

Breast Cancer Information Dissemination Strategies --Finding Out What Works

Report Summary December 2004

In 2002 the Ontario Breast Cancer Information Exchange Partnership's Coalition partners met to discuss an increasingly common complaint from breast cancer survivors that "no information" was given to them at the time of their diagnosis and/or treatment for breast cancer. Despite the creation of many resources for those dealing with breast cancer in the past 10 years women still reported that acquiring information was an issue for them. The purpose of the study was to learn the difference between what women say is happening and what information providers believe should be happening and to identify the most effective method(s) of making appropriate information available to those who need it, when they need it.

Method

Between November 2003 and August 2004 OBCIEP interviewed 28 breast cancer survivors and two information providers and held focus groups with 127 breast cancer survivors and 24 information providers. The themes arising from the preliminary interviews provided the springboard for discussions in the focus groups that were held in Kingston, Ottawa, St. Catharines, Burlington, Sarnia, Woodstock, Windsor, Dryden, Thunder Bay and Toronto. The main themes that emerged from the conversations are discussed below.



Discussions with Breast Cancer Survivors

Nine focus groups were held with women affected by breast cancer in Ottawa, Kingston, Burlington, St. Catharines, Woodstock, Sarnia, Windsor, Thunder Bay and Dryden. OBCIEP was interested in speaking with those who had received a diagnosis within the last three years.

Profile of Participants

Overall 127 women participated. Participants ranged in age from 33 to 81 (average 55) and over 80% had been diagnosed within the past three years (average age at diagnosis 52). Sixty percent (60%) indicated they were members of a breast cancer support group. All had high school level education, 63% had university or graduate degrees and 95% indicated English as their first language.

Theme 1 - The Shock of Diagnosis

I was numb for a long time . . . I didn't even think to look anywhere [for information] I was just stunned. Maybe I didn't want to know.

It was clear from our discussions in the focus groups that cancer still has the power to terrify people. The fear and panic it triggers has a profound impact on how women respond to information about their disease, if at all. Many who had received information brochures or books at the time of diagnosis admitted they did not read the material as the challenge of accepting their diagnosis was in itself overwhelming.

Some of the words used to describe reactions to the diagnosis included "shocked", "terrified", "like being on a roller coaster", "numb", "scattered", "lost", "a nightmare", "in the twilight zone", "absolutely stunned", and "being in a fog". Disbelief and denial were other common reactions and many admitted to feeling hopelessly alone. Some reported guilt feelings about what they had done to "cause" their cancers and the impact their diagnosis may have on their families, particularly on the health of their daughters and granddaughters. Many who had received information brochures or books at the time of diagnosis admitted they did not read the material as the challenge of accepting their diagnosis was in itself overwhelming.

Theme 2 - Being Your Own Advocate

I wanted to know . . . whether it was good or it was bad, it made no difference, but I needed to know. I didn't find out anything anyway. You had to find it yourself. You were left on your own.

Most participants reported that the onus was on them as a cancer patient to identify resolve their own information needs and learn about and understand their own medical treatments. Many found that they were left to decipher the information they were given and had to search out the more detailed information of interest only to them about their particular disease.

Many reported that seeing and talking to other women who had experienced breast cancer had biggest impact—it calmed them down and provided a lot of first-hand information from people who had been through it, provided a "road map" for experience that medical system did not provide. "I think most of us found our own information" said one participant.

Some have turned their experiences into community activism through local support groups. Volunteers prepare information packages, make visits to newly diagnosed patients as part of the local support group or some other program, and lead other health promotion initiatives.

Theme 3 - Different Types of Information Women Want

The hardest thing I found with the information was finding where I slotted into a spot.

Participants acknowledged that each woman's interest in obtaining information is as distinct as her particular disease. Some want to know everything, others nothing and many reported that their information needs changed during their treatment. It was agreed that general information on breast cancer is available but information specific to the individual woman's disease and interest was a challenge to find. The timing of receiving information was also discussed. A variety of formats was preferred—written, audio or video tapes, telephone contact, interactive online chat rooms or message boards, and one-on-one or group interaction with medical professionals or breast cancer survivors. "Finding yourself in the information" became a major challenge for some women.

There was agreement that a significant number of women do not want information at all, of any kind; "for as many people that want information, there are just as many people that just, I don't want to hear it." While women respected each individual's need and desire to be informed, they also pointed out that information needs can change over time and opportunities to receive information should not be reduced to one or two points in the treatment continuum. The medical or technical aspects of the disease were often sought first but many reported that they also appreciated reading or hearing of others' experiences. A "one size fits all" approach was not recommended for breast cancer information.

