Women's views on chemoprevention of breast cancer

Qualitative study

R. Heisey, MD, CCFP, FCFP **N. Pimlott,** MD, CCFP **M. Clemons,** MB BS, MD, MRCPUK **S. Cummings** **N. Drummond,** PHD

ABSTRACT

OBJECTIVE To determine, in a family practice setting, women's views on incentives for and barriers to taking chemopreventive therapy for breast cancer.

DESIGN Descriptive, qualitative study using in-depth semistructured interviews.

SETTING Women's College Family Practice Health Centre, an academic centre in Toronto, Ont.

PARTICIPANTS Three groups of women were recruited: women who might in future be candidates for chemoprevention, women who were then candidates for chemoprevention, and then-current participants in the Study of Tamoxifen and Raloxifene (STAR) chemoprevention trial.

METHOD Women were asked about their views on taking a pill to prevent breast cancer, their hopes and expectations regarding chemoprevention, incentives for and barriers to accepting chemopreventive therapy, and their preferred sources of information. Visual analogue scales were used to estimate perceived risk of breast cancer and personal interest in chemoprevention. Participants' Gail scores, perceptions of risk of breast cancer, perceptions of likelihood of accepting chemopreventive treatment, attitudes, views, and experiences were recorded.

MAIN FINDINGS The 27 women interviewed (median age 61 years, range 38 to 77) had a mean Gail score of 3.3 (indicating a 3.3% estimated risk of breast cancer within the next 5 years), range 1.4 to 6.8. Women were very interested in chemoprevention (62% to 67% likelihood of their taking it in the next 5 years). Perceived risk of breast cancer was not correlated with actual risk or with likelihood of taking chemopreventive therapy. To accept chemoprevention, women needed to know it would lead to an acceptable decrease in risk of breast cancer and needed more information about the medication. Incentives for acceptance included clear evidence of efficacy, prevention of cancer, altruism (contributing to an important area of research), secondary gain, and the feeling of being proactive and in control. Barriers included fear of side effects, lack of information, denial, aversion to medication, the term "chemoprevention," and the effect of the "HRT fiasco." Women's most trusted information source was their family physicians. Women overestimated their risk of breast cancer.

CONCLUSION Women were interested in chemoprevention, but required more information, preferably from their family physicians. Our data suggest that at least 4 conditions must be met for women to accept chemopreventive therapy. They must believe in its effectiveness, be proactive about their health care, believe side effects will be tolerable, and be able to overcome the fear of ingesting a pill. To make the therapy more acceptable, the term "chemoprevention" should be discontinued.

EDITOR'S KEY POINTS

- Chemoprevention for women at risk of breast cancer has been shown to be effective (40% to 50% reduction in risk), but women have been slow to accept it. This study explores the expectations and barriers regarding use of tamoxifen or aromatase inhibitors for preventing breast cancer.
- At-risk women were interested in chemoprevention if there was strong evidence of its efficacy, if they had had a personal experience (eg, a friend) with cancer, or if they were "proactive" people who liked to control their own health.
- Barriers included fear of side effects, the association (by name) with chemotherapy, lack of information, denial, and the "HRT fiasco."
- Women vastly overestimated their individual risk of breast cancer, but most seemed in favour of chemoprevention. More than 60% said they would likely take it.

This article has been peer reviewed.
Full text available in English at **www.cfpc.ca/cfp**
Can Fam Physician 2006;52:624–625.

Breast cancer remains a major global health issue; around 200 000 new cases were diagnosed in North America during 2004.[1] Unfortunately, despite improvements in management of breast cancer, many women still die of it.

For women at increased risk of breast cancer, traditional options for primary prevention include bilateral prophylactic mastectomy or oophorectomy.[2-4] Understandably, these strategies are unacceptable to most women. The concept of chemoprevention, however, is gaining increasing acceptance. Results of large randomized trials using such agents as tamoxifen and raloxifene for prevention among high-risk women have shown relative reductions in breast cancer risk of 38% to 50%.[5-10] Chemoprevention might, therefore, prove the most acceptable and useful long-term strategy against breast cancer.

