Breast cancer information dissemination strategies – Finding out what works

by Margaret I. Fitch, Irene Nicoll and Sue Keller-Olaman

Abstract

This study aimed to identify the best strategies for dissemination of information about breast cancer. In November 2004, 28 breast cancer survivors were interviewed. Three themes emerged from these discussions: the shock of diagnosis; the onus being on the patient to search for information; and the different types of information that breast cancer survivors want. To learn multiple viewpoints, 12 focus groups were held with breast cancer survivors (n=127) and three focus groups were conducted with information providers (n=25) in the spring of 2005. Participants validated the themes and identified two programs using “best practices” to provide information for women dealing with breast cancer. This article highlights the study findings, including implications for practice, education, and research.

Introduction

The Ontario Breast Cancer Information Exchange Partnership (OBCIEP) is a coalition of organizations working together to improve access to information and support for women and their families affected by breast cancer. While there has been a decade of work on developing various forms and types of information resources on breast cancer in many settings, survivors continue to comment that “no information was available for me”. Indeed, OBCIEP studies have found that breast cancer survivors consistently identify gaps in information and support and express dissatisfaction with the extent to which their information needs are met (OBCIEP, 1999, 2000, 2003). This is supported by further studies of Canadians dealing with cancer, where accessing information about the disease, treatment and support services remains a major obstacle (Canadian Cancer Society – Ontario Division, 2003; Gray & Grassau, 2002). Furthermore, several studies have reported that the greatest frustration is expressed by those with specific concerns relating to cultural sensitivity and resources in languages other than English (Austin, 2004; Willow, 2000), in remote or rural locations (CBCN, 2001), age (CBCN, 2003) or disease-related issues (Gray, Greenberg, Fitch, et al., 1998; ABCIS, 2003).

There is a second approach in the literature that is equally important – focusing on information and support practices that can ease frustrations. For example, information programs at treatment centres (Whelan, Rath, Willan, et al., 1998; De Grasse, 1996; Geiger, Mullen, Sloman, et al., 2000) indicate that structured dissemination of information can increase patient satisfaction and offer assistance on how and where to access information. Evaluations of current practices (Gray & Grassau, 2002; Beattie-Huggan & Smith, PEI Breast Cancer Information Partnership, 2002) show that interventions about diagnosis and treatment can be helpful to patients and increase their sense of control. More recently, the United States Institute of Medicine reported that meeting the psychosocial needs of breast cancer patients can serve as a model for other cancer sites and can provide significant benefits to cancer survivors and their families (National Academy of Sciences, 2004). This is supported by a recent review (Hack, Degner & Parker, 2005) that shows physician-patient communication can be enhanced if the physician addresses the emotional needs of their patients. Although these positive findings demonstrate that something can be done to

moderate the information and support concerns of those affected by cancer, it is alarming to know that many barriers and gaps still exist. At a time when more information on breast cancer is available than ever before and in many different formats (print, audio, video, and online), OBCIEP's coalition partners identified this apparent discrepancy as a priority for study.

Objectives

In 2003, the Community Capacity Building Component of the Canadian Breast Cancer Initiative approved a project designed to help groups and individuals who are engaged in the dissemination of information about breast cancer to learn the best strategies or practices to use to ensure that women have easy access to information and support. Specifically, the project objectives were: (1) to gain an understanding of what women mean when they say “no information was available for me” (what is [still] not working?); (2) to understand the perspectives of those engaged in the dissemination of breast cancer information about current approaches to providing information (what is being done?); (3) to identify best practice approaches in the dissemination of breast cancer information (what is really working well?); and (4) to study and evaluate the best practice approach for disseminating breast cancer information (document the best practices). This article focuses on the findings of the first three objectives.

Method

The qualitative research was conducted in two phases over 10 months by the project director, a project coordinator and the OBCIEP coordinator. Ethics approval for the study was granted by an institutional review board. Phase one involved in-depth interviews with breast cancer survivors to gain a broad understanding of the phenomenon; Phase two involved focus groups with survivors and with providers of breast cancer information to validate and enlarge the understanding of various perspectives on breast cancer information.

