Québec Breast Cancer Screening Program

Meeting the Social Support Needs of Participants *A Challenge for Staff*

Research Report

Highlights

Training needs Lack of time Stress

rqasf

Under What Conditions Are the Personnel Assigned to the QBCSP Providing Social Support to Program Participants?

Since 1998 in Québec, a breast cancer mammographic screening program has been offered to all women between 50 and 69 who exhibit no symptoms of the disease. A program like this one makes it possible to discover lesions that cannot be detected by palpation alone. The goal of detecting cancer at an early stage is to limit invasive treatments and improve affected women's chances of survival. The participation rate of the Québec Breast Cancer Screening Program (QBCSP) in 2005 was 50%, which is some small progress toward the targeted rate of 70% that would significantly reduce deaths attributed to this form of cancer. Breast cancer remains the most frequently diagnosed form of cancer in women and the second cause of death by cancer in Québec women.

Mammographic screening of asymptomatic women, and especially, the announcement of abnormal results following such an exam, generates anxiety and apprehension. To counter these negative effects, the QBCSP and other community organizations established various social support measures for participants. Noting the under-utilization of these resources, the Réseau québécois d'action pour la santé des femmes (RQASF) initiated an evaluation of the level of anxiety and support needs of women awaiting a diagnosis. Published in 2004, the RQASF's report (RQASF, 2004) revealed physicians' fundamental role in reducing women's anxiety level and the close link between emotional and informational dimensions of support. It also shed light on the gap between participants' expressed needs and the support being offered them, raising the question of where responsibility should be laid.

In an effort to find answers, today the RQASF is giving QBCSP staff in the region of Montréal an opportunity to speak. What priority is given to social support in their work mandates? What are the conditions for staff interventions? What resources are they offered? What are their principal needs? The aim of this study is to identify the conditions that would enable QBCSP staff to provide adequate social support (emotional and informational) to Program participants.

QBCSP Staff Members who Participated in the Survey

The research with Program staff began in early 2006 and was carried out in two stages: a mail survey (quantitative component) followed by semi-directed interviews (qualitative component).

Mail Survey

The mail survey was addressed to health network personnel who work with QBCSP participants, either face to face or over the telephone.

Nearly two-thirds (63.5%) of the staff took part, representing all categories of QBCSP practitioners–a significant participation rate for this type of survey. All together, 265 questionnaires were returned to us. Of these, 18 individuals refused to answer and 61 individuals did not intervene with Program participants. In all, 186 questionnaires were counted, over half of which were completed by the staff of designated screening centres (CDD).

* Office staff includes receptionists, administrative secretaries, reception clerks and appointment clerks.

Table 1 Sociodemographic Profile of the Cohort (mail survey)

Indicator	n (=186)	%
Sex		
Women	166	89.2
Men	18	9.7
No answer	2	1.1
Age		
20-29	22	11.8
30-39	47	25.3
40-49	44	23.7
50-59	70	37.6
No answer	3	1.6
Birthplace		
Canada	159	85.9
Other	24	12.9
No answer	3	1.6
Level of schooling		
High school	16	8.6
College	71	38.2
University	89	47.8
No answer	10	5.4
Job category		
Technologist	66	35.5
Office staff*	41	22.0
Nurse	38	20.4
Radiologist	20	10.8
Physician	13	7.0
Other	8	4.3
Overall employment experience		
Less than 1 year	6	3.2
1-5 years	27	14.5
6-10 years	26	14.0
11-15 years	26	14.0
16-20 years	19	10.2
21 years or more	75	40.3
No answer	7	3.8
Experience with QBCSP participants		
Less than 1 year	24	12.9
1-2 years	16	8.6
3-5 years	43	23.1
Over 5 years	85	45.7
Don't know	7	3.8
No answer	11	5.9

Interviews

The 39 individuals who took part in the mail survey were asked to participate in semi-directed interviews. The goal of the interviews was to obtain a better understanding of the different dimensions of the intervention conditions addressed in the first questionnaire; these included staff relationships with participants, the impact on participants of the amount of time allocated to support tasks, and work climate. Also explored were conditions and support practices according to the different personnel categories. The aim of the analysis stage was to identify, based on the comments of personnel, obstacles and factors favourable to support, with a view to improving intervention conditions.

The sociodemographic profile of the interviews resembled that of the mail survey cohort. Excepting the three radiologists, all those who were interviewed were women.

