



# Health care strategies to promote earlier presentation of symptomatic breast cancer: perspectives of women and family physicians

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## ABSTRACT

### Background

Many women with symptoms suggestive of a breast cancer diagnosis delay presentation to their family physician. Although factors associated with delay have been well described, there is a paucity of data on strategies to mitigate delay.

### Objectives

We conducted a qualitative research project to examine factors related to delay and to identify health care system changes that might encourage earlier presentation.

### Methods

Individual semi-structured interviews were conducted with women who sought care 12 weeks or more after self-detection of breast cancer symptoms and with family physicians whose practices included patients meeting that criterion.

### Results

The women and physicians both suggested a need for clearer screening mammography guidelines for women 40–49 years of age and for better messaging concerning breast awareness. The use of additional hopeful testimonials from breast cancer survivors were suggested to help dispel the notion of cancer as a “death sentence.” Educational initiatives were proposed, aimed at both increasing awareness of “non-lump” breast cancer symptoms and advising women that a previous benign diagnosis does not ensure that future symptoms are not cancer. Women wanted empathic nonjudgmental access to care. Improved methods to track compliance with screening mammography and with periodic health exams and access to a rapid diagnostic process were suggested.

### Conclusions

A list of “at-risk situations for delay” in diagnosis of breast cancer was developed for physicians to assist in identifying women who might delay. Health care system changes actionable both at the health policy level and in the family physician’s office were identified to encourage earlier presentation of women with symptomatic breast cancer.

### KEY WORDS

Cancer, diagnosis, qualitative, family physician

## 1. INTRODUCTION

Despite extensive measures to promote early detection of breast cancer, an estimated 20%–30% of women will wait at least 3 months before seeking help for breast cancer symptoms<sup>1,2</sup>. Women with delayed presentation often have larger tumours and poorer long-term survival<sup>1,3,4</sup>. Reasons for delay have been broadly categorized as “utilization delay” (that is, because of issues in the health care system) and “presentation/illness delay” (that is, because of psychological or social factors specific to the individual)<sup>2,5,6</sup>.

In quantitative and qualitative studies to date, a number of potential risk factors for delayed presentation of breast cancer have been identified<sup>1,2,4,7–19</sup>, including older age at diagnosis<sup>4</sup>, fear of cancer<sup>11,13,14</sup>, symptom other than a breast lump<sup>2,9,10,14</sup>, competing life demands<sup>13</sup>, belief in alternative therapies<sup>13–19</sup>, lower level of education<sup>17</sup>, spiritual beliefs<sup>17,19</sup>, and African American or Hispanic descent<sup>17</sup>. Other factors include failure to disclose concerns to a friend or relative<sup>2,9</sup>, associated anxiety or depressive symptoms<sup>19</sup>, reservations about seeing the family physician, and presenting to the family physician with a non-breast problem<sup>2</sup>.

Investigation into the decision-making processes, barriers, and facilitators for treatment-seeking behavior has resulted in some general recommendations

to encourage women with breast cancer symptoms to present earlier. Some studies have suggested that women need more information about atypical breast cancer symptoms and need to be encouraged to seek medical advice when a symptom is ambiguous<sup>2,6,15</sup>. Women may also benefit from increased awareness of the advantages of early detection and of improvements in breast cancer treatments<sup>19</sup>.

We previously reported on some of the complex social and psychological determinants in a woman's decision to seek care<sup>20</sup>; however, we are not aware of any studies that have asked women themselves for specific suggestions to encourage earlier presentation. Identifying individuals at high risk for presentation delay and introducing effective health care strategies to mitigate that delay could result in earlier diagnosis of breast cancer. More women presenting with less-advanced disease could reduce deaths from breast cancer<sup>21</sup>. In addition, family physicians are often the first point of contact for women with breast concerns. We were therefore interested in the opinions of family physicians with respect to delayed presentation. Few data<sup>22</sup> examining their perspectives or how they determine which patients are at risk for delayed help-seeking for abnormal breast symptoms are available.

