

# Women's Perceptions of Breast Cancer Risk: Are They Accurate?

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## ABSTRACT

**Background:** The objective was to compare women's personal estimates of their risk with objective breast cancer risk estimates and to describe the risk factors for breast cancer identified by women.

**Methods:** Telephone survey of a random sample of 761 rural and urban women with no history of breast cancer. Survey instrument included measures of perceptions of lifetime risk for breast cancer for themselves and for the average woman, perceptions of risk factors that influenced their risk and the average woman's risk for breast cancer. Objective estimates of breast cancer risk were calculated using the Gail et al. algorithm. Descriptive statistics and multiple linear regression were used to analyze the data.

**Results:** Women's estimates of their own lifetime risk for breast cancer were significantly higher than their Gail model risk estimates (mean difference=19%,  $p<0.001$ ). The women's personal breast cancer risk estimates were lower than estimates of risk for a hypothetical average woman (mean difference=-8%,  $p<0.001$ ). Fifty percent of the sample reported a perceived risk estimate at least 15% above their Gail risk estimate. The risk factors for breast cancer most frequently identified included family history, nutrition/diet, smoking, lifestyle, environment, stress and age. Although the risk factors used to calculate the Gail model risk estimates were reported by some study participants, these women consistently identified only family history as their personal risk factor.

**Conclusion:** Women have difficulty accurately estimating their breast cancer risk and identifying known risk factors for breast cancer. Individual risk information may be more useful in enhancing accurate risk perceptions than the "1 in 9" message.

*La traduction du résumé se trouve à la fin de l'article.*

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Health care professionals are increasingly involved in providing information and advice to women who are concerned about their risk for breast cancer. Counselling about breast cancer risk, however, may be complicated by difficulties in understanding risk estimates, probabilities, and the relative importance of breast cancer risk factors.<sup>1-3</sup> Despite widespread availability of risk information, many women hold inaccurate perceptions of their own risk and the population risk for breast cancer.<sup>2,4-7</sup> Misperceptions have been linked to innumeracy,<sup>8,9</sup> limited knowledge about breast cancer,<sup>8,10</sup> denial,<sup>4</sup> perceived lack of control over the disease,<sup>11</sup> and anxiety or excessive breast cancer worry.<sup>7</sup>

When American women's estimates of their personal breast cancer risk (subjective estimates) are compared to estimates obtained from the Gail et al. algorithm (objective estimates),<sup>12-14</sup> the majority of women greatly overestimate their risk.<sup>6,9,15-17</sup> Researchers in Britain<sup>4,7,18</sup> and Australia<sup>19</sup> have reported similar results. Confounding this overestimation is the observation that women lack knowledge of the most significant risk factors for breast cancer.<sup>2,3,20</sup> To our knowledge, the most recent population-based study in Canada to assess women's perceptions of their risk for breast cancer was conducted in Montreal in 1995.<sup>10</sup> In this study, the majority overestimated the average lifetime risk of breast cancer despite reporting being exposed to information about breast cancer. Most women considered themselves at average or low risk for breast cancer as compared to other women their age.

Ongoing study of risk perceptions and the risk factors women associate with breast cancer are needed to identify trends in their understanding of breast cancer risk. These results will assist health care professionals in responding more effectively to requests for information about breast cancer and in providing breast cancer risk information in ways that support the development of accurate risk perceptions. The purposes of this study were to: 1) compare women's subjective and objective breast cancer risk estimates, 2) identify demographic characteristics associated with discrepancies between objective and subjective assessments of breast cancer risk, 3) describe the risk factors for breast cancer that women identify for a hypothetical

“average” woman and for themselves, and 4) describe the relationship between perceived risk and breast cancer screening practices.

## METHODS

### Sample

A telephone survey was conducted in early 2000 with a random sample of women ( $n=761$ ), residing in the province of British Columbia, following approval from the UBC Behavioural Ethics Committee. A geographically stratified sample of 6,918 telephone numbers were generated using the Canada Survey Sampler software program to obtain a desired sample of 750 women, with 250 women in each of three age groups (20-39 years, 40-59 years, and 60-79 years) to ensure representation across all age groups and a maximum margin of error of  $\pm 3.8\%$  for estimated proportions, with 95% confidence. Eligible women had no history of breast cancer, spoke English, and were able to be contacted by telephone. A total of 2,006 eligible individuals were identified from the initial sampling frame (37.9% response rate).

### Data collection

The survey instrument included items selected from well-established questionnaires and standardized measures. It was administered by trained female interviewers using computer-assisted telephone interviewing technology.

