Why women delay seeking assistance for locally advanced breast cancer

by Judy Gould, Barbara Fitzgerald, Karen Fergus, Mark Clemons and Fauzia Baig

Abstract
Locally advanced breast cancer (LABC) occurs in 10% to 30% of all new primary breast cancer diagnoses. For reasons that are not well-understood, 20% to 30% of women with breast cancer (at all stages) wait eight weeks or more from the time they notice the breast symptom(s) to when they seek assistance from a health care provider. Comprehending the mechanisms that support the health appraisal and health seeking behaviour is paramount and not well understood, particularly for women with LABC. The purpose of this study was to qualitatively explore the cognitive, emotional, and contextual experience of women with locally advanced breast cancer in the time between symptom discovery and seeking health care. In-depth qualitative interviews and a cross-case, content analysis revealed that the participants delayed their search for assistance because they did not perceive themselves to be at risk for developing breast cancer, had a symptom other than a lump, and so misattributed or minimized the gravity of the symptom, had a previous experience with a benign tumour, and/or were experiencing concurrent stressful life events. These participants were motivated to seek attention if they had an already scheduled appointment with a health professional for another matter, felt the symptom worsen over time, or were motivated by a loved one to seek help. Implications for health promotion and for education with women with benign breast disease, as well as the general public, are discussed.

Background
Locally advanced breast cancer (LABC) occurs in 10% to 30% of all new primary breast cancer diagnoses (Kauffman, Hortobagyi, Goldhirsch, et al., 2006). Locally advanced breast cancer tumours include those that are more than 5 cm, with or without lymph node involvement, or tumours that protrude beyond the breast tissue into nearby skin or muscle (Singletary, Allred, Ashley, et al., 2002). Despite advances in early detection and treatment, the five-year survival for women with LABC is poor at around 55% (Huang, Tucker, Strom, et al., 2003; Sant, Allemani, Capocaccia et al., 2003).
For reasons that are not well-understood, 20% to 30% of women with breast cancer (at all stages) delay more than eight weeks (Burgess, Ramirez, Richards & Love, 1998; Caplan & Helzlsouer, 1992; Harirchi, Chaemmaghami, Karbakhsh, Moghim & Mazaherie, 2005; Nosarti et al., 2000) between when they notice the breast symptom(s) and when they seek assistance from a health care provider (Grunfeld, Ramirez, Hunter & Richards, 2002; Ramirez et al., 1999; Richards, Westcombe, Love, Littlejohns & Ramirez, 1999a). Indicators of breast cancer can include a lump, an inverted nipple, dimpling, nipple discharge or rash. Unfortunately, delays in seeking care result in higher mortality rates (Olivotto, Bancej, Goel, et al., 2001; Richards, Smith, Ramirez, Fentiman & Rubens, 1999b; Richards et al., 1999a).

Comprehending the mechanisms that support the health appraisal and health-seeking behaviour outside the realm of health system responsibility is paramount and not well understood for women with breast cancer and, particularly, for women with LABC (Meechan, Collins & Petrie, 2003; Smith, Pope & Botha, 2005). There is a paucity of data concerning how, expressed in their own words, women understand their own health-seeking or delay behaviour (Smith et al., 2005). In the literature that does exist, anxiety and fear about breast cancer, downgrading the seriousness of a concern (i.e., not wanting to be perceived as alarmist or as a hypochondriac), fear of the medical system, expectations that only a lump was indicative of a breast cancer symptom and not wanting to disrupt busy schedules have been cited by women with breast cancer as reasons to delay seeking care (Burgess, Hunter & Ramirez, 2001; Burgess, Potts, et al., 2006; Facione, 2002; Facione & Facione, 2006; Facione, Miaskowski, Dodd & Paul, 2002; Katapodi, Lee, Facione & Dodd, 2004; Lauver, Coyle & Panchmatia, 1995; Smith et al., 2005).

The purpose of this study was to qualitatively explore the cognitive, emotional, and contextual experience of women with locally advanced breast cancer in the time between symptom discovery and seeking health care.