A number of theoretical models<sup>23–26</sup> have been used to understand help-seeking behavior in patients with cancer symptoms. The Hunter hybrid model<sup>27</sup>—which includes features of the Self-Regulation Model<sup>25</sup> and the Theory of Planned Behaviour<sup>26</sup>—and Bish's Explanatory Model<sup>8</sup> seem best suited to explain delay in women with breast cancer symptoms. The Health Belief Model<sup>28</sup> seems best suited to explain women's reluctance to engage in health screening. Those models form the theoretical underpinning for the discussion of our findings.

Ethics approval for the present study was obtained from the Research Ethics Board at University Health Network, Toronto, Ontario, Canada.

## 2. OBJECTIVE

This qualitative study sought to examine factors related to delay in presentation of breast cancer from the perspective both of the women who delayed and of the physicians whose practices include women who delayed. A qualitative approach using thematic analysis was adopted so that a range of facilitators to medical help-seeking not readily discernable with a quantitative approach could be examined. As in other qualitative approaches<sup>29</sup>, a guiding assumption underlying the present study was that the meanings participants ascribed to the delay process (from the patient and the expert clinician perspective alike) would contribute meaningfully to the development of informed strategies to reduce delay. In addition, respondents were asked to identify health care system changes and specific interventions that could encourage earlier presentation.

## 3. METHODS

Participants included women and physicians meeting the following eligibility criteria:

- Women
  - Had been diagnosed with self-detected breast cancer (versus cancer detected through mammography or clinical breast exam)
  - Sought care 12 weeks or more after onset of self-detected breast cancer symptoms
  - Were English-speaking
  - Had completed adjuvant breast cancer treatment, except for ongoing endocrine or trastuzumab treatments, if applicable
- Physicians
  - In the preceding 5 years, cared for 1 or more women who sought care 12 weeks or more after onset of self-detected breast cancer symptoms

The women were recruited from diagnostic or locally advanced breast cancer clinics at the Princess Margaret Hospital, Toronto, Ontario. Based on existing documentation in the health record of a 12-week or more delay in presentation with breast cancer symptoms, women were identified by clinicians working in the breast clinics. Interested participants were consecutively approached by the study coordinator. Women with metastatic disease were not excluded. Of 70 eligible women who were approached, 15 consented to participate; 1 of the 15 subsequently declined.

Family physicians were randomly selected from a list of referring physicians to Princess Margaret Hospital's breast clinics. They were contacted by the study coordinator to determine whether they met eligibility criteria, and if so, whether they had an interest in participating. The referring physicians of the women who were interviewed were also approached (with their patient's consent). Physicians who participated were asked to identify potentially suitable colleagues. Of 74 physicians who were approached, 10 agreed to participate.

A semi-structured interview protocol (Table 1) with open-ended questions was used to guide in-depth face-to-face interviews.

### 3.1 Data Collection

Interview questions ("probes") were based on the existing literature, health psychology models<sup>8,15</sup>, and previous work in this area by four of the investigators (BF, MC, KF, LG). The probes aimed to explore the process by which the women decided to seek health care<sup>20</sup>. Women were asked to share their personal experiences, to identify factors related to their delay, and in particular, to identify changes or

