

breast cancer *Info Exchange*

Winter/Spring 2008; Volume 12, Issue 1

INSIDE THIS ISSUE

- 1 My Support Group Meets in My Bedroom
- 4 Online Professionally Led Support Groups
- 5 Building Bridges to Better Breast Health
- 6 Towards an Agenda for Cancer Survivorship
- 8 Navigating the Cancer System
- 10 What's Next for OBCEP?
- 11 "Who Gets What?" - A Look at Access and Utilization of Cancer Care Services
- 12 Breast Cancer Navigation Map

Ontario Breast Cancer Exchange Partnership (OBCEP)

Phone 416-619-5778

info@cancersupportnetwork.ca
www.obciep.on.ca

Editor: Irene Nicoll

Contributors:

Dr. Sue Keller-Olaman
Dr. Joanne Stephen
Kathy Thompson

My Support Group Meets in My Bedroom

by Kathy Thompson



OBCEP has been involved in a four-year project using technology to enhance support and to provide information to cancer survivors. Three main project activities were conducted with evaluation done throughout. A needs assessment was conducted in eight locations across Ontario, and the website www.CancerSupportNetwork.ca was developed. The website provides information and support options that can be tailored to individual needs of breast, lung, ovarian and prostate cancer survivors. Peer-led online and teleconference support groups were piloted for breast and ovarian cancer survivors.

Type of Support

After completion of the website, the online chat was developed. While we wanted to examine online support, teleconference support was also offered as not everyone has access or a comfort level using the internet. Many who had experience with the internet still preferred the telephone option.

Our project objectives were to provide a venue for support, especially for those who may not be able to attend a face-to-face support group; to facilitate information exchange with other survivors; increase knowledge; reduce feelings of isolation; enhance coping skills; and, reduce stress and anxiety.

Recruitment

Participant recruitment efforts included posters, web postings on discussion/bulletin boards, emails, and newsletters to OBCEP contacts. The Canadian Cancer Society-Ontario Division and Willow Breast Cancer Support Canada recruited facilitators. Recruitment of participants became an ever-increasing challenge for the project.

Continued on page 2

My Support Group Meets in My Bedroom.....continued



*“Being at home,
privacy at home, after
going through the
treatment I’m tired.
Online I can think
about what to say and
can read...I can plan
my words more.”*

Support Groups

A chat component was attached to the website so users could securely login to the chat room using a password, without the need to download software. The chat program was easy to use. Teleconference groups connected using a toll-free teleconference number. A manual was developed which provided users with detailed descriptions of how to use the chat room and teleconference along with some “rules of the road” for online and general support group etiquette.

The groups met weekly for six consecutive weeks at a predetermined day and time. All joined in from their home phone or home computer with a password. Each group met for 90 minutes and follow-up evaluations were conducted weekly and at the end of the six-week session.

Challenges

Attendance: Consistent attendance was a challenge due to the limited number of meetings and small group size. Each group consisted of four to six participants. The meetings were greatly impacted if one or two from a group of four to six missed a meeting.

Time Zones: Though the groups were intended for Ontario participants only, it proved impossible to proceed without recruiting beyond provincial borders for sufficient numbers. Participants came from across the country sometimes with a three-hour difference in meeting times. This was a challenge in accommodating participation.

Screening and Referral Options: Screening for severe depression and having options for professional referral became evident needs in some groups. These issues are being examined to assist facilitators in dealing with participants who may need additional support. Facilitators may need additional training to identify those individuals and to facilitate online and teleconference groups where they do not the benefit of visual cues to “read” individuals’ body language and mood.

Achievements

When participants were asked what they liked and what was working, several key themes surfaced. Dealing with emotions, feeling connected (strong emotional bond), anonymity, uplifting experience, and the depth of connection with others were named. The online groups also mentioned that they liked building connections and learning new information, and that they were satisfied with the format.



What have we learned?

Screening: Modify screening questions to identify those not suited for peer support.

Matching: Match participants at similar stages of disease/treatment and those who prefer structured chats and those who prefer less structure.

Mandatory attendance:

Recruit eight people to commit to all six weeks, or a guarantee for Weeks 1 and 2.