Phase one – Interviews

Participants

Participants for the initial telephone interviews were recruited via e-mail and promotional flyers displayed by local support groups and OBCIEP network partners. Participants indicated their interest by e-mailing or telephoning the OBCIEP coordinator directly. The OBCIEP coordinator interviewed 28 breast cancer survivors by telephone. The interviews were recorded on tape with participants' permission. The women interviewed were between the ages of 32 and 75 years (average

Margaret I. Fitch, PhD, Sunnybrook & Women's Health Sciences Centre, Toronto.

Irene Nicoll, MBA, Ontario Breast Cancer Information Exchange Partnership, Toronto.

Sue Keller-Olaman, PhD, Ontario Breast Cancer Community Research Initiative, Toronto.

E-mail: irene.nicoll@sunnybrook.ca

56 years) and were diagnosed between the ages of 32 and 65 years (average 51 years). One participant had been diagnosed within six months of the interview and one had been diagnosed 16 years earlier with the average diagnosis within five years of the interview. Seventy-one per cent of the interviewees had some college- or university-level education. Ten participants received the diagnosis from their family physician and 17 from the referred surgeon.

Procedure

Participants were asked five questions about their experiences in receiving or finding breast cancer information (see Table One). The responses to the interview questions were summarized in writing and reviewed by the project director, the project coordinator, OBCIEP coordinator and the project oversight group that included survivors, information specialists, peer support leaders, and health professionals.

Phase one findings

During investigation of an abnormality, 75% of the interviewees indicated they received no information at all. This dropped to 43% at diagnosis, 25% at treatment and 36% after treatment. There were no significant differences noted between those who received the diagnosis from the family physician or another health professional. Many reported receiving most information during the treatment phase. The information received ranged from a full binder of information (including phone numbers to local support groups) to simple fact sheets about treatment and its side effects or referrals to online sources of information. Many interviewees noted that, initially, they were unable to absorb much information about their disease, but this usually changed when treatment began. Most reported they were not satisfied with the verbal or written information provided by health professionals during all aspects of their treatment (where provided) and believed that contact with others who had experienced the diagnosis was important. Many reported being left to find their own information and would have appreciated more guidance and direction from health professionals with their information searches. Sixty-four per cent reported knowing of women recently diagnosed who experienced the same dissatisfaction with information provided or reported receiving no information at all. Many believed that a more structured process should be offered to ensure that all women have access to the information they need through personal help from a health professional or survivor. Interviewees also commented that they wanted information specific to their diagnosis and personal circumstances.

Table One: Telephone Interview Questions

1. When you think back to the time before your diagnosis, what was your experience in obtaining breast cancer information:
 - a) prior to diagnosis (during period when abnormality was being investigated)?
 - b) once you were diagnosed?
 - c) once your treatment started?
 - d) since treatment ended?
2. What did you find particularly helpful in seeking information, either in what you found or what others found for you?
3. What would you have liked to see? What would have been most helpful for you?
4. Do you hear other women who have been treated for breast cancer talk about receiving "no information" about their diagnosis and/or treatment? If so, what do you think has happened to make women report this?
5. What do you believe are the barriers for women in obtaining this information?

Three themes relevant to information concerns emerged from these interviews: (1) in the beginning, the diagnosis is overwhelming and it is hard to take much in; (2) in large measure, the onus is on you as a cancer patient to search out answers/information and make sense of it; and (3) there are many different types of information women may want and a wide variation in how information is provided by health care providers.

Phase two – Focus groups

Participants

Participants for the focus groups were recruited via e-mail and promotional flyers displayed by local support groups and OBCIEP network partners. Participants indicated their interest by e-mailing or telephoning the OBCIEP coordinator directly to register. OBCIEP purposively sought those who had been diagnosed recently to share recent experiences in obtaining information. The goal was to focus on those who were recently diagnosed, defined as within the last three years, to learn about survivors' recent experiences, but others expressed a keen interest in being involved. The majority of the focus group participants (84%) had been diagnosed within the last three years. Others who specifically requested to participate in the discussions were also included (16%).