**Methods**

For this study, the time interval between self-detection and deciding to seek care was defined as delayed if the woman presented to a health care professional eight weeks or more after detecting a breast abnormality. Delay was determined by reviewing within patient charts the notes made about the time between symptom detection and first visit to a health care provider. The inclusion criteria for this study were: female patients diagnosed with LABC who were at least three months post-diagnosis and who self-detected their symptom. Participants were recruited conveniently from a unique multidisciplinary LABC clinic in a large regional cancer centre in southern Ontario (Fitzgerald, Clemons & Dent, 2006) and, as such, are not necessarily representative of the population of women with locally advanced breast cancer who delayed seeking care. Local research ethics board approval was obtained for this study.

Interviews were conducted in person (n = 8) or on the telephone (n = 6) by the research coordinator with patients who volunteered to participate in the study. Interviews lasted 40 to 60 minutes, were recorded and then transcribed. During the research interview, we asked women to address how they discovered and then cognitively and emotionally assessed the symptom, what they perceived would occur if they brought the symptom to the attention of a health professional, what else was occurring in their lives at the time of symptom discovery, whether or not they disclosed their concern about the symptom to a friend or family member, and any previous experience with cancer of a loved one.

**Analysis**

The participants provided a great deal of information, as they described their experiences or their thoughts, feelings, and behaviours associated with the time between symptom discovery and seeking health care. The research team assumed the relativist position that the participants were experts of their own experience and we would report and analyze that experience (Guba & Lincoln, 1994).

To begin the content analysis process, research team members and co-authors BF, FB and JG each read the first four interview transcripts and then met to formulate the initial cross-case coding framework constituted from anticipated or deductive themes and emergent or inductive themes (Patton, 2001; Cresswell, 2003).

Initial themes were anticipated from the literature. For example, since we knew from the literature that women underestimated their risk for breast cancer, a question about how serious the participant considered the symptom was inserted in the interview guide. *Risk perception* was identified as an important part of the experience of women between the time of symptom discovery and seeking health care and, so, it was identified as a higher order theme. For the purposes of this study, risk perception was defined as “cognitive evaluations of the likelihood of experiencing personal harm if no action is taken” (McQueen, Vernon, Meissner & Rakowski, 2008, p. 57). When coding the transcript data, any data that were associated with perception of risk were coded using that theme. When a more detailed coding of the interview transcripts was performed on the data and managed using the NVivo 2.0 qualitative software package, this initial code of Risk Perception was further subdivided into sub-themes *Knowledge of Breast Symptoms, Knowledge of Risk Factors, Previous False Alarms, and Assessing and Monitoring the Symptom*.

One example of a sub-theme that the research team did not anticipate a priori was *Previous False Alarms*. Though in the interview guide we asked the participants about their perceived seriousness of the breast symptom, we did not anticipate that many of the participants would discuss their previous and resolved history of breast abnormalities. This sub-theme was unanticipated in the literature and emerged in the data coding process (Patton, 2001).

Overall, the research team concluded that four higher-order themes and their supporting sub-themes sufficiently organized women’s experiences between the discovery of the breast symptom(s) and the presentation of the symptom to a health professional. These themes include: 1) *Risk Perception* and the sub-themes *Knowledge of Breast Symptoms, Knowledge of Risk Factors, Previous False Alarms, and Assessing and Monitoring the Symptom*, 2) *Reactions to the Possibility of Cancer*, as well as the sub-themes *Fear* also defined as cancer worry or the “affective evaluation of unwanted and, perhaps, uncontrollable thoughts about a threatening outcome” (McQueen, Vernon, Meissner & Rakowski, 2008, p. 57), and *Avoidance*, 3) *Life Context/Obstacles* including sub-themes: *Competing Demands* and *Previous Experience with Cancer*, and 4) *Triggers to Action*, and its sub-themes *Already Scheduled Appointment, Worsening Symptom, Motivated by Loved One*.

The team determined that saturation of themes was reached within the 14 interview transcripts*. All themes are discussed below. All names associated with quotes below are pseudonyms.

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*Note that authors Guest, Bunce, and Johnson (2006) found that saturation of qualitative data could be reached after coding and analyzing 12 research interviews.*
Findings

Selected demographic findings

Most of the participants were between the ages of 50 and 69 (64%) and 57% were pre-menopausal. Most of the participants were Caucasian (93%), employed (57%), 93% had a stage III tumour, 22% had a history of anxiety or depression, and 36% had a history of benign breast disease. All participants had post-secondary school education, which was the norm for this locally advanced breast cancer clinic (B. Fitzgerald, personal communication, October 16, 2009) (see Tables One and Two).