Recently, the United States Food and Drug Administration (FDA) approved tamoxifen for reduction of breast cancer in women at increased risk of the disease. The definition of "high risk" is complex, but most randomized trials have used an individual risk of breast cancer score derived from the Gail model.[11] This model computes individualized absolute 5-year and lifetime risk estimates (ie, the chance that women with specific risk factors will develop breast cancer within a specified future period). Variables in this model include current age, age at menarche, age at first live birth, number of breast biopsies, history of atypical hyperplasia, and number of first-degree relatives with breast cancer.

Several groups have produced guidelines that support counseling women at higher risk of breast cancer (Gail index >1.66% at 5 years[11]) on the potential benefits and drawbacks of breast cancer prevention with tamoxifen.[12,13] The Canadian Task Force on Preventive Health Care recommends such counseling (B recommendation). Their examples of high-risk patients are any women with 2 first-degree relatives with breast cancer or with a personal history of lobular carcinoma in situ or atypical hyperplasia.[12] The Task Force does not suggest routine use of the Gail model in family physicians' offices, but suggests it could be used when either physicians or women are concerned about increased risk. Then, if a woman has a risk score higher than 1.66% over the next 5 years, further discussion on chemoprevention could follow. Women at low or normal risk of breast cancer should not be offered chemoprevention (D recommendation).

Breast cancer risk assessment: *More information is available from the National Cancer Institute website*, **http://bcra.nci.nih.gov/brc/q1.htm.**

Assessment includes the following risk factors

- Age
- Age at menarche
- Age at first live birth
- Number of first-degree relatives (mother, sister[s], or daughters) with breast cancer
- Number of previous breast biopsies
- History of atypical hyperplasia
- Based on the Gail model.[11]

Despite the impressive results of these individual trials and FDA approval for tamoxifen, in actual practice, women's uptake of chemoprevention has been poor.[14] Studies of women from families with hereditary breast and ovarian cancer suggest that women with a higher perceived risk of breast cancer are more likely to accept chemoprevention,[15] but very little is known about women's views on chemoprevention. Until more is understood about chemoprevention, it is unlikely that tamoxifen or other agents, such as raloxifene[16] and aromatase inhibitors,[17] currently being evaluated as chemopreventive therapies will be used outside the setting of a clinical trial.

There is evidence that physicians' recommendations influence women's decisions to start chemoprevention.[18,19] Because most women at increased risk of breast cancer first present to their family doctors, it is important to assess their views on chemoprevention in the family practice setting. We undertook a qualitative study to assess women's general level of interest in chemoprevention and to explore their hopes and expectations, perceived incentives for and barriers to chemopreventive therapy, factors that influenced their decision making, and their preferred sources of information.

METHODS

Subjects and setting

Women recruited from the Women's College Family Practice Health Centre, an academic facility in downtown Toronto, Ont, were assigned to 1 of 3 groups. Group 1,

Dr Heisey *is a family physician and an Assistant Professor in the Department of Family and Community Medicine at Women's College Hospital and a Clinical Associate in the Department of Surgical Oncology at Princess Margaret Hospital in Toronto, Ont.* **Dr Pimlott** *is Director of Research and an Assistant Professor in the Department of Family and Community Medicine at Women's College Hospital.* **Dr Clemons** *is a medical oncologist and an Assistant Professor in the Division of Medical Oncology at Sunnybrook Health Sciences Centre. At the time of the study,* **Ms Cummings** *was a research assistant in the Department of Family and Community Medicine at Women's College Hospital.* **Dr Drummond** *is an Associate Professor in the Department of Family Medicine at the University of Calgary in Alberta.*

women who might already or in future be candidates for chemoprevention, consisted of women 35 years old or older who had a first-degree relative with breast cancer. Group 2, women who were then potential candidates for chemoprevention, consisted of women 60 years old and older who by virtue of their age alone met Gail criteria for increased risk of breast cancer. Group 3 was made up of women already participating in the STAR (Study of Tamoxifen and Raloxifene) chemoprevention trial,[16] the National Cancer Institute's randomized, double-blind trial comparing tamoxifen and raloxifene in women with a Gail score of ≥1.66. Groups 1 and 2 were chosen from the patient roster at the Family Practice Health Centre by age and by using the Ontario Health Insurance Plan billing code for benign breast disease or mammary dysplasia. History of a first-degree relative with breast cancer in group 1 women was determined from cumulative patient profiles. Group 3 included STAR participants seen by a family physician. Low- and average-risk women were not included, as they would not be candidates for chemoprevention.