TABLE 1 Interview guideline

	<i>Women</i>	<i>Probes for</i>	<i>Physicians</i>
1	Tell us your story of how you came to be seen at Princess Margaret Hospital.		Can you recall a patient that presented 3 months or more after detection of her breast cancer symptoms?
2	Do you recall when you first noticed a change in your breast?		Tell us her story.
3	Do you recall when you first thought it might be cancer? Why?		What were your feelings at that time?
4	Do you recall when you first confided in a friend or relative?		Why do you think it took her so long to present?
5	Do you recall your emotions around this experience?		Can you think of anything that might have helped her seek help sooner?
6	Do you recall your first visit to your family physician? Your feelings at that time?		In hindsight, did you have any idea that she had a breast problem earlier?
7	Is there anything we could have done differently that would have made it easier to seek care?		Are there any characteristics of this patient that you feel enhanced the delay? <ul style="list-style-type: none"> <li>• Personality traits</li> <li>• Living arrangements</li> <li>• Life demands</li> <li>• “Not wanting to bother the doctor”</li> <li>• History of abuse</li> </ul>
8	What changes would you like to see in our health care system that would help women with similar symptoms to seek care? <ul style="list-style-type: none"> <li>• Information</li> <li>• (what would help? from whom and how?)</li> <li>• Support</li> <li>• Empowerment</li> <li>• Accessibility</li> <li>• Stigma</li> </ul>		What changes would you like to see in our health care system to help women with similar symptoms seek care? <ul style="list-style-type: none"> <li>• Information</li> <li>• Support</li> </ul>
9	What do you think your family physician might do to encourage other women with similar symptoms to seek help?		Is there anything you would have done differently if you could go back in time?
10	Anything he or she could say? <ul style="list-style-type: none"> <li>• Empowerment</li> <li>• Accessibility</li> <li>• Stigma</li> </ul>		
Fundamentally: What could we have done that might have made it easier to seek care earlier?			

enhancements to the health care system that might have encouraged them to present earlier.

Physicians were asked to describe patient characteristics associated with delay. They were also asked to identify health care system changes that might encourage women with similar symptoms to seek care earlier, and also to identify anything that they personally would do differently if presented with a similar situation in the future.

All interviews were audio-recorded and transcribed verbatim. Transcripts were anonymized. Interviews with the women lasted approximately 60–90 minutes; physician interviews were approximately 45–60 minutes in length.

### 3.2 Data Analysis

The thematic analysis was guided by the overarching principles outlined by Miles and Huberman<sup>30</sup>, in which data are reduced and displayed, and conclusions are drawn through a process of verification with all members of the research team.

To begin the analysis process, co-authors RH, BF, and LG read the first 3 interview transcripts and then met to formulate the initial coding scheme. The codes or categories constituting the scheme were based on anticipated or deductive notions about where the data were perceived to fit with existing knowledge, and new codes were developed to capture emergent

themes not yet addressed in the literature<sup>31,32</sup>. Thus, any datum associated with an anticipated theme was coded using a label that coincided with categories from the literature, and new labels were developed for emergent themes. Disconfirming cases were specifically sought to clarify findings. The investigators (RH, BF, LG) consulted regularly with the other team members regarding the adequacy and clinical face validity of emerging themes and their interrelationships, thus assuring researcher triangulation. Recruitment stopped when the team determined saturation of the themes had been reached<sup>33</sup>.

#### 4. RESULTS

The study sample comprised 14 English-speaking women and 10 family physicians. The sample of women represented diverse ages, ethnicities, and participant characteristics (Table II). Presentation delay ranged from 3 months to 54 months. The diagnoses included locally advanced breast cancer (stage III) in 6 women, metastatic disease (stage IV) in 3, and early-stage disease (stage I or II) in 5. The family physicians (8 women, 2 men) practiced mostly in an urban setting, and their clinical experience ranged from less than 1 year to 25 years; the average experience was 18 years.

Examination of the perspectives of women and family physicians led to identification both of “at-risk situations for delay” in a diagnosis of breast cancer (Table III) and of changes in the health care system to mitigate delay in the presentation of women with breast cancer symptoms (Table IV). Results are reported in that manner, with supporting quotations from either the participating women (marked “P”) or the family physicians interviewed (marked “FP”).

#### 4.1 “At-Risk Situations for Delay” in a Diagnosis of Breast Cancer

Certain factors were common among women who delayed in presentation with breast cancer symptoms:

- A non-lump presenting symptom

Most of these women did not present in the classic fashion, with a solitary painless breast lump. Many clearly lacked awareness of the more ambiguous presentations of breast cancer such as nipple discharge, in-drawing, nipple inversion, or multicentric disease, and thus concluded that a visit to their physician was not warranted.

