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Abstract

Women of all ages have been found to overestimate both the incidence and the mortality rate from breast cancer and the reasons for this are unclear. A qualitative study asked eighty three women (mean age = 44 years) how likely they thought they were to get breast cancer and to explain the reasoning behind their choice. Based on their responses, women's perceptions were categorised as: no risk (5%); reasonably accurate (30%); overestimated (22%); and greatly overestimated (43%). Four main themes emerged from the reasons given: 'Don't know/guess', 'family history' of breast cancer, 'age' related reasoning, and making their decision from the information sheet read prior to answering the questions. The information currently available to women may be creating falsely high estimates of their risk of developing breast cancer as the risk factors of age and family history appear to be poorly understood. Meaningful communication of health risk in need of further improvement if it is to be useful in changing health related knowledge and behaviours.

Keywords

risk, cancer, breast, estimation, i, so, know, t, don, women, guess, really, reasons

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RESEARCH COMMUNICATION

“I Don’t Really Know, So It’s a Guess”: Women’s Reasons for Breast Cancer Risk Estimation

Nancy Humpel, Sandra C Jones

Abstract

Women of all ages have been found to overestimate both the incidence and the mortality rate from breast cancer and the reasons for this are unclear. A qualitative study asked eighty three women (mean age = 44 years) how likely they thought they were to get breast cancer and to explain the reasoning behind their choice. Based on their responses, women’s perceptions were categorised as: no risk (5%); reasonably accurate (30%); overestimated (22%); and greatly overestimated (43%). Four main themes emerged from the reasons given: ‘Don’t know/guess’, ‘family history’ of breast cancer, ‘age’ related reasoning, and making their decision from the information sheet read prior to answering the questions. The information currently available to women may be creating falsely high estimates of their risk of developing breast cancer as the risk factors of age and family history appear to be poorly understood. Meaningful communication of health risk in need of further improvement if it is to be useful in changing health related knowledge and behaviours.

Key Words: breast cancer - risk factors - risk estimation - themes

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Introduction

Breast cancer is the most common type of cancer in women (Australian Institute of Health and Welfare, 2002; Jemal et al., 2003). It is estimated that one in twelve Australian women, and one in eight US women will develop breast cancer in their lifetime (American Cancer Society, 2003; BreastScreen, Australia, 2003). The differences in rates between countries are a result of the upper age limit used for calculation, thus the risk is very similar for both countries. The risk of developing breast cancer increases with increasing age. In the US, a woman has a 1 in 288 chance of developing breast cancer up to 39 years of age; 1 in 24 at 40 to 59 years; and 1 in 14 at 60 to 79 years (Jemal et al., 2003).

It is well known that people’s estimate of cancer risks can vary widely from their actual risk (Erblich, Bovbjerg, Norman, Valdimarsdottir, & Montgomery, 2000). The perceived risks of most diseases are generally underestimated due to optimistic bias, where the risk is perceived to be less for the individual than for their peers (Clarke, Lovegrove, Williams, & Machperson, 2000; Fontaine & Smith, 1995; Gouveia & Clarke, 2001). However, studies have found that

perceived risk of developing cancer is regularly overestimated (Erblich et al., 2000; Helzlsouer, Ford, Hayward, Midzenski, & Perry, 1994; Paul, Barratt, Redman, Cockburn, & Lowe, 1999; Wilcox & Stefanick, 1999), and this tendency is more pronounced with breast cancer. For example, women of all ages have been found to overestimate the mortality rate from breast cancer compared to the mortality rate from lung or colon cancer (Wilcox & Stefanick, 1999).

The reasons for this overestimation are unclear (Leventhal, Kelly, & Leventhal, 1999), although it has been suggested that fear of cancer is a major contributor (Anonymous, 1997; Borland, Donaghue, & Hill, 1994; Ruiter, Verplanken, & Van Eersel, 2003). In order to improve the accuracy of people’s risk perceptions, we need to understand the reasoning behind their overestimation.

The purpose of this study was to examine the reasoning behind women’s estimates of their risk of developing breast cancer, and to gain a greater understanding of why overestimation of breast cancer risk is so common. This study was part of a larger, on-going study of the impact of different risk presentation formats on risk estimations for cancer.