Potential participants were mailed an information package containing a letter of invitation, an information sheet on the study, and a consent form. Eligible women who returned signed consent forms were contacted by telephone and invited to an interview at the family practice research office. The Research Ethics Board of Sunnybrook and Women's College Health Sciences Centre granted approval for the study.

Interviews

The study coordinator conducted open-ended, semi-structured interviews. At the beginning of each interview, women were asked to provide basic demographic data. The interviewer followed a guide designed to encourage women to explore and discuss their knowledge and feelings about chemoprevention of breast cancer. Among the topics explored were women's views on taking a pill to prevent breast cancer; their hopes and expectations in doing so; their perception of incentives for and barriers to chemoprevention; and their preferred sources of information about chemoprevention. Issues raised in the 5 pilot interviews were tested in subsequent interviews.

The interviewer was free to vary the wording of questions and the order in which they were asked. Subjects were asked for detail and clarification. The flexibility of this method allowed informants to express thoughts and feelings about chemoprevention that were important to them and not be constrained by the researchers' interests. All interviews were audiotaped and transcribed verbatim. Names were omitted. Transcripts were checked for accuracy.

Women were asked to estimate their risk of developing breast cancer within the next 5 years and their likelihood of accepting chemoprevention using two 100-mm visual analogue scales. The first was anchored between "no risk at all" and "absolute certainty," the second between "no likelihood at all" and "absolute certainty."

Analysis

Two of the investigators (R.H. and N.P.) independently reviewed the transcripts to explore and reflect on the text and to identify statements judged to specify incentives for or barriers to accepting chemoprevention. All team members met to review transcripts and ensure saturation was reached. Basic statistical analysis was performed to compare characteristics of participants in the 3 groups (**Table 1**[11]). In keeping with the Framework[20] approach to ethnomethodologic data analysis, themes were identified within and across all 3 groups, and the frequency of themes was documented to establish their commonality. Themes were examined to discover whether any nonconfirming views could be identified. Where no such nonconfirmation existed, the theme was allowed to stand.

Table 1. Characteristics of participants: *Group 1 comprised women who might in future be candidates for chemoprevention; group 2 comprised women who were potential candidates for chemoprevention; group 3 comprised then-current participants in the STAR chemoprevention trial.*

CHARACTERISTIC	GROUP 1 N = 8	GROUP 2 N = 10	GROUP 3 N = 9
Mean age in years (range)	48.8 (38-56)	66.3 (61–77)	61.9 (56–74)
Married	63%	50%	67%
Mean no. of children	2	3	2
Occupation: professional	75%	60%	44%
Education: postsecondary	87.5%	60%	66.6%
Household income	High	Low-middle	Middle-high
Risk of developing breast cancer in the next 5 years (range)*	3.11% (1.40%-6.80%)	3.09% (1.50%-5.40%)	3.71% (2.60%-6.30%)
Perceived risk of developing breast cancer in the next 5 years (range)	40% (15%-80%)	37% (0-63%)	35% (11%-56%)
Likelihood of taking chemoprevention in the next 5 years (range)	62.5% (9%-100%)	62% (0-99%)	67% (0-100%)

*Gail model score.[11]

FINDINGS

Participants' characteristics are summarized in **Table 1**.[11] We chose a purposive sample of 27 women (median age 61 years, range 38 to 77 years) and

interviewed them. Most were highly educated, and all but 1 overestimated their actual 5-year risk of developing breast cancer. Their average risk score was 37%, more than 10 times their actual score as calculated using the Gail model (mean score 3.30%, range 1.4% to 6.8%). Women thought they had a strong likelihood (mean 63.8%, range 62.5% to 67%) of taking chemoprevention in the next 5 years. Perceived 5-year risk of developing breast cancer was not correlated with either actual risk (Gail score) or the likelihood of taking chemoprevention.

Hopes and expectations

When asked about their hopes and expectations from taking a pill to reduce their chances of getting breast cancer, these women said they needed an acceptable decrease in risk. For them, an acceptable decrease in risk ranged from 50% to 100%. "...I believe that there's a high possibility of me having breast cancer and the doctor said, 'If you take this pill for 5 years, there's a 75% chance that you won't get it.' Well I would take it—I would be silly if I didn't."