Absenteeism: Vary schedules (e.g. eight meetings for 16 weeks) and provide discussion topics in advance.

Provide or suggest topic framework: Predetermine topics for at least some of the weeks.

Group length: For some, six weeks was not enough and they wanted monthly sessions after the six weekly meetings ended.

“I enjoyed the anonymity, I could talk about things you think about but never say...just blurt them out...It humanizes you...Cool, I’m not nuts, or morbid – so I like the anonymity.”

Sustainability

There are intrinsic challenges to offering online and teleconference support for the long-term:

Recruitment: Project partners and peer organizations are needed to recruit participants and facilitators to offer group support via internet and teleconference. Facilitator training and support also needs to be addressed.

Coordination: Coordination is required to set-up and monitor the groups, provide support for facilitators and participants and maintain continual evaluation and review.

Talking versus typing: Explore lower cost options and be alert to innovations (i.e. VOIP: *Voice Over Internet Protocol* options such as “Skype” enable individuals to make free conference calls).



“The online group is “less intimidating” and ... quieter. One of the members prefers the online group I think. It seems to suit her quiet, shy nature. There was also a discussion about the tendency of certain people to dominate an in-person group.”

Where do we go from here?

Developing and implementing peer-led support is clearly worthy of further investigation. This pilot work also raised some important issues about the processes and how to meet the needs of survivors.

OBCEP received further funding for a new project “Enhancing Access to Psychosocial Care, Information and Support for Cancer Patients and Family Members” to implement and evaluate peer-led online and teleconference support for cancer survivors across Canada. This project also links to a project exploring the feasibility and effectiveness of professionally-led support groups (See page 4). The website may provide an initial connecting point for people to learn about and register for groups such as peer-led online and telephone support groups, or professionally-led online support groups. Future technologies must also be on the research agenda.

This four-year study was funded by a grant from the Canadian Breast Cancer Initiative, Public Health Agency of Canada.

Online Professionally-led Support Groups

by Dr. Joanne Stephen



Cancer survivors, family members and caregivers are the groups identified for this service.

Dr. Joanne Stephen of the BC Cancer Agency, Fraser Valley, is leading a team to investigate the feasibility and effectiveness of professionally-led online support groups for those dealing with cancer. Cancer survivors, family members and caregivers are the groups identified for this service. Early work began in British Columbia with support from a Canadian Breast Cancer Foundation grant. Work is continuing in this area with additional support from the Canadian Partnership Against Cancer and the Public Health Agency of Canada. The team is working with The Wellness Community based in the United States as a recognized leader in providing professionally-led online group support.

The provision of professionally-led support groups is an emerging area with little precedent and the steering group is working through many issues. Some experts have expressed the view that professionally-led online support groups are risky because of legal, privacy and safety factors. However, patients are already seeking and accessing online support, and the view of Dr. Stephen and her colleagues is that online services are most likely to be safe and effective when delivered by professionals who develop and maintain specialty expertise. Another challenge to be resolved is the legal issue of clinicians counselling patients outside the province where the clinician is licensed to practice.

Dr. Stephen's team is designing and implementing procedures and practices that are appropriate to the individuals in the groups and that address professional and organizational concerns. Eight Canadian counsellors have been trained and to date four groups have been conducted. Three groups have been completed and more are planned.

The peer-led and professionally-led groups are working together to finalize a common evaluation process and to identify the effectiveness and benefits of each group for particular individuals. Further work will include more demonstration groups and a manual to document best practices and guidelines on how to set up and run professionally-led online support groups.



Building Bridges to Better Breast Health

by Kathy Thompson

Bridges to Better Breast Health is the focus of a new project of the Breast Action Coalition-Sudbury in partnership with the Regional Cancer Program of the Hôpital régional de Sudbury Regional Hospital. The project includes four initiatives: a breast health awareness campaign, a breast health passport, a breast cancer guide, and a newly redesigned website. All four projects are pulled together with a branded look and feel, using the same colour scheme and similar images; all linking to the new website.

The advertising campaign promoting breast health and awareness among women and men uses the catch-phrase *"Breasts, we all have them! Do you know how to take care of yours?"* This eye-catching ad of four bras and a tie on a clothes line links to the website www.breasthealth.info as a place to get more information. CTV television ads are being broadcasted across the northeast starting in June 2008.