Twelve focus groups were held with 127 breast cancer survivors in nine different locations to learn about women's experiences in all parts of the province: Ottawa, Kingston, Burlington, St. Catharines, Woodstock, Sarnia, Windsor, Thunder Bay and Dryden. The participants ranged in age from 33 to 81 years (average 55 years) with the average age at diagnosis being 52 years. Ten per cent of the focus group had been diagnosed within one year and some were completing treatment. Ninety-three (73%) had been diagnosed between one and three years of the focus group and 34 (17%) four years or more. Seventy-seven survivors indicated they were members of a breast cancer support group. Twenty-one (27%) said they joined the group at the time of diagnosis; 29 (38%) during treatment; and 21 (31%) in post-treatment. All had high school education, 63% had university degrees and 95% indicated English as their first language.

Focus groups were held with information providers in Ottawa, Thunder Bay and Toronto. A total of 23 information providers participated in the focus groups and included nurses, social workers, health promotion specialists, diversity consultants, librarians, managers, and volunteers. To gain a diverse perspective, support and information group personnel who had contact with breast cancer patients at various stages on the treatment continuum also participated. Most worked in screening centres, hospitals, cancer centres, and for information and support group organizations such as the Canadian Cancer Society, Willow Breast Cancer Support & Resource Services, and regional breast cancer action or breast health coalition groups. Two individual interviews were also conducted with personnel working in Woodstock and Toronto who were unable to attend the focus group.

Procedure

In phase two, the themes arising from the phase one interviews provided a framework to guide focus group discussions with both survivors and with information providers. The project director and coordinator each facilitated the focus groups. Participants at all focus groups received the same five-page handout that included a summary of the project objectives, activities from phase one of the study, and a series of quotes reflective of the three themes discussed in the interviews. Participants were asked to review the quotes and consider four questions (shown in Table Two) in the focus group discussion. The discussions were taped and later transcribed. All focus group participants signed consent forms and completed an evaluation at the conclusion of the discussion. Each individual received an honorarium, a summary of the evaluations for the group in which they participated and a brief report summary on which they were invited to comment. All received a copy of the report summary and were offered a copy of the final report.

Phase two findings

All focus group discussions were transcribed and underwent a content analysis to identify the common themes. The themes were reviewed by the project coordinator, OBCIEP coordinator and a research student. Quotes from the transcripts were organized by theme and then reviewed by the other project coordinator and the project director. The entire project team then reviewed and discussed the theme summaries and agreed upon presentation of the findings. The initial three themes were validated by the focus groups' discussions and one additional theme emerged. For brevity the three themes were renamed – (1) the shock of diagnosis; (2) being your own advocate; and (3) the different types of information women want. Women's experiences and information providers' observations were remarkably similar and each group presented various suggestions to deal with the issue of providing timely, accurate and appropriate information. The next section discusses the findings from the focus groups.

Results

Theme one: The shock of diagnosis

Breast cancer survivors talked at length about the emotional devastation they experienced when they were diagnosed with cancer and how those feelings affected their information needs. The fear and panic triggered by the diagnosis have a profound impact on how women respond to information about their disease. Descriptions of reactions included: "terrified", "shocked", "a nightmare", and "in the twilight zone." "I was numb for a long time... I didn't even think to look anywhere [for information] I was just stunned," said one survivor. Disbelief and denial were also 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 might have on their families, particularly on the health of their daughters and granddaughters. Many who had received 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. "You get the sense that knowing more information isn't going to make a difference," said one woman.

Survivors frequently commented that they did not receive information from their doctors. "When the surgeon says 'you have cancer', that's the end of the discussion," said one woman. Survivors talked about feelings of isolation, even from their families and friends, as they attempted to minimize the impact of the diagnosis on their children and partners.

Several information providers had personal experiences with breast cancer and were able to bring a unique dual perspective to the discussions. "I'm a health professional... but when you're given the cancer diagnosis... you fall apart," admitted one nurse.