“That’s, as far as I didn’t know about the discharge that was one of the symptoms. I didn’t read about that. It was just a lump. I didn’t know if there is ejaculation from the teats ... If you don’t find a lump then you’re doing okay. And I hadn’t found a lump.... If I had learned that some of the symptoms are inverted nipples, then my ears would have gone ‘ka-ching’, what? ... I’d never heard anything about inverted nipples possibly being breast cancer.”

— P4

- A previous breast complaint that was benign or a “false alarm”

Women were often reassured by an earlier medical encounter in which they were told that their breast symptom was benign. This previous experience influenced the decision not to seek care sooner for what was later diagnosed as a malignant tumour.

TABLE II Demographics of women participants

<i>Ethnicity</i>	<i>Age at diagnosis (years)</i>	<i>Recruited from</i>	<i>Presenting symptom</i>	<i>Delay (months)</i>
Caucasian	51	LABC	Lump	4
Caucasian	44	LABC	Two lumps	3
Caucasian	48	Diagnostic clinic	Nipple discharge and pain	6
Caucasian	46	LABC	Inverted nipple	12
Asian	67	LABC	Lump and pain	3
Asian	51	Diagnostic clinic	Mass and tenderness	6
Caucasian	80	Diagnostic clinic	Inverted nipple	54
African American	40	LABC	Lump	24
Caucasian	42	Metastatic clinic	Lump	4
Caucasian	64	Metastatic clinic	Two lumps	9
Asian	65	Diagnostic clinic	Lump and pain	7
Caucasian	34	Diagnostic clinic	In-drawing	3
Caucasian	75	Metastatic clinic	Lump	12
Asian	74	LABC	Inverted nipple	9

LABC = locally advanced breast cancer clinic.



TABLE III “At-risk situations for delay” in diagnosis of breast cancer  
When a woman has

1	A non-lump presenting breast symptom
2	A history of a previous breast complaint that was benign or a “false alarm”
3	No regular periodic health care or screening
4	A comorbid condition such as fibromyalgia or chronic fatigue syndrome
5	A history of a previous negative health care experience
6	Competing life demands—for example, busy job, caring for children or parents

TABLE IV Health care system changes to mitigate delay in presentation of women with breast cancer symptoms

1	Consistent messaging about mammographic guidelines (40–49 years of age)
2	Better messaging about breast awareness
3	Better compliance tracking and reminders for screening mammography and periodic health exams
4	Improved access to a rapid diagnostic process
5	Provide education: <ul style="list-style-type: none"> <li>a) A previous benign breast diagnosis does not ensure that future symptoms are not cancer</li> <li>b) Non-lump presentations of breast cancer</li> </ul>
6	Present additional hopeful testimonials: “Breast cancer is not a death sentence”
7	Validate women presenting with breast complaints
8	Recognize subtle clues and indirect communication (doorknob syndrome, “Do I need a mammogram?”)

“It was a fibro [something]. Yeah, benign. No treatment, it was just, let’s take the lump out, we’ll send it to the lab, everything’s fine. So ... I don’t know.... I mean it was a few years later, the breast started to feel a similar kind of way. I said, oh, it’s the same thing, you know.... And I ignored it.”  
— P9

- A comorbid condition

Many of the women had other chronic health conditions, such as fibromyalgia or chronic fatigue syndrome. The women noted that the myriad of presenting health symptoms interfered with their ability to attribute significance to the breast symptoms.

“It almost seemed like it was put on the back burner, because I was dealing with some other health issues.... Because we were concentrating on how to manage my health with the chronic fatigue and the fibromyalgia. And so, therefore, we sort of left the lumps alone, just monitoring them, basically.”  
— P3

- A previous negative health care experience

Some women described disappointment with their earlier medical care. They felt that their concerns had not been taken seriously and that they were in some way dismissed. That experience deterred them from seeking prompt attention for the current breast symptom.