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Methods

Participants

A total of 83 women, aged 21 to 81, were recruited for this study. Fifty three were recruited at their workplace (a non-government administration organisation). An additional 30 women were recruited at a craft group meeting to meet a quota for the proportion of older women. Participants were provided with a gift voucher (approximate value US\$6) as a thank you for being part of the study. Exclusion criteria were working in a health related industry and being unable to speak or read English fluently.

Measures and Procedures

The women were asked to read out loud a short paragraph (see Figure 1) about breast cancer that was sourced from the BreastScreen Australia website (BreastScreen Australia, 2003). The participants then answered two questions: 'How likely are you to get breast cancer in the next 10 years'; and 'How likely are you to get breast cancer in your lifetime'. For both questions, response was on a linear number scale from 0 to 100, where 0 in 100 (0%) = 'no chance of me getting breast cancer' and 100 in 100 (100%) = 'I will definitely get breast cancer'. Along the response line, 10% (10 in a 100) intervals were marked. This same question and response scale has been used in numerous previous studies of perceived breast cancer risk (e.g., Erbllich et al, 2000; Helzlsouer et al, 1994; Lipkus et al, 2000).

For each question, the women were asked to 'talk aloud' their thoughts as they were deciding on the risk level most appropriate for them, and to explain the reasoning behind their choice. These reasons were tape-recorded for the purpose of verbatim transcription. All the women consented to the taping of their responses. The University Human Research Ethics Committee approved the study protocol.

Results

The mean age of participants was 44 (SD=17) years;

Breast cancer is the most common type of cancer in women in Australia. One in twelve women will develop breast cancer in their lifetime. And most of these women are over 50. Age is the biggest risk factor, not family history. Nine out of 10 women who get breast cancer DO NOT have a family history of breast cancer.

A number of other factors may be involved in the development of breast cancer. These include age at first full-term pregnancy, number of pregnancies, and age at menopause. However, the relationship between these factors and breast cancer is very weak.

Figure 1. Breast Cancer Information Read Aloud by Participants

41% were aged 18-34 years; 23% aged 35-49 years and 36% aged 50 and over. For all but one woman, English was the language usually spoken at home. Forty one percent had an education level 12 years or less (i.e. 5 years of secondary or less), and 59% had a TAFE (technical) or degree qualification.

Not all of the women in the study reported a reason for their risk estimate. Many of the women found it difficult to verbalise their thoughts on the topic and simply stated what risk they were marking on the questionnaire. Of the 83 women who were taped when completing the questionnaire, 53 gave a reportable reason.

The current population lifetime risk of breast cancer is 8% for Australian women. The risk estimations of the women were grouped into three categories: those who were reasonably accurate, that is, estimates between 5 and 15% (30% of respondents); those who overestimated their risk, with estimates from 20 to 45% (22%); and those who greatly overestimated their risk, with estimates of 50% or higher (43%). Five percent (four women) decided they had no risk of developing breast cancer, although they were unable to give an explicit reason as to why they decided this. There were no significant differences in age between the three risk categories, and non-significant differences were reported in the mean 10-year risk estimate between age groups. As we did not collect data which would enable us to calculate each woman's objective risk, we have used mean risk for the women as a group. This method is standard practice (eg. Evans, D., Burnell, L., Hopwood, P., & Howell, A. 1993; Helzlsouer et al., 1994). As perception of risk for breast cancer in the next 10 years was asked first, this elicited the most comments from the women. This paper will focus mainly on the results for this question.

Themes Among the Reasons for Risk Estimation

Four main themes emerged from the reasons for deciding on a risk of breast cancer (Table 1). 'Don't know/guess' (40%), 'family history' of breast cancer (32%), 'age' related reasoning (19%), and making their decision from the information in the paragraph they read prior to answering the questions ('read about it'; 9%). The presence of each of these reasons will be discussed by perceived risk level.

Accurate Perception of Risk

Eleven of the 25 women who accurately perceived their risk of breast cancer reported a reason verbally. The two most common reasons for the choice were related to 'age' (five women) and 'uncertainty' (four women). One woman reported having a family history of breast cancer as the reason for her estimate, and one that her estimate was because of what she had just read.