Qualitative findings

Risk perception

This higher order theme is focused on the participants’ perceived risk for developing breast cancer. The sub-themes relate to the way in which participants thought about the risk/actuality of a malignancy and include their knowledge of breast cancer risk factors (Knowledge of risk factors) and knowledge of breast cancer symptoms (Knowledge of breast symptoms), previous breast-related medical concerns (Previous false alarms) and monitoring the symptom(s) over time (Assessing/monitoring the symptom). Each sub-theme also emphasizes the fact that the participants thought about versus avoided thinking about and monitoring the symptoms. Most were also very aware of the possibility that the symptom might require the attention of a health professional.

Table One. Patient demographics

<table>
<thead>
<tr>
<th>Variables</th>
<th>Qualitative study with delayers N = 14 Number of participants (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>30–49</td>
<td>5 (36.0)</td>
</tr>
<tr>
<td>50–69</td>
<td>9 (64.0)</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>13 (93.0)</td>
</tr>
<tr>
<td>Black</td>
<td>1 (07.0)</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
</tr>
<tr>
<td>Married/Common law</td>
<td>8 (57.0)</td>
</tr>
<tr>
<td>Divorced</td>
<td>2 (14.0)</td>
</tr>
<tr>
<td>Widowed/Separated</td>
<td>1 (07.0)</td>
</tr>
<tr>
<td>Single</td>
<td>3 (22.0)</td>
</tr>
<tr>
<td><strong>Children</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>9 (64.0)</td>
</tr>
<tr>
<td>No</td>
<td>5 (36.0)</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
</tr>
<tr>
<td>Elementary</td>
<td>0</td>
</tr>
<tr>
<td>High school</td>
<td>0</td>
</tr>
<tr>
<td>More than high school</td>
<td>14 (100)</td>
</tr>
<tr>
<td><strong>Employment</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>6 (43.0)</td>
</tr>
<tr>
<td>No</td>
<td>8 (57.0)</td>
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<tr>
<td><strong>Income (Canadian)</strong></td>
<td></td>
</tr>
<tr>
<td>&lt; 18,371</td>
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<tr>
<td>18,372–46,793</td>
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<tr>
<td>&gt; 46,793</td>
<td>7 (50.0)</td>
</tr>
<tr>
<td>Missing</td>
<td>2 (14.0)</td>
</tr>
</tbody>
</table>

Part of the reason I was so complacent...was that I wasn’t a candidate for the disease...I mean, I’ve sat around the table with pre-menopausal women who’ve had breast cancer and...they’re just ordinary women...completely different careers, some have kids and some don’t, and you know I mean there’s just no pattern... (Sephura)

Knowledge of risk factors

Whether or not participants knew the etiology of breast cancer and associated risk factors, such as family history, they did not perceive themselves to be at risk for developing breast cancer. As one woman succinctly stated:

...So much is made of risk factors and, yet, my understanding is that the vast majority of us have no risk factors who are diagnosed. I had no risk factors, no one in my family with cancer... which isn’t to say that I thought I would never get it, but certainly at age 39 it wasn’t really on my radar... (Sephura)

Another participant suggested that she did not consider herself at risk for cancer because, based on family history, she expected instead to contract heart disease, stroke or diabetes.

Knowledge of breast symptoms

All of the women discovered the breast symptom(s) without the assistance of a health professional. Seven women made the discovery after performing a breast self-exam. The women reported noticing various initial symptoms including a small lump (n = 5), that their breasts looked “not quite right” (n = 1), indention on their breasts (n = 2), an inverted nipple (n = 3) and a lump between armpit and breast (n = 1).

