

Breast Cancer Screening: Women's Experiences of Waiting for Further Testing

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Purpose/Objectives: To describe anxiety experienced by participants in a breast cancer screening program who have received an abnormal screening mammography result and are waiting for further testing and diagnosis and to identify the social support needed during this period.

Design: Exploratory, descriptive.

Setting: Quebec Breast Cancer Screening Program (QBCSP) participants in Montreal, Canada.

Sample: Nonprobability sample of 631 asymptomatic women, aged 50–69, who had abnormal screening mammogram results in the two months prior to the survey and who spoke or read French or English.

Methods: Mailed self-report questionnaire.

Main Research Variables: Anxiety, social support, and breast cancer screening.

Findings: Fifty-one percent of the participants were quite or very anxious at every stage of the prediagnostic phase. Seventy-five percent expressed their feelings to family and friends whose support was comforting but did not diminish participants' anxiety. Satisfaction from social support offered by healthcare professionals reduced their anxiety.

Conclusions: To decrease anxiety in the prediagnostic phase, women need support from healthcare professionals during the early stage of the screening process to prevent exacerbation of their concerns. Support has to be integrated into a continuity-of-care process.

Implications for Nursing: Nurses can play a significant role in breast cancer screening programs. They can evaluate, at an early stage, participant anxiety and offer the appropriate social support. They also can ensure the follow-up and personalized support required while a patient awaits a diagnosis.

Key Points . . .

- Patient satisfaction with social support provided by healthcare professionals can reduce anxiety.
- Healthcare professionals should evaluate and satisfy women's needs for social support from the start of screening and throughout the investigative process.
- Social support must be integrated into the quality standards of a breast cancer screening program.

Northouse, Jeffs, Cracchiolo-Caraway, Lampman, & Dorris, 1995; Pineault; Seckel & Birney, 1996).

Screening mammograms focus on asymptomatic women who hope to obtain confirmation of good health (Ong, Austoker, & Brett, 1997). News of an abnormal result is disconcerting and for some women is synonymous with a diagnosis of breast cancer (Pineault, 2001; Scaf-Klomp, Sanderman, van de Wiel, Otter, & van den Heuvel, 1997). The waiting period for different stages of additional investigation and final test results is characterized by uncertainty and fear. For most women, it is a very distressing period (Fridfinnsdottir, 1997; Hislop et al., 2002; Lampic, Thurfjell, Bergh, & Sjoden, 2001; Poole & Lyne, 2000). According to Marteau (1994), the uncertainty women experience during the waiting period is more upsetting than the test results, whether positive or negative (Sandin et al., 2002).

Studies have shown that women who benefit from social support are less anxious during the screening and additional tests (De Grasse, Hugo, & Plotnikoff, 1997; Fridfinnsdottir, 1997; O'Mahony, 2001; Seckel & Birney, 1996). Social support positively affects health and contributes to well-being by satisfying the person's needs for assistance, a sense of belonging, information, and socialization. In addition, it facilitates the marshalling of psychological resources and helps people to overcome emotional problems (Caplan, 1974; Smith, Fernengel, Holcroft, & Gerald, 1994).

According to Schaefer, Coyne, and Lazarus (1981), the principal functions of social support are emotional, informational,

The numerous advantages associated with systematic breast cancer screening programs no longer need proving; however, some healthcare professionals have expressed reservations about the extent of psychological morbidity experienced by participants (Bakker, Lightfoot, Steggle, & Jackson, 1998; Brett, Bankhead, Henderson, Watson, & Austoker, 2005; Fridfinnsdottir, 1997; Lowe, Balanda, Del Mar, & Hawes, 1999; Ong & Austoker, 1997; Pineault, 2001; Poole et al., 1999; Thorne, Harris, Hislop, & Vestrup, 1999). Indeed, manifestations of anxiety have been recorded at every stage of screening, beginning with the letter inviting women to participate in the program (Elkind & Eardley, 1990; Hurley & Kaldor, 1992; Marteau, 1990). Furthermore, women who receive an abnormal screening mammogram result must undergo additional investigative tests. The experience can produce intense anxiety (Aro, Absetz, van Elderen, van der Ploeg, & van der Kamp, 2000; Brett et al.; Fridfinnsdottir; Lowe et al.; Ong & Austoker; Sandin, Chorot, Valiente, Lostao, & Santed, 2002), especially for women who must have a biopsy, because the test often is associated with a serious condition (Benedict, Williams, & Baron, 1994; Deane & Degner, 1997;