An innovative "Breast Health Passport" is packed with helpful information including: facts about breast awareness, breast cancer, breast cancer risks, healthy lifestyle, what to report to your doctor, when to have a mammogram and clinical breast exams. Assessment and diagnostic tests are explained and contact information for the Ontario Breast Screening Program, the Canadian Cancer Society, Canadian Breast Cancer Foundation and patient libraries are listed. There is also an area to record dates and locations of mammograms, ultrasounds, breast MRI, breast clinic and genetic referrals.

For those who receive a cancer diagnosis, The Circle of Strength Sudbury Breast Cancer Support Group's publication "An Information Guide About Breast Cancer" has been updated and reprinted using the branded look. The third edition of this booklet is scheduled to be available in June and a PDF format will be posted on the website.

An attractive newly designed website www.breasthealth.info is available in both English and French and provides information on breast health, diagnostic tests, breast cancer, survivorship, services, travel, and a calendar of events.

Project information will be shared at the 2008 World Conference on Breast Cancer. For more info contact: Carole Mayer, Project Leader for Bridges to Better Breast Health, Clinical Leader & Admin. Mgr, Supportive Care Program, Regional Cancer Program, HRSRH; cmayer@hrsrh.on.ca or 705-522-6237 ext. 2700.



All four projects are pulled together with a branded look and feel, using the same colour scheme and similar images; all linking to the new website.
www.breasthealth.info



National Invitational Workshop: Towards an Agenda for Cancer Survivorship

CANADIAN PARTNERSHIP
AGAINST CANCER



PARTENARIAT CANADIEN
CONTRE LE CANCER

The Canadian Partnership Against Cancer held a **National Invitational Workshop: Towards an Agenda for Cancer Survivorship** in Toronto on March 25 and 26, 2008.



The Canadian Partnership Against Cancer is an independent organization funded by the federal government to accelerate action on cancer control for all Canadians. Cancer survivors, patients and families, cancer experts and government representatives are coming together to implement the first pan-Canadian cancer control strategy. The vision is to achieve a focused approach that will help prevent cancer, enhance the quality of life of those affected by cancer, lessen the likelihood of dying from cancer, and increase the efficiency of cancer control in Canada.

The ReBalance Focus Action Group of the Canadian Partnership Against Cancer, recently renamed the “**Cancer Journey Action Group**” was created to “rebalance the focus” of cancer care. The challenge is to help move the system from a tumour-centred approach to a patient-centred care approach. This rebalanced system would take into account the needs of the whole person—including psychological, social, spiritual, informational, practical, emotional, and physical issues—in addition to clinical care and treatment.

The workshop objective was to develop a Canadian survivorship agenda through identifying survivorship priorities for program development, education, and research. Speakers from Canada, the USA and Australia presented current views on survivorship. Representatives were invited from across Canadian jurisdictions. Eighty-six individuals, including 34 who had experienced cancer, participated.

Day 1 featured seven presentations. Two presentations featured the patient perspective. Lesley Washington of the Canadian Cancer Society - Alberta Division in Calgary spoke about the physical and psychosocial aspects of cancer survivorship including recovery and healing issues and had suggestions for improving delivery of psychosocial supportive care for survivors.

The vision is to achieve a focused approach that will help prevent cancer, enhance the quality of life of those affected by cancer, lessen the likelihood of dying from cancer, and increase the efficiency of cancer control in Canada.

Towards an Agenda for Cancer Survivorship...continued

Heidi Adams from Austin, Texas of the LiveSTRONG Young Adult Alliance (www.livestrong.org) talked about the unique challenges of young adult cancer survivors and how the current cancer system often fails young adults.

The Clinical and Research Perspectives of Survivorship were addressed by Dr. Mary McBride of the BC Cancer Agency in Vancouver and Dr. Les Robison of St. Jude Children's Research Hospital in Memphis, Tennessee. Dr. McBride described the CAYACS (Childhood, Adolescent, and Young Adult Cancer Survivor) Research Program that integrates research into population-based, clinical, and health services issues facing survivors of a cancer diagnosed before 25 years of age. Dr. Robison spoke about the Childhood Cancer Survivor cohort study of over 14,000 five-year survivors of selected pediatric cancers and the expansion of the study.