Table 2 – Interview Group: Job Category and Location

Indicator	n (=39)
Job category	
Technologist	14
Office staff*	10
Radiologist	8
Nurse1	4
General practitioner[1]	3
Employment location	
CDD[2]	20
CRID[3]	13
CDD and CRID	6[4]

1 Nurses and general practitioners do not work in the CDDs.

2 CDD: (French acronym) refers to designated screening centre, in other words, a private radiology clinic designated by the QBCSP.

3 CRID: (French acronym) refers to a designated referral centre, attached to a hospital.

4 One female technologist and five radiologists divide their working hours between a CDD and a CRID.

Principal Observations

The principal aim of this study was to identify the conditions that would enable QBCSP staff to provide an optimal response to the social support needs (emotional and informational) of Program participants. In short, the goal was to discover how to reduce the gap between, on one hand, the services being offered by staff and the demands expressed by women in the RQASF's 2004 evaluation, and, on the other, the standards set in the QBCSP's reference framework.

Supported by our analysis of the questionnaires and interviews, this study focuses on the following points:

- a comparison of staff perspectives and practices with regard to supporting participants;
- the establishment of links between the staff's existing intervention conditions and participants' anxiety factors;
- an examination of the specific type of support offered to participants who are either from minority backgrounds or are living with functional limitations;
- an analysis of the needs of staff assigned to the QBCSP.

The study traces a striking portrait of the situation of QBCSP staff and critiques current intervention conditions in terms of the social support offered to Program participants.

Social Support According to Participants and QBCSP Standards (RQASF, 2004)

- **waiting periods** and the **means of communicating** an abnormal screening mammogram are determinant anxiety factors in QBCSP participants.
- **social support** (emotional and informational) helps to reduce participants' anxiety;
  - women need to communicate with attending staff to obtain personalized information that will diminish their apprehension;
  - women share their feelings with their immedate support network, but only the support offered by health professionals reduces their anxiety;
  - yet, only a limited number of women express their emotions to health professionals because they are not encouraged to do so;
  - participants prefer to be informed of an abnormal result, **personally**, by a health professional; ideally, their **personal physician**;
  - women want more **written information** and **references** (resource person or self-help group) during additional tests.
- The **QBCSP** mentions a number of measures that directly affect the work of staff members:
  - the announcement of an abnormal screening mammogram is the attending physician's responsibility;
  - additional tests should be given in a CRID;
  - training of staff involved in the screening process.
- The QBCSP's social support standards are vague and open to interpretation.

Existing Social Support Provided by QBCSP Staff

- In 8 CDDs out of 11, the announcement of an abnormal screening mammogram is made by office staff.
- In 60% of cases, additional tests are conducted in CDDs (RQASF, 2004).
- The presence of individuals who are specifically assigned to offer participants social support appears to be very unequal:
  - 70% of CRID staff versus 8% of CDD staff report that one person is assigned this responsibility in their establishment;
  - in the CRIDs, nurses and general practitioners provide support and assume responsibility for coordinating the process for QBCSP participants;
  - in the CDDs, participant support and follow-up may be added on to the duties of all staff members, with no specific mention of this in their job description.
- Most QBCSP staff believe that their job description includes the provision of emotional support to participants:
  - this is true of 82% of CRID staff and 71% of CDD staff;
  - 21% of CDD office personnel do not know if this type of support is part of their job;
    - yet, these employees are responsible for reception and calling women back for additional tests;
    - office staff admit they are often **overwhelmed** when confronted with the anxiety of participants;
  - 21% of the technologists who work in the CRIDs do not know if this type of support is part of their job.
- Most QBCSP staff believe that their job description includes the provision of informational support to participants:
  - most staff members (93%) prefer **verbal information** as a means of support; one-third of staff transmit written information;
  - staff members feel more comfortable with this dimension of support work;
  - staff tend to **underestimate** the importance of **written information**, and frequently will only offer it on request;
  - staff members deplore participants' lack of prior information about the screening process and additional tests.

Staff Members and Support for Women with Specific Needs

- **For participants living with a disability,**
  - staff members do **not always seem to be aware** of the specific obstacles encountered by these women;
  - CDD staff believe that the CRIDs are more "used" to interacting with these women and these public institutions give them **more time**;
  - staff members leave it to the persons accompanying women with intellectual disabilities to communicate with them;
  - CDD staff often redirect women in wheelchairs to the CRIDs, which are **better equipped** to receive them.
- **For participants from ethnocultural communities or racialized groups,**
  - staff members sometimes have **difficulty** communicating with certain women;
  - most of the time, the personnel manage to communicate with the help of family or friends, but productive communication concerning a personal or disease-related topic is a major challenge;
  - staff are often left alone to solve communications problems (language or cultural differences);
  - in general, staff members are very sensitive in dealing with these women, but the language barrier and lack of adapted tools affects the quality of services they are offered.

