Unraveling women’s perceptions of risk for breast cancer

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Abstract

Inconsistent reports of the prevalence of risk perception accuracy may be related to the use of different classification strategies. The purpose of this study was to compare two approaches for assessing the accuracy of women’s breast cancer risk perceptions. A telephone survey was conducted with an age-stratified random sample of British Columbian women 20–79 years of age without a breast cancer diagnosis (n = 761). A comparison of two methods employed to determine perception accuracy revealed substantial differences between the methods with regard to the classification of women as under- and over-estimators. The study highlights the need for researchers to consider the method used to determine the accuracy of risk perceptions and the implications of using different strategies to assess risk perception accuracy when such information is used in research or to guide interventions.

Introduction

Perceptions of risk are subjective assessments of information that help individuals to make sense of their vulnerability and reach decisions about health behavior (Weinstein, 1999). Many factors influence individuals’ risk estimates. Sources of risk perception inaccuracy have been related to a variety of factors including misinformation or a lack of knowledge, personal experiences and beliefs, and cognitive processes or biases that work to minimize threats. Based on the assumption that accurate risk perceptions lead to desired health behavior, helping people more accurately understand their health risks has become one of the key goals of risk communication (Vernon, 1999). Accordingly, information about risk perceptions including the identification of over- and under-estimations of risk has been used to tailor clinical and educational interventions aimed at correcting misperceptions.

In the context of breast cancer, methods to assess the accuracy of risk perception involve identifying over- and under-estimations of risk by comparing perceived risk to objective estimates of risk. In a review of risk perception in the context of cancer, the influence of risk perception on screening decisions was reported to be inconsistent (Vernon et al., 1993). For example, some researchers have linked over-estimation and high levels of distress to excessive breast cancer screening (hypervigilance), while others have reported under-utilization of recommended screening (Kash et al., 1992; Lerman et al., 1993, 1994; Clemow et al., 2000). Despite the importance of risk perception in theories of health behavior and the extensive research that has been undertaken to study risk perceptions, standard measures of breast cancer risk perception have not been consistently utilized. The use of a variety of assessment procedures to measure risk perception and its accuracy may contribute to conflicting research findings.
In general, two approaches have been used to assess breast cancer risk perception accuracy. Women’s personal estimates of their risk for breast cancer have been directly compared to objective risk estimates (e.g. the Gail model or cumulative incidence rate of 1:9) to identify those who under- and over-estimate their risk (Bowen et al., 1997; Watson et al., 1999). Alternatively, women have been asked to compare their own breast cancer risk to that of the ‘average woman’ (or the average woman of similar age) using qualitative or numerical assessment procedures (Evans et al., 1993). The continued use of a variety of assessment methods without specific rationale appears to imply that the classifications of perception accuracy produced by the different approaches can be interpreted as equivalent (i.e. an under-estimator under one approach would also be identified as an under-estimator using another approach). The prevalence of breast cancer risk perception accuracy varies, however, depending on the classification strategy used, suggesting that the method of assessment may play a role in this variability (McCaul and O’Donnell, 1998). Insufficient attention has been given to the measurement of risk perception and the subsequent assessment of perception accuracy. The purpose of this study was to examine the degree of discrepancy between two commonly used approaches to assess breast cancer risk perception accuracy and to determine if the discrepancy varied among specific population groups (i.e. by age group and by family history of breast cancer).

**Methods**

A telephone survey using random digit dialing was conducted in early 2000 with an age-stratified random sample of women residing in the province of British Columbia, Canada. Eligible women included those 20–79 years of age, without a breast cancer diagnosis and able to be contacted by telephone. From the 2006 eligible individuals identified in the initial sampling frame, 761 women completed the survey (37.9% response rate).

Perceived personal lifetime breast cancer risk estimates were obtained by asking subjects to rate their likelihood of developing breast cancer in their lifetime from 0 (definitely will not get it) to 100 (definitely will get it). Using the same scale, the women’s perceptions of the average woman’s breast cancer risk were then obtained by asking subjects to rate how likely it was that the average woman would develop breast cancer sometime in her lifetime. Objective lifetime risk estimates for breast cancer for each subject were calculated using the Gail model (Gail et al., 1989). Demographic information including age, education and family history of breast cancer was also collected. The research protocol was approved by the University of British Columbia Behavioral Research Ethics Board.

Two methods were used to measure the accuracy of the women’s risk perceptions. The first method involved comparing perceived personal lifetime breast cancer risk estimates to the Gail risk assessments (Method A). Women whose perceived personal risk estimates were within 10% of their Gail score were classified as ‘accurate’. Perceived risk estimates beyond this range were classified as ‘under-estimation’ (more than 10% below the Gail estimates) and ‘over-estimation’ (more than 10% above the Gail estimates). The 10% range on either side of the Gail model risk estimate has been commonly used to provide a reasonable margin within which responses are labeled as accurate (Kreuter and Strecher, 1995; Daly et al., 1996; Stalmeier et al., 1999).

