

Educating women about breast cancer

An intervention for women with a family history of breast cancer

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ABSTRACT

OBJECTIVE To evaluate an "information aid" for women with a family history of breast cancer.

DESIGN Before-after descriptive study.

SETTING Family practices in Ontario.

PARTICIPANTS Of 405 randomly selected Ontario physician members of the College of Family Physician's of Canada's National Research System, 97 agreed to participate and to recruit three consecutive female patients with any family history of breast cancer.

INTERVENTIONS Patients completed a baseline questionnaire and, after reviewing the information aid, a satisfaction questionnaire. Four weeks later, they completed a third questionnaire.

MAIN OUTCOME MEASURES Patient satisfaction, knowledge, worries related to breast cancer, risk perception, and attitudes toward screening.

RESULTS Of 203 patients recruited, 160 (79%) completed all three questionnaires. The information aid was rated excellent or very good by 91% of the women; 99% would recommend it to other women. Knowledge improved significantly; worry about breast cancer did not increase.

CONCLUSION The information aid is a useful resource for women and primary care physicians and could facilitate appropriate risk assessment and management of women with a family history of breast cancer.

RÉSUMÉ

OBJECTIF Déterminer la valeur d'une trousse d'information à l'intention des femmes qui présentent une histoire familiale de cancer du sein.

TYPE D'ÉTUDE Étude descriptive de type avant-après.

CONTEXTE Établissements ontariens de pratique familiale.

PARTICIPANTS Sur 405 médecins ontariens choisis au hasard parmi les membres du National Research System du Collège, 97 ont consenti à participer à l'étude. On leur a demandé de recruter trois cas consécutifs de patientes avec un ou plusieurs cas de cancer du sein dans leur famille.

INTERVENTIONS Les patientes ont d'abord répondu à un questionnaire de base. Après avoir pris connaissance de la trousse d'information, elles ont ensuite rempli un second questionnaire. Quatre semaines plus tard, elles ont rempli un troisième questionnaire.

PRINCIPAUX PARAMÈTRES MESURÉS Le degré de satisfaction des patientes, leurs connaissances et inquiétudes relatives au cancer du sein, leur perception des risques et leur attitude vis-à-vis le dépistage.

RÉSULTATS Sur 203 patientes recrutées, 160 (79%) ont répondu aux trois questionnaires: 91% d'entre elles ont jugé la trousse excellente ou très bonne et 99% la recommanderaient à d'autres femmes. On a constaté une augmentation appréciable de leurs connaissances; leurs préoccupations au sujet du cancer n'ont pas augmenté.

CONCLUSION Cette trousse d'information constitue une ressource utile pour les patientes et les médecins de famille et elle peut favoriser une évaluation plus adéquate des risques ainsi que la prise en charge des femmes qui présentent une histoire familiale de cancer du sein.

This article has been peer reviewed.

Cet article a fait l'objet d'une évaluation externe.

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As a result of media attention to breast cancer in general and to hereditary breast cancer in particular, women with a family history of breast cancer want information about their risk of getting cancer and strategies for preventing it and detecting it early. While up to 20% of women have a family history of breast cancer, only 5% have a history that suggests they have inherited a genetic mutation that puts them at greatly increased risk of breast and ovarian cancer.¹ Most women overestimate their risk of breast cancer attributable to family history.²⁻⁶ For most women, family history has a negligible or, at most, moderate effect on their risk. Education about the true risk might decrease anxiety and avoid unnecessary referral to high-risk clinics and unnecessary investigations.

An "information aid" is an educational tool that uses an unbiased approach to present all aspects of an issue in a comprehensive, easily understood format. Information aids facilitate health care providers' communication with patients by helping patients identify important questions they want to ask these health care providers and by giving patients information they can share with family and friends and discuss after visiting a physician.⁷

We developed an information aid consisting of a booklet (grade 8 reading level) and a 30-minute audiotape. We hope it will help women with a family history of breast cancer to identify for themselves the risk attributable to their family history in the context of other risk factors. Women with a low-risk family history, assuming they have no other important risk factors, can then be followed using screening recommendations for the general population. Women with a higher-risk family history are encouraged to consult their family physicians to decide whether they are at moderate risk or high risk.⁸ Women at moderately increased risk should be considered for earlier or more frequent screening and prophylactic antiestrogens.^{9,10} High-risk women should

be offered referral to specialized clinics for counseling about prevention and surveillance strategies and possibly genetic testing.