Experiences in the Health Care System

An issue that emerged in these discussions that linked all themes was the positive and negative experiences women reported in the health care system.

Women shared a variety of experiences that expose the fragmented and disjointed "system" in cancer care. There were a variety of unfortunate experiences with members of the medical team from significant breaches of protocol (receiving test results of another patient) to rude and insensitive behaviour by medical or administrative staff.

Many commented on the fragmentation of the health care system, where patient test results and files are not shared routinely between hospitals and cancer centres. Women reported having to complete the same forms over and over again for different specialists and to report information about symptoms and side effects repeated to different specialists. "It's like the left hand doesn't know what the right hand is doing", reported one

participant. Some stories reveal shocking lapses of judgment by some health care professionals while others are more examples of a cancer care system stretched to capacity. Reported experiences ranged from severe errors—misdiagnosis, lost test results, test results confused with those of another patient—to incompetence, rudeness, and insensitive behaviour on the part of surgeons, doctors, radiologists, nurses, and administrative staff working in medical offices and hospitals.

I went to see my oncologist...I said, "I think I have lymphedema swelling." He said, "No, you just have fat arms."

Women also expressed frustration with health professionals who did not take time to explain treatment options and felt insulted when their requests for information and explanations were ignored or met with sarcasm. Women also reported mistrusting doctors and/or the medical system brought on by witnessing mishaps, errors, abnormalities not investigated in a timely manner, or what were perceived to be false reassurances by the medical team that everything was fine, only to find out later that an abnormality was malignant. "What if they made a mistake on the pathology report?" one participant admitted thinking. "Do they know what they're talking about?"

By contrast however women shared many stories about family physicians, surgeons, nurses, social workers and different health professionals who went out of their way to calm them down and explain information to them about breast cancer and treatment options. Most valued by women was the time health professionals spent with them and the encouragement they provided. High praise was often reserved for members of the nursing staff. "I sat and talked with (the nurse) for a good hour and a half", said one woman. Women fortunate to be connected to a breast cancer program or treatment site commented on how much they appreciated having contacts throughout their treatment experience. "Superb", "fabulous", and "fantastic" were some of the words used to describe these nurses.

"You're going to be okay" is what my doctor said. "It's treatable, curable, fixable whatever. You're going to be okay" . . . I just left his office and said "I know breast cancer isn't going to kill me."

On learning of her recurrence of breast cancer one participant said "when I went to the cancer centre I said 'as long as you give me hope . . . I'm not ready to give in' and they said 'oh there's plenty of hope'. So you need to hear that, you need to see that light at the end of the tunnel . . . that was three and half years ago. They need to give you that, I mean I know they can't give you a guarantee." Women appreciated having the same nursing contacts and doctors responsible for their care throughout their treatment. Many also appreciated learning about peer support and other types of information and support services from their doctors and nurses.

Advice to Women and Health Professionals

Breast cancer survivors were asked to consider recommendations to newly diagnosed women, health professionals and other information providers about the most effective methods of distributing information on breast cancer.

Advice to Women

I think that one of the biggest things to overcome is the fear that we all have of cancer and breast cancer itself . . . the information has got to get out there. It has to be a subject that people can talk about comfortably because if you are afraid of something you can't go and fix it properly.

Overall the focus groups participants expressed the belief that, despite the challenges in obtaining and understanding information about breast cancer, it was important that those affected by the disease make every effort to empower themselves with information. "I think (searching for information) is the one thing you do have control of . . . you don't have any control over a lot of things", said one participant. Resources and services mentioned most frequently by participants included *Dr. Susan Love's Breast Book*, local support groups, Canadian Cancer Society information pamphlets, Cancer Information Service, Willow, and the Look Good,

Feel Better program. The benefits of having information far outweighed the "not knowing" option. "I was really educated so I could make a good treatment decision", one participant said.

Advice to Health Professionals and Information Providers

There needs to be a bit of everything. We all learn in different ways.