Perceived risk for breast cancer was assessed by asking subjects to rate their perceived likelihood of developing breast cancer in their lifetime from 0 (definitely will not get it) to 100 (definitely will get it).<sup>21-25</sup> Using the same scale, subjects were asked to report how likely it was that the average woman would develop breast cancer sometime in her lifetime. Objective lifetime risk estimates for breast cancer were calculated using the Gail et al. model,<sup>14</sup> which is based on age, number of affected first-degree relatives, age at first live birth, age of menarche, number of benign breast biopsies, and history of breast biopsies with hyperplasia. Women were asked to list factors that they thought increased a woman's risk for breast cancer. Using a similar open-ended question, the respondents were subsequently asked to identify factors influencing their own risk for breast cancer. Questions relat-

TABLE I

Women's Breast Cancer Lifetime Risk Estimates

Type of Lifetime Risk Estimate	Age Group	Mean Percent Risk Estimate	Standard Deviation for Mean Percent	95% CI for Mean Percent
Perceived average woman's risk for breast cancer	Under 50	39.03	19.03	37.23-40.82
	50 plus	38.57	20.17	36.06-41.09
Perceived own risk for breast cancer	Under 50	32.29	21.45	30.26-34.31
	50 plus	27.84	23.67	24.89-30.79
Gail risk estimate for breast cancer	Under 50	12.22	4.21	11.82-12.62
	50 plus	9.46	6.34	8.67-10.25

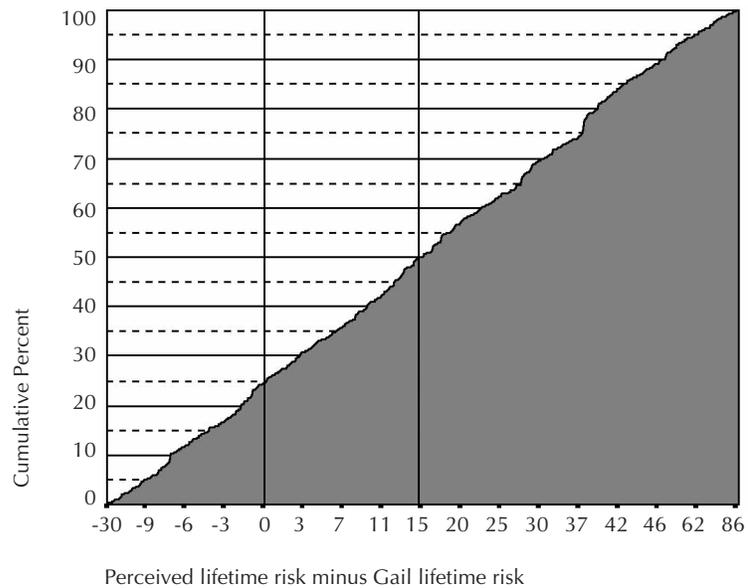


Figure 1. Cumulative density plot for difference between perceived personal lifetime risk estimate and Gail model risk estimate

ed to the frequency with which women participated in screening mammography, clinical breast examination and breast self-examination were included.

### Data analysis

Weighting factors based on the 1996 age-stratified population distributions of women living in BC in the Canadian Census Profile Tables were applied to each individual. To facilitate comparisons between pre- and post-menopausal women, the sample was dichotomized into  $<50$  and  $\geq 50$  years to describe women's perceived risk estimates (personal and the hypothetical “average” woman) and their Gail risk estimates. Paired sample t-tests were used to determine whether the differences between these estimates were significantly different from zero. Multiple linear regression analysis was conducted using the difference between the perceived personal risk estimates and the Gail risk estimates as the dependent variable (risk difference), with age (years), education ( $\leq 12$  years or

$>12$  years), and family history of breast cancer (yes or no) as independent variables. Risk factors for breast cancer identified by women who reported one or more Gail model risk factors were examined to determine if the women acknowledged the presence of the Gail risk factor(s) for themselves. All statistical analyses were conducted with SPSS, version 10.0.

## RESULTS

### Demographic and personal characteristics

The women in the study sample had a mean age of 45.5 years ( $\pm 1.1$  years; 95% CI) and had 14.6 years of education ( $\pm 0.2$  years; 95% CI). Twenty-four percent ( $\pm 3.3\%$ ; 95% CI) of the women reported a family history of breast cancer (at least one first or second degree relative). The majority (59% [ $\pm 3.8\%$ ; 95% CI]) of the women reported being employed in paid work and 86.8% ( $\pm 2.6\%$ ; 95% CI) were urban dwellers.