Theme two: Being your own advocate

Most survivors reported the onus was on them, as cancer patients, to identify and resolve their own information needs, as well as learn about and understand their own medical treatments. Many found they were left to decipher the generic information they were given. In addition, they often had to search for more detailed or specific information that was relevant to their situation. Said one survivor, "I wanted to know... whether it was good or it was bad, it made no difference, but I needed to know." Some recruited the assistance of family, friends, co-workers and colleagues to connect them with other cancer survivors and to conduct information searches over the internet. Survivors commented they had to "take charge" of their treatment by constantly monitoring appointments, symptoms, and following up with health professionals. Many reported that how they felt was influenced by meeting other women who had experienced breast cancer.

Information providers expressed little surprise that breast cancer survivors felt the onus was on them to find and decipher information about their disease. Spending time with patients to assess their information needs was identified as essential, yet some health

professionals acknowledge current practice is lacking. Nurses in the focus group reported they believed 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 attempt to pick up cues that patients may need further attention although women may not ask for help. "I don't think we always do a good job of having the patient know what they need to know in order to participate in decision-making", admitted one nurse. They acknowledged also, that for some patients, the experience of receiving and researching information on their disease could be more stressful than doing nothing.

Information providers talked about the special challenges of helping cancer patients understand and manage the information, particularly information from the internet that may not be consistent with what their oncologist is advising. While survivors may find sharing experiences with other breast cancer survivors helpful, information providers talked about the challenge presented by recommendations from other survivors that may not be appropriate or "medically sound advice" for that particular survivor. Providers expressed sympathy with survivors' frustrations in evaluating information from various health professionals, American versus Canadian websites, well-meaning friends and family, and the media. They also noted that resources are scarce to non-existent for those who do not choose to have treatment.

Theme three: Different types of information women want

The breast cancer survivors acknowledged that each woman's interest in obtaining information is as distinct as her particular disease. Some want to know "everything". On the other hand, several indicated that they had met other survivors who expressed no interest in obtaining information. Some of these survivors were happy to leave their care entirely to the medical team; some found the process of finding and deciphering the information overwhelming; others found that learning more about the disease created more fear and anxiety that they preferred to avoid. While participants respected each

Table Two: Focus Group Discussion Questions

Survivors

1. How well do the themes resonate with your experiences searching for and making sense of information about breast cancer?
2. What advice would you offer to women about searching for breast cancer information?
3. What advice would you offer to women about searching through, making sense of, and managing breast cancer information?
4. What advice would you offer to health care professionals about how breast cancer information should be provided?

Information Providers

1. Do these themes (the shock of diagnosis, being your own advocate and the different types of information women want) reflect what you hear from women and their families affected by breast cancer who are searching for and trying to understand information about their disease?
2. What advice would you offer to women about searching for breast cancer information?
3. What advice would you offer to women about making sense and/or managing breast cancer information?
4. What advice would you offer to health care professionals about how breast cancer information should be provided?

individual's need and desire to be informed, they pointed out that information needs can change over time and opportunities to receive information should not be limited to one or two points in the treatment continuum.

"Finding yourself in the information" is a major challenge for some survivors. Many reported that there is a lot of generic information available, but it is difficult for survivors to find specific information relevant to their particular situation. For example, young mothers face different health and domestic challenges than post-menopausal women. Survivors living in remote or rural areas face completely different challenges in finding information sources and support groups compared with those living in urban areas. Information providers reported that they find survivors increasingly want more specific information pertinent to survivors in their age group, receiving the same treatment, and with other health issues similar to their own.

A variety of formats was preferred – written, audio or videotapes, telephone contact, interactive online chat rooms or message boards, and one-on-one or group interaction with medical professionals or breast cancer survivors. The type of information was also an important consideration. 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.

Information and health care providers spoke at length about the challenges they face addressing the individual information and support needs of breast cancer patients. They shared their frustrations about learning about and accessing current resources in breast cancer information, finding culturally sensitive information on breast cancer and resources in languages other than English; and reaching women in rural and remote areas. Providers also discussed the diversity in scope and random nature of services available within regions and from institution to institution within the same region and ongoing struggles with acquiring resources with limited funds. The information providers noted that existing and relatively accessible 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.