Breast cancer survivors made recommendations to health professionals and information providers to improve the provision of information and support care services. Frequently mentioned suggestions to improve the cancer care system include:

- develop a province-wide, structured, coordinated effort to disseminate breast cancer information in a standardized package with region-specific information such as contact information to local support agencies that involves the entire medical team and local support groups
- create a documented "road map" or "clinical pathway" that describes the treatment process in detailed steps and includes references to local doctors by name and descriptions of local support agencies—something "to tell you . . . what was going to be happening next . . . what the steps are", said one participant
- introduce nurse navigators to act as regular ongoing contacts for breast cancer patients throughout treatment and to provide accurate, updated information and support for women and their families
- reduce waiting times for appointments, tests results, treatment, and follow-up
- ensure that those who need additional support receive it
- offer guidance to women in managing information resources
- offer breast cancer and coping information continually as people's needs for information change over time so "the dissemination of information can't just be through one point"
- respect your patients—remember that you are treating a whole person, not simply a disease, and be aware of rushing patients from appointments, being too booked to take time to answer questions, or "tossing out statistics" as an answer to disease related questions
- promote widely existing services such as the Cancer Information Service and Willow and regional and local support services
- provide information in languages other than English, in plain language, and in graphic or pictorial formats and that are designed for different cultural groups

They always say, breast cancer's unique, no single two women have the exact same . . . so I think they have to treat us as people first and realize . . . the holistic approach treating not just the disease, but treating your body, treating your mind.



Discussions with Health Professionals

Information providers participated in focus groups and interviews. Focus group participants included nurses, social workers, support and information group personnel who had contact with breast cancer patients/clients at various stages on the treatment continuum. Most worked in screening centres, hospitals, cancer centres, and for information and support group organizations such as the Canadian Cancer Society, Willow and regional breast cancer action or breast health coalition groups. Focus groups were held in Ottawa with six participants, Thunder Bay with seven, and Toronto with 10, and two separate interviews were conducted with personnel in working in Woodstock and Toronto. Nurses, social workers, information specialists, health promotion specialists, diversity consultants, librarians, managers, and volunteers) from the following organizations attended the sessions.

Theme 1 - The Shock of Diagnosis

Several information providers had personal experience with breast cancer were able to bring a unique dual perspective to the discussions as health care or information providers and breast cancer survivors.

I'm a health professional. I knew the contacts, but when you're given the cancer diagnosis, it just falls apart. You fall apart. Your family falls apart.

Most information providers agreed with breast cancer survivors that most people do not absorb information well just after learning news of their diagnosis. Although a strong emotional response lingers, within a week or two there is not as much "shock and the denial that would block the capacity to understand", and most women assimilate information more appropriately. It is at this point where providers view their role "to respond (when) the woman is ready to ask for information." This view is supported by the feelings expressed by survivors who said that they only came "out of the fog" when they began treatment and felt prepared to deal with information. Even basic level information is appreciated at this stage said a nurse, "when people are suffering through a diagnosis like this, the thing is to make it as easy as possible for them." They also acknowledge that many women need guidance in sorting through the information maze. Said one nurse, "they will say 'I need to know what's good for me, what source is good for me. I can't read these two hundred (web) sites that I got. What should I be looking at? What's good for me?'"

Theme 2 – Patients as Advocates

Providers were not surprised to learn that breast cancer survivors felt that the onus was on them as cancer patients to find and decipher information about their disease. Spending time with patients to determine their information needs was identified as a key element of screening that nurses who participated in the focus groups acknowledge is lacking. Time constraints reduce their ability to screen appropriately in all cases. Nurses indicated that one of their greatest challenges is to understand where women are in their cancer journey *and* in their information journey. They noted also that for some women the experience of receiving and researching information on their disease could be more stressful than doing nothing.

There's two issues for us: one is making sure that people get the information that is proper to what they need in terms of both decision- making and episode of care preparation, and the other is screening for when people need additional support to understand the information.

There was agreement that if the support needs of breast cancer patients are addressed in a timely and appropriate way, it often improves how the patient copes with the cancer experience.

Theme 3 - Different Types of Information Women Want – Gaps and Challenges

Information and health care providers spoke at length about the challenges they face within the current health care system. They shared their frustrations about learning and accessing current resources in breast cancer information; the diversity in scope and random nature of services available within regions and from institution to institution within the same region; cultural issues and information resources; lack of funding; and reaching women in rural and remote areas.

Participants recognize the challenge in keeping aware of all updated resources on breast cancer and where to access them but noted that existing services are often underused. Information specialists from both the Cancer Information Service and Willow commented that they are as likely to be asked questions about where to buy wigs and prostheses as questions on breast disease and treatment. They also discussed the challenges of providing culturally sensitive information on breast cancer and resources in languages other than English. The current system depends on "catching" those in need commented one participant, "we kind of build in standardized information provision and then the issue for the physicians, nurses, social workers, is to screen for people who need additional support."

Providers also expressed frustration that programs, resources are often developed by a single institution or agency but then cannot be continued and/or reproduced due to cost constraints. Other providers or centres do not learn about these services and resources and they are then are forced to develop their own programs and "reinvent the wheel."