Incentives and barriers to chemoprevention

Incentives and barriers articulated during interviews are presented in **Table 2**. Key issues for us were what factors women thought would encourage them to take the preventive treatment (ie, incentives) and what factors they thought would hinder them from doing so (ie, barriers).

Table 2. Incentives for and barriers to chemoprevention: *Group 1 comprised women who might in future be candidates for chemoprevention; group 2 comprised women who were potential candidates for chemoprevention; group 3 comprised then-current participants in the STAR chemoprevention trial.*

INCENTIVES FOR AND BARRIERS TO CHEMOPREVENTION	MENTIONED BY GROUPS
INCENTIVES	
Effectiveness	1,2,3
Prevention of breast cancer	2,3
Personal experience with cancer	1,2,3
Personal risk of breast cancer	1,2,3
Altruism	2,3
Secondary gain	3
Being proactive and in control	1,2,3
BARRIERS	
Side effects	1,2,3
Term "chemoprevention"	2,3
Lack of information	1,2,3
Denial	1,2,3
The "HRT fiasco"	1,2
Aversion to medication	1,2,3
Cost	1,2

Incentives. The most frequently mentioned incentive was the existence of clear, incontrovertible evidence of the effectiveness of the treatment: "...very strong scientific evidence that it is advisable, on balance. I'd probably have to be pretty strongly convinced." Twelve women identified the concept of preventing cancer. "I guess just the mere thought that you could prevent breast cancer. It would be enough to spur me to do it, sure."

Women's personal experience with cancer (not always breast cancer) could act as an incentive or barrier, but more commonly acted as an incentive to taking preventive therapy: "...I think that [prevention] is great and uh, with my husband having [cancer] doesn't mean that I have to wait...."

Nine women stated that an increased personal risk of breast cancer made them more likely to be interested in chemoprevention. "Because my mother and 3 of her sisters had breast cancer, so anything I can do to prevent cancer I would do." Women with higher Gail scores were no more likely than women with lower scores to take preventive therapy as measured by our visual analogue scale.

Altruism was a prevalent theme for women in groups 2 and 3. They described the motivation they felt to advance understanding of the disease and its prevention through research. This was despite uncertainty regarding the effectiveness of treatment and the potential for side effects. "It's a good cause, and uh, I feel that I'm contributing a tiny bit for the cause." "I think I'm doing it for science, for history. I'm not doing it for me. I'm not looking for medals, or anything."

The desire to benefit others at potential cost to oneself, however, is not straightforward. "Well, obviously you need research done into this. If I was assured that—or somewhat assured that this was going to help—be in my interest—I think most people would do that." Secondary gain was an incentive for group 3 participants. "Um, it's also very reassuring to get the regular checkups and be looked after the way I am in the study, because I tend then to just forget about it."

The experience of being proactive and attempting to take control over their disease was also considered to be an incentive. "I think I learned from my experience with my mother that being aggressive about treatment is a worthwhile approach, avoiding any sort of complacency. It [could] be that that would incline me to take a pill rather than not."

Barriers. When asked to identify the specific barriers they perceived as potentially inhibiting them from taking the treatment, the most common concern was side effects.

> Obviously there would be side effects ... that if you had a particular sensitivity to the drug, then you would see that almost immediately, or in the very short term, which is fine ... that I could deal with ... nausea, vomiting, hair loss, skin rashes, this kind of thing ... the long-term effects would concern me.... They could be something detrimental to your immune system; it could affect the liver, kidney function.

Respondents recognized, however, that while side effects range from trivial to severe, noticeable effects on what each individual considered "normal" functioning indicated the border between acceptability and unacceptability. "Well, I guess I'd be concerned about—let's put it—any that would actually affect my routine."

Many of the feared side effects, however, included nausea and hair loss, which are more commonly associated with chemotherapy than chemoprevention. Indeed the name chemoprevention might itself act as a barrier because it can be easily confused with chemotherapy. "Just so I know, for example, my mother takes a pill a day now. Is that in fact a chemotherapy drug? This is something that's not a chemotherapy drug?"