Dr. Linda Carlson of Tom Baker Cancer Centre in Calgary summarized the state of the research knowledge regarding issues facing adult cancer survivors, and discussed various recommendations for survivorship care. She also reviewed key areas for future research and implementation possibilities in Canada.

Professor Afaf Girgis from the Centre for Health Research & Psycho-oncology, Newcastle, Australia provided another international perspective. She provided examples of research recently completed and underway in Australia as well as the results of a population-based study of the unmet needs and psychosocial well-being of cancer survivors five to six years post diagnosis.

Dr. Svetlana Ristovski-Slijepcevic of the BC Cancer Agency, Vancouver, presented results of an environmental scan that provided a Canada-wide overview of cancer survivorship, conceptualization, research and practice based on individual interviews with key informants.

On Day 2 workshop group discussions took place in three break-out sessions. The discussion sessions addressed key issues facing Canadian cancer survivors; developing action plans for priority issues; and, forging a plan of action with implications for clinical care, education, and research.

Copies of the presenters PowerPoint slides are available on the Partnership's website at <http://www.partnershipagainstcancer.ca> under "News and Information". A full workshop report is being compiled and will be available soon. Contact info@partnershipagainstcancer.ca for more information.

The challenge is to help move the system from tumour-centred care to a patient-centred approach. This rebalanced system would take into account the needs of the whole person—including psychological, social, spiritual, informational, practical, emotional, and physical issues—in addition to clinical care and treatment.



Navigating the Cancer System

by Kathy Thompson

Navigating the cancer system is difficult for patients, particularly while they are making important decisions regarding their treatment and care.

The Cancer Journey Action Group of the Canadian Partnership Against Cancer conducted a series of one-day **Cancer Patient Navigation National Workshops** in Winnipeg, Fredericton and Edmonton. The purpose of these workshops was to build a collaborative Canadian approach to planning navigation systems for cancer patients, survivors and their families.



The cancer journey is complex and challenging. Navigating the cancer system is difficult for patients, particularly while they are making important decisions regarding treatment and care. Cancer Patient Navigator programs are proven to increase access to cancer care and improve the coordination and continuity of care for patient and families. Based on the experience of two successful models, one in Nova Scotia and one in Québec, the workshops presented a planning framework for development of a cancer patient navigation program, and a forum for sharing experiences and information about developments and research in navigation across Canada.



"We should not just be about tumour care, but [about] patient care," said Dr. Margaret Fitch, Chair of the Cancer Journey Action Group, "We want to promote that shift."

The Cancer Journey Action Group was created to influence the current system. "We should not just be about tumour care, but [about] patient care," said Dr. Margaret Fitch, Chair, Cancer Journey Action Group. "We want to promote that shift." Intervention in the form of navigation can make a difference, she said, but navigation comes in more than one shape, and one shape does not fit all. Dr. Fitch concluded, "The goal is to have a cancer system that pays attention to the person through compassionate and coordinated care, through treatment and beyond. These are the "whys", the platform for what we're trying to accomplish today."

While the term "navigation" might seem strange in the context of health care, Sandra Cook, Patient Navigation, Surgical Oncology Network Cancer Care Nova Scotia, said that when they are examined in detail, the following terms do apply to cancer care:

- *Navigation is the process of planning, recording, and guiding the movement of a craft or vehicle from one place to another safely and efficiently involving assessment and reassessment.*

- *The navigator is the person responsible for developing a comprehensive plan and advising the captain of hazards and changing conditions.*
- *The navigator must be well qualified for the job, which is seen as critical for a safe and efficient journey.*

So the question remains: what are the roles of navigators, and where should they be placed within the complex cancer system? Navigators' goals are to assist patients and families as an advocate, educator, and support person throughout the cancer journey, to link patients with professional and volunteer helpers, maximize patients' ability to cope, and to enhance their psychosocial well-being and quality of life.