There are no new dollars that I know of, that are available to us. . . . so I think we have to be very creative, again, by using what's available in our community to meet the needs of these women, information needs.

Information providers talked about the challenges of providing appropriate information resources for women and being aware of everything available. They also acknowledged the administrative difficulties and costs of providing information resources at many points on the cancer continuum and in many languages other than English. Both survivors and information providers discussed the enormous challenges of providing information and support services for those in remote and rural communities and suggested that innovative methods may be needed to reach those women.

Advice to Health Professionals and Cancer Care System

Information providers discussed the current state of support in Ontario and recommendations for themselves and health care institutions in dealing with the information and support needs of women dealing with breast cancer.

Information providers recognized that support through the information search process was critical for some women. To tackle an information search and to make sense of the results is overwhelming for many but with assistance from a credible health professional or information provider those individuals can reap the benefits of a guided information search and make treatment and health promotion decisions independently.

They also talked about the importance of the personal connection with people dealing with breast cancer. "Information is not enough," said a participant. They commented that women welcomed encouragement as much as facts and figures. "They sometimes just want reassurance too that the doctor is doing the proper treatment . . . and you can talk about the practice guidelines and how they came into being and so it just reassures them . . . And that's one of the things that we try to encourage no matter where the person is in the province, there are guidelines that the doctors follow."

A number of alternatives and ideas were explored to improve the state of breast cancer information dissemination, particularly directed to breast cancer treatment facilities. Many of the suggestions pertained to improving the support needs of women and helping to manage information about their disease to ensure they feel comfortable making decisions about treatment.

I think to have an organized process, where you weave in supportive care with the diagnostic aspect as women go through it and receive their diagnosis . . . it's having that support built in through that experience, for women and her family.

One suggestion was the development of a framework, template, or inventory of services for health professionals so everyone from a busy family physician to cancer treatment professionals can learn what is being done in all parts of the province to learn and share strategies that work. The framework could include an inventory of the most current and/or "best" resources (online, paper, video, audio, etc.) recommended for use by information providers. Another suggestion was the widespread introduction of nurse navigator/breast focussed nursing support already established in some of the Atlantic provinces that would be a woman's primary contact during and after treatment.

Different forms of advocacy for patients were discussed: patient advocacy and support in assisting the patient deal with the diagnosis and treatment; and, advocacy on behalf of the patient that treatment was being assessed and administered properly. Providers recognized that if the issues pertain to treatment there is a delicate balance between advocating for better care and the risk of alienating the health care team.

Information providers advised that each providers and medical staff should be aware of existing services and use them to capacity. Information services like the Cancer Information Service and Willow can be accessed by health professionals and those affected by breast cancer alike. Every opportunity to promote these services at wellness days and other health related events should be used although there was agreement that effective

promotion may be difficult to measure. Typically women do not seek information about breast cancer until they need it. Providers also agreed that they should work together to ensure that the same messages are being communicated and conflicting or confusing information is kept to a minimum. The use of lay language rather than medical terminology in resources would be an improvement. They felt that the limitations within the health care system should be recognized and professionals' time used efficiently.



Best Practices

Components of a Successful Dissemination Strategy

Both groups made recommendations to women and to information providers to improve the current situation. These recommendations will be explored in detail in the final report. From the discussions a series of components of a "good" breast cancer information dissemination strategy were identified:

- information or links to information early on in the process, even prior to diagnosis
- allowing time for news of a cancer diagnosis to sink in and providing contact with a health professional for support
- a consistent health professional contact or information provider to answer questions pertinent to a woman's particular disease
- a road map or critical pathway to spell out steps in treatment, let women know what to expect
- consistent medical team to coordinate treatment
- encouragement, optimism and honesty from medical staff
- share information about existing services in the community
- referrals to credible information sources.

The report describes two programs that disseminate information and support with some success, the Ottawa Regional Women's Breast Health Centre and the Oxford County Reach to Recovery program.

The Ottawa Regional Women's Breast Health Centre

Ottawa Regional Women's Breast Health Centre, affiliated with The Ottawa Hospital Regional Cancer Centre is a regional program that provides a comprehensive service to women with breast abnormalities and their families and assists health professionals to ensure a coordinated diagnostic work-up of breast problems. Women receive an accurate and prompt diagnosis of their breast abnormalities, and treatment options are discussed. Women and their families are offered information and emotional support on site and are directed to appropriate resources in the community to meet their needs. "We based this process on what women have told us they need and what we know they need to have as far as medical care. And we've set out very clearly what outcomes we'd like that patient to have", said Director Cathy De Grasse. Services at the Centre include diagnostic imaging services (mammography, ultrasound, core needle biopsy), high risk breast assessment, coordination of diagnostic services and presentation of treatment options and supportive services regarding breast health and disease.