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and tangible. Emotional support is comforting and is given and received in the context of a relationship founded on trust, affection, empathy, and a willingness to listen. After receiving an abnormal screening mammogram test result, women need to share their concerns and fears about the experience. They want someone to listen to them and to reassure them, such as family and friends; healthcare professionals also might be called on to provide such support (De Grasse et al., 1997; Fridfinnsdottir, 1997). Informational support refers to information and advice that individuals might use to deal with stressful situations and relieve their fears (Drageset & Lindstrom, 2003; Northouse et al., 1995). In addition, tangible support involves material aid, services, and actions related to practical problems (Schaefer et al.). In the course of additional medical care, tangible support may solve problems such as access to parking and transportation to clinics.

The purpose of the present study was to describe the anxiety experienced by women who received an abnormal screening mammogram result and were awaiting a diagnosis. Another goal was to explore the social support that women require during that period. To achieve this, the women's efforts to obtain social support were examined, as well as the support that they received, their degree of satisfaction with that support, and their desired improvements.

Methods

Setting

The study was conducted in Montreal, Canada, where the Quebec Breast Cancer Screening Program (QBCSP) was introduced in 1998. The QBCSP consists of a screening mammogram performed every two years in designated screening centers located in private radiology clinics. The majority of women who undergo systematic screening obtain a normal mammogram result. Eleven percent of women, however, receive an abnormal result because of lesions discovered during the test (Ministère de la santé et des services sociaux, 2005). They also must have additional tests, usually comprising a second mammogram, ultrasound, or biopsy. The period spanning the announcement of an abnormal screening mammogram result to the final result of additional investigation is known as the prediagnostic phase.

In the QBCSP, the women's physicians must communicate abnormal screening mammogram results to them and set up any additional tests necessary. The tests should be performed in a designated assessment center located in a hospital, where nurses are responsible for providing social support to QBCSP participants (Ministère de la santé et des services sociaux, 1996). However, in Montreal, women frequently have their additional tests in private clinics where no one specifically is assigned to offer them social support.

Participants

During a four-month period, all Montreal women involved in the QBCSP who had abnormal screening mammogram test results were contacted to take part in the study ($n = 951$). To be in the study, women had to be aged 50–69, have had a screening mammogram in the two months prior to the survey and obtained an abnormal test result, be waiting for or have had additional tests, and be able to answer the questionnaire in French or English.

Data Collection

Three weeks after learning their abnormal screening mammogram test results from the QBCSP, women meeting the selection criteria were mailed a self-administered questionnaire. In addition to the survey questionnaire, the mailing included a letter explaining the nature and objectives of the study and a prepaid return envelope. A reminder was mailed two weeks later; if necessary, after another two weeks, a reminder telephone call was made. Women who were not interested in participating in the survey were asked to return their questionnaires intact. The study was endorsed by the Université de Montreal's health sciences ethics committee.

Instruments

The anxiety of the participants was evaluated with the help of two measuring instruments. Psychological consequences linked with screening mammography were evaluated with the **Psychological Consequences of Screening Mammography (PCQ)**, developed in Australia by Cockburn, De Luise, Hurley, and Clover (1992). This instrument assesses the positive and negative effects inherent to the experience of screening. It comprises 22 questions related to three different fields: emotional, social, and physical. Score items ranged from 0 (not at all) to 4 (quite a lot of the time). Different psychometric testing made by the authors confirmed the stability of the results and the coherence between the instrument and the aims pursued by the research. Only the 12 items related to negative consequences were used in the present research—5 apply to emotional reactions, 4 apply to physical responses, and 3 apply to social reactions.