“I already had lumpy breasts.... Anytime I’d go [to the doctor, he] said you know, breasts are not always the same size. [Yes, you’ve] already been told you have lumpy breasts ... did not pay any attention. I said, I mean, probably it’s the same thing going on. So having been dismissed the first time, I said, I’m overreacting, just leave it alone. So that’s why I’m saying that my first experience kind of influenced me even getting the follow-up the first time I noticed any slight change.”  
— P9

- Competing life demands

For many women, caring for others, working, moving, renovating, “waiting for her son to move out,” or not wanting to “jinx the adoption” took precedence over seeking care for breast cancer symptoms.

“Yeah, probably I didn’t want to give in to it. Because you know in the back of your head that this isn’t something to fool with. But you just moved, you’ve got your house to unpack. You ... you don’t have time for worrisome things like cancer.”  
— P11

#### 4.2 Health Care System Changes to Mitigate Delay in Presentation with Breast Cancer Symptoms

- Clearer screening mammography guidelines in women 40–49 years of age

Physicians expressed confusion over the screening guidelines in 40- to 49-year-old women, and many women in that age group wanted the option of screening mammography.

“A young woman in her mid- to late 40s, maybe 46, 47, no family history, no lumps, nothing palpable on the breast exam at her physical, talked about mammograms, offered ... probably said some people would want it, in the [United States] they do it; in Canada it’s not recommended till 50, so she decides to wait till she’s 50. And the next year, she came in the summer—so this [is] about a year later—came in with a lump that turned to be multifocal breast disease with positive nodes. That’s one of the people we should have screened, but the guidelines don’t recommend

that for someone of her age. So it's confusing."  
— FP1

"Honestly, I would have preferred to have been having mammograms younger ... to be honest. At 48, I think I would have been happier to start at age 40, or you know ... I think that would have kept me on top of things and more aware of changes or what's going on."  
— P7

- Better messaging about breast awareness

A striking finding was the confusion about the messaging concerning breast self-examination (BSE), particularly the media attention about the revision of the Canadian Task Force guidelines from a C/I recommendation [insufficient evidence for or against] to a D recommendation [sufficient evidence to recommend against], including as part of a regular periodic health exam<sup>34</sup>.

"I guess that they should stop telling people not to come in if they find a lump. That's basically what the message was. That if you have a self-examination and you find a lump it doesn't mean anything ... (is) basically the message that's out there."  
— P14

- Better compliance tracking, and reminders for screening mammography and periodic health exams (including clinical breast exam)

Women who delayed seeking care for breast cancer symptoms tended not to follow-up with regular health care checks or mammography. Physicians were particularly concerned about women in the 40–50 age group, who are more likely to wait a few menstrual cycles to "see if it goes away" when they find a lump.

"If [the physician had] followed it up [and said,] 'What happened to that mammogram?' Because she gave me a form to go—I think twice—and I didn't go. But if she followed it up maybe [I really would have]."  
— P6

Women suggested that frequent reminders might improve compliance with screening mammography. A targeted e-mail message or telephone call or a more general newsletter could be used. Physicians believed that introduction of electronic medical records systems and of government-issued records of screening compliance for rostered patients could assist in tracking. Women also wanted reminders to attend periodic health exams at which time a clinical breast exam is performed.

"Yeah, because when I think about it, from 28, 29, maybe [by the] time I had surgery [for breast cancer] until 36, we didn't do any breast exam, I was doing it all on my own.... You see, I wasn't even doing yearly checkups; I just went whenever I had whatever. And he didn't say, you know, we haven't done a yearly checkup. And in all the years I went to him, I never once did a yearly checkup."  
— P8

- Improved access to a rapid diagnostic process

Women and physicians wanted improved access to a rapid diagnostic process, especially for younger women with faster-growing tumours.

