether this was the case. One woman expressed her personal belief that family history is not a risk factor for breast cancer: “Oh well I don’t believe that it’s heredity. Well I just think that, often it’s just coincidence where people lose a mother and a sister …”

When asked generally about risk factors for breast cancer, only one woman specifically mentioned age, after having suggested other factors first. Not having had children was stated as a risk factor by two of the women. Another woman raised this issue as a potential risk factor during a later section of the interview. Having had a first child late in life was also raised by two of the women. Whilst one woman stated it as a risk factor for breast cancer, the other woman dismissed the possibility. Stress was perceived as a risk factor for breast cancer by two of the women, while another woman stated that “women who internalize negative emotions” were more likely than others to get breast cancer. “People who don’t get examined” were suggested by one woman as being more likely than others to get breast cancer. The issue of being knocked on the breast was raised by two of the older women. Whilst one of the women suggested that it does increase the risk of breast cancer, the other expressed uncertainty.

**Perceived breast cancer risk**

All the women interviewed were asked to rate their own chances of getting breast cancer, and indicate how their risk of breast cancer compared to that of women in general. Two of the women felt that their risk of breast cancer was about average, as stated by one woman:

Oh well look I just think it’s what the 1 in 13, I suppose. I don’t, I’m beginning to think it’s not so much the fact that my mother had it, it’s just the 1 in 13, yeah.

Another woman was unsure of her risk of breast cancer, due to her uncertainty about the link between family history and breast cancer, as expressed in the following response:

Oh well, if I’m wondering about this hereditary business I’d probably have a little bit more of a chance of getting it than the normal run of people, but if that’s not so well, I’ve got as much of a chance as everybody else’s of getting it ... or not getting it.
The remaining seven women felt that their risk of breast cancer was higher than average, however, their levels of concern about their risk varied. Four of the women indicating a “higher than average” breast cancer risk perception could be considered “optimistic” in terms of their level of concern about breast cancer. For example, one “optimist” stated that:

Well the specialists told me that seeing as how it’s in my family, uh, probably 90 to 95 per cent chance that perhaps I’ll end up with it. And my response was that well I’ll take the 5, 10 per cent chance that I won’t!

Three of the women expressed considerable concern about their risk of breast cancer. All of these women had only one first-degree relative with breast cancer, and the relatives had all been diagnosed after the age of 60. They felt that their chance of getting breast cancer was higher than others’, and expressed their concern, for example: “I don’t know and it’s a dread I don’t like to face. I worry. I do worry actually.”

An interesting point was made by two of the women in the sample, whilst discussing their perception of their own breast cancer risk. These women indicated that when their relative had been diagnosed with breast cancer, they had initially been very concerned about their own risk of breast cancer, but that with time, they had become less concerned about their own risk. Both of these women’s relatives had survived their diagnoses of breast cancer.

**Understanding of family history as a breast cancer risk factor**

The perceived importance of family history as a risk factor for breast cancer was further examined by asking the women how important they thought that having a family history of breast cancer was for the risk of getting breast cancer. Six of the women felt that having a family history of breast cancer was a very important risk factor for breast cancer. However, one of these women stated that it would be important only if there was more than one relative in the family who had had breast cancer. Two women believed that family history was not much of a risk factor, at least for their own risk of breast cancer.

Perceptions of the meaning of the term “family history” were varied among the women in the sample. The women were simply asked what they thought might be meant by the term “family history” when talking about breast cancer. Four women referred to specific family members in defining family history. For example, one woman believed that “it should only really relate to fairly immediate family”, while another referred to “mother, female siblings, and female children”. A more skeptical respondent gave the following answer: “Um, my mother’s had breast cancer so they think you’re a high risk ’cause she’s had it. But her mother didn’t, and her sisters didn’t and her grandmothers didn’t!” Two women defined family history with reference to genetic terms, for example: “… that you’ve got similar genes and so you might be predisposed towards it because of those family genes”. An additional two women described the meaning of family history in very general terms, such as “if they’ve found it in the family” and “the people who’ve had it before”.

**Relevant relations**

The women were asked to state which family members they thought should be considered, if they were thinking about a family history of breast cancer. All of the women suggested that both mothers and sisters would be important if they were thinking about their risk of
breast cancer. Eight women believed that aunts would also be important, and six women suggested that grandmothers should also be considered. Four of the women felt that cousins should be included, and only one woman mentioned daughters in thinking about a family history of breast cancer.