Women from all 3 groups cited "lack of information" as a barrier to informed decision making.

> I want to know a little more, because then when you have to make a decision with information ... and ... you can't give me an answer for everything, but at least if you give me all the information you have, and I know that information, then I can assess it, and then I make my decision, and then I realize it.

Denial was also identified as a barrier. "It's like death; people don't want to talk about death ... I think they're scared or don't want to acknowledge it. Because if you acknowledge something you have to then do something about it."

The recent "HRT fiasco" was described as having a strong influence over the women's views on chemoprevention.

> I think this HRT business, and I don't mean to suggest that I'm upset about it, I'm not because nothing happened and so on. But, you know, 30 years is an awfully long time to tout something as being a panacea and then to turn around and say, "We made a mistake."

Several women remarked on their aversion to taking "unnatural" medication, and such medication's interference with body integrity: "...whether I had any concerns about introducing something that would strike me immediately as unnatural into my body on a daily basis."

Finally, cost was identified as a possible barrier.

Evaluating incentives and barriers

Faced with deciding to have chemopreventive treatment or not, several women described the trade-off involved in making a decision. This included their subjective perception of their personal risk of cancer, the risk of severe side effects, the risk of adverse events, and the likelihood of benefit. For some women, the risk-benefit analysis was quite straightforward.

> Well, I guess it made me realize that I should really think about what I take before I take it, and investigate, learn as much as you can about whatever it is, but I mean when I make a decision, the pros are on this side, the cons are on this side, and I add them up [demonstrates with hands], and I look at them both, and I think in this situation it was pro for me personally. It's just kind of cut and dried for me. Very simple.

For others, the decision-making process was more complex. Assessing the uncertainty of the trade-off, long-term side effects, and efficacy against the likelihood of getting breast cancer seemed difficult.

> Will [chemoprevention] lessen the risk for me to get breast cancer? Or will I take a pill 5 years and ... maybe contaminate my body and have secondary effects, be sick, have 5 years of dealing with that medication, and actually ... never have cancer? ... It's longer term and it's based on a hypothesis, not on a fact. It's a hypothesis I may get cancer. They are two different things.

All women seemed to weigh their hopes, expectations, incentives and barriers in the context of their personal experiences with breast cancer to arrive at a decision about preventive therapy.

Preferred information sources

Although most women (17/27) stated that their family physicians were their preferred source for information regarding chemoprevention, they acknowledged that this might not be their sole source. Other information sources mentioned are listed in **Table 3**.

DISCUSSION

For women at increased risk of breast cancer, chemoprevention has been shown to be an effective risk-reduction strategy.[21] Although many factors could be responsible for the documented low uptake of chemoprevention,[14] we wanted to understand better how women make decisions about chemoprevention in a family practice setting. This is the first study we are aware of in this setting. This is important, as family physicians are often the first health care professionals patients approach for information about risk reduction.

Table 3. Preferred sources of information on chemoprevention: *Group 1 comprised women who might in future be candidates for chemoprevention; group 2 comprised women who were potential candidates for chemoprevention; group 3 comprised then-current participants in the STAR chemoprevention trial.*

SOURCE	MENTIONED BY GROUPS
Family doctor	1,2,3
Media (television, magazines, newspapers)	1,2,3
Gynecologist	1
Professional colleagues	1
Scientific reports	1
Reputable journals	1
STAR trialists	3
Family members	1,2,3
Pharmacy or pharmacist	3
Internet	1,2,3
Breast specialist	1,2,3
Library	3

A previous study of the "determinants of having an interest" in taking chemoprevention consisted of telephone interviews with women aged 40 to 45 or 50 to 55 who were already enrolled in a randomized controlled trial to assess the efficacy of a decision aid for mammography.[22] Although only 8% of the 1273 women qualified as high risk (by the Gail model) for considering chemoprevention, 23% expressed interest. Increased personal risk based on Gail score was not associated with interest in chemoprevention.