Developed and validated in Switzerland by Meystre-Agustoni, Paccaud, Jeannin, and Dubois-Arber (2001), the **Breast Cancer Anxiety Indicator (BCAI)** is a single-item questionnaire arranged in a 4-point Likert format from 0 (not at all anxious) to 4 (very anxious). This instrument and the PCQ were used simultaneously to evaluate the anxiety of women screened for breast cancer. The correlation between the two instruments then was demonstrated. Moreover, good reliability and validity for the BCAI also was reported by the authors.

In the present study, the BCAI measured participants' anxiety at specific moments during the prediagnostic phase (i.e., after learning of an abnormal screening mammogram result, during the waiting period before having additional tests, and during the wait for test results). A strong correlation between the PCQ and BCAI was established, in particular with respect to the announcement of an abnormal screening mammogram result ($p = 0.645$) and during the wait for additional test results ($p = 0.665$).

Information about social support (e.g., emotional, informational, and tangible) was gathered using a 13-item questionnaire that addressed notably the support needs by the participants, the support they received, women's satisfaction with the support, and the desired improvements to the offered support. It was based on various items taken from Barrera, Sandler, and Ramsay's (1981) **Social Support Measurement Questionnaire** and different topics inspired by Ong et al. (1997). Content validity was assured by an exhaustive review of the literature and consultation with health professionals just as women became involved in the screening program.

The questionnaire concluded with a section reserved for sociodemographic data and was pretested with 12 QBCSP

participants who already had experienced the wait for diagnosis after an abnormal screening mammogram result and three practitioners who worked with these women.

Statistical Analysis

The SPSS® (SPSS, Inc.) version 11 was used for data analysis. Descriptive statistics, Kendall's correlation, and Pearson chi-square were used to evaluate the data. Statistical significance was set at $p \leq 0.05$.

Findings

Of the 951 questionnaires mailed, 631 were completed, representing a 66% participation rate. Of the survey participants, 77% were aged 50–59 years, and 79% were born in Canada (see Table 1). Fifty-three percent completed up to 12 years of formal schooling, and 30% attended a university. Sixty-one percent lived with a spouse, and 27% lived alone. Most women worked outside the home (60%). Thirty-eight percent had a family income of \$30,000 or less, and 36% had a family income of more than \$50,000. The majority of the participants (60%) had their additional tests in private clinics.

Anxiety

Women manifested anxiety at every stage of the prediagnostic phase, which was exacerbated when a biopsy had to be performed. When an abnormal screening mammogram result was announced, 49% of participants were “quite or very anxious,” whereas more than half registered the same levels of anxiety during the wait for additional tests (52%) and test results (53%). A new surge of anxiety was evident when women learned that they would have to have a biopsy; 63% of the women were then “quite or very anxious.” The anxiety level remained constant during the wait before the biopsy was performed (61%), lasting until the biopsy result was given (63%) (see Table 2).

Determinants of Participants' Anxiety

Determinants influencing participants' anxiety levels can be grouped as factors preexisting the screening, factors linked to the screening process, and structural factors. Women who were anxious before the screening process, women taking medication to treat anxiety, and women who were worried about having a mammogram were more anxious during the prediagnostic phase (see Table 3). The group included more women for whom it was not their first experience with mammography ($p = 0.005$).

With regard to factors linked with screening, the more anxious women were at the announcement of an abnormal screening mammogram test result, the more anxious they were at different times during additional testing. The same was true of women receiving an abnormal mammogram test result for the first time and of women in the younger age group (between 50–59). Structural factors contributed to heightened anxiety in women, notably, when an abnormal screening mammogram result was not communicated by physicians and when the waiting period was prolonged.