Anne Plante, Infirmière en Soins Spécialisés en Oncologie Centre Intégré de Lutte Contre le Cancer de la Montérégie (CICM), began her presentation with a walk back in time to 1995, when "Québec had the highest death rate in Canada for cancer patients and the highest health care costs," she said. The Ministry of Health launched a task force to better understand what was happening. Results from a focus group recommended the introduction of a patient liaison to serve as patients' first single point of access into the system.

In 2000, nurse navigators were introduced in Québec's oncology clinics. Since then, nurse navigators have increased in number, as patients and professionals have recognized their roles. Plante went on to say, the activities associated with the nurse navigator role are: *assess* (at the beginning and throughout the care path); *inform/teach/empower*; *support*; and, *coordinate* (the clinical follow-up). One participant asked what the caseload of a nurse navigator would be. Plante replied that in small centres, the nurse navigator would handle all diseases, not just cancer of which there approximately 200 new cases per year, a substantial caseload.

"The three needs that patients require are information, communication, and access to support," said Dr. Fitch. "Fortunately, we know a lot about the process and now need to put it into practice."

An implementation manual is currently being produced as well as a full report on the navigation workshops. The work is supported by the Public Health Agency of Canada, the Canadian Association of Provincial Cancer Agencies, and the Canadian Partnership Against Cancer.

For information contact info@partnershipagainstcancer.ca.



"The three needs that patients require are information, communication, and access to support. Fortunately, we know a lot about the process and now need to put it into practice."



What's Next for OBCEP?

by Kathy Thompson

Our New Name

OBCEP:

Ontario

Breast

Cancer

Exchange

Partnership

As part of an environmental scan conducted in the fall of 2007, 23 interviews were conducted with OBCIEP network partners to review current mission statements, challenges and barriers to doing work, and predictions or plans for the future.

The major challenges and barriers reported were in the areas of: funding; serving diverse populations; diminishing resources and volunteers; marketing and the confusion of who is who and who does what; technological advances; and public policy.

Plans for the future centred on: initiatives to increase public profiles and clarify roles; reaching out to underserved populations; looking at innovative ways to educate and inform; examining new technologies for support, screening and treatment; prevention and public policy; and survivorship issues as cancer is now viewed as a chronic disease.

The OBCIEP Mission

When asked whether OBCIEP's mandate—"to improve access to information and support for women and their families affected by breast cancer"—is still valid, the majority agreed it is still valid. It was also recognized that provincial stakeholders have difficulty staying connected and OBCIEP's networking efforts have brought stakeholders together and kept them informed. Issues raised regarding repositioning OBCIEP for the future included:

Information and Education: For some stakeholders information and resources shared or produced by OBCIEP is all that they receive. It was recommended OBCIEP continue its role of sharing information with the breast cancer community.

Diversity: Addressing the increased demand for informational needs of specific groups including cultural diversity, language, age and geographical location.

Marketing: Increasing the profile of OBCIEP

Expansion of Mission: Broadening the mission to include other cancers, women's cancers, for example, to share resources, lessons learned, networks, etc. with other cancer groups.

Change of Name and Next Steps

The findings were presented and discussed at the annual OBCIEP meeting of stakeholders in March, 2008. Those present felt that OBCIEP's mission was indeed still valid but the name should change for clarity and brevity to the Ontario Breast Cancer Exchange Partnership (OBCEP). There was also discussion about expanding the mission to include women's cancers but ultimately the group chose to keep its focus on breast cancer but to continue to work with other cancer site groups. Currently OBCEP continues to investigate increasing access to information and support for cancer patients, survivors and their families using online, teleconference, and new telecommunication technologies, and standardized facilitator training and support for these media.



OBCEP continues to investigate increasing access to information and support through the use of technology.

“Who Gets What?": A new look at access and utilization of cancer care services

by Dr. Sue Keller-Olaman

What is the issue?

Questions of access and equity are becoming more complex and gaining urgency in cancer care. With shorter hospital stays and a focus on outpatient care, people with cancer are spending more of their recovery at home. At the same time, public funds for home care have been cut; and drugs once delivered in hospital are now being handled by the patient with the costs often borne by the patient and the family.

While studies have examined how social position (measured by income, education, occupation for example) affects cancer treatment, care and recovery, revealing the ways social position 'matters' are not always straightforward. Qualitative social science research suggests that "who gets what" in health care is negotiated, with both providers and patients active participants.

