

Supportive Care for Women with Advanced Breast Cancer



Research Team (L-R): Back Row: Bev Lawson, Tallal Younis, David Haardt, Janice Howes, Marianne Arab; Middle Row: Fred Bruge, Chris Skedgel, Robin Urquhart, Judith Fisher; Front Row: Melanie Keats, Lynn Lethbridge, Nicole McQuinn, Jennifer Payne, Grace Johnston; Missing: Geoff Porter, Danny Rayson, Jillian Demmons.

Over the next ten years in Nova Scotia (NS), more than 3,000 women living with advanced breast cancer will need supportive care. A number of Halifax-based researchers have been investigating ideas that have the potential to improve supportive care (SC) for women with advanced breast cancer (ABC). For the most part, these researchers had been working independently from each other.

Funding for an ABC-SC project now provides a formal process of communication and consideration of their independent forms of research and the application of their findings for the benefit of these women. Using Kelley's¹ model of change and a participatory action research (PAR) process, the ABC-SC project brings together innovative, young researchers with experienced cancer researchers to build new research to improve supportive care for women with advanced breast cancer.

ABC-SC research project will tackle two primary questions:

- 1) What can be learned by 'mining' existing NS research, using an advanced breast cancer lens, to improve supportive care for women with breast cancer?
- 2) How does an adapted PAR approach facilitate knowledge exchange within the ABC-SC Research Team and lead to new supportive care research development for women with advanced breast cancer?

Expected Impact

- insights and interventions by cancer patient navigators and others who screen for distress;
- an improved understanding of pain medication use for women with breast cancer;
- completion of a study on the benefits of physical activity;
- greater understanding of factors that influence the likelihood of receiving palliative care in three District Health Authorities including:
 - the impact of having diabetes and/or cardiovascular disease
 - living in a rural versus an urban area
 - minority culture status, and
 - other socio-demographic factors;
- data to demonstrate the importance of listening to the views of next-of-kin
- an analysis of the type and extent of costs of community-based supportive care;
- greater understanding of best practices and barriers to breast cancer research team building;
- new research project proposals; and
- presentations, publications, and other knowledge exchange of new findings.

¹Kelley ML. (2007) Developing rural communities' capacities for palliative care: a conceptual model. *J Palliat Care*, 23(3): 143-153.

ABC-SC is a two year Breast Cancer grant led by Dr Grace Johnston and Robin Urquhart. Funding for ABC-SC has been received from the Breast Cancer Society of Canada and the QEII Foundation through the Beatrice Hunter Cancer Research Institute.

Information on ABC-SC is available at <http://abc-sc.healthadmin.dal.ca>.



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NELS ICE support for ABC-SC

ABC-SC is a product of the Network for End of Life Studies (NELS). NELS is a Halifax-based research team which received multi-year funding from the Canadian Institutes of Health Research (CIHR) through an Interdisciplinary Capacity Enhancement (ICE) grant to build research capacity to improve care for vulnerable populations at end of life. NELS ICE funding and data supported the initial stages of ABC-SC. NELS ICE processes for team and project development have been translated for use in ABC-SC to see if successes can be replicated and to further investigate how best to build interdisciplinary research.

Information on NELS ICE can be found at <http://nels.dal.ca>.