Social Support

Emotional support: Most participants (75%) expressed their feelings about being informed of an abnormal screening mammogram test result. They mainly talked with their

Table 1. Sociodemographic Profile of Study Participants

Characteristic	n	%
Age (years) (N = 623)		
50–54	235	38
55–59	187	30
60–64	121	19
65–69	79	13
70 and older	1	0
Language of correspondence (N = 631)		
French	535	85
English	96	15
Living situation (one response or more)		
Living with a spouse (man or woman)	375	61
Living alone	165	27
Living with one or more children	112	18
Living with a friend (man or woman)	18	3
Living with a parent, brother, sister, etc.	12	2
Living with a religious order	3	1
Other	7	1
Women's birthplace (N = 614)		
Canada	485	79
Europe	75	12
Africa	14	2
Middle East	13	2
Asia	12	2
Central America	9	2
South America	4	1
United States	2	0
Formal education (N = 613)		
7 years or less	72	12
8–12 years	254	41
College of general and professional education or equivalent	104	17
University	183	30
Occupation (N = 515)		
Work outside the home	307	60
Work in the home	146	28
Receiving social assistance	27	5
On sick or disability leave	23	5
Receiving employment insurance	7	1
Other	5	1
Income (\$) (N = 472)		
9,999 or less	45	10
10,000–29,999	134	28
30,000–49,999	124	26
50,000 or more	169	36

Note. N values vary because of missing responses or inapplicability.

spouses (67%), other family members (65%), and friends (70%). Less than half of the women (48%) confided in their physicians; 48% spoke with hospital staff; and 32% talked with clinic staff. According to participants, their silence was a result of not feeling the need to talk (67%), not wanting people's pity (61%), or not wanting to bother others with their problems (58%).

Study findings revealed that the offer of emotional support depends on the healthcare professionals who women encounter in the course of additional tests. For instance, 80% of the women who had their tests in a private clinic were “not at all” encouraged by the staff to talk about their feelings; this was the case for 57% of women who went to a hospital, where nurses provided their support, and 48% of women who met

Table 2. Participant Anxiety by Stages of the Prediagnostic Phase

Stage of the Prediagnostic Phase	Not at All Anxious		Slightly Anxious		Quite Anxious		Very Anxious		Total		Not Applicable or No Answer
	n	%	n	%	n	%	n	%	n	%	
Learn of abnormal result.	45	45	38	6	169	27	132	21	619	100	12
Wait for additional tests.	40	40	46	8	173	29	141	23	602	100	29
Wait for results.	37	37	50	10	142	28	128	25	512	100	119
Learn that a biopsy is needed.	28	28	8	10	22	35	22	27	80	100	5
Wait for biopsy.	31	31	6	8	23	33	21	28	75	100	10
Wait for biopsy result.	30	30	6	8	24	30	26	32	80	100	5

with their physicians. Analysis shows, however, that the more women were encouraged to talk, the more they expressed their feelings to physicians ($p = 0.0001$), clinic staff ($p = 0.019$), and hospital staff ($p = 0.026$). In addition, the vast majority of participants (95%) were not given the name of resources to contact in case of need.

When they received emotional support, women were “quite or very satisfied” with support offered by family and friends

Table 3. Determinants of Anxiety During Screening for Breast Cancer

Factor	p
Preexisting the screening	
When women are stressed prior to screening, they are more anxious	
• At the announcement of an abnormal screening mammogram	< 0.0001
• During the wait for additional tests to be done	< 0.0001
• During the wait for test results.	< 0.0001
When women use medication for anxiety, they are more anxious	
• During the wait for additional tests to be done.	0.001
When women are worried at the idea of having a mammogram, they are more anxious	
• After learning of an abnormal screening mammogram	< 0.0001
• During the wait for additional tests to be done	< 0.0001
• During the wait for the test results.	< 0.0001
Linked to screening process	
When women are worried at the announcement of an abnormal screening mammogram, they are more anxious	
• During the wait for additional tests to be done	< 0.0001
• During the wait for the results of these tests.	< 0.0001
When women learn their first abnormal screening mammogram result, they are more anxious	
• At the announcement of their abnormal screening mammogram	0.0123
• During the wait for additional tests to be done.	0.0139
Younger women (aged 50–59 years) are more anxious	
• During additional tests	0.0246
• During the wait for biopsy results.	0.0003
Structural	
When the abnormal screening mammogram result is communicated by the women's physicians, they are more anxious.	0.0406
When waiting periods are prolonged, they are more anxious	
• During additional tests	0.0088
• During the wait for biopsy results.	0.0415

(85%), by physicians (86%), hospital staff (85%), and clinic staff (79%). The more satisfied women were with the emotional support offered by clinic staff, where most of them had their additional tests, the less anxious they were during the wait for additional test results ($p = 0.0092$). Conversely, no significant relationship existed between satisfaction with emotional support offered by family and friends and the reduction of women's anxiety while awaiting test results (spouse: $p = 0.7946$; family: $p = 0.9773$; friends: $p = 0.4582$).