Components of a successful dissemination strategy

From the combined discussions, components of a "good" breast cancer information dissemination strategy were gathered from across the three themes. They are described below and appear in Table Three.

It was clear from the discussions that timing of information was a key component of a successful strategy. Although many reported that they did not receive information at the time of diagnosis, this was a time when information was needed. This was the case even if various folders and resources provided at the time of diagnosis were not opened immediately. There was agreement among the information providers that most people do not absorb information well just after learning news of their diagnosis. While a strong emotional response lingers, information providers observed that within a week or two most breast cancer patients 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 they only came "out of the fog" when they began treatment and felt prepared to deal with information.

In addition to being sensitive to certain times when information is sought, emotional support was also seen as an essential part of a successful strategy. Information providers shared their belief that those survivors who share the news and their search for information with family and friends seem to have a more proactive approach to their recovery. Providers indicated that women dealing with breast cancer value the counsel and support of health care and information providers in their information search and that "they want to know there is someone there". It seems that the survivors prefer to know that the same person is there – continuity of staff was seen as an important element, especially during treatment.

Individualized help was also discussed as a successful component. Nurses supported patients in searching for information, but noted that information specific to each individual may be difficult, if not impossible to find. Nurses also noted that this type of information search was unlike any other most survivors would have conducted. "They're not in an emotional state where they would search for information the same way they would if they were looking for a recipe to cook artichokes or something," observed one nurse. Information providers noted that learning and understanding the steps in treatment is another source of stress for women. "There's another element of anxiety that is different than the fear related to mortality," said another. "Some of what you're able to assist with at the time is the anxiety around where am I going, who am I going to see, what is going to happen at that appointment?" Information providers agreed with breast cancer survivors' assessment of currently available information resources. "There's a lot of information about the same areas, but there's not a lot of information... about what might be needed for the individual," indicated one information provider. An additional feature of a successful information strategy would include established links to survivors. Many survivors felt that emotional support and guidance from a trusted person familiar with the cancer treatment system was critical, particularly at the early stages of diagnosis. Not only could other survivors provide practical advice, they could offer calm reassurance from credible information resources, individuals who had been through the experience first-hand. In particular, other survivors could share a "road map" of experience the medical system often does not provide.

Some final suggestions for a successful strategy relate to the content of the information itself. While patients appreciate having treatment options, they become frustrated if these options are not well-explained. Said one survivor, "Your estrogen receptors are negative or positive. You're told what they are, but you don't understand what that means." Many still want a health professional to work with them to determine an appropriate treatment plan, commented one nurse, "instead of hearing 'these are your options and these are the risks and please make your decision yourself'. Misinterpreting information can create its own problems."

Table Three: Components of a Good Breast Cancer Information Strategy

Information Early	Provision of information early in the process, even prior to diagnosis
Time	Allow sufficient time for news of a breast cancer diagnosis to sink in and determine what type of information is needed at specific times
Consistent Advisors	Contact with the same nurse or health professional team to provide credible information and to coordinate treatment
Road Map	Critical pathway to explain steps in treatment that lets women know what to expect
Individualized Help	Information tailored to suit an individual woman's needs, interests, means, language, comprehension level and contact with a survivor who has 'been there'
Links/Resources	Resources and links/connections to existing information and support resources on the internet, in print, audio, and video, and in the community

In addition to discussing a successful strategy, breast cancer survivors and information providers made recommendations for women and for health care and information providers on how to improve current circumstances (Table Four). From these recommendations, two programs were identified by survivors as examples of best practices – a regional, structured breast assessment centre and a grassroots peer-led support group. While neither program encompassed all components of a good breast cancer information dissemination strategy, the survivors suggest that these could serve as models for other programs. The two are, therefore, highlighted in the final study report (published online at www.obciop.on.ca).