Most (n = 10) of the participants mentioned regretfully that prior to their diagnosis they did not realize that any other symptom, other than a lump, was indicative of breast cancer. So, the majority of

Table Two. Clinical variables

<table>
<thead>
<tr>
<th>Variables</th>
<th>Qualitative study with delayers N = 14 Number of participants (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Stage</strong></td>
<td></td>
</tr>
<tr>
<td>II</td>
<td>1 (07.0)</td>
</tr>
<tr>
<td>III</td>
<td>13 (93.0)</td>
</tr>
<tr>
<td><strong>Histology</strong></td>
<td></td>
</tr>
<tr>
<td>Ductal</td>
<td>12 (86.0)</td>
</tr>
<tr>
<td>Lobular</td>
<td>2 (14.0)</td>
</tr>
<tr>
<td><strong>Menopausal status</strong></td>
<td></td>
</tr>
<tr>
<td>Pre-menopausal</td>
<td>8 (57.0)</td>
</tr>
<tr>
<td>Post-menopausal</td>
<td>6 (43.0)</td>
</tr>
<tr>
<td><strong>History of benign breast disease</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>5 (36.0)</td>
</tr>
<tr>
<td>No</td>
<td>9 (64.0)</td>
</tr>
<tr>
<td><strong>History of anxiety/depression</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>3 (22.0)</td>
</tr>
<tr>
<td>No</td>
<td>10 (71.0)</td>
</tr>
<tr>
<td>Missing</td>
<td>1 (07.0)</td>
</tr>
<tr>
<td><strong>Prior mammogram or ultrasound</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>7 (50.0)</td>
</tr>
<tr>
<td>No</td>
<td>7 (50.0)</td>
</tr>
</tbody>
</table>
participants did not realize that their symptoms, such as indentations, change in breast shape, “a muscular ridge” and swollen lymph nodes in the armpit could also indicate breast cancer and, thus, their perception of risk remained low.

...Had I known that swollen lymph nodes are a sign of breast cancer, I would have... been to the doctor so fast and insisted on having an ultrasound or mammogram. (Sephura)

Only one woman, who was also a laboratory technician, stated that she knew that her symptom likely indicated breast cancer.

Another woman added that even if she recognized the lump as a symptom of breast cancer, she also thought that lump could be symptomatic of benign, cystic breasts.

Well, whenever you get a lump, you know lumps are always associated with cancer, I mean it doesn’t mean that they are, because I had very cystic breasts, so I can feel lumps in there all the time, and how to know what type of lump it is? (Kelly)

Previous false alarms

Nine participants disclosed that they had a previous experience with a benign tumour, which, they reported, might have contributed to their decision not to seek care sooner from a health professional and lowered their perceived risk. Previous health system investigations into the breast symptom(s) included ultrasounds and mammograms (n = 7), needle aspirations, core biopsies and surgery. None of these earlier investigations revealed cancerous cells.

It was deceptive, I think. If I had not had cysts and this was the first lump that I had ever had in my life... (that I had) could have lessened the scariness of it (this time). (Robin)

...Having that benign diagnosis, I think, gave me false comfort... (Linette)

Seven participants assumed that the symptoms were related to other health concerns, such as weight gain, stress, menopause, blocked milk ducts, heart problems and mastitis.

Okay, lumps are something... but shooting pain, for all I knew, could be my heart. (Linette)

...What I thought at the time was that it was related to stress... I’ve seen what stress can do to people... so I just related this to stress, and I thought once I get another job... I thought that everything would go back to normal. (Francesca)

...I lost my period... and I noticed that my breasts changed, they became harder, were lumpier, and I wasn’t too concerned because I thought this is part of menopause, and I was 48, and this was just the start. (Melanie)

Some of these ascriptions to other illnesses were made because of the women’s experiences with previous false alarms, in which symptoms they thought meant cancer were attributed to different conditions.

I had had identical symptoms 20 years before and I had thought oh my goodness, I’ve got cancer, but it turned out it was mastitis... (Jessica)

Assessing/monitoring the symptom

All participants discussed how they assessed and monitored the symptom(s) in the period between discovering the symptom and seeking the assistance of a health professional. Three participants hoped that the symptom would simply go away over time.

I thought they [the symptoms] were... gone, can you imagine how great that would have been? So (my husband) said, “Oh it probably just drained”, or you know... and then I got up (out of bed) and thought, no, they’re still there. (Sephura)

Though a few women monitored or “kept checking” the symptom on a daily basis, they also did not notice or were not sure about any changes over time and perceived the risk to be low enough not to take immediate action.

If I had noticed any difference, I probably would have done something, but (the symptoms) didn’t feel significantly different to me... I did feel a little one over here and they didn’t seem to be changing much. (Elizabeth)

Usually I’d check to see when it (would) occur... usually during stressful times at work. So, I thought it might be related to stress more than anything else. And then I sort of noticed... it was bigger, but I wasn’t sure because I never measured it. (Linette)

I kept checking myself, I would check myself once a month, and then I would come out of the shower and I would express my breasts to make sure that there was nothing, no blood or anything was coming out... because I’ve had that checked (by the doctor)... I thought okay, then it’s not serious. (Melanie)

One woman did talk about monitoring the symptom, thinking the symptom could indicate cancer and playing the odds that it did not indicate cancer.