In previous work, we tested the information aid in a pilot study of 67 women on a waiting list for a hereditary cancer clinic.¹¹ The aid significantly increased knowledge, did not increase depression or anxiety, and decreased worry about breast cancer, particularly among lower-risk women.¹¹

The goal of this study was to evaluate, in a family practice setting, the usefulness of the information aid for women with a family history of breast cancer. The study's specific objectives were to evaluate women's satisfaction with the aid and to assess the effect of the aid on women's knowledge, breast cancer-related anxiety, risk perception, and attitudes toward screening.

METHODS

Development of the information aid and pilot-test results have been previously published.¹¹ In brief, the content was developed by a multidisciplinary team of health care professionals and breast cancer survivors and their relatives through focus groups, literature review, and key informants. Topics include breast cancer pathogenesis, risk factors, prevention, screening, and presentation; an overview of breast cancer genetics; and criteria to help women identify their risk level themselves. Three case scenarios of women at low, moderate, and high risk of breast cancer are presented at the beginning of the booklet and followed throughout. The audiotape can be used while reading the booklet to supplement the information read.

The information aid was first pilot-tested in a hereditary cancer clinic population and was then modified according to comments received.¹¹ An 11-item Breast Cancer and Heredity Knowledge (BCHK) scale was developed and validated specifically for this purpose.¹²

Recruitment

For this study, 405 family physicians were randomly selected from the membership list of the College of Family Physicians of Canada's (CFPC) National Research System (NaReS), a network of family physicians interested in participating in family medicine research with clinical relevance. The 97 who agreed to participate were asked to recruit three consecutive, English-speaking, female patients older than 18 with any family history of breast cancer. Each patient who gave written consent completed a baseline questionnaire in the office and was then given the information

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aid and a second questionnaire to complete after reviewing the aid at home.

The first questionnaire asked about patient demographics, family history of breast or ovarian cancer, breast screening, breast cancer worry, risk perception, and attitudes toward breast screening, and included the 11-item BCHK. The second questionnaire evaluated satisfaction with the booklet and audiotape using multiple-choice and open-ended questions. A third questionnaire, which repeated the questions about anxiety and risk perception, attitudes to screening, and the BCHK, was mailed 4 weeks after the second questionnaire was returned.

After 4 months, too few patients had been recruited, so we sent a letter to the physicians asking them to recruit up to six patients. The study received ethical approval from the University of Toronto Human Subjects Review Committee.

Data analysis

Based on family history, responding patients were classified at low, moderate, or high risk of hereditary breast cancer (HBC) using previously validated criteria.⁸ χ^2 comparisons were used to detect differences between risk groups. McNemar's matched pair test was used for before-after differences in dichotomous outcomes; paired *t* tests were used for continuous outcomes. Significance was set at $P < .05$ (two-tailed).

RESULTS

Recruitment and baseline data

Recruitment took place from February 1999 to May 2000. Of the 97 physicians who agreed to participate, 59 (61%) enrolled a total of 203 patients in the study with a median of three patients (range one to six) per physician. Of the 203 patients, 160 (79%) completed all three questionnaires. There were no significant demographic or family history differences between the women who responded to all three questionnaires and the 21% who did not.

Of the 160 women who completed the family history questions, 39% were classified low risk, 35% moderate risk, and 26% high risk for HBC. Patient demographics (**Table 1**) did not differ significantly across the three risk categories. Patients' self-reported baseline breast screening behaviour is summarized in **Table 2**.

Satisfaction

Study patients were highly satisfied with the booklet and tape; 91% gave the aid an overall rating of excellent

or very good (**Table 3**). The low-risk women rated the HBC component of the aid more highly than the higher-risk women did. There were no differences in overall satisfaction between the women who completed only the first two questionnaires and those who completed all three (92% vs 91%, $P = .84$). All but one woman said they would recommend the aid to other

Table 1. Patient demographics: Mean age 45 years, range 20 to 74 years ($N = 203$)

CHARACTERISTIC	N* (%)†
Marital status	
• Single	31 (16)
• Married or common-law	135 (71)
• Separated or divorced	21 (11)
• Widowed	4 (2)
Have children	135 (71)
Highest education	
• Elementary or some high school	16 (8)
• High school	33 (17)
• Some vocational school or college	22 (11)
• Technical or college diploma	41 (22)
• Some university	22 (11)
• University degree	38 (20)
• Postgraduate degree	21 (11)
Religion	
• None	3 (2)
• Protestant	94 (49)
• Catholic	67 (35)
• Other Christian	9 (5)
• Jewish	8 (4)
• Other	11 (6)
Race	
• White	175 (90)
• African-American	2 (2)
• Asian	6 (3)
• Other	10 (5)
Born in Canada	168 (84)
Language spoken at home	
• English	183 (94)
• English and other	7 (4)
• French	2 (1)
• Other	2 (1)

*Some respondents did not reply to some questions.