Discussion

Despite an array of information and support resources available, many women affected by breast cancer report that there was a lack of information when they needed it. This study examined the viewpoints and experiences of survivors, health professionals and information providers. The main goal was to identify and describe what women mean when they report that there was a lack of appropriate breast cancer information for them. The findings 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 discussions, we were also 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.

The study results 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 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. The mismatch between patients’ expectations and the services that currently exist is fully acknowledged by those working in the cancer care system. These findings support previous research, such as the Survey of the Community Contacts in Newfoundland and Labrador (Collier & Beattie-Huggan, 2003) in which breast cancer

survivors noted that “during treatment, you are shuffled all over the place – there is no consistency.” In addition, the Canadian Cancer Society’s patient needs study noted that 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 study shows that these issues are still relevant but also that the cancer care may be under greater pressures than in the past.

The 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.

Whenever a health professional is interacting with an individual diagnosed with breast cancer, the challenge is to understand where that individual is in their journey through the cancer experience and to know what may be most helpful to the patient 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 to communicate questions to their health care team.

Implications for nursing

Currently, many health professionals in Ontario 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. To address gaps in screening for individuals who require assistance seeking information and support, it is recommended that nurses implement improvements to assessments to ensure that those who need additional support and information receive assistance. For example, a conversation is a basic intervention to determine what breast cancer patients need and what concerns them. Ideally, this dialogue should occur as many times throughout the treatment phase as necessary for the health professional to understand the questions patients have and where help is required. It

Table Four: Recommendations from Women and Information Providers

Breast Cancer Survivors’ Recommendations	Information Providers’ Recommendations
To Women Dealing with Breast Cancer . . .	
<ul style="list-style-type: none"> • Become educated - about your disease, and information needs, and different options for support. • 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 	<ul style="list-style-type: none"> • Confirm that information is power. Encourage women and their families to seek information about breast cancer • Counsel women to accept that there may not be specific answers to every question they may ask
To Information Providers Assisting Women Dealing with Breast Cancer . . .	
<ul style="list-style-type: none"> • Recognize support as essential, particularly at diagnosis • Be aware of existing services in the community • Encourage family physicians to play a larger role in providing information and support • Develop a “road map” for patients, teaching the steps of cancer care – what to expect • Coordinate care, provide consistency in medical team/ patient contact • Help patients understand medical information and implications of treatment choices • Address special needs of women in rural and remote areas • Treat patients with respect 	<ul style="list-style-type: none"> • Maximize existing information and support services in the community • Develop a critical pathway or road map for breast cancer patients • Focus attention on support services • Investigate nurse or patient navigator models • Work together to avoid duplication • Develop resource to help information providers stay updated on new and locally relevant resources, and how to obtain existing ones • Use existing networks in remote communities to improve communication and monitoring among health care and support agencies • Look for unique opportunities to work together

is suggested that they 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.

Providing a contact for breast cancer patients who has knowledge of the disease and treatment protocol 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, or a social worker, among others. Collaboration with other breast cancer information and support agencies and peer support groups can create innovative approaches to dissemination of breast cancer information and support services. Resources available through existing channels should be maximized and connections with other community service agencies can be forged to assist ethnic and culturally diverse groups who may not seek help through established agencies.

Information about support services in local communities can offer patients to a range of potentially helpful information and support options. Services within and outside of health care may be used to communicate with women dealing with breast cancer and local and regional health care personnel managing their care in rural and remote regions. We also draw attention to the fact that women diagnosed longer than three years ago were eager to be involved in the study and to talk about information issues. Although many of their experiences

mirrored the main themes, it is worth noting they felt there is a lack of information relevant to their situation as survivors. This has further implications for information provision. In addition to the needs of women recently diagnosed, the concerns of women post-treatment and of long-term survivors must also be addressed.

Conclusion

These findings should remind health professionals that for every cancer patient, the diagnosis is a new and devastating experience. People do not choose to be part of the cancer system and every patient deserves to be treated with dignity and respect. Psychosocial management should be a priority in professional education, as well as in cancer treatment.