...When anything grows that fast, you’re really not expecting it to be benign, but yeah. It’s a gamble, it could go either way (laughs). You have a 50/50 chance. (Fiona)

Assessment and monitoring also included searching for information about the symptom on the internet (n = 3), in medical texts (n = 1), or with a health professional acquaintance (n = 1). The health professional acquaintance recommended one participant to apply ointment to what appeared to be an infection and then to call a doctor if the infection persisted.

... I checked with a couple of nurses, and then I started putting Polysporin on it, because it seemed a bit infected... and it came partly out and got better for a while... (they said) keep trying that, but if it doesn’t clear up you see a doctor. (Jessica)

Another aspect to assessing and monitoring the symptom included sharing the knowledge of the symptom with a partner, family member or friend. Of the 10 women in partnered relationships, nine stated that they were intimate in these relationships and seven of the women told their partner about the breast abnormality. Some women whose partners failed to notice the breast lump for a variety of reasons (e.g., the breasts had always been lumpy, the lump was tiny and unnoticeable, the breast was aging normally and the symptom was not a lump) expressed a lower sense of risk than women whose partners were concerned about the changes in the breast.

I mentioned it to my husband, and he said he had noticed it for a little while, but he thought it was a sign of old age, so he didn’t want to upset me, so he hadn’t told me about it. (Jessica)

Three women did not disclose their concerns about the symptom to their partner. Reasons for not telling included not wanting to worry their partner, assuming the partner would invalidate their concern, that the symptom would go away or too much else was happening in their lives. These reasons also served to keep perceptions of risk at bay.

A few participants disclosed their worry about the symptom to friends or coworkers and the reactions they received encouraged non-action and low-risk perception. In one instance, a friend agreed that the symptom was likely an indicator of menopause, another encouraged the participant not to worry. In other cases, speaking to a friend or family member mobilized the women into action (addressed in Triggers to action: Motivated by a loved one below).
Reactions to the possibility of cancer

At some point before contacting a health professional, 12 participants contemplated the possibility that the symptom could indicate cancer and were frightened. Their fear did not motivate them to immediately seek care and some participants wondered whether they might have denied the gravity of their breast symptom(s).

Fear

Not surprisingly, women reported experiencing fear, worry or were scared about the possibility of cancer.

I was afraid at first, too, because I thought you know, so many women die of breast cancer. (Renata)

So yeah, it was kind of scary, but there’s nothing you can do about it, you have to accept it. (Fiona)

There was just stuff under the surface, so I didn’t you know, I mean cancer is always, it’s very scary, so you know even if you think it’s not, that it might be, is scary. (Kelly)

Denial

Seven participants reported rationalizing their fears and actively denying the possibility of cancer.

…You don’t really believe it until you have to. You don’t really believe you have cancer. (Kelly)

Well it was just the look of my breast, I just felt I had a problem there, and then I would say definitely I was in denial, and trying not to think about it, and don’t ask me why I did that… I don’t know… (Josephine)

Another two women spoke about both fearing and denying the existence of a malignancy.

I was a bit frightened, I guess, because I thought this doesn’t feel like a cyst… but at the same time I thought oh my god… I thought no it can’t be, it’s nothing, you know, it’ll just disappear in a few days and so on. So, I think that was my initial reaction, I found something and it feels different, but you try to rationalize it in your own mind that this is just perfectly normal and nothing to worry about. (Robin)

…The rationalization is that there is nothing wrong. The fear was that oh my god, this is bad, you know…it’s the rationalization that outweighs the fear. (Jodie)

While fear alone might have accentuated the perception of risk, the act of denial and of making rationalizations could have lowered the sense of risk. Alternatively, great fear could have heightened the perception of risk, but rendered the women immobile to seek immediate care.

Life context/obstacles

Considered next are participants’ accounts about the life events that occurred before symptom detection and during the period between detection and assistance seeking. This theme also includes text related to any previous experience with cancer of a loved one.