†Percentages are rounded up.

Table 2. Baseline breast screening behaviours: N = 203.

BEHAVIOUR	N* (%)†
Ever had a mammogram	
• Age 50 or older (n = 60)	59 (98)
• Younger than 50 (n = 127)	64 (50)
Practises breast self-examination	
• Monthly	56 (34)
• Every 2 to 3 months	58 (35)
• Every 4 to 6 months	26 (16)
• Never	27 (16)
Breasts examined by a health professional	
• More than once a year	50 (30)
• Yearly	105 (62)
• Less than once a year	11 (7)
• Never	3 (2)

*Some respondents did not reply to some questions.

†Percentages are rounded up.

Table 3. Patients' satisfaction with the information aid by hereditary breast cancer risk level: N = 172.

ASPECT OF THE AID	RATED EXCELLENT OR VERY GOOD			P VALUE
	LOW (%)	MODERATE (%)	HIGH (%)	
Overall	95	90	87	NS
Ease of use	92	98	87	NS
Design and layout	94	95	92	NS
Simplicity of language	95	93	92	NS
General information about breast cancer	97	95	94	NS
Description of risk factors	92	88	85	NS
How much it increased knowledge of HBC	97	78	72	.001
How well it increased understanding of HBC risk	95	82	81	.034
How well it answered questions about HBC	92	78	77	.051
Explanation of prevention and screening	90	85	87	NS
Presentation of sensitive issues	87	85	83	NS

HBC—hereditary breast cancer, NS—not significant.

women, and 96% thought it should be available in family physicians' offices.

At baseline, the percentage of women answering a particular question correctly ranged from 8% to 87%. Following the intervention, there was a highly significant overall improvement in knowledge on all items of the BCHK (Table 4). Although baseline knowledge was higher among more educated women ($P = .034$), knowledge increased among all women.

Anxiety and risk perception

Worry about breast cancer did not differ at baseline across the three risk groups and was not affected by use of the aid. The risk of breast cancer for average women was greatly overestimated or underestimated by a substantial proportion of the women; reviewing the aid did little to improve many women's estimation of risk.

On average, patients in all risk groups overestimated their risk at baseline with a trend toward higher average risk perception with increasing risk group. Reviewing the aid substantially reduced the mean risk estimate of low- and moderate-risk groups to a more appropriate level (Figure 1); however, there were still women who greatly overestimated or underestimated their risk of developing breast cancer.

Breast screening intentions

After reviewing the aid, there was no change in intent to undergo mammography or breast self-examination, but there was a significant increase (from 85% to 96%, $P < .0001$) in intent to undergo clinical breast examination, particularly in the low- and moderate-risk groups.

Physician demographics

The demographic characteristics of the 59 physicians who recruited patients to the study (Table 5) were compared with those of the 38 physicians who had agreed to participate but did not enrol patients, with the 308 NaReS physicians who were approached but did not agree to participate, and with the 4682 CFPC members in Ontario. Only two significant differences were found across the four groups. The proportion of female physicians was higher among study participants (55%, 39%, 33%, and 43%, respectively, $P = .001$) and physicians who participated or agreed to participate were more likely to have hospital admitting privileges (83% and 86% vs 66% and 67%, $P = .004$).

DISCUSSION

Women with a family history of breast cancer are an ideal target group for an information aid because of