The second method, based on the work of Kreuter and Strecher (Kreuter and Strecher, 1995), examined risk perceptions in relation to other women (Method B). This method takes into consideration comparisons between women’s absolute judgments about their own breast cancer risk and the ‘average woman’s’ breast cancer risk (comparative perceived risk), and comparisons between their individual Gail risk estimates and population Gail risk estimates for women of the same age (comparative objective risk) to identify accuracy of risk perceptions. Women’s comparative perceived breast cancer risk estimates were grouped to form three categories: about average perceived risk (personal risk estimates within
10% of perceived estimates for the average woman), higher than average perceived risk (personal risk estimates more than 10% above perceived risk estimates for the average woman) and lower than average perceived risk (personal risk estimates more than 10% below estimates for the average woman).

In a similar way, the participants’ Gail scores were compared to age-specific (within 10 years) Gail model population risk estimates and divided into three categories of comparative objective risk: about average objective risk (individual Gail estimate within 10% of the age-specific population risk estimate), above average objective risk (individual Gail estimate more than 10% above the age-specific population risk estimate) and lower than average objective risk (individual risk estimate more than 10% below population risk estimate). To identify the accuracy of women’s risk perceptions, ‘comparative perceived risk’ and ‘comparative objective risk’ categories were contrasted. Under-estimation occurred when a woman’s comparative perceived risk was less than her comparative objective risk and over-estimation occurred when the opposite was true (see Table I). Risk perception was considered accurate when a woman’s comparative perceived risk and comparative objective risk were congruent.

Descriptive statistics were used to characterize the sample and summarize study variables.

### Results

#### Demographics

The mean age of women in this sample was 45.5 years [±1.1 years; 95% confidence interval (CI)] and had 14.6 years (±0.2 years; 95% CI). The majority of the sample was employed in paid work (59 ± 3.8% years; 95% CI) and lived in an urban setting (86.8 ± 2.6%; 95% CI), with 24% (±3.3%; 95% CI) reporting at least one first- or second-degree relative with breast cancer.

#### Risk perceptions

When women’s perceived breast cancer risk estimates were directly compared with their personal Gail scores (Method A), the majority of women (n = 506; 74%) were classified as over-estimators (see Table II). When population comparisons were added to the determination of perceived and objective risk estimates (Method B), only 205 (30%) women were classified as over-estimators.

When the two methods for classifying the accuracy of risk perception were compared, only 274 of a possible 684 women (40.1%) were classified in the same way (see bold numbers in Table II). The overall proportion of agreement between the two methods was low (κ = 0.14). There is one notable
discrepancy in classification between the two methods. Of the 184 women who were identified as under-estimators by Method B, 111 (60.3%) were classified as over-estimators using Method A. There was no significant difference across the two age groups in the pattern of classification agreements between Methods A and B \(\chi^2(2) = 1.54, P = 0.463\) (see Table III). However, a significant difference between the family history groups was observed \(\chi^2(2) = 6.90, P = 0.03\) (see Table III). Among those women with a family history of breast cancer there were more classification disagreements involving higher-risk categories assessed under Method A than Method B.

**Table II. Breast cancer risk perception classification discrepancies**

<table>
<thead>
<tr>
<th>Classification methods</th>
<th>Method A (perceived versus Gail model)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Over-estimation</td>
<td>Accurate</td>
</tr>
<tr>
<td>Method B (perceived versus Gail model with population comparisons)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>over-estimation</td>
<td>192*</td>
<td>9</td>
</tr>
<tr>
<td>accurate</td>
<td>203</td>
<td>18</td>
</tr>
<tr>
<td>under-estimation</td>
<td>111</td>
<td>9</td>
</tr>
<tr>
<td>Total</td>
<td>506</td>
<td>36</td>
</tr>
</tbody>
</table>

*Bold numbers represent consistent classification of risk perceptions by both methods.

**Table III. Classification disagreements between Methods A and B by age group and family history**

<table>
<thead>
<tr>
<th>Age group</th>
<th>Family history of breast cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;50 years</td>
<td>No (n = 497)</td>
</tr>
<tr>
<td>(n = 434)</td>
<td>(n = 250)</td>
</tr>
<tr>
<td>Method A provides higher perceived rating*</td>
<td>208 (47.9%)</td>
</tr>
<tr>
<td>Method A equals Method B</td>
<td>176 (40.6%)</td>
</tr>
<tr>
<td>Method A provides lower rating than Method B*</td>
<td>50 (11.5%)</td>
</tr>
</tbody>
</table>

*Method A provides a higher perceived rating than Method B. For example, Method A suggests over-estimation while Method B suggests accurate or under-estimation.

*Method A provides a lower perceived rating than Method B. For example, Method A suggests under-estimation while Method B suggests over-estimation or accurate.