"You know, if they don't feel like they're entering a scary system with long wait times in which they will lose control.... Reassure people that we are going to get you a mammogram within, you know, 1 or 2 days. An appointment, you know, to have, to be able to reassure people as they come in that the system will work smoothly.... Then, hopefully, get a different message out to people out there; you know, if they hear about people [said], "Oh, I went in with my lump, and within three days I knew it was not cancer."  
— FP8

- More education on non-lump presentations

Women and physicians articulated the need for more information on the more ambiguous (non-lump) presenting features of breast cancer. There was no consensus concerning the format in which the information should be presented: through the media, the Internet, pamphlets, a poster in the doctor's waiting room, from the physicians themselves, or through a regular newsletter from the family physician. Women also need to be advised that previous breast symptoms diagnosed as benign do not ensure that future similar symptoms will also be benign.

- Additional hopeful testimonials

Physicians and women suggested that hopeful testimonials from women living with breast cancer would demystify the disease and promote the perception that breast cancer is curable and "not a death sentence." One suggested using "known people," similar to the current mental health campaign at the Centre for Addiction and Mental Health in Toronto.

"And, maybe, you know, how [Centre for Addiction and Mental Health] has this whole series of ads now where you have famous people saying,

you know, I have depression, or my father had depressions, where they're demystifying the whole thing. So having people who are well known speaking up and saying, you know, I have breast cancer....

"That's exactly the image that you need, because, you know, your average person doesn't respond to a famous surgeon saying, you know, I have surgical techniques that do blah blah blah. But totally responds to a young woman saying, you know, I was diagnosed and ...

"And it was in my bones, but it's 8 years ago, and I'm OK. You know, they've bought me this much life, this much extra life. And education, if they want to produce stuff for the waiting room that kind of goes 'Breast cancer does not have to be a death sentence'."

— P4

- Validation for women presenting with breast complaints

Physicians suggested that a woman who comes in for a breast complaint that is shown to be consistent with benign disease be validated as part of building a trusting therapeutic relationship and encouraging future presentation with breast concerns.

"I always validated them; I always say, 'I'm concerned about your breast. You came in. Good!'"

— FP9

- Recognition of subtle clues and indirect communication "Do I need a mammogram?"

Some women did not understand that screening mammography is for women without breast symptoms. Some women asked, "Do I need a [screening] mammogram?" as a way of alerting their physician to a breast problem. If these women had instead indicated the presence of a symptom, it is likely that assessment would have been timelier. The question "Do I need a mammogram" should be followed by "Do you have any breast concerns?" That approach allows for rapid triaging for timely diagnostic mammography and a clinical breast exam compared with routine screening mammography.

[Patient noticed a lump] "And then when I did phone to get a mammogram [in June], I phoned to get a mammogram, and she said, 'Well, you're not due till February [for a screening mammogram].'" Like this coming February, because you get one every two years."

— P11

Family physicians identified "the doorknob syndrome"<sup>35</sup>, whereby the woman makes an offhand

remark as to the true nature of her visit as her hand or her physician's hand is on the doorknob to leave.

"Okay, this was a patient who actually had come into the office about totally different things. As she was going out the door, [she] said, "Oh and I wondered about something in my breast, but I think it's gone away." And I said, "Well, I should examine you." She said, "No, I'll come back if it stays." [Patient returned 6 months later with locally advanced breast cancer]

— FP8

Family physicians said that the woman who minimizes a breast symptom while her hand is on the doorknob to leave should be examined at that visit.

## 5. DISCUSSION

Given that delay in the presentation of breast cancer is associated with worse outcomes, the purpose of our study was to identify "at-risk situations for delay" and health care system changes that might encourage earlier presentation of symptomatic breast cancer.

Our findings with respect to certain predictors of delay are consistent with those in earlier studies<sup>2,10,11,27,36,37</sup>: presenting symptom other than a breast lump, previous benign biopsy, competing life demands, and a previous negative health care experience. New findings include the presence of pervasive comorbid conditions predisposing to delay, confusion in the messaging concerning breast awareness and screening mammography for women 40–49 years of age, and the identification of specific "subtle clues or indirect communication" of breast cancer symptoms.