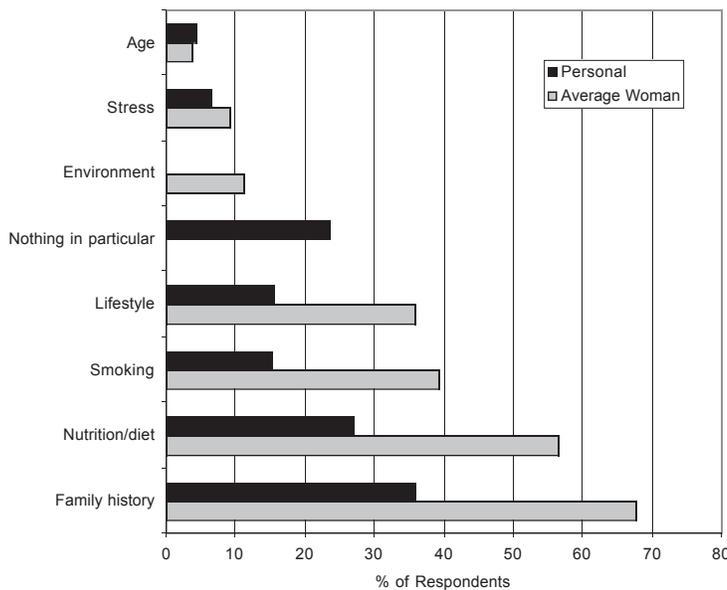
**TABLE II**  
**Identification of Gail Model Risk Factors**

Risk Factors	Number of Women with Risk Factor Present	Number of Women with Risk Factor Present who Identified the Factor (%)
Early menarche (<12 years)	153	0
Family history	176	123 (70.0)
Abnormal biopsy	48	0
No children (among women 40+ years)	64	3 (4.7)
Age (among women 60+ years)	166	10 (6.0)

**TABLE III**  
**Women's Screening Behaviour and Lifetime Breast Cancer Risk Estimates**

Screening Behaviour	Reported Participation (n)	%	Perceived Lifetime Breast Cancer Risk Estimate	
			Mean Percent	95% CI for Mean Percent
Breast self examination within past 3 months	Yes (563)	83.7	31.0	29.1, 33.0
	No (110)	16.3	28.0	24.1, 31.8
Clinical breast examination within past year	Yes (430)	64.8	30.8	28.6, 33.0
	No (234)	35.2	29.2	26.2, 32.2
Screening mammogram within past 2 years*	Yes (199)	79.0	28.5	25.0, 32.0
	No (53)	21.0	25.1	18.6, 31.5

\* In British Columbia, mammography screening is recommended every 2 years for women 50-69 years of age. Women younger than 50 years of age and over 69 years of age were excluded from the analysis.



**Figure 2.** Identified breast cancer risk factors

**Estimates of breast cancer risk**

Respondents' estimates of the hypothetical "average" woman's and their own lifetime risk for breast cancer were substantially higher than their objective lifetime risk estimates obtained using the Gail model (Table I). The women's estimates of their own risk for breast cancer, however, were lower than their estimates for the average woman. This tendency was consistent for women under 50 years of age and for those over 50. Considering both age groups together, the mean difference between perceived lifetime risk and Gail risk was 19% (SD = 22%;  $t_{(697)} = 22.9$ ,  $p < 0.001$ ) and the

mean difference between perceived personal lifetime risk and perceived risk for the hypothetical "average" woman was -8% (SD = 20%;  $t_{(690)} = 11.0$ ,  $p < 0.001$ ). As shown in Figure 1, 50% of the sample reported a perceived risk estimate at least 15% above their Gail risk estimate while 25% underestimated their risk.

**Importance of demographic characteristics in predicting discrepancies**

In the multiple linear regression analysis, age and having a relative with breast cancer were significant predictors in the model ( $p < 0.005$ ). However, the  $R^2$  (total amount

of variance explained by these predictors) for the model was only 0.05. There were no significant differences in mean risk difference between urban and rural dwellers.

**Knowledge of risk factors**

The breast cancer risk factors identified by women for themselves and for the hypothetical "average" woman are illustrated in Figure 2. Although responses to the questions posed to calculate the Gail model risk estimates indicated the presence of strong breast cancer risk factors among some respondents, only family history was consistently identified as a personal risk factor by these women (Table II).