All ten women interviewed believed that a woman should think about her father’s relatives as well as her mother’s relatives when thinking about their family history of breast cancer. Three believed that relatives on the mother’s side are more important than relatives on the father’s side.

**Importance of family history**

Perceptions of the importance of family history as a risk factor for breast cancer were also assessed by asking the women how much they thought having a family history of breast cancer would increase the risk of breast cancer. Two women exclaimed that they really did not have any idea and could not possibly give an answer. Another woman indicated that, from her reading, she had learned that the increase in breast cancer risk due to family history was very low, at around 3 per cent. The remaining seven women felt that having a family history of breast cancer increased the risk of breast cancer either “a lot” or “quite a bit”.

Three women, however, felt that this considerable increase in risk was evident only if there were several affected relatives. One woman suggested that the increase in breast cancer risk was greater if the affected relatives in the family were diagnosed pre-menopausal, than if they were diagnosed post-menopausal.

**Number of relatives**

The women’s perceptions of how many relatives there would have to be in the family to have an increased risk of breast cancer, was also assessed in the interview. Three women indicated that only one relative with breast cancer is enough to be of concern, with an additional woman stating that one would be enough if that relative was diagnosed before menopause. Two women suggested that they would have to have two affected relatives to be worried about their risk of breast cancer. The remaining three women believed there would have to be more than two family members diagnosed with breast cancer to have an increased risk of breast cancer. As one woman said, “… a few generations really, because one person’s not enough”.

**Discussion**

The studies reported here employed different samples of women, with the focus groups drawing on women from the general public and the interviews assessing the perceptions of women who have a family history of breast cancer. The results suggest a general consistency in the findings across the two studies. However some differences are evident, which may be attributable to the women’s family histories.

**The two methodologies**
The focus group and interview methodologies differ in the types of information they provide. While focus groups present an opportunity to gather a large amount of information concerning general attitudes and knowledge, individual interviews allow the researcher to ask the participants more personal questions.

Relative to interviews, the focus group method also provides a more appropriate setting for exercises that involve participation or the provision of feedback, by the participants. In this research, the focus groups allowed an exploration of the participants’ reactions to various formats for the presentation of quantitative risk information. While such an activity would have been possible in the context of the individual interviews, it was less time-consuming to include it in the group discussions, where the reactions of a greater number of participants could be examined simultaneously. One potential disadvantage of focus groups is that attitudes may be shaped by the dynamics of the group setting. Thus information from focus groups may be biased due to social influence, with some members of the group agreeing with the first participants who respond to a question. An example of group polarisation of attitudes occurred during the focus group discussions on the relative importance of maternal and paternal relatives for breast cancer risk, as three groups felt that maternal and paternal relatives were equally important, and one group believed the maternal side of the family to be of greater influence on breast cancer risk. For this particular question, the responses appeared to be consistent within each group. This consistency may have resulted from social influence processes operating within the group, as the group members tended to run with the first respondent’s suggestion.

Risk factors

The focus group participants and the women who were interviewed exhibited a high level of awareness that having a family history of breast cancer is an important risk factor for breast cancer. However, not all of the women interviewed believed that having a family history of breast cancer increases the risk of developing breast cancer. Overall, the results suggest that perceptions of the breast cancer risk associated with a family history of breast cancer depend very much on the women’s interpretations of the meaning of “family history”, in terms of the number and type of relatives in the family who have been diagnosed with breast cancer.

The women’s perceptions of risk factors for breast cancer focussed mainly on family history, but other commonly reported risk factors, such as reproductive factors, psychological factors, and diet were also suggested. The frequency with which they mentioned different risk factors indicated a potential misconception, as psychological risk factors were mentioned equally as often as reproductive factors, and late first birth and early menarche were rarely mentioned. The biggest risk factor for breast cancer, increasing age, was suggested by only one woman in response to the general question about risk factors. In addition, the misconception that being knocked on the breast can increase the risk of breast cancer was also evident, in the responses of several women. Similar findings have been reported elsewhere (Savage and Clarke, 1998). These results indicate a need for further education on breast cancer risk factors.