Comments on why 'age' was the reason included: 'that makes me 34 in the next 10 years, so 10%' (age 24); 'well for me, I'm only 26, so from what I've just read the chances of it are very unlikely. It doesn't mean I won't get it. So I'll cross 10%'; 'I guess 10%, I guess because I'm young' (age 21). 'Don't know/guess' comments included: 'who can say

Table 1. Reason for Risk Estimation by Risk Estimation Category

	Don't know/ guess	Family history	Age related	Related to what just read	Those reporting reason	Total sample
					N (%)	N (%)
No risk						4 (4.8)
Accurate risk	4	1	5	1	11 (44)	25 (30.1)
20-45% risk	5	4	2	1	12 (66)	18 (21.7)
50% plus risk	12	12	3	3	30 (83)	36 (43.4)
	21/53 (40%)	17/53 (32%)	10/53 (19%)	5/53 (9%)		

no chance, I don't know, 10%, I like to be an optimist' (age 58) ; 'I don't really understand it...lets say its 10%' (age 59); 'probably.... I don't know, a slim 10%' (age 28).

Perceptions of Those Overestimating

Twelve of the 18 women who were categorised as overestimating their risk of developing breast cancer (20-45%) reported a reason verbally. The two most common reasons reported were 'don't know/guess' (five women) and 'family history' (four women). Two women reported age as the reason, and one said that she had made her judgment based on the information she had read.

Similar to the previous group, reasons in the 'don't know' category included: 'I suppose maybe 20%, you never know what is around the corner for your body, so I'm not too sure.... I don't know, maybe 30%' (age 31); umm....I don't know, maybe 30% (age 24)'. Reasons related to 'family history' of breast cancer included: 'Um, well going on family history, it been when my mum, grandmother and her sister developed it when they were in their sixties, so percentage answer....I'd say probably maybe 40% (age 47), and 'Probably about 40% - my sister had breast cancer at age 42, and my mother had bowel cancer and between that the doctors have given me a 1 in 5 chance of getting either or both and I probably know quite a bit about breast cancer overall'¹ (age 58).

Perceptions of Those Greatly Overestimating

Thirty of the 36 women who greatly overestimated their risk (that is, estimated a 50% or greater risk) reported a reason verbally. The two most common reasons were 'don't know/guess' (12 women) and 'family history' (12 women). Three gave their reason as 'age' related and three because of the information they had read.

Again, the women in this group exhibited a lot of uncertainty. There were a lot of 'the luck of the draw' and '50/50 chance' type opinions observed. Typical comments were: 'um....ok well....I guess there is an equal that I will as I won't so I'll put myself in at 50%' (age 60); 'um....I've no idea, 50% only because I don't know' (age 27); and 'um....I would say 50 out of 100, 50% in the middle, I could and I could not, so' (age 38).

Women who reported having breast cancer in their family tended to report very large overestimations. For example: 'There is a good chance because it is in my family, so probably 60% chance maybe' (age 31); 'my sister's had breast cancer - about 90%' (age 65); and 'oh Jesus Christ I hope its never happening to me. Well, I have a big chance because my mother died of breast cancer, I smoke, I drink so, I don't have a baby yet. I'm thinking of having a baby now and I know after the pregnancy the body changes a lot so that is when my problem's going to start. I'll say 50 (%)' (age 30).

An age related reason from an older woman was: 'I'm 80 year old so I haven't got long to go have I? Laugh'; whilst a woman aged 24 years stated 'I would probably say 80 (yes she said 80) out of a 100 because I'm not in the high risk factor age'.

Discussion

Most studies have reported a weak association between what people perceive as their risk of developing cancer and what is their actual estimated risk (Arkin, 1999; Evans et al., 1993; Leventhal et al., 1999). The purpose of this study was to gain a better understanding of the reasons behind women's inaccurate estimation of their risk of developing breast cancer. The women identified a range of reasons with the majority falling into four themes with the main two themes being 'don't know/guess' and 'family history'.

Women who were able to report their risk estimate for breast cancer approximately accurately were less explicit as to the reasoning behind their estimate. As overestimation increased, an increasing number of women were able to verbalise the reasons for their risk estimate. A study of Australian women (Paul et al., 1999), found two-thirds overestimated the average lifetime risk of developing breast cancer. The most common reasons given by the women in the Paul et al (1999) study who perceived their risk as high or very high, were family history (55.6%) and lumpy breast or previous lumps (13.5%).