Discussion

Despite extensive public health education regarding breast cancer risk, the findings of this study suggest that many women have inaccurate perceptions of their risk. When two methods were employed to determine the accuracy of risk perceptions, substantial differences were found. The proportion of women classified as holding accurate perceptions of their breast cancer risk ranged from 5 to 43% depending on the method of classification used. Furthermore, the majority of individuals classified as under-estimators by one method were classified as over-estimators using the other method. The pattern of agreement across the two classifications methods varied depending on family history of breast cancer, although the difference does not appear to be substantial from a clinical perspective. In contrast, age did not have any influence on risk perception classification. We acknowledge that a split at 50 years of age is crude, but the number of cases available did not allow us to conduct a more refined analysis.

Understanding one’s actual risk for breast cancer is important because it allows women to make
informed decisions about preventive action and health care (e.g. hormone replacement therapy, genetic testing for breast cancer risk) and enhances appropriate participation in recommended screening (Leventhal et al., 1999; Lipkus et al., 2001; Hopwood, 2003). Furthermore, knowledge of one’s actual risk may enhance quality of life among those who experience heightened levels of stress and anxiety related to over-estimates of their risk for breast cancer as well as reduce unnecessary use of health-care services (Kreuter and Strecher, 1995).

Perceived risk is an important factor in theories of health behavior. The Precaution Adoption Model (Weinstein, 1988), for example, emphasizes the important role of risk perceptions in adopting precautionary behavior. Decreasing risk misperceptions is linked with receptivity to adopting behavior change and as such provides a basis for informed decision making. With the introduction of quantitative models of breast cancer risk assessment, efforts to identify effective ways to reduce both over- and under-estimations of risk have stimulated research in cancer-related risk communication (Lipkus et al., 2001). There is emerging evidence that different kinds of misperceptions of risk require different interventions and that tailoring interventions to individual characteristics such as perceived risk has a positive effect on a number of health behaviors (Skinner et al., 1999). The study findings highlight the potential implications of using different strategies to evaluate the accuracy of risk perceptions when this information is being used to tailor interventions to change unrealistic perceptions of risk. Depending on the type of error that one is willing to tolerate with regard to potential misclassifications, one method or the other may be more appropriate.

If an educational intervention were specifically tailored to enhance the accuracy of risk perception for women who over-estimate their risk for breast cancer, it would be critical to minimize its use with under-estimators because the intervention may further reduce perceived risk. In assessing the classification discrepancies between Methods A and B, Method B would be the most appropriate method to identify over-estimators for this kind of intervention. By using Method B (rather than Method A), the inclusion of women who are possibly under-estimators is minimized.

On the other hand, if an intervention were tailored to enhance the accuracy of risk perception among women who under-estimate their risk for breast cancer, Method A (a direct comparison between perceived risk and Gail estimates) is the preferable assessment tool. Wanting to avoid any further increases in anxiety among over-estimators, an assessment method that reduces the chance that over-estimators will be included in the program is important. Method A minimizes the inclusion of women who would be identified as over-estimators by Method B.

Study limitations related to the risk perception measures and methods to determine accuracy of risk perception need to be acknowledged. These include the influence of innumeracy (especially percentages and the concept of probability) and the lack of well-validated measures of perceived risk (Woloshin et al., 1999). Although risk perceptions have been assessed using both comparative or absolute judgments, in this study absolute judgments were used in Method B (i.e. respondents rated their own risk and that of the average woman, but were not asked to make a direct comparison). The use of comparative judgments may have resulted in different findings. For example, qualitative comparative risk assessments in which women are asked to indicate whether their risk is higher, lower or about the same as the average woman also have been used to describe women’s risk perceptions. Although qualitative response formats may be a simpler cognitive task than using numerical ratings and therefore may be a better, albeit less precise, indicator of women’s sense of perceived risk (Woloshin et al., 1999), it has been suggested that direct comparative judgments are more susceptible to comparative biases (e.g. unrealistic optimism) (Hoorens and Buunk, 1993). In addition, it is recognized that the Gail model may not be the most appropriate objective risk assessment tool for all women (MacKarem et al., 2001; McTiernan et al., 2001).
Finally, the findings need to be understood in the context of Canadian public health education programs where the primary message has been that ‘1 in 9’ women will get breast cancer sometime in their lives. The women’s misperceptions about their risk may be linked to their misunderstanding of lifetime risk as well as the lack of opportunity available to obtain individual risk information.

When assessments of the accuracy of risk perception are sought, at least in the context of breast cancer, the method used to determine risk perception is important. Identification of under- and over-estimation is dependent on sound measures of perceptions of risk that effectively capture how individuals understand and make sense of their risk. Given the importance of risk perception in relation to a wide range of health promotion issues and increased availability of quantitative risk estimates, greater attention needs to be directed toward developing consistent methods to measure and compare risk estimates.

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