Participatory Action Research (PAR) within ABC-SC

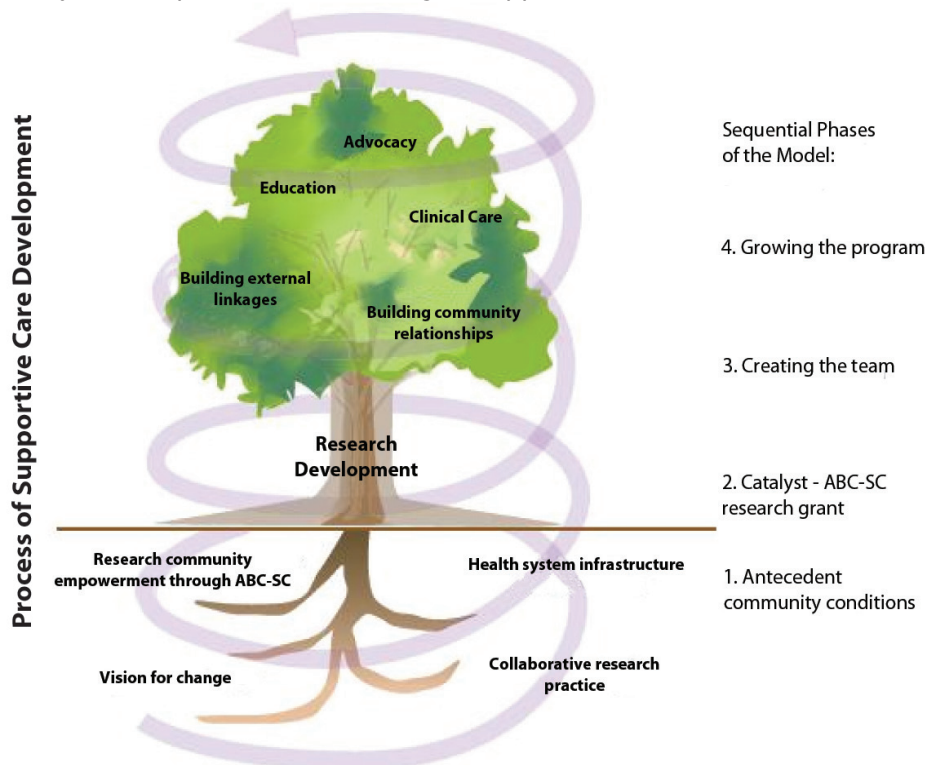
A vital part of the ABC-SC project is to use and evaluate a participatory knowledge exchange process with the intention of expediting the development of supportive care research, and thereby improving supportive care for women with advanced breast cancer.

ABC-SC moves beyond the basic interactions between the “producers” and “users” of knowledge within a discipline or profession towards a multidisciplinary approach - crossing professions and organizational boundaries.

The project will apply a PAR approach to its knowledge exchange process. PAR focuses on bringing about change in practices, with participants advancing a specific plan for addressing the important issues on which they are collaborating.

ABC-SC’s PAR approach has been adapted using Kelley’s conceptual model of change (Figure 1).

Figure 1:
Kelley’s Conceptual Model of Change as applied to ABC-SC Research



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Adapted from Kelley ML. Developing rural communities’ capacities for palliative care: a conceptual model. *J Palliat Care* 2007; 23(3): 143-153.

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PAR is a research-based model of change that encompasses collaborative processes. Capacity development requires broad-based participation, cultivating and building on local capacities, continual learning and adaptation, and integration of activities across disciplines/boundaries to address complex problems.

A key characteristic of PAR is its cyclical nature, whereby “thinking” and “doing” processes are repeated throughout the research. Figure 2 demonstrates the PAR process that will be implemented throughout the ABC-SC 2-year cycle.

This process is being used to:

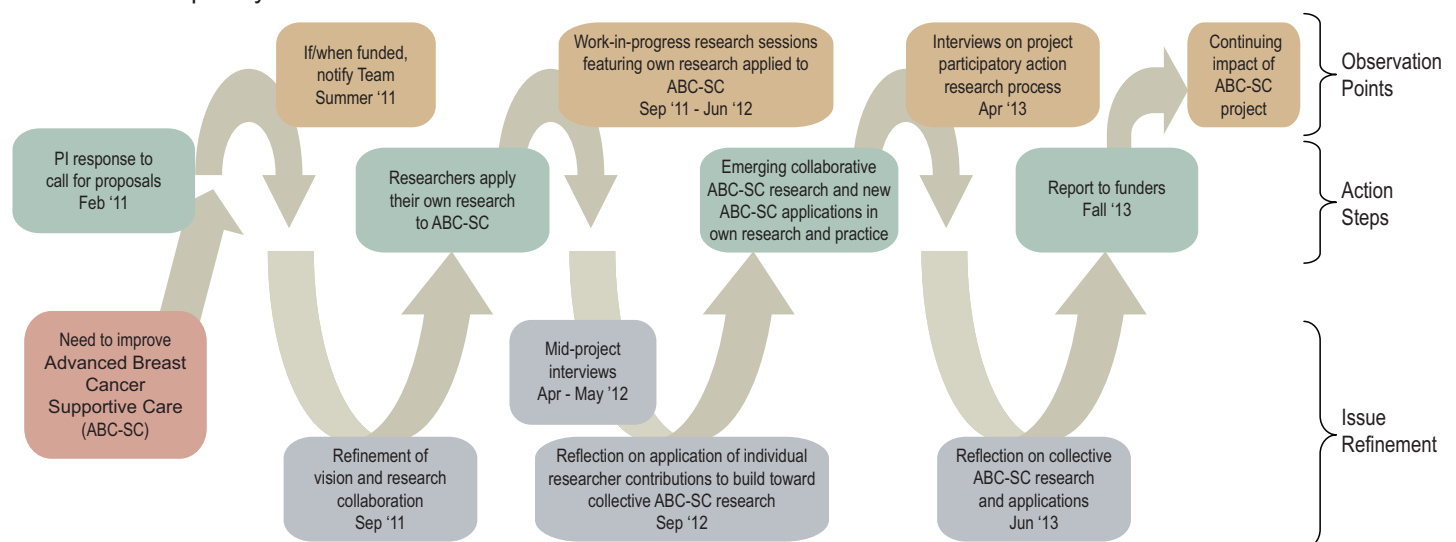
- engage Team members,
- support effective KE processes/practices, and
- strengthen members’ capacity to develop and carry out ABC-SC research.