The main reasons supplied by the greatly overestimated risk group in the present study were 'don't know/guess' and

¹ This woman states that her doctor estimates her risk at 20%, but then gives her estimate as 40%

'family history'. The women reporting 'family history' as the reason may perhaps feel more confident in their estimate because they feel they are more knowledgeable on the subject. Perceived risk of breast cancer has been found to be associated with having a family history (Erblich et al, 2003; Montgomery et al, 2003). Erblich et al (2003) found that women with a family history of breast cancer reported a significantly higher perceived absolute risk than those with no family history of breast cancer (54.3% versus 25.8%). They also reported a significantly higher perceived relative risk compared to women of similar age with a family history (3.2 versus 2.6).

For the women reporting 'don't know' as the reason for their risk estimate, the element of chance or 'guess' was often reported, which suggests they felt unable to make an accurate estimate. Four women in the approximately accurate risk estimate group appear to have guessed accurately by chance. The finding that 40% of those who reported a reason did not feel they had enough knowledge to make an accurate assessment demonstrates that the meaningful communication of health risk is complex, and in need of further improvement, if it is to be useful in changing health related behaviours and result in disease prevention. The women in this sample may have overestimated simply because they were guessing. Future studies should include a question asking about the reason for the risk estimation decision.

The risk factors of age and family history appear to be poorly understood. A study of Americans' knowledge of cancer risk factors (n = 12,035) found the majority of participants were unable to identify the major cancer risk factors (Breslow et al, 1997). Seventy percent of women identified family history as a risk factor for breast cancer, while only 29% identified age as a risk factor. Age is the strongest risk factor for breast cancer (Australian Institute of Health and Welfare, 2002). A Canadian study of 1,284 women also found knowledge of breast cancer risks generally low and that knowledge decreased with age (Mah and Bryant, 1992).

It is likely the women in this study have been previously exposed to numerous conflicting messages about breast cancer risk, particularly from the media (Jones, in press). The information currently available to women may be creating falsely high estimates of their risk of developing breast cancer. The issue of the age of women being diagnosed seems especially prone to misunderstanding. Stories in the print media reporting cancer in young women because of its rarity, could be contributing to the misperceptions. These stories could also lead older women to think they are less at risk and so be less likely to participate in early detection programs (Jones, 2004).

The 24-year-old woman reporting her risk as 80% in this study, and also stating that she is not in the high risk factor age group, demonstrates that there may also be a lack of understanding amongst women when risk estimates are reported numerically. Research on risk estimation reports that most people have difficulty understanding probabilities

and percentages (Nelson, 2000).

The method of presentation of health risk information has been found to influence an individual's personal assessment of risk (Leventhal et al., 1999). The format used for the risk estimation questions in this study is commonly used in this field of research (Woloshin et al, 2000). Although this is a standard format, many of the older women in this study reported difficulty in understanding what they were required to do. These comments came from women aged 59 to 79 years: 'I'm sorry, what do I do?'; 'I really don't understand'; and 'so what do I do?'. The researcher frequently had to explain in simple language the requirements. As women in the older age group have the greatest risk for developing breast cancer, this has important implications for whether the use of this format for measuring risk estimates is accurate in older women.

The linear number scale used may have encouraged the large overestimations as there was a limited range for choosing a low risk estimate. Future studies could consider using Woloshin's (Woloshin et al., 2000) magnifier scale which provides more scope for lower likelihood estimates. Asking the women to provide 10-year breast cancer risk estimates may have been difficult, as they may not have been exposed to the current age-specific risk as opposed to lifetime risk.

Sixty five percent of the women overestimated the risk of developing breast cancer. From the results, conclusions cannot be clearly drawn whether women overestimate because they 'didn't know' and therefore guess, or they overestimated because they perceive the risk is high because of a poor understanding of the risk factors. Previous studies showing risk overestimations did not ask the participants about the reasoning behind the decision. The possibility that some of the variance in overestimation could be from 'taking a guess' has important implications for future research.

Education is needed to increase breast cancer knowledge overall, and specifically that age, rather than family history is the biggest risk factor for breast cancer. Most women in this study did not seem to realise that increasing age is the main risk factor. The women gave their reasons after they read out loud information about breast cancer that included the statement 'age is the biggest risk factor, not family history' suggesting that the belief about the importance of family history as the main risk factor is firmly held and difficult to counteract. An accurate perception of risk is necessary for making informed choices about such things as breast examination and the use of mammography for early detection of breast cancer.

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