Negotiating equity project

The "negotiating equity" project is the first in Canada to integrate three research approaches to address questions about "who gets what" in cancer care. The project involves researchers from universities, research organisations and a cancer centre in Ontario. The work is funded by the Canadian Institutes of Health Research (CIHR).

This study will increase our knowledge about resource distribution in cancer care both quantitatively (examining resource allocation by social position) and qualitatively (looking into the often subtle ways that differences in access and utilisation may actually come about).

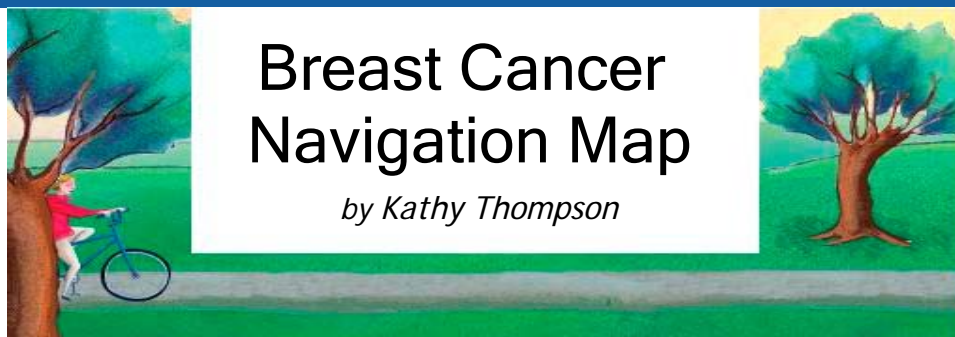
The three approaches

1. One approach will examine how social position may be linked to differences in referral rates and utilization of specific cancer services and treatments. To achieve this, data will be collected from 300 breast cancer patients.
2. A second approach focuses on understanding how patients and professionals negotiate cancer care resources. This will involve following 16 breast cancer patients over the course of their care. The clinic interactions between the patients and physicians will be tape-recorded and patients and professionals will be interviewed. Analysis of the interactions will be used to describe how resource allocation is accomplished and social science theory will be used to reveal how social position shapes the negotiations.
3. The third approach builds capability for change. Opportunities for cancer care providers to share concerns and strategies about disparities are not yet realised. The third approach will draw together care providers from cancer centres and community hospitals. The network Knowledge Exchange for Equity Network (KEEN) is designed to structure a relationship between researchers and cancer care providers - to increase the likelihood that knowledge relevant to access and equity will influence cancer care practice and policies.

What is happening?

To date 30 people have agreed to be part of the first approach (using data to describe the links between social position and who gets what) and data collation will begin soon. The researchers hope to start the KEEN network part of the project by early June.

For more information about the Negotiating Equity Project, contact Dr. Christine Sinding at McMaster University, sinding@mcmaster.ca.



Canadian Breast Cancer Foundation BC/Yukon Chapter in partnership with Canadian Cancer Society BC and Yukon Division have developed a web-based Breast Cancer Navigation Map. This interactive map takes the user on a journey through the cancer experience. The map is intended to help at each step along the way, giving an overview of what to expect as well as suggestions on what to do to help make the decision that is right for the user.

The map begins at diagnosis, giving tips on how to cope, and who to talk to and then on to the treatment planning stage and decisions about surgery. A "decision point" arrow pops up for more information at all decision-making stages. As the map progresses, a timeline at the bottom of the screen highlights the time it should take for the surgery, for the incision to heal, how long before receiving the pathology report, etc.

Additional therapies are discussed along with what to expect at visits to the cancer centre. Post treatment options and resources are listed along with strategies to leading a full life after breast cancer. This is followed by a section on 'Living Life'. A 13-year survivor is quoted: *"Now's the time to create your new 'normal', to find satisfaction in your inner life, to reconnect with friends and family and to celebrate each day as a gift."*

Throughout the map, video clips of cancer survivors of all ages are available to view with a click of a mouse. These survivors provide tips, suggestions, personal insights and stories of their experiences with breast cancer. Visit www.breastcancernavigationmap.org.

Canada Post Indicia
40048439