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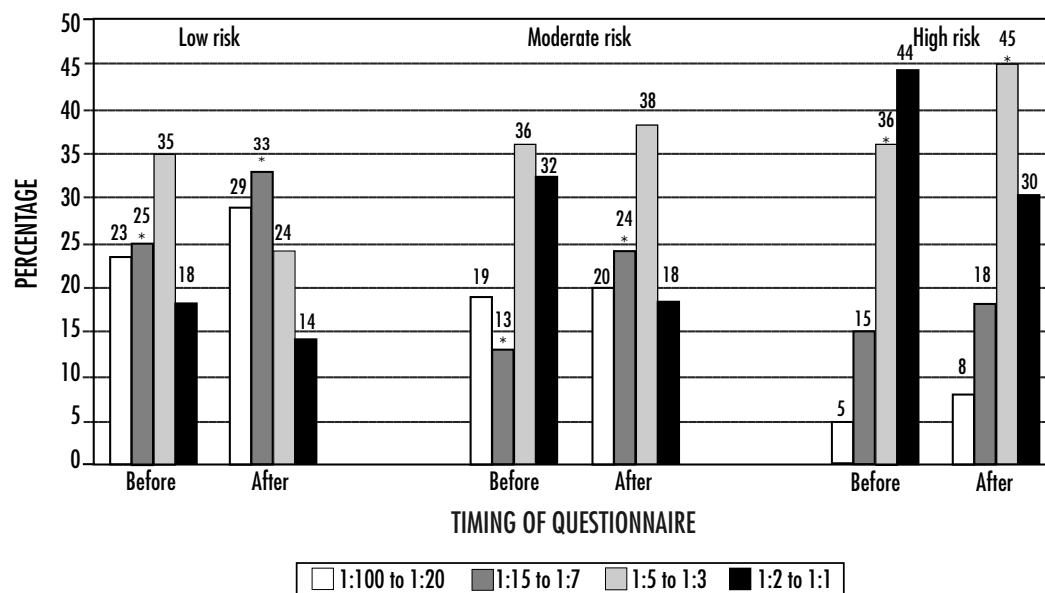
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Table 4. Effect of reviewing the information aid on patients' knowledge: N = 160.

ITEMS	BEFORE (%)	CORRECT RESPONSES AFTER (%)	P VALUE
GENETICS			
Testing for breast cancer gene mutations will tell a woman if she has cancer (F)	35	52	.001
Men cannot inherit breast cancer gene mutations (F)	74	83	.021
A woman whose mother was diagnosed with breast cancer at age 69 is considered at high risk for breast cancer (F)	40	65	<.0001
Ovarian cancer and breast cancer in the same family can be a sign of HBC (T)	74	84	.105
INCIDENCE			
Out of every 100 women diagnosed with breast cancer, 75 are alive and well after 10 years (T)	44	75	<.0001
Stress has been proven to increase the risk of breast cancer (F)	9	42	<.0001
Women older than 50 are more likely to get breast cancer than younger women are (T)	72	78	.001
Over a lifetime, one in nine women will develop breast cancer (T)	56	68	.01
DISEASE PREVENTION AND TREATMENT			
A change in the size or shape of one breast could be a sign of breast cancer (T)	69	81	.005
Chemotherapy is always used in treatment of breast cancer (F)	72	81	.014
Women older than 50 should have mammograms at least every 2 years (T)	87	94	.027

Note: Mean number of correct responses (maximum score = 11) was 6.2 (99% confidence interval 5.9 to 6.6) before and 8.1 (99% confidence interval 7.5 to 8.3) after, P <.0001.

Figure 1. Perception of lifetime risk of breast cancer before and after reading information aid: Before-after differences across the four categories are borderline significant (P = .072, .058, and .132 for low-, moderate-, and high-risk categories, respectively), but change in mean lifetime risk estimates is highly significant (P <.0001, = .001, and = .003 for low-, moderate-, and high-risk women, respectively.)



Note: Response categories have been collapsed from 14 to the 4 shown.
* Optimal response category for each risk level.

Table 5. Characteristics of participating physicians: Mean age was 45 years; 55% were men ($N = 59$).

CHARACTERISTIC	%*
Practice location	
• Suburban	36
• Urban	36
• Rural	23
• Inner city	3
• Geographically isolated	2
Method of remuneration	
• Fee-for-service	81
• Salary	5
• Other	14
Hospital admitting privileges	
• <20 h/wk	4
• 20-39 h/wk	38
• 40-59 h/wk	38
• ≥60 h/wk	21

*Percentages are rounded up.

the complexity of the information involved, the potential benefits of identifying women at increased risk of cancer, and the potential harm that the misinformation that is prevalent in the community can cause.¹³ We chose a self-administered audiotape and booklet as the format for our information aid based on the results of our focus groups and successful use of this format for women considering hormone replacement therapy¹⁴ or surgical options for breast cancer.¹⁵ There are no specific information aids for average women in the community with a family history of breast cancer, and, specifically, there has been nothing to help these women identify the risk attributable to family history for themselves.