Women in our study were very interested in the concept of chemoprevention; they expressed a 62% to 67% likelihood of taking it in the next 5 years. Personal risk of breast cancer did not correlate with increased likelihood of accepting preventive therapy as assessed by our visual analogue scale. This might be due to the fact that the overall likelihood was so high. All 3 groups of women overestimated their risk of breast cancer. Even STAR participants, who had received personalized education in risk assessment and had been given Gail scores indicating their personal risk of breast cancer in the next 5 years, overestimated their risk; a phenomenon that is well documented.[23] Our study group overestimated their risk by an average of 34%, which is similar to the 25% reported by Davis et al.[24]

Cyrus-David and Strom[18] assessed knowledge of and attitudes toward chemoprevention in 26 women at increased risk of breast cancer. A physician's recommendation, after thorough discussion of risk-benefit issues, to take chemopreventive treatment seemed essential for women to accept treatment. As Cyrus-David and Strom[18] did, we found that personal experience, as in having a close friend or relative with breast cancer, tended to increase the likelihood that a woman would accept preventive therapy. Our data suggest that women who like to be proactive and in control are more likely to consider preventive therapy.

Women said that they needed to know the chemopreventive agent had proven efficacy and that they needed more information, which they overwhelmingly preferred to get from their family doctors. Evidence shows that primary care physicians widely endorse mammography and counseling about lifestyle behaviour for breast cancer prevention and risk reduction, but are less likely to refer high-risk patients for genetic evaluation and newer therapeutic options, such as chemoprevention.[23] This is understandable, as the field of genetics and the concept of preventive therapy for breast cancer is relatively new and rapidly evolving.

Women from groups 2 and 3 interested in chemoprevention tended to be more altruistic, a concept documented in elderly people with respect to other preventive therapies.[25] There was a suggestion that the women in group 3 who had chosen chemoprevention had a more fatalistic outlook on life; researchers have observed that otherwise healthy women with no history of serious medical problems are unlikely to accept chemoprevention and that optimism is negatively associated with acceptance of preventive strategies.[26] Our study showed that women in group 3 believed they derived important secondary gain from being part of a clinical trial.

Port et al[27] studied 43 women at increased risk of breast cancer recruited from surgical practices in the Special Surveillance Breast Program at the Memorial Sloan-Kettering Cancer Center in New York. Women were first given questionnaires to assess their knowledge of tamoxifen and its risks and benefits and then provided with educational sessions and literature on tamoxifen. Afterward, the women's knowledge was assessed again and subsequently reassessed by telephone interview. Only 2 of the 43 women elected to start tamoxifen. Educational sessions did not influence their decisions. Fear of side effects and lack of available information on tamoxifen were reasons these women declined the drug. In fact, we found fear of side effects and lack of information were notable barriers to chemoprevention. Many women in our study attributed to chemoprevention many of the potential side effects normally associated with chemotherapy. Groups 1 and 2 stated that the "HRT fiasco," to use their terminology, strongly influenced their reluctance to take medication.

Evidence from our study suggests that at least 4 conditions must be met in order for women to accept chemopreventive treatment (**Table 4**). Conditions for acceptance included a belief in the effectiveness of the chemopreventive agent, preferably supported by scientific evidence; an ability to overcome reluctance to ingesting manufactured substances of uncertain safety;

Table 4. Conditions for acceptance of chemoprevention

• Women must believe in the effectiveness of the chemopreventive agent, and its efficacy should be supported by scientific evidence
• Women must be able to overcome their reluctance to ingest manufactured substances of uncertain safety
• Women must believe that side effects will be tolerable
• Women must prefer to be proactive and in control in health-related matters

a belief that side effects will be tolerable; and a preference for being proactive and in control in health-related matters. These conditions were then factored in the context of personal decisions influenced by the previously mentioned incentives and barriers.

Limitations

Weaknesses of this study include a fairly homogeneous sample of well educated women. The substantial overestimation of breast cancer risk and of the likelihood of taking chemoprevention might reflect an inability to use our visual analogue scale effectively. Visual analogue scales are accepted widely for assessment of cancer pain but are not as widely used for assessment of cancer risk. Possibly, women were more likely to indicate their family physician (R.H.) as their preferred source of information because she was the primary investigator. We did not ask women directly how they arrived at their decisions; this might be an area for further research. Family physicians' views on chemoprevention would also be interesting to study. Despite these limitations, our findings do help us better understand women's views on chemoprevention.