The cycle is conceptualized as a repeated iteration of three steps:

1. **Looking**, or building a picture and gathering information;
2. **Thinking**, or interpreting, reflecting, and explaining; and
3. **Acting**, or resolving issues, judging the value, effectiveness, and outcomes of the activities, and formulating solutions to move forward.

This “strengths-based” approach strives to enhance existing research/knowledge exchange capacities and develop cutting-edge supportive care research through collective problem solving and reflection.

Figure 2:
ABC-SC Participatory Action Research Process



Adapted from Figure 21.1 in “Chapter 21: Participatory Action Research” of *Social Research Methods* by Maggie M Walter (2009), Oxford, South Melbourne, Australia.

Year One of ABC-SC

Approval of ABC-SC funding occurred in the Summer of 2011. Draft Terms of Reference and an ABC-SC logo were developed. The first ABC-SC Team meeting was in September 21, 2011 when these Terms of Reference were approved.

In the Fall, the ABC-SC financial accounts were set up at Dalhousie University, an application for ABC-SC project funding was drafted, and an ABC-SC website was developed by Nicole McQuinn. For the website, each member of the Team provided information about themselves and their research. See: <http://abc-sc.healthadmin.dal.ca/team.html>. Nicole continues to update the website and helped prepare this first ABC-SC newsletter.

None of the ABC-SC investigators were ready to present a work-in-progress session in Year One. In the Spring of 2012, Jillian Demmons was hired as the ABC-SC coordinator so that more attention could be given to the project. In April and May, Jillian interviewed each of the ABC-SC investigators to determine the status of ABC-SC development. After the interviews, the application form for ABC-SC project funding was finalized and circulated to the ABC-SC investigators along with the Terms of Reference and original ABC-SC proposal.

Interview Findings

Jillian Demmons met with each of the ABC-SC team members to discuss the purpose and process of ABC-SC and the description

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of their role. These interviews were initiated to aid in identifying needs for support, team building, and project development. Jillian shared her findings with the ABC-SC Principal Investigators, Grace Johnston and Robin Urquhart. Further actions were then planned including the development of an agenda for the next ABC-SC team meeting which will be September 27, 2012.

The interview process identified that all interviewees remained interested in participating in ABC-SC. While ABC-SC was tangential to their other research activities, the investigators were committed to ABC-SC, although it has not been their top priority. Some retained their original interests. Others reported changes, given new circumstances and opportunities, e.g., one investigator now has a graduate student working on an ABC-SC project and another accepted a new position necessitating a change in research role. Others had developed additional areas of research interest. All had previous projects upon which to build. Many have data with which to work; however, in many instances the number of women with breast cancer was limited in these databases. As well, additional investigators, beyond those in the proposal application, have become interested in ABC-SC.