Women considered the following strategies to be “quite or very important” to improving emotional support.

- Reducing waiting periods (98%)
- Allowing women to speak with a healthcare professional at any time (97%)
- Always giving the results in person (93%)
- Encouraging women to talk about their worries (92%)
- Organizing care so that it is offered by the same healthcare professional (91%)
- Performing all additional tests in the same place (87%)
- Providing the name of a person or agency to contact if needed (86%)
- Contacting women by phone to see if they need support (81%)

Informational support: After learning of an abnormal mammogram result, 34% of women looked for more information. The required information consisted mainly of further explanation about the additional tests (78%), details on the risk of having breast cancer (55%), the consequences of an abnormal screening mammogram (49%), information about breast cancer treatments (26%), and the name of a person or agency to contact if needed (15%).

The main reasons why 66% of the women did not look for information are that they felt they received all the necessary information at the clinic or at the hospital (65%), they did not think they needed it (57%), and that they were nervous about knowing anything more (28%). The information transmitted by healthcare professionals was principally provided verbally (see Table 4). Very few women received written information. When they did receive it, however, 87% of them read it all, 83% understood the contents, and 83% believed that information in the form was useful to them. No information was given to 21% of the women who had their additional tests in a private clinic.

In all, participants who received information were “quite or very satisfied” with information offered by their physicians (79%), in hospitals (88%), and in clinics (74%). The more satisfied women were with the information they received, the less anxious they were while they waited for their results (physician: $p = 0.0005$; hospital staff: $p < 0.0001$).

Table 4. Types of Information Received by Participants

Information Type	%
Verbal	
From the attending physician	81
In the hospitals	70
In the clinics	59
Written	
From the attending physician	3
In the hospitals	8
In the clinics	13
Verbal and written	
From the attending physician	4
In the hospital	12
In the clinics	7
None given	
By the attending physician	11
In the hospitals	10
In the clinics	21

The main desired improvements considered to be “quite or very important” to informational support were

- Making sure women properly understood the information (98%)
- Allowing women to ask more questions (97%)
- Explaining the additional tests better (97%)
- Adapting information to women’s understanding (90%)
- Providing resources to call if needed (86%)
- Providing more written information (73%).

Tangible support: Few problems of a practical nature were reported. The main problems were related to parking or the difficulty of getting an appointment outside of working hours.

Discussion

Interest in the study is reflected by the 66% participation rate, a very satisfactory result for a mail survey. In addition, 63% of women wrote comments and details about their experiences with screening and additional tests on their questionnaire, revealing their need to express what they had gone through during that period. Representation of all social groups was ensured because the study included women with different levels of schooling and diverse socioeconomic backgrounds.

As shown by other studies, half the women participating in the Montreal QBCSP were “quite or very” anxious at all stages of the prediagnostic phase. In addition, as described in the literature, the need to undergo a biopsy sparks heightened anxiety (Benedict et al., 1994; Deane & Degner, 1997; Northouse et al., 1995; Pineault, 2001; Seckel & Birney, 1996). Of equal concern is that women who had mammograms before were more anxious at the idea of having the test again. The data suggest that the screening experience is potentially anxiety-producing for participants, especially for women who received a false-positive result in the past (Brett & Austoker, 2001; Lampic et al., 2001) and for women who had an earlier unsatisfactory screening experience (Dolan et al., 2001). Considering that the success of a systematic screening program depends most on women’s long-term adherence, wondering

about the reliability of women who experience the stress on a repeated basis is appropriate.