Understanding of prevalence data
This issue was explored in depth only in the focus groups. The women’s understanding of quantitative risk information about breast cancer varied greatly depending on the presentation format of the information. The results of the focus group study revealed a preference for risk information to be presented as “1 in X” rather than as a percentage, or as a table of age-related risks. The women participating in the focus groups generally perceived “1 in 13” women getting breast cancer as more alarming than “7.5 per cent”. Most of the women expressed a preference for the “1 in 13” statement over the “7.5 per cent” statement because the “1 in 13” is more personal and easier to visualize than the percentage risk statement.

The table expressing age-related breast cancer risks across 5, 10, 15 and 20 year time periods was perceived by most women in the focus groups as too complicated to be useful, although a small number of women found it useful because it presented risks specific to their age groups. These women were in the younger age group, and from the higher socioeconomic status suburbs. These findings on perceptions of quantitative risk information confirm other research that indicates that different forms of the same piece of risk information, although mathematically equivalent, are perceived differently, providing evidence that qualitative aspects of risk information are important (Wilson et al., 1987).

**Perception of personal breast cancer risk**

The interview study provided information on perceptions of personal breast cancer risk. Seven of the ten women felt that their risk of breast cancer was higher than average, but for only three of these women was this higher perceived risk translated into concern about breast cancer. Several women stated that although they believe their risk of breast cancer is probably higher than average, they do not worry about it. This finding may alleviate concerns that informing women of their breast cancer risk may lead to unnecessary anxiety.

**Family history**

Across the two studies, the women gave various definitions of the term “family history”, and indicated similar perceptions of the importance of particular types of relatives when thinking about the risk of breast cancer associated with family history.

The women in the focus group study (who did not have a family history of breast cancer) attributed greater importance to family history as a risk factor for breast cancer than did the women in the interview study. While most of the women in the focus group study believed that having just one family member diagnosed with breast cancer would be sufficient for them to consider themselves as having an increased risk of breast cancer, a greater proportion of the interviewees believed that there would have to be several affected relatives to have an increased risk of breast cancer. This discrepancy between the two samples is consistent with research on perceptions of relative risk, which suggests that people perceive themselves as less susceptible to unpleasant occurrences than others (Weinstein, 1982). Perhaps the focus group participants perceived a greater risk associated with having one relative affected with breast cancer than did the interviewees, because they did not have a family history of breast cancer and therefore remained at “average risk”, whilst the interviewees already had one relative with breast cancer, and thus needed to perceive a greater number of affected relatives as increasing the risk of breast cancer in order to protect their perceptions of their relative risk of breast cancer.
There were some specific aspects of familial breast cancer on which knowledge was lacking in the focus group participants. For example, some women believed that relatives on the mother’s side of the family exert a greater influence on breast cancer risk than do relatives on the father’s side. No-one in the focus groups mentioned age of diagnosis of the affected relatives as an important familial risk factor. Similarly, the importance of age at diagnosis was rarely mentioned by women who were interviewed. The fact that family history was mentioned first as a risk factor by all focus groups is problematic, given the small number of women whose risk status is affected by a family history of breast cancer.

Practical implications of the study

The results of these qualitative studies have several implications for the development of resources communicating information about familial risk of breast cancer. Specifically, the findings reported here indicate that:

- Risk information should be conveyed in the format of “1 chance in X” rather than as a percentage, or table.
- Information about risk factors for breast cancer and their relative importance needs to be communicated to women in the community. In particular, the importance of age as the biggest risk factor for breast cancer should be stated.
- The meaning of terms such as “family history”, “first-degree relatives”, and “second-degree relatives” should be stated in information resources. The results of the two studies indicated confusion concerning family history and the role of genes. The terms “first-degree relatives” and “second-degree relatives” were not used by any of the respondents.
- The role of both maternal relatives and paternal relatives in breast cancer risk associated with a family history, should be conveyed to women in the community.
- Awareness of the role of the age of diagnosis of the affected relatives in relation to familial breast cancer risk should be addressed.
- There should be some reassurance that having only one family member diagnosed with breast cancer does not constitute a high personal risk of breast cancer.
- Women with a familial risk of breast cancer should consult their general practitioners for further advice.

References