Once diagnosed each patient is scheduled for a pre-surgery appointment that last from one and a half to two hours. A primary nurse is assigned to the patient and most cases remains the contact for the patient throughout the patient's care at the Centre. The nursing staff is available to answer questions by telephone throughout the patient's treatment phase. About 15 to 25 calls are received each week. The pre-op visits can be long but one nurse pointed out, "it takes time up front, but it saves time in the long run." The pre-op visit is often the only meeting required with follow-up contact by telephone with the primary nurse. The social worker is introduced to every woman who is diagnosed with breast cancer and offered the option of available services that includes emotional and/or peer support. Typically a patient will have one to two post-operative appointments at the Centre before follow-up treatment begins at the Ottawa Hospital cancer treatment facility.

A key element of the education and support service provided is a 160-page spiral bound information and educational resource that is provided to every woman who is diagnosed with cancer. The book entitled Personal Breast Cancer Information Guide was developed originally in 2001 through an educational grant from the Canadian Breast Cancer Foundation. The book includes organizational hints and information on the practical issues such as appointments, medical test results, questions for the health care team and even a decision guide to assist women in determining a treatment option. It also addresses emotional support, lifestyle issues, and information on breast cancer disease and treatment. The guide is distributed with a relaxation audiotape and includes sections for patients to journal and pockets to store test results, medical reports and contact information.

As a joint effort between the Breast Center, Breast Cancer Action Ottawa, and the local Canadian Cancer Society Unit, the three campuses of the Ottawa Hospital and a multi-disciplinary committee that included doctors, pharmacists, nurses, and breast cancer survivors, etc., a patient care map for patients in breast cancer surgery was piloted. The care map is slated to become a regional resource that will standardize care within the catchment area of the Ottawa Hospital.

The Oxford County Reach to Recovery Program

Reach to Recovery, initiated by the Canadian Cancer Society over 30 year ago, brings together breast cancer survivors with women who are newly diagnosed or who are currently undergoing treatment. Reach to Recovery volunteers are breast cancer survivors who have received training by the Canadian Cancer Society. Volunteers offer emotional support to newly diagnosed women and provide a free resource kit that may include information for the woman dealing with the disease, updated information for family members, a temporary prosthesis (if the woman has had surgery), and a list of community resources.

The Reach to Recovery program operating in Oxford County was well known to many breast cancer survivors who spoke with us at the focus group in Woodstock. While not part of a comprehensive breast service the Reach to Recovery program in the region has received permission to deliver information kits to women who have had breast surgery and agree to receive a visitor. Some women contact the Society directly and organize a visit by request. Doctors in the local hospital verify that a woman is interested in having a visitor a call is placed to the Canadian Cancer Society. Within one or two days a Reach to Recovery representative makes a visit. Inside package are information brochures, a bag; a pillow; a ball and a rope with an exercise pamphlet; an Assistive Devices Program form and locations to find prostheses; and, the telephone number for the Cancer Information Service. The main complaint echoed by many in the group is that they were not linked with the program soon enough and made choices about surgery before being educated about their options. About one third of the newly diagnosed attend regular support group meetings that are held in the evenings and afternoons in Oxford County.

The challenge for this group is ensuring that every woman who wants a visit receives one and confidentiality is still an issue. There is the belief that some may refuse a visit not realizing what they are turning down. The group's intake is at the point after a woman has had surgery and they agree it is beneficial for women to research options and talk to other women before they make a choice about surgery. Recently a new approach is being attempted where a hospital staff member delivers information and extends the invitation for a visitor.

The Woodstock focus group drew the largest attendance of any focus group as 25 women participated. Only half self identified as members of support group. Many talked about having to find additional information and advocating on their own behalf with the medical team but there was a sense, not shared in every focus group, that these women had a basic knowledge of their disease and that the Reach to Recovery visit was beneficial. Not every question they had was answered, and there were exceptions, but they moved forward with the contact information they received to seek out more information on their disease. Many spoke with appreciation about this visit with the volunteer and the connections it provided to further information and support.



Summary of Findings

The project revealed that the general response “I did not get any information or the right information for me” does in fact represent a wide range of different aspects and understandings among women affected by breast cancer.

From the focus groups, we were able to identify specific components of a good information dissemination system as defined by women themselves and for the most part confirmed by health professionals and information providers. We learned about the current status of health care and services, as reported by the women. In addition, we gained insight into some of the challenges faced by information providers. Table 1 provides an overview of the main themes that emerged from the focus groups.