Competing demands

Eleven women reported that life obstacles prevented them from dealing with the breast symptoms. Obstacles to seeking assistance for the breast symptom(s) included the inability to take time from work for appointments, moving, vacation, caring for others, and dealing with other physical or emotional health issues.

Work emerged as the most frequently cited single barrier (n = 6). Two participants reported that they were not able to take time from work to visit their physician for fear of reprisal from their employer.

...We weren’t allowed to take time off… like to see a doctor, no, the company doesn’t allow you to do that. (Francesca)

Two women reported that having a busy life, in general, prevented them from seeking medical assistance for their symptom.

...There was a physical I skipped, which might have caught this… But because of my schedule … I missed a whole bunch of… annual stuff, because that year was really, exceptionally stressful. (Linette)

Two women described life situations fraught with chaos, abuse and/or mental illness. In both of these situations the women waited longer than a decade to present their symptoms and both reported that contemplating the possibility of cancer was of secondary concern.

I think the only major health concern that I have had is depression. And you know that really fits in with not looking for help… you know there’s the cancer…(a) small incident compared to the [emotional] pain that was happening around that time. (Elizabeth)

Previous experience with cancer

During the interview many participants discussed their experience with a loved one who had encountered cancer. While four women reported no previous experience with a loved one with cancer, seven recalled how this experience had a powerful and often negative effect on their reaction to their symptom.

...My cousin fought breast cancer for more than 12 years… it did scare me, you know, because she went through a lot of pain… she lived for 12 years, but… eventually the cancer had spread, and you know, she died, but for sure it had an effect on me, for sure, I was very close to her. (Josephine)

Triggers to action

The participants relayed several factors that precipitated their contacting a health professional about the breast symptom(s): scheduling an appointment for another health matter, worsening symptoms and receiving strong words of motivation from friends or partners.

Already scheduled appointment

Six participants finally met with a health professional and discussed the breast symptom(s) only because they had a pre-booked appointment for an unrelated matter (e.g., an annual physical exam).

I was due for a physical and I was due immediately after Christmas, so I thought oh well, I’ll see if it goes away, that was my initial reaction… ‘cause I was convinced it was going to go away. (Robin)

Worsening symptom

Five participants talked about contacting a health professional because their symptom had worsened. Signs of worsening symptoms included: a now recognizable lump, a growing hardness of the lump or other obvious changes to the breast (e.g., thickening).

So, one night I was just going to bed, and all of a sudden I saw it again and I felt it, and I felt a really hard lump where the indent was, and I thought, ‘oh my god’ and you know something, as soon as I felt that, I said to myself, ‘oh no, this can’t be what I think it is’, anyway, so I called my GP the very next day… it got more and more that I could identify it more, and so I thought that’s my, what is that, and finally when I felt the lump, I said oh no, this isn’t right. (Renata)
Motivated by loved one

Four participants noted that they were motivated by a loved one to contact a health professional about their symptom.

“I told my sister I was doing what she wanted, mostly because she was so insistent. It’s probably a good thing, because otherwise I don’t know when I would have gone anywhere… (seeing a health professional) was definitely in response to my sister’s pushing. (Elizabeth)

I’d been going, ‘oh geeze, what is this, what is this?’ and then finally, like my husband said, ‘Go to the doctor and find out, don’t keep thinking about it.’ (Renata)

Discussion

Risk perception and, specifically, the ambiguous or unchanging breast symptoms emerged as reasons participants delayed seeking assistance for breast symptoms from a health professional. The inability to correctly identify a range of potential breast cancer symptoms and the inability to determine threat potential is a significant predictor of delay across all age groups (Bish, Ramirez, Burgess & Hunter, 2005; Burgess et al., 1998; Grunfeld et al., 2002; Meechan et al., 2003). Consistent with a recent study, patients with well-recognized specific symptoms like a lump promptly attributed the symptom to a serious illness while patients with vague or non-specific initial symptoms frequently delayed attributing them to signs of illness (Smith et al., 2005). Facione (2002) noted that cancer-free women did not overestimate their cancer risk if they also had knowledge and education about cancer and its symptoms. Facione (2002) posits that assisting women to understand their relative risk for breast cancer should be a mandatory aspect of health promotion.