Many of our findings are better understood using the Hunter<sup>27</sup> and Bish<sup>8</sup> models of help-seeking behaviour for women with breast cancer symptoms. Women with non-lump presenting symptoms or previously diagnosed benign conditions appeared to have more difficulty at the symptom attribution and appraisal phase; they misattributed their symptoms to a benign process<sup>8</sup>. Preoccupation with other symptoms in women with comorbid conditions such as fibromyalgia or chronic fatigue syndrome also explained the failure of some women to attribute significance to their breast symptoms. The presence of the comorbid conditions fibromyalgia or chronic fatigue syndrome has not emerged as a theme in the existing breast cancer literature, but a general delay in help-seeking in some patients with fibromyalgia because of normalizing of symptoms has been reported<sup>38</sup>.

Some of the women spoke of negative previous experiences with a health care provider, often a family physician, that undermined the woman's sense of safety with her current doctor or her feeling of trust

in the health care system at large. Such experiences set up negative expectations with respect to help-seeking in relation to the current breast symptom and contributed to the delay process.

Other women felt the need to legitimize health-seeking by “raising issues when consulting a health care provider for another issue”<sup>37</sup>. In our study, this indirect approach manifested itself as the “doorknob syndrome,” or as the question “Do I need a mammogram?”

Some strategies to encourage earlier presentation, such as improved access to a rapid diagnostic process, might provide women with a perceived behavioural control<sup>27</sup>. The exposure to “positive testimonials” might favourably affect attitudes toward help-seeking.

In our study, women with painful breast lumps or multiple lumps delayed. Broader education about breast cancer symptoms other than the solitary painless lump is important, because even prompt help-seekers can’t identify all potential symptoms of breast cancer<sup>27</sup>.

A woman’s attitude toward help-seeking may affect her choice to attend periodic health care and screening. The Health Belief Model<sup>28</sup> suggests that a sufficient perceived threat of breast cancer must exist before a woman will embark on screening ventures. The tailored approach<sup>39</sup>—based on assessment of individual risk factors and of attitudes, intentions, and stage of change—if taken by family physicians, might more effectively encourage health screening.

Some identified changes to the health care system to reduce delay in presentation are actionable both at the health policy level and in the family physician’s office; others would be more suitable for the family physician’s office only.

- At the health policy and family physician level:
  - Need for improved messaging about breast awareness

Misinterpretations by women of the messaging around breast awareness and BSE was striking and indicates a need for clarity. This confusion is understandable because currently our Canadian Task Force recommends against BSE<sup>34</sup> and does not address the concept of breast awareness. By contrast, many health advocacy groups such as the Canadian Cancer Society recommend breast awareness (“getting to know your breasts”<sup>40</sup>). Because breast cancer is frequently self-detected, particularly in younger women<sup>41</sup>, it is important to advise women that self-detected breast changes should not be ignored. Our findings underscore the importance of educating women through media campaigns and health advocacy groups about breast awareness and of encouraging them to report abnormal breast findings to their family physician.

- Screening mammography and clinical breast examination for 40- to 49-year-olds

Some women who delayed were not offered mammography before age 50, and many did not have regular clinical breast exams. These women felt that their cancer would have been detected sooner if screening had commenced earlier.

Our Canadian Task Force evidence-based guidelines recommend regular (every 1–2 years) clinical breast exams in conjunction with screening mammography for women aged 50–69 years<sup>42</sup>. Women in their 40s at average risk for breast cancer should “be informed of the potential benefits and risks of screening mammography and assisted in deciding at what age they wish to initiate the maneuver”<sup>34</sup>. Given that the most recent Swedish study of screening mammography<sup>43</sup> reported a substantial reduction in mortality for women in the 40–49 age group, it is essential that family physicians offer these women the option of screening mammography before age 50.