Discussion

The main goal of this project was to identify and describe what women mean when they report that there was a lack of appropriate breast cancer information for them. To achieve this goal, preliminary interviews were conducted with a group of women, to gain feedback regarding specific areas of concern to focus on. Three major themes arose from our discussions: the shock of diagnosis, the onus on the patient to become her own advocate, and the different types of information that women want. These three themes informed a framework that was used to further understand information (and support) issues among focus groups of breast cancer survivors and among groups of information providers, across the province.

The present findings indicate that women dealing with breast cancer want: specific information on their disease; different types of information in a variety of formats; guidance from health professionals to decipher and manage the information; compassion from health professionals; and, options for contacting others dealing with similar circumstances. We have also learned about two sides of the current status of health care. Women's frustrations are the result of a lack of time, poor coordination, and a perceived lack of continuity of support services. Having said that, the mismatch between patients' expectations and the services that current exist, is fully acknowledged by those working in the cancer care system. These findings support previous research, such as the 2002 Atlantic Breast Cancer Information Kit Evaluation where breast cancer survivors noted that "during treatment you are shuffled all over the place—there is no consistency—there is a real need for one person to manage your treatment." The Canadian Cancer Society's 2002 patient needs study where 31% of cancer patients with an emotional need reported that a substantial barrier to fulfilling this need was not knowing what local support programs are available. This is in part because cancer patients are usually treated as outpatients and that limits their contact with nursing and other medical staff. The present study, however, shows that these types of issues are still relevant but also that the cancer care may be under greater pressures than in the past.

Both breast cancer survivors and information providers had recommendations for women and health care and information providers on how to improve current circumstances (see Table 1). Of note, these recommendations highlight the importance of psychological support as an integral part of treatment and acknowledge that new and creative means are needed to meet this need as cancer care services are stressed.

Overall, the study identified that both breast cancer disease and its management are complex and have a huge impact on women and their families. A diagnosis of breast cancer can lead to uncertainty and difficult questions about mortality and quality of life issues. At a certain level there is no point of certainty or closure that breast cancer survivors can expect. For some, the realization that these circumstances cannot be controlled or are certainly not within their control is a constant struggle. The challenge for health care professionals is to understand whenever they interact with an individual diagnosed with breast cancer, where that individual is in their journey through the cancer experience and exactly what they think would be helpful to them at that particular time. This also presents a challenge for those dealing with breast cancer to be aware of and understand their own needs for information and support to help them search out some of their own answers and communicate questions to their health care team. Below we suggest implications for practice, education, and research.

Implications for Practice

Currently many health professionals admit that assessment of information and support needs are random, more "hit and miss" than the result of a streamlined, structured assessment and information delivery system. These gaps in screening for those who require additional assistance in seeking information and emotional support must be addressed. It is recommended that health professionals:

- Implement improvements to screening to ensure that those who need additional support and information receive assistance. A conversation is a basic intervention to determine what breast cancer patients need and what concerns them. Ideally this dialogue should occur many times throughout the treatment phase as necessary for the health professional to understand the questions patients have and where help is required.
- Establish standard approaches for information provision that might include distribution of information that would link patients to other information sources. An information package could consist of the Cancer Information Service or Willow information telephone numbers; pertinent written information from the cancer or treatment centre; and a directory of local support and information services
- Remember that all patients deserve to be treated with dignity and respect. Interactions with health professional emerged repeatedly as a pivotal point for those dealing with breast cancer.
- Provide a contact for breast cancer patients who has knowledge of the disease and treatment protocol who can assist women to determine appropriate information for their particular disease. This function can be addressed by a family physician, a nurse navigator, an oncologist, a surgeon, a social worker, among others.
- Collaborate with other breast cancer information and support agencies and peer support groups to investigate creative and innovative approaches to dissemination of breast cancer information and support services. One example is the patient care map program being tested in Ottawa that is the result of a collaboration of two local information and support groups and a breast assessment centre.
- Recognize the limitations of the current system and maximize resources already available through existing channels.
- Keep informed about information and support services in their local communities to be able to refer patients to a range of potentially helpful information and support options.
- Connect with other community service agencies to assist ethnic and culturally diverse groups who may not seek help through established agencies.
- Investigate options within and outside of the health care system to communicate with women dealing with breast cancer and local and regional health care personnel managing their care in rural and remote regions.
- Promote existing resources and assist women to conduct their own information searches.