We attribute the high satisfaction with our information aid to the process used to develop it that included focus groups of the target population, input from a multidisciplinary team, pilot testing followed by refinement of the aid, and finally testing in the field. The only area of relative dissatisfaction was that a substantial number of women at highest risk of HBC thought that the amount of information about HBC in the aid was inadequate. This suggests that the aid is achieving its aim in supplying sufficient information to women at low and moderate risk of HBC, while allowing higher-risk women to identify their risk themselves and approach their family physicians for

discussion about referral for genetic counseling. In addition to one-on-one counseling, there is abundant information available^{16,17} and under development for these high-risk women.

The aid significantly increased knowledge across all risk groups and educational levels. Even after reviewing the aid, however, the widely held misconception that stress definitely causes cancer was retained by more than half the women. Risk perception also remained relatively refractory to change, a phenomenon well described in the literature, even after individual genetic counseling.^{3,18-21}

Limitations

The main limitations of this study were the relatively low rate of participation by the family physicians who had originally indicated interest in the study and the highly selected study population. The participation rate of the physicians in our study is comparable to that reported in other recent NaReS studies and likely reflects shortages of physicians, the lack of financial compensation for participating in studies, and the work involved in the study.

The patient population was overwhelmingly white, Canadian born, English speaking, and generally highly educated. Also, 98% of the women older than 50 had had previous mammograms compared with 79% of all Canadian women over 50,²² the age group for which population screening is recommended in Canada. This is precisely the profile of the women who are already being disproportionately referred to familial cancer clinics.^{23,24} Although physicians were asked to recruit three consecutive women with a family history of breast cancer, it is likely that there was at least subconscious selection bias. To reach a broader group of Canadian women, we have translated the booklet and tape into French and are publicizing the aid to specific groups, such as aboriginal women.

Although a potential limitation of our aid is that it focuses on an area in which new developments are occurring rapidly, the aid deals predominantly with principles that will not quickly become outdated. We have also created an Internet version of the aid that is available through the Canadian Cancer Society (CCS) website in English or French at <http://www.hereditarybreastcancer.ca> in both audio and read-only versions. This format will be easier to update in the future.

To help family physicians assess higher-risk women identified by the aid, a companion package for physicians has been developed. It includes a family history risk assessment and management algorithm

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on a two-sided laminated page. In a companion study, these materials and the information aid were evaluated very highly by participating physicians.

The booklet, audiotape, and physician package are currently available free of charge through the CCS Cancer Information Service at 1-888-939-3333. Brief evaluation forms are included with each copy and on the website to enable us to determine whether these materials are now reaching a wider spectrum of Canadian women and physicians, and, if so, whether they are as satisfied with the material as our study participants were.

Conclusion

Our information aid for women with a family history of breast cancer was highly rated by our study patients. It could be a useful tool for educating and reassuring low-risk patients and helping higher-risk patients to identify themselves and receive appropriate management. ✦

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Contributors

Dr Warner, the principal investigator, prepared the grant proposals for funding and wrote the manuscript. **Drs Carroll, Heisey, Goel, Meschino, Lickley, Doan, and Chart** contributed to study design and interpretation of data. **Ms Orr**, who was study coordinator at NaRes, helped with data analysis and interpretation. **Ms Lothian** set up the database and analyzed the data. All the authors helped revise the manuscript and gave final approval to the version submitted.

Competing interests

None declared

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Editor's key points

- This study evaluates the usefulness of a package of information on breast cancer (booklet and audiotape) as assessed by 160 Ontario women recruited by their family physicians.
- These women, who had a family history of breast cancer, completed a questionnaire before and after reviewing the package of information and again 4 weeks later.
- Women's level of satisfaction with the information was very high. Their knowledge was significantly greater after the intervention, and there was no evidence that they were more worried about breast cancer.

Points de repère du rédacteur

- Cette étude évalue une trousse d'information sur le cancer du sein (livret et cassette audio) auprès de 160 femmes ontariennes recrutées par leur médecin de famille.
- Ces femmes, qui avaient une histoire familiale de cancer du sein, ont complété un questionnaire avant et après avoir parcouru la trousse d'information de même que 4 semaines plus tard.
- Le niveau de satisfaction des femmes face à la trousse d'information a été très élevé. Les connaissances des femmes se sont significativement améliorées après l'intervention sans qu'on mette en évidence une augmentation de l'anxiété.

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