Further research is needed in order to address the information and support needs of women affected by breast cancer. In this study, the women wanted 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, 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 studies should be encouraged in an effort to develop and evaluate innovative processes, products, and services that strive to address the gaps the women have identified. In future research, comparisons to information dissemination strategies for other diseases, such as heart or diabetes, may be useful to learn about gaps and successful strategies. 🍀

References

- Austin, S. (2004). **Femmes Francophones atteintes du cancer du sein: Qu'est-ce qu'elles ont à dire? Qu'est-ce qu'il reste à faire?** Toronto, ON: L'initiative de recherche communautaire sur le cancer du sein de l'Ontario: Author.
- Alliance for Breast Cancer Information and Support (ABCIS), B.C. & Yukon. (2003). **Information and support needs of women with recurrent and metastatic breast cancer.** Vancouver, BC: Author.
- Beattie-Huggan, P., & Smith, N.A., for the PEI Breast Cancer Information Partnership. (2002). **The Atlantic Breast Cancer Information Kit Evaluation Final Report.** Charlottetown, PE: The Quaich Inc.
- Canadian Breast Cancer Network (CBCN) and Ontario Breast Cancer Community Research Initiative (OBCCRI). (2001). **Perspectives of rural women with breast cancer.** Ottawa, ON: Author.
- Canadian Breast Cancer Network and Ontario Breast Cancer Community Research Initiative. (2003). **"Nothing Fit Me": The information and support needs of Canadian young women with breast cancer.** Ottawa, ON: Author.
- Canadian Cancer Society - Ontario Division. (2003). **Breaking down the barriers – Study of cancer patient and caregiver needs in Ontario.** Toronto, ON: Author.
- Collier, C., & Beattie-Huggan, P. (2003). **The community contact program in Newfoundland and Labrador, "I'd Rather Have a Person than a Book", survey of the community contacts in Newfoundland and Labrador.** St John's, NL: Purple Lupin Project.
- De Grasse, C., & Hugo, K. (1996). Supportive care needs of women undergoing breast diagnostics and their families: A focus for nursing interventions. **Canadian Oncology Nursing Journal**, 6(4), 185-190.
- Geiger, A.M., Mullen, E.S., Sloman, P.A., et al. (2000). Evaluation of a breast cancer patient information and support program. **Effective Clinical Practice**, 3(4), 157-165.
- Gray, R.E., & Grassau, P. (2002). **Needs and issues relevant to future breast cancer research in Ontario.** Toronto, ON: Ontario Breast Cancer Community Research Initiative.
- Gray, R.E., Greenberg, M., Fitch, M.I., et al. (1998). Information needs of women with metastatic breast cancer. **Cancer Prevention and Control**, 2(2), 57-62.
- Hack, T., Degner, L., & Parker, P. (2005). The communication goals and needs of cancer patients: A review. **Psycho oncology**, 14(10), 831-847.
- National Academy of Sciences, National Cancer Policy Board, Institute of Medicine. (2004). **Meeting the psychosocial needs of women with breast cancer.** Washington, D.C.: Author.
- Ontario Breast Cancer Information Exchange Partnership. (2004). **Breast cancer information dissemination strategies – Finding out what works, Community Capacity Building Project Report.** Toronto, ON: Author.
- Ontario Breast Cancer Information Exchange Partnership. (2003). **Implementing a virtual community for breast cancer information and support in Ontario, Community Capacity Building Project Report.** Toronto, ON: Author.
- Ontario Breast Cancer Information Exchange Partnership. (1999). **Think tank on breast cancer information and support, Community Capacity Building Project Report.** Toronto, ON: Author.
- Ontario Breast Cancer Information Exchange Partnership. (2000). **Virtual community feasibility project: Building capacity for tomorrow, Community Capacity Building Project Report.** Toronto, ON: Author.
- Whelan, T.J., Rath D., Willan, A., et al. (1998). Evaluation of a patient file folder to improve the dissemination of written information materials for cancer patients. **Cancer**, 83(8), 1620-1625.
- Willow Breast Cancer Support & Resource Services. (2000). **Hopes and needs: A profile of the needs of Francophone women with breast cancer and the resources available to them.** Toronto, ON: Author.