One key finding from the present study, emerging as a sub-theme of Risk Perception, is the experiential correlation between having a history with benign breast abnormalities and delayed presentation. Nine of the 14 women who delayed seeking health care had previous experiences with benign tumours and dismissed their most recent symptoms because previous investigations did not reveal a malignancy. This conclusion possibly led them to a false sense of security that the new symptoms were not indicative of cancer. Facione (2002) and Absetz, Aro and Sutton (2003) found that women who had had benign breast disease were more likely to overestimate their risk of breast cancer and were also more distressed about a future cancer diagnosis than were the matched healthy controls (see also Andrykowski, Carpenter, Studts, Cordova, Cunningham, Beacham, et al., 2002).

Perhaps the women in this current study were more likely to retrospectively explain their delay as a function of having had benign breast disease. Perhaps there is a certain constellation of features in the experiences (competing life demands or having a higher education and, therefore, feeling more confident and in control of their own health) and emotional lives (rationalizing their fear more than is common) of these women that render them less likely to overestimate their risk or to seek immediate or follow-up care. Conceivably, women might feel quite distressed about their risk, but might not seek immediate care. One study concerning the risk perception of women with benign breast disease found that when recommended to return for follow-up, 34% were classified as nonadherent. Nonadherent women were younger, were confident in performing breast self-exam, had higher perceived risk for breast cancer and displayed greater breast cancer-specific distress (Andrykowski, Carpenter, Studts, Cordova, Cunningham, Mager, et al., 2001). Because the women in this study appeared to demonstrate lower perceived risk, our finding does raise the issue of creating health promotion messages that more specifically influence the risk perception of this subpopulation of women.

Another key finding was the trigger for delaying women to seek care. Given that some women waited until their annual physical exam before raising their concerns highlights the importance of physicians initiating discussions of breast issues during women’s annual physical exams. Also, that some women contacted a health professional only with the support or motivation of a loved one illustrates the need to target friends and family with health promotion interventions.

Finally, given the finding that women find it difficult to attend to their own needs while living busy lives, there is a need to develop interventions to empower women to value their own health above competing life demands.

Limitations of study

At the time of the interview, all participants had been diagnosed with locally advanced breast cancer. As such, we can only know about their perspectives about their delaying experience since diagnosis. Any associated thoughts and feelings about their motivations and actions prior to diagnosis are informed by their confirmed malignancy and any possible self-blame could impact their recalled and subjective experience of delaying. It would be interesting to sensitively interview delaying as yet undiagnosed participants about their experience between symptom detection and health care seeking to illuminate their reasons for delaying without the possible weight of self-recrimination that might accompany the concern of “having waited too long”.

Future research

Reasons for delay presented in this paper are consistent with the literature (Facione & Giancarlo, 1998; Facione et al., 2002; Bish et al., 2005; Ramirez et al., 1999). Determining the reasoning behind the decision of symptomatic women to seek or to delay seeking health care is complicated. Facione and Facione (2006), who looked more deeply into the reasoning of symptomatic women, found that women who waited relied on false information, poorly reasoned arguments and repeatedly rationalized that they were making the right decision. The women in this study also spoke about denying the possibility that the symptom could be cancerous even though they felt fearful that it was a malignancy.

In future, it could be valuable to longitudinally investigate the variables associated with self or self-with-other arguments to delay, such as how women selectively seek facts or formulate arguments that support their choice to wait, how women attempt to gain a greater sense of control over their health outcome (e.g., seeking complementary and alternative medicine)** or how women understand the consequences of help-seeking (e.g., effect of cancer treatments) and how these arguments sustain the decision to delay (Facione & Facione, 2006). It is unclear whether or not the repeated and rationalized arguments used by delayers would change if participants were challenged (again, through health promotion messaging) to re-examine their thinking. Additionally, women who have experienced benign breast disease might benefit from individual counselling within which their perceptions of risk could be realistically discussed (Absetz, Aro & Sutton, 2003). Reaching women and challenging their misinformation, reframing mistaken stories, and gently focusing on the consequences of delaying might help prompt women to seek a diagnosis earlier.

Acknowledgments

This research was funded by the Canadian Breast Cancer Foundation, Ontario Chapter.

We would also like to thank Dr. Danielle Kerr-Cresswell for her invaluable assistance with the planning of this project.

** Though the topic of complementary and alternative medicines was broached during the interviews, none of the participants reported using these therapies.
References