Conclusion

Women at increased risk of breast cancer are interested in taking a pill to prevent it, and they want information about this therapy from their family doctors. Certain conditions must be met for women to accept chemoprevention. Family physicians will need more information and education about this aspect of breast cancer prevention, as they are the most favoured and trusted source of information. The word chemoprevention should not be used because it conveys negative connotations associated with chemotherapy.

Acknowledgment

This project was made possible through the generous support of the Canadian Breast Cancer Foundation-Ontario Chapter. The Foundation had no involvement in study design; data collection, analysis, or interpretation; manuscript preparation; or the decision to submit the paper for publication. We thank **Christine Lalonde** *for her editorial comments.* **Dr Heisey** *gratefully acknowledges a Janus Research Grant from the College of Family Physicians of Canada.*

Contributors

This research was a collaborative effort. **Dr Heisey** *conceived the idea of exploring women's views in the area of chemoprevention and was lead author. She reviewed transcripts and led preparation of the manuscript.* **Dr Pimlott** *helped with concept and design of the study, reviewed transcripts, and helped prepare the manuscript.* **Dr Clemons** *assisted with study design, evaluation of data, and preparation of the manuscript.* **Ms Cummings** *assisted with study design, evaluation of data, and preparation of the manuscript.* **Dr Drummond** *was integral to development of study design and evaluation of data and assisted in preparation of the manuscript. All researchers were independent from funders.*

Competing interests

None declared

Correspondence to: **Dr Ruth Heisey,** *Family Practice Health Centre, Women's College Hospital, 76 Grenville St, Toronto, ON M5S 1B2; telephone 416 323-6060; fax 416 323-7323; e-mail* **r.heisey@utoronto.ca**

References

1. Jemal A, Tiwari RC, Murray T, Ghafoor A, Samuels A, Ward E, et al. Cancer statistics, 2004. *CA Cancer J Clin* 2004;54(1):8-29.
2. Hartmann LC, Schaid DJ, Woods JE, Crotty TP, Myers JL, Arnold PG, et al. Efficacy of bilateral prophylactic mastectomy in women with a family history of breast cancer. *N Engl J Med* 1999;340(2):77-84.
3. Schairer C, Persson I, Falkeborn M, Naessen T, Troisi R, Brinton LA. Breast cancer risk associated with gynecologic surgery and indications for such surgery. *Int J Cancer* 1997;70:150-4.
4. Meijer WJ, Van Lindert AC. Prophylactic oophorectomy. *Eur J Obstet Gynecol Reprod Biol* 1992;47:59-65.
5. Fisher BF, Constantino JP, Wickerham DL, Redmond CK, Kavanah M, Cronin WM, et al. Tamoxifen for prevention of breast cancer: report of the National Surgical Adjuvant Breast and Bowel Project P-1 Study. *J Natl Cancer Inst* 1998;90:1371-88.
6. Powles T, Eeles R, Ashley S, Easton D, Chang J, Dowsett M, et al. Interim analysis of the incidence of breast cancer in the Royal Marsden Hospital tamoxifen randomized chemoprevention trial. *Lancet* 1998;352:98-101.
7. Veronesi U, Maisonneuve P, Costa A, Sacchini V, Maltoni C, Robertson C, et al. Prevention of breast cancer with tamoxifen: preliminary findings from the Italian randomized trial among hysterectomised women. Italian Tamoxifen Prevention Study. *Lancet* 1998;352:93-7.
8. Cuzick J, Forbes J, Edwards R, Baum M, Cawthorn S, Coates A, et al. First results from the International Breast Cancer Intervention Study (IBIS-I): a randomised prevention trial. *Lancet* 2002;360:817-24.
9. Cummings SR, Eckert S, Krueger KA, Grady D, Powles TJ, Cauley JA, et al. The effect of raloxifene on risk of breast cancer in postmenopausal women: results from the MORE randomized trial. Multiple Outcomes of Raloxifene Evaluation. *JAMA* 1999;281:2189-97.
10. Cuzick J, Powles T, Veronesi U, Forbes J, Edwards R, Ashley S, et al. Overview of the main outcomes in breast-cancer prevention trials. *Lancet* 2003;361:296-300.
11. Gail MH, Brinton LA, Byar DP, Corle DK, Green SB, Schairer C, et al. Projecting individualized probabilities of developing breast cancer for white women who are being examined annually. *J Natl Cancer Inst* 1989;8:1879-86.
12. Levine M, Moutquin JM, Walton R, Feightner J. Chemoprevention of breast cancer. A joint guideline from the Canadian Task Force on Preventive Health Care and the Canadian Breast Cancer Initiative's Steering Committee on Clinical Practice Guidelines for the Care and Treatment of Breast Cancer. *CMAJ* 2001;164(12):1681-90.
13. Kinsinger LS, Harris R, Woolf SH, Sox HC, Lohr KN. Chemoprevention of breast cancer: a summary of the evidence for the U.S. Preventive Services Task Force. *Ann Intern Med* 2002;137:59-69.
14. Evans D, Lalloo F, Shenton A, Bogges C, Howell A. Uptake of screening and prevention in women at very high risk of breast cancer. *Lancet* 2001;358:889-90.
15. Meiser B, Butow P, Price M, Bennett B, Berry G, Tucker K, et al. Attitudes to prophylactic surgery and chemoprevention in Australian women at increased risk for breast cancer. *J Women's Health* 2003;12(8):769-78.
16. National Cancer Institute, National Surgical Adjuvant Breast and Bowel Project. *Prevention Study of Tamoxifene and Raloxifene (STAR) in postmenopausal women at increased risk for invasive breast cancer.* Bethesda, Md, and Washington, DC: National Cancer Institute and National Surgical Adjuvant Breast and Bowel Project; 1999. Available at: **http://www.nsabp.pitt.edu/STAR/Index.html**. Accessed 2002 October 15.
17. Goss PE, Strasser-Weippl K. Prevention strategies with aromatase inhibitors. *Clin Cancer Res* 2004;10(1 Part 2):372-9s.
18. Cyrus-David MS, Strom SS. Chemoprevention of breast cancer with selective estrogen receptor modulators: views from broadly diverse focus groups of women with elevated risk for breast cancer. *Psychooncology* 2001;10(6):521-33.