Implications for Education

Women Dealing with Breast Cancer

While it may seem unfair to burden the ill with additional responsibilities at a vulnerable time, the reality of health care today requires that patients take some responsibility for their own information needs in cancer care. Frequently people do not seek out information about cancer or the cancer care system until they are forced to become a participant. Many at this time feel vulnerable and experience an inability to concentrate. Having to search for information is an additional burden for the person. Profound emotional reactions to a diagnosis of cancer can hinder the information search and obstruct understanding information about the disease. Most women in the focus groups believed that information was crucial to understanding the disease and making treatment choices. It is recommended that women dealing with breast cancer:

- Communicate with health professionals about their personal information needs and be prepared to do some work and/or enlist the assistance of family and friends to resolve some of their questions.
- Remain open to different types of information resources and forms of support as needs change over the treatment continuum.
- Be aware that the current information delivery systems will not automatically meet every person's needs

for information and support.

- Make efforts to live with some unanswered questions as a level of uncertainty may be a reality long after cancer treatment has ended.

Health Professionals

In the 1999 report, *Think Tank on Breast Cancer Information and Support* a key recommendation to medical schools and professional development training was an emphasis on perfecting skills in interpersonal relations and communications. The issue was raised as well in the Canadian Cancer Society's 2002 report *Breaking Down the Barriers* and in *Meeting the Psychosocial Needs of Women with Breast Cancer*, 2004, National Cancer Policy Board study about the psychosocial needs of women with breast cancer. These findings should remind teachers of health professionals that:

- Psychosocial management is a priority in professional education as well as in cancer treatment.
- People do not choose to be part of the cancer system and every patient deserves to be treated with dignity and respect.
- For every cancer patient the diagnosis is a new and devastating experience.

Implications for Research

There is no doubt that more research work is needed in order to address the information and support needs of women affected by breast cancer. In the present study, the women want improved access to information options, plus the opportunity to receive information and/or support at multiple points along their cancer journey. In addition, the women wanted more information available via the Internet, yet presented in a user-friendly manner. Women often seek very specific information that is tailored to their own needs at any given point in time. Further research should be encouraged to develop and evaluate innovative processes, products, and services that strive to address the gaps that the women have identified. Comparisons to information dissemination strategies for other diseases such as heart or diabetes may be useful.

Building on this project OBCIEP has recently received funding for a new study to explore breast cancer survivors' preferences for information and support through Internet delivery. This research will develop and pilot a web-based information and support 'hub' that draws mainly from existing resources, and allows women to tailor information and support to suit their needs. It is also worth noting that one focus is to address the needs of those living in rural and remote communities where there are few established channels and services. The project will therefore explore creative ways to use technology, help to standardize approaches to information and support delivery, and respond to the individual woman's specific information and support needs.

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See Tables 1 and 2 and Acknowledgements that follow.



**Table 1: Summary of Themes Emerging from the Focus Group Discussions**

| Theme                                     | Breast Cancer Survivors                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           | Information Providers                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
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| Shock of Diagnosis                        | Find impact of diagnosis overwhelming —emotional wallop has profound effect on how, when and if women seek or take up information about their disease.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            | Observe high levels of stress in those having breast abnormalities investigated or those recently diagnosed. Recognize that women need support and guidance at these stages.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
| Onus on the Patient                       | Report that women are left to find and decipher information on their own.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         | Face challenges in meeting this need and recognize that women are becoming increasingly specific about the information they want.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| Experiences in Medical System             | Expose well known problems in the health care system —waiting times, fragmented services, time delays, shortage of funding, staffing constraints—but also reveal a lack of respect and compassion by some health workers.                                                                                                                                                                                                                                                                                                                                                                                                                                                         | Acknowledge that services are not standardized (rural and remote areas face special challenges) and that screening and providing service for those who need additional support are not meeting current needs.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
| Different Types of Information Women Want | Recommend all types of resources in many different formats be available at different points along treatment continuum, ie - everyone seeks information and learns differently.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    | Note barriers to providing appropriate information in many languages, appropriate for different cultures and in multiple formats (usually due to funding constraints).                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
| Recommendations to Women                  | <ul style="list-style-type: none"> <li>• Become educated - about your disease, and information needs, and different options for support.</li> <li>• Recognize that your information needs may change over time and leave yourself open to the many forms and ways different types of information can reach you</li> </ul>                                                                                                                                                                                                                                                                                                                                                         | <ul style="list-style-type: none"> <li>• Confirm that information is power. Encourage women and their families to seek information about to breast cancer</li> <li>• Counsel women to accept that there may not be specific answers to every question they may ask</li> </ul>                                                                                                                                                                                                                                                                                                                                                                                                                                                |
| Recommendations to Information Providers  | <ul style="list-style-type: none"> <li>• Recognize support as essential particularly at diagnosis.</li> <li>• Be aware of existing services in the community to refer patients</li> <li>• Encourage family physicians to play a larger role in providing information and support</li> <li>• Develop a "road map" for patients, teach them the steps of cancer care, what to expect</li> <li>• Coordinate care, provide consistency in medical team/ patient contact</li> <li>• Help patients understand medical information and implications of treatment choices</li> <li>• Address issues for those in rural and remote areas</li> <li>• Treat patients with respect</li> </ul> | <ul style="list-style-type: none"> <li>• Maximize existing information and support services in the community</li> <li>• Develop a critical pathway or road-map for breast cancer patients</li> <li>• Focus attention on support services</li> <li>• Investigate nurse or patient navigator models of support</li> <li>• Work together to avoid duplication</li> <li>• Develop template/resource to help information providers stay updated on new and locally relevant resources, and how to obtain existing ones</li> <li>• Use existing networks in remote communities to improve communication and monitoring among health care and support agencies</li> <li>• Look for unique opportunities to work together</li> </ul> |