Conditions of Staff Interventions

- In general, the conditions of intervention (allocated time, work space, etc.) are **more advantageous** for staff in the public sector (CRID) than for private sector (CDD) personnel.

Time

- More than half of the staff considered that they have **little time** for listening to, comforting and informing QBCSP participants;
  - in the CDDs, the pace appears to be quite busy: 41% of the office staff state that they have no time for this type of support.

Work place

- The **CRIDs' premises are more suited** to ensuring the confidentiality of conversations;
  - nearly 75% of CRID staff consider that their work place is adequate compared to 60% of CDD personnel.

Tools for facilitating support (pamphlets, anxiety evaluation grid and protocols)

- Nearly one-third of practitioners have no tools to facilitate their support work;
  - tools are **not always adequate**, particularly those concerning the additional tests.
- Pamphlets are the most frequently used tools.
- Few tools have been developed by the establishments themselves: one-third of the CRIDs and less than 20% of the CDDs have done so.

Resources for assisting personnel (coordinator, psychologist, etc.)

- Only one-third of the staff reported having benefited from a resource or person who helped them to offer emotional support to particpants;
  - nearly two-thirds of CRID staff know of the existence of such resources;
  - this proportion sinks to 17% in the CDDs.
- Nearly half of staff reported having benefited from a resource or person who helped them offer informational support to participants:
  - nearly two-thirds of CRID staff know of the existence of such resources compared to 36% of CDD staff;
- Still, **mutual aid and strong team spirit**–more present in the CRIDs due to their interdisciplinary approach–make it possible for staff to get support and reassurance.

References to be furnished to participants (psychologist, social worker, self-help group, etc.)

- 45% of staff know the name of an agency or individual to whom participants can be referred: twice as many practitioners in the CRIDs (65%) as in the CDDs (32%) know to whom to refer participants;
  - CDD staff deplore this situation.

Needs of Staff

Training

- The majority of staff consulted (64%) had received no training on how to support QBCSP participants:
  - **less than one-quarter** of the staff was **trained by the QBCSP**;
  - over half of the technologists in the CRIDs had received the QBCSP training compared to a little over one-third of those in the CDDs;
  - only one-quarter of the CRID office staff had received this training compared to 3% in the CDDs.
- Barely **6% of the cohort** interviewed had completed **intercultural intervention training**.

Better working conditions

- Despite a work climate the respondents judged to be satisfactory, **stress, lack of time** and **pressure to produce** in some CDDs hampers the capacity of colleagues to forge closer relationships:
  - yet, support from the work place makes it possible, not only to find comfort in difficult periods, but also to better perform one's duties.
- In general, QBCSP staff need training and information. They themselves need support and optimal working conditions in order to properly fulfill their role. Staff also want clear rules concerning the support participants require and better communication with Program authorities.

Principal Recommendations

Instituted in 1998, the Québec Breast Cancer Screening Program (QBCSP) is a relatively recent public health initiative. The following recommendations are about improving the Program's quality and operations in the region of Montréal. They are aimed at improving the intervention conditions of staff assigned to the QBCSP to enable them to better meet participants' social support needs. These recommendations reaffirm the importance of respecting women's needs and rights–one of the Program's five fundamental principles. In consideration of this, the RQASF calls on the following bodies:

The Ministère de la Santé et des Services sociaux (MSSS) and QBCSP Provincial Directors

1. Apply the reference framework standards and ensure that additional breast imaging tests are conducted in the CRIDs. Until this is implemented:
   - CDDs that choose to carry out additional breast imaging tests should ensure that participants receive social support equivalent to that offered in the CRIDs, in other words, by health professionals (physician or nurse);
     - add this requirement to the prerequisites for designating these establishments as designated screening centres (CDD).
2. Develop innovative and accessible information and awareness-raising approaches for Program participants.
3. In the upcoming year, review the content of pamphlets concerning additional tests.[1]
4. In the next year, commence the process of revising the QBCSP reference framework,
   - to include a clear definition of social support;
   - to establish accessibility standards for establishments regarding women with special needs;[2]
     - add this requirement to the prerequisites for designating these establishments CDDs or CRIDs.