**Risk perception and screening behaviour**

No significant differences in estimates of perceived lifetime risk for breast cancer were found between respondents who took part in recommended breast cancer screening and those women who did not report regular breast cancer screening (Table III).

**DISCUSSION**

Overestimations of risk for breast cancer reported here are similar to those reported in the studies in Canada<sup>10,26</sup> and in the United States.<sup>6,9,17</sup> Despite the widely publicized "1 in 9" message about breast cancer risk and the increase in the availability of information about breast cancer risk, this study demonstrates that gaps remain in women's understanding.

Demographic factors including age, education and having a relative with breast cancer do not appear to play a major role in determining the magnitude of the discrepancies between subjective and objective risk assessments. Tendencies to overestimate risk for breast cancer may be related to a number of factors, including the complexity of understanding and applying probabilities or percentage estimates, the high profile of breast cancer in popular media, and the impact of breast cancer diagnoses experienced by relatives or friends. Despite deliberate attempts by health care organizations and breast cancer interest groups to make current scientific information about breast cancer accessible in a wide range of formats, the findings indicate that many women lack knowledge of the risk factors for this disease. Many of

the risk factors that women identified were modifiable factors that are weakly, if at all, associated with breast cancer. With the exception of family history, women identified few non-modifiable risk factors for breast cancer. Age received surprising little recognition as a breast cancer risk factor, even among those over 60 years of age. The emphasis that women place on controllable albeit questionable risk factors may reflect the personal responsibility they hold for their level of breast cancer risk<sup>27</sup> or their lack of understanding of the difference between risk factors and risk behaviours.

Women who took part in recommended breast cancer screening (i.e., mammography screening, clinical breast examination, and breast self-examination) estimated their own lifetime risk of breast cancer to be slightly higher than women who were not following recommendations for screening, although this trend was not statistically significant. Although it has been suggested that perceptions of risk may influence screening practices, the screening rates found in this study may be a reflection of the intensive recruitment strategies used by the BC Screening Mammography Program and physician adherence to practice guidelines related to annual clinical breast examinations.

The findings of this study must be considered in light of the fact that the sample included only English-speaking women, who were resident in British Columbia. The numerical measures used to assess perceptions of risk may not adequately capture women's interpretations of their risk for breast cancer.<sup>9</sup> Additionally, although the Gail model is widely used in clinical practice and research settings, it is not intended for use as an objective measure of breast cancer risk for all women (e.g., other models of risk estimation are recommended for women with a strong family history). We acknowledge that assessments of screening behaviour based on self-report are susceptible to recall bias and social desirability response. Comparisons with the 1996 BC Census data suggested that study respondents may be better educated than non-responders (75% vs. 48% reporting at least some postsecondary education). Finally, since our response rate was 37.9%, the possibility of response biases cannot be ruled out.

Heightened perceptions of risk for breast cancer can have a significant impact on women's health and quality of life. Undue anxiety or excessive worry about breast cancer influence women's health decisions (e.g., with respect to hormone replacement therapy),<sup>28</sup> overshadow the importance of other high risk diseases<sup>9</sup> and cause psychological distress.<sup>29</sup> Health care providers have an important role to play in discussing breast cancer risk with all women. Although discussions of breast cancer risk often occur with the presentation of breast symptoms, other opportunities to discuss breast cancer risk should be fully utilized. Continued use of the "1 in 9" message, however, may not be the most effective approach in situations where individual information about risk for breast cancer could be presented. Researchers have reported that providing women with information about their risk factors and their corresponding Gail risk estimates, presented numerically and in visual form, was effective in enhancing women's accuracy regarding their perceived risk for breast cancer, without diminishing their screening intentions.<sup>30,31</sup> A website developed by the US National Cancer Institute provides health care professionals and women with an interactive tool to project individualized risk for breast cancer based on the Gail model (<http://bcra.nci.nih.gov/brc/>). In counselling women concerned about the significance of their family history in relation to breast cancer, the Canadian risk triage algorithm developed by Warner et al.<sup>32</sup> identifies women at low, moderate, and high risk of hereditary breast cancer and provides screening and counselling guidelines. Research is needed to determine the most effective strategies for enhancing women's understanding and accuracy of their risk for breast cancer.

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## RÉSUMÉ

**Objectif :** Le but de cette étude était de comparer l'opinion des femmes sur leur risque personnel et le risque objectif de cancer du sein et de décrire les facteurs associés au cancer du sein signalés par les femmes.