The survey findings are distinguished by new elements regarding the anxiety of women awaiting diagnosis and their social support needs. The identification of determinants influencing women’s anxiety at different times during the prediagnostic phase illustrates the importance of offering social support at an early stage to prevent heightened anxiety during later stages. Research data affirm that women who are adequately reassured and informed before additional investigation experience less anxiety later on. Women’s physicians clearly play a key role when the abnormal screening mammogram result is announced because their intervention effectively calms women’s anxiety.

Offering social support to women awaiting a diagnosis decreases anxiety (De Grasse et al., 1997; Fridfinnsdottir, 1997; O’Mahony, 2001; Seckel & Birney, 1996). Study findings expand on that, demonstrating that emotional support offered by intimates (e.g., spouse, family, friends), although comforting, did not relieve the anxiety. So, even though women were satisfied with the support, their anxiety did not diminish. Only the support offered by healthcare professionals reduced their anxiety because it comprised emotional and informational dimensions that are indispensable to calming women as they await a diagnosis. The need for professional support is demonstrated by the strong majority of women calling for increased emotional support from healthcare professionals with whom they want an opportunity to express their concerns.

Most women did not look for more information after an abnormal mammography result because they were given information in the establishments they visited. Because support decreases participants’ anxiety, why then were the women anxious? The answer possibly lies in the quality of information being given. Most women only received verbal information, even though in moments of stress, the capacity to understand and retain information is considerably reduced (Deane & Degner, 1998; O’Mahony, 2001). Written information, therefore, is indispensable because it can be consulted and taken in later, when some degree of calm has been restored. Very few of the survey participants received written information, and nearly three quarters of the women would like to have had more. In addition, the vast majority of them were not given contact information for any resources. Having that information is in itself a form of support because, even if they do not use the resource, they can have access to it whenever they need it (Drageset & Lindstrom, 2003). Consequently, women found themselves alone with their questions, uncertain about information that had been given to them, and lacking anyone to whom they could turn for needed support. Those situations perpetuate uncertainty and become a source of anxiety.

The research data and the improvements desired by women who must have additional testing and are waiting for a diagnosis point to the importance of offering social support at an early stage of the prediagnostic phase. Moreover, the support required during that period demands a personalized approach on the part of healthcare professionals, in which women’s needs are heard and taken into account. Such an approach involves a brief but precise evaluation at the start to assess women’s degree of vulnerability and, at the same time, determine their support needs. A single type of support offered to all women, whether emotional or informational in nature, will not satisfy their needs.

In this way, personalized support can be offered to women as needed and, if necessary, maintained throughout additional testing. Those standards of practice only can be achieved in a continuity-of-care process in which each woman's specific situation is addressed and supervised by healthcare professionals who are skilled in assuming those functions (e.g., nurses).

Implications for Nursing

Survey findings showed that women with abnormal screening mammograms who proceed with additional testing suffer anxiety during that period. Organizing adequate social support is imperative to minimizing the negative psychological impact of the experience. Access to a healthcare professional responsible for providing women with support should be ensured in all institutions where the tests are conducted. Nurses possess all the competencies required to fulfill that mandate.

Nurses who are specifically assigned to QBCSP participants become the main contact for women throughout the numerous stages that additional investigation can entail. Nurses make the appointments for the tests to ensure they are performed with a reasonable amount of time. Nurses also act as an intermediary between women and their attending physicians, who often are

hard to contact. More specifically, nurses are responsible for providing social support to screening program participants.

The survey demonstrated that women require personalized social support. Considering the high number of participants who are called back for further testing, expecting nurses to be able to meet individually with everyone is unrealistic. A need exists to rapidly spot the most vulnerable women or those with particular needs. This can be achieved by developing and distributing a short questionnaire to women, the purpose of which would be to assess anxiety, social networking, information received, and their understanding of the information. Nurses then would be able to identify the women who need more attention, in terms of support, and could prevent heightened or spiraling anxiety. Nurses would meet with those women and those who had a biopsy, which is the most anxiety-causing test. In short, nurses are responsible for listening to women's concerns, providing a personalized response to their questions, referring them if needed, and ensuring service continuity.

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