The QBCSP Regional Service Coordination Centre of Montréal

1. Offer staff in all establishments training about the QBCSP;
   - offer an initial training session to all current staff
   - develop a continuing training program and refresher courses for experienced staff members;
   - offer compulsory training to all new staff before they begin work.
2. Standardize social support services in all participating establishments,
   - by offering all staff the "support" component of the QBCSP training;
     - adapt training to the specific roles of the different categories of practitioners;
   - develop or distribute adequate tools in all establishments.
3. Sensitize staff to the problems encountered by participants with special needs;
   - offer training to raise awareness of these participants' situations;
   - set up a continuing training program for new staff members;
   - propose regular refresher courses to experienced personnel.
4. Ensure the availability of different resources to support both participants and personnel.

The Management of CDDs in Montréal

1. Comply with the reference framework standards and refer participants who need additional breast imaging tests[1] to the CRIDs. Until this is implemented:
   - CDDs that choose to carry out additional breast imaging tests should ensure that participants receive social support equivalent to what is offered in the CRIDs, in other words, support given by health professionals (physician or nurse);
   - follow-up of abnormal screening mammographies should be carried out by participants' physicians, radiologists or designated health professionals.

1 Breast imaging tests refer to ultrasound and biopsies.
2 Women with special needs comprise, in particular, women from ethnocultural communities or racialized groups, Aboriginal women living in Montréal, women with functional limitations, women with intellectual disabilities, women with weak literacy skills and lesbians.

2. Define the roles and shared responsibility for supporting women of each category of personnel that works with participants.
3. Set up intervention conditions that facilitate the work of personnel and promote improved support of participants:
   - facilitate and encourage staff participation in QBCSP training activities;
   - offer QBCSP training to all new staff before they begin work;
   - ensure that staff have the time they need to offer support;
   - provide adequate premises;
   - provide personnel with information materials to give to participants;
   - furnish a list of resources to which participants may be referred;
   - determine or inform staff of the available resources to support them in their work.

The Management of CRIDs in Montréal

1. Inform staff about the organization of services offered in the CRID.
2. Facilitate and encourage permanent and temporary staff to participate in QBCSP training activities.

Conclusion

By giving staff members who are assigned to the QBCSP an opportunity to speak, this study reveals the role played by public authorities in the observed gap between participants' needs and the social support they are being offered.

The shortcomings in the social support offered to women who have an abnormal screening mammogram or who are awaiting a diagnosis cannot be attributed–or if so, only marginally–to the intervention of staff assigned to the QBCSP. Indeed, regardless of the job category, this study shows that the vast majority of them do not under-estimate participants' anxiety and needs. On the contrary, many are extremely sensitive to the experience of these women.

In Québec, unlike elsewhere in Canada, the government has accepted the decision of the Agence de Montréal (health and social services agency) to adopt a public/private partnership model to deploy its screening program. This, despite the fact that private sector services do not match the quality of those offered by the public sector: intervention conditions in the CRIDs are superior to those in the CDDs. It is about time that the MSSS and the Agence de Montréal ensure compliance with the standards set out in the reference framework regarding the referral of participants to CRIDs for additional breast imaging tests. Furthermore, concrete requirements should be formulated and reinforced with respect to the social support of participants.

This study reaffirms the role of the QBCSP in establishing standards, organizing services and training personnel. The entire reference framework of the Program, in fact, should be revised. The support tasks must be reassessed and clarified, especially for office staff. Training on the QBCSP and social support for participants, adapted to each practitioner's specific role, would help all staff improve their work. In addition, intervention with women who have functional limitations and women from ethnocultural communities or racialized groups demands knowledge that the current staff do not possess. It is imperative that better access to QBCSP services be provided for participants in these categories. Clearly, those in charge of the Program must be made aware of the impotence many staff members feel when confronted with women's anxiety and come up with constructive solutions.

Québec Breast Cancer Screening Program

Meeting the Social Support Needs of Participants

A Challenge for Staff

Research >Isabelle Mimeault
>Patricia Pineault

Writing of research highlights >France Lord, Pirogue Communications

Translation >Nicole Kennedy

Graphic Design >ATTENTION design+ Alain Roy

Cover illustration >Jade Lussier

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rqasf

Réseau québécois d'action pour la santé des femmes

4245, av. Laval, Montréal, Québec, H2W 2J6
telephone : (514) 877-3189
e-mail : rqasf@rqasf.qc.ca
www.rqasf.qc.ca