19. Fallowfield L, Fleissig A, Edwards R, West A, Powles TJ, Howell A, et al. Tamoxifen for the prevention of breast cancer: psychosocial impact on women participating in two randomized controlled trials. *J Clin Oncol* 2001;19(7):1885-92.
20. Ritchie J, Spencer L. Qualitative data analysis for applied policy research. In: Bryman A, Burgess R, editors. *Analysing qualitative data*. London, Engl: Routledge; 1994. p.173-94.
21. Freedman AN, Graubard BI, Rao SR, McCaskill-Stevens W, Ballard-Barbash R, Gail MH. Estimates of the number of US women who could benefit from tamoxifen for breast cancer chemoprevention. *J Natl Cancer Inst* 2003;95:526-32.
22. Bastian LA, Lipkus IM, Kuchibhatla MN, Weng HH, Halabi S, Ryan PD, et al. Women's interest in chemoprevention for breast cancer. *Arch Intern Med* 2001;161(13):1639-44.
23. Haas JS, Kaplan CP, Gregorich SE, Perez-Stable EJ, Des Jarlais G. Do physicians tailor their recommendations for breast cancer risk reduction based on patient's risk? *J Gen Intern Med* 2004;19:302-9.
24. Davis S, Stewart S, Bloom J. Increasing the accuracy of perceived breast cancer risk: results of a randomized trial with Cancer Information Service callers. *Prev Med* 2004;39(1):64-73.
25. Tolomie EP, Mungall MM, Louden G, Lindsay GM, Gaw A. Understanding why older people participate in clinical trials: the experience of the Scottish PROSPER participants. *Age Ageing* 2004;33(4):374-8.
26. Biesecker BB, Ishibe N, Hadley DW, Giambarresi TR, Kase RG, Lerman C, et al. Psychosocial factors predicting BRCA1/BRCA2 testing decisions in members of hereditary breast and ovarian cancer families. *Am J Med Genet* 2000;93:257-63.
27. Port ER, Montgomery LL, Heerdt AS, Borgen PI. Patient reluctance toward tamoxifen use for breast cancer primary prevention. *Ann Surg Oncol* 2001;8(7):580-5.