**Table 2: Suggested Resources/Services for Breast Cancer Information and Support**

| Service                                                                                                                                                                                                                                                                                                                                                                                                               | Info Line/Site                                                                       |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------|
| <p><b>Cancer Information Service</b><br/>                     A bilingual, toll-free service offering comprehensive information about cancer and community resources. Support services include one-to-one and group support programs. Web site includes breast chapter of the cancer encyclopedia.</p>                                                                                                                | <p><b>1-888-939-3333</b><br/> <a href="http://www.cancer.ca">www.cancer.ca</a></p>   |
| <p><b>Willow Breast Cancer Support &amp; Resource Services</b><br/>                     Provides toll-free, accessible, community-based, survivor-driven information and support services to help those living with breast cancer. Web site includes newsletter for those dealing with metastatic breast disease and information for peer support facilitators.</p>                                                   | <p><b>1-888-778-3100</b><br/> <a href="http://www.willow.org">www.willow.org</a></p> |
| <p><b>Cancer Care Ontario</b><br/>                     Cancer Care Ontario is the government's principal adviser on cancer issues and works in partnership with hospitals providing cancer care across the province. Cancer Care Ontario directly manages the Ontario Breast Screening Program, the Ontario Cancer Registry and the New Drug Funding Program, and runs a multifaceted program in cancer research.</p> | <p><a href="http://www.cancercare.on.ca">www.cancercare.on.ca</a></p>                |
| <p><b>Canadian Breast Cancer Network</b><br/>                     A survivor-directed network of organizations and individuals who are concerned about breast cancer that represents the concerns of all Canadians affected by breast cancer and those at risk.</p>                                                                                                                                                   | <p><a href="http://www.cbcn.ca">www.cbcn.ca</a></p>                                  |
| <p><b>Ontario Breast Cancer Information Exchange Partnership</b><br/>                     A coalition of over 70 organizations working together to improve access to information and support for women and their families affected by breast cancer. Web site includes links to over 100 Canadian and USA breast cancer and cancer information and support sites.</p>                                                 | <p><a href="http://www.obciep.on.ca">www.obciep.on.ca</a></p>                        |

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After Breast Cancer (ABC) Support Group, Oxford County  
Breast Cancer Action Kingston  
Breast Cancer Action Ottawa  
Breast Cancer Research and Education Fund, St. Catharines  
Breast Cancer Support Services, Burlington  
Canadian Cancer Society - Lambton Unit, Sarnia  
Canadian Cancer Society - Oxford Unit, Woodstock  
Dryden Breast Cancer Support Group  
Hospice of Windsor & Essex County, Windsor  
Ottawa Regional Women's Breast Health Centre  
Sarnia Living with Breast Cancer  
Thunder Bay Breast Health Coalition  
Thunder Bay District Health Unit

## **PROJECT SPONSOR**

### **Ontario Breast Cancer Information Exchange Partnership**

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### **Canadian Cancer Society – Ontario Division**

1639 Yonge Street  
Toronto, ON M4T 2W6

### **Willow, Breast Cancer Support & Resource Services**

785 Queen Street East  
Toronto, ON M4M 1H5

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The complete final report is posted online under “OBCIEP Activities” on the OBCIEP web site at [www.obciep.on.ca](http://www.obciep.on.ca). For further information please contact Irene Nicoll at 416-351-3815 or by e-mail [irene.nicoll@sw.ca](mailto:irene.nicoll@sw.ca).