It is also possible that some younger women are not receiving regular breast exams, although there appears to be some value to clinical breast exams in younger women, especially those not receiving screening mammography<sup>44</sup>. This situation may be a result of the tendency of these women not to arrange for regular periodic health exams. To increase the likelihood of detecting earlier-stage breast cancers, women should be encouraged to receive regular clinical breast exams<sup>42</sup> and to make an informed choice regarding screening mammography.

- In the family physician’s office
  - Pattern recognition aid: “at-risk situations”

We were able to identify “at-risk situations for delay” (Table III) that can assist physicians in identifying the woman who might delay.

## 5.1 Strengths and Limitations

We are not aware of any other studies that directly asked women and family physicians alike for strategies to promote earlier presentation of women with breast cancer symptoms. Interviewing family physicians gave a unique perspective on the characteristics and behaviours of women who present late and provided useful information about subtle clues or indirect modes of communication of possible breast cancer symptoms.



Women were recruited from diagnostic, locally advanced, and metastatic breast cancer clinics, thus ensuring a broad sampling base. However, all women were recruited from an urban tertiary care cancer centre, and they may not be representative of women who live in rural or remote areas or who are non-English-speaking or new immigrants, thus reducing the generalizability of our findings. Similarly, most family physicians were recruited from an academic urban setting, thus possibly reducing the generalizability of our findings to physicians in community or rural and remote family practices.

Nevertheless, the interdisciplinary nature of the research team allowed for interpretation and reflection of the data from many different perspectives, and enhanced the depth of the analysis and the development of recommendations to promote more timely breast cancer diagnosis.

Our work is hypothesis-generating only, and further verification of the findings (via focus groups or survey instruments, or both) is warranted to better determine effective strategies that encourage women with breast cancer symptoms to present earlier.

## 5.2 Implications for Future Research and Clinical Practice

Strategies are currently being implemented to encourage timely help-seeking for breast concerns.

In the National Health Breast Screening Program in the United Kingdom, Burgess and colleagues<sup>45</sup> developed a research-based psycho-educational intervention comparing a “booklet only” with a “booklet and interview conducted by a radiologist,” which uses behavioural change techniques to encourage older women with breast concerns to present earlier to their physicians. The authors postulate that if their initiative is effective at encouraging earlier presentation, then it should be tested in the primary care setting as well.

Our data supports the need for a similar initiative in the primary care setting and not just for older women. It can be used in conjunction with motivational interviewing techniques<sup>46</sup> and tailored information<sup>39</sup> to encourage women to attend regular mammographic screening and periodic health exams (with clinical breast exams). In addition, like their dental colleagues, family physicians should adopt a more organized approach using e-mail messages, letters, or telephone calls to remind patients about mammographic screening and regular health check-ups rather than rely on opportunistic finding<sup>42</sup>. Positive testimonials from breast cancer survivors should continue, and clearer messaging to family physicians and women concerning breast screening recommendations should be a focus. Initiatives such as rapid diagnostic breast clinics designed to offer quick access to imaging, clinical expertise, and pathology for breast abnormalities are currently underway<sup>47</sup>.

However, even the most astute, caring family physician will encounter a woman presenting late with advanced breast cancer. There will be women who delay their presentation because of complex contextual or personal factors that are beyond the influence of their family physician; this problem requires more investigation<sup>20</sup>. Better understanding of these complicated dynamics might further enhance the development of strategies to encourage earlier presentation.

## 6. CONCLUSIONS

Family physicians are uniquely positioned to encourage women to present earlier with breast cancer symptoms. Our work suggests that establishment of an ongoing supportive therapeutic relationship and an expectation of regular periodic health exams (including clinical breast exam) and mammographic screening, coupled with broader education about non-lump breast cancer symptoms and recognition of the “at-risk situations for delay”, may reduce the likelihood of women presenting late with breast cancer symptoms. More consistent messaging about breast awareness, screening mammography recommendations in 40- to 49-year-old women, and hopeful testimonials from women living with breast cancer is warranted.

## 7. CONFLICT OF INTEREST DISCLOSURES

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