**Méthodes :** Sondage téléphonique avec un échantillon aléatoire composé de 761 femmes de milieux urbains et ruraux, sans antécédents familiaux de cancer du sein. Le sondage comportait des instruments de mesure des perceptions du risque individuel et collectif à long terme, ainsi que des perceptions des facteurs associés au risque. Les estimations objectives du risque de cancer du sein ont été calculées par l'algorithme de Gail et al. Les données ont été analysées au moyen de statistiques descriptives et par régression linéaire multiple.

**Résultats :** Les estimations des femmes quant à leur propre risque de cancer du sein étaient considérablement plus élevées que le risque estimé par le modèle de Gail (différence moyenne = 19 %,  $p < 0,001$ ). Les estimations des femmes quant à leur risque personnel à long terme étaient inférieures à leurs estimations du risque collectif (différence moyenne = -8 %,  $p < 0,001$ ). Pour la moitié de l'échantillon, l'estimation du risque était de 15 % supérieure à celle obtenue par le modèle de Gail. Les facteurs les plus fréquemment associés étaient les antécédents familiaux, l'alimentation, le tabac, le mode de vie, l'environnement, le stress et l'âge. Bien que certaines répondantes aient signalé les facteurs de risque utilisés dans le calcul du modèle de Gail, ces femmes ont uniformément cité les antécédents familiaux comme seul facteur de risque personnel.

**Conclusion :** On constate que les femmes estiment difficilement leur risque de cancer du sein, ainsi que les facteurs associés. Plus que le message « une sur neuf », le fait de présenter des informations individuelles sur le risque pourrait peut-être créer une perception plus juste du risque.

*A Fond Farewell, continued from page 404...*

Canadian International Immunization Program which involved 95 projects in 43 Commonwealth and Francophone countries, contributing towards immunizing 80% of children against the six crippling and deadly diseases: diphtheria, tetanus, pertussis, tuberculosis, polio and measles. Currently, CPHA is working with partners in 30 developing countries in Africa, Latin America and Caribbean, Asia and Pacific, Middle East and Northern Africa, and Central and Eastern Europe, in such areas as primary health care, HIV/AIDS training programs, technical exchange and sustainability development projects with multiple partners internationally (WHO, PAHO, UNICEF, UNFPA and the World Bank).

As I leave CPHA, I would like to express my sincere appreciation to all members of CPHA, former presidents and Board members who were supportive and helpful throughout the years, as well as to many colleagues and friends I have worked with in other national/provincial NGOs, and at the federal, provincial and local government levels. Most of all, I would like to thank the hundreds of employees who have worked with me and supported both myself and the Association over my 30 years at CPHA.

To quote my mother when, as a child, I was going to attend a special party or event, "at the end of the party, be sure to say, 'I have enjoyed myself very much, thank you, I am going home now.'"

My best wishes and good fortune to you all.

Gerald H. Dafoe  
Chief Executive Officer, CPHA

*Adieu, suite de la page 404...*

de la Francophonie et a contribué à vacciner 80 % des enfants contre six maladies invalidantes ou fatales : la diphtérie, le tétanos, la coqueluche, la tuberculose, la polio et la rougeole. Aujourd'hui, l'ACSP travaille avec ses partenaires dans 30 pays en développement, en Afrique, en Amérique latine et aux Caraïbes, en Asie-Pacifique, au Moyen-Orient, en Afrique du Nord et en Europe centrale et de l'Est, dans des domaines comme les soins de santé primaires, les programmes de formation sur le VIH/sida, les projets d'échanges techniques et de développement durable, et avec de multiples partenaires à l'étranger (l'OMS, l'OPS, l'UNICEF, le FNUAP et la Banque mondiale).

En prenant congé de l'ACSP, je tiens à exprimer mes sincères remerciements à tous les membres de l'Association, aux anciens présidents et administrateurs qui m'ont soutenu et aidé pendant toutes ces années, ainsi qu'aux nombreux collègues et amis avec qui j'ai travaillé dans d'autres ONG nationales et provinciales et aux paliers fédéral, provincial et local du gouvernement. Par-dessus tout, je remercie les centaines d'employés qui ont travaillé avec moi et qui nous ont aidés, l'Association et moi, durant mes 30 années à l'ACSP.

Comme me le rappelait ma mère lorsque j'étais enfant et que j'étais invité à une fête ou à un événement spécial, « quand ce sera fini, n'oublie pas de dire "Je me suis beaucoup amusé, merci, et maintenant je dois rentrer à la maison." »

Meilleurs vœux et bonne chance à tous et à toutes.

Gerald H. Dafoe  
Chef de la direction de l'ACSP