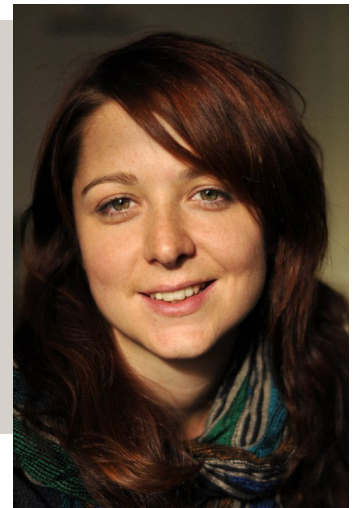
When asked about obstacles to their ABC-SC research, interviewees reported limited time and energy; questions regarding the scope, nature, direction, and timelines of ABC-SC; funding availability; and the need for more networking and collaborating. One investigator stated the following which may well summarize the Year One process: "In my experience disparate group grants evolve over time. They figure themselves out. I sort of waited for this to happen."

At the upcoming ABC-SC meeting, most participants wanted a succinct review of what other investigators were doing and a renewed understanding of the ABC-SC

Jillian Demmons joined ABC-SC as the project coordinator in the Spring of 2012.

Jillian completed her undergraduate work at Mount Saint Vincent University and her graduate studies at Yale Divinity School, where she explored existential questions of human suffering. Jillian continued to pursue training as a Chaplain focusing on work with senior citizens in Geriatrics and Palliative Care.

She can be contacted at abc-sc@dal.ca



purpose, processes, and scope. Many expressed the desire for focused, structured and productive networking. Most seem interested in ABC-SC being the foundation for future research. This is consistent with the Principal Investigators goal of ABC-SC leading to a large grant proposal and/or a number of smaller collaborative projects.

In summary, ABC-SC is in the Research Development (tree trunk) stage of Figure 1 (Page 2). ABC-SC is drawing to some extent on the "roots" of empowerment through the grant itself, an emerging vision, the existing health system, and collaboration. Greater use of these four roots will hopefully occur in Year Two. The interviews demonstrated that ABC-SC is on target with the PAR approach presented in Figure 2. ABC-SC investigators have been considering their own research in relation to potential new opportunities through ABC-SC. If the PAR process continues as planned into Year Two, new collaborative research should begin to emerge.

Emerging Research Ideas

To address the ABC-SC investigators' interest in learning more about what the other investigators are doing, and to help set the stage for our next ABC-SC meeting, the following description of some of the interests of the ABC-SC team was prepared. Any errors and omissions will hopefully be corrected when we meet in September.

Dr Melanie Keats now has a graduate student, Hillary Woodside, who will be doing her thesis in 2012/13 on home-based yoga for palliative care patients with cancer. Hillary has been funded through the Beatrice Hunter Cancer Research Institute. Melanie and Hillary have been working on a paper exploring palliative care models for young adults focusing on physical activity.

Dr Janice Howes is a clinical psychologist with cancer patients, many of whom have advanced disease. In association with the Canadian Partnership Against Cancer (CPAC), she has been developing a distress screening tool for use in Nova Scotia. More than 1400 screens from across the nine District Health Authorities are already in a database. On February 29, 2012, Janice presented on the screening tool at a NELS ICE workshop. She described how the Edmonton Symptom Assessment System (ESAS), the distress thermometer, and the Canadian Symptom Checklist are being used for screening. The workshop Report of Symptoms and Outcomes Measurement for End of Life Care in Nova Scotia will be circulated shortly.

Dr Daniel Rayson is a medical oncologist who has been treating persons with breast cancer for ten years. He has developed a database looking at advanced breast cancer

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with the drug Herceptin, including its potential for the exploration of the palliative use of this therapy. This database might potentially provide a foundation for ABC-SC related research.

Dr Jennifer Payne's area of ABC-SC research interest relates to her role with the provincial breast cancer screening program. In particular, she is interested in studying the value of ongoing breast imaging for women who have been diagnosed with breast cancer, are post-treatment, and are being followed through the Department of Radiology with ongoing breast imaging. Her questions include: Does annual follow up make a difference? Are there variations in practice across the province? Jennifer also provides epidemiological support to three provincial disease programs: diabetes, cardiovascular and renal.

Dr Fred Burge is the director of research for Family Medicine. **Bev Lawson** is his Research Associate. They and their colleagues have completed data collection and are now carrying out analysis of a major Mortality Follow Back Survey. While approximately 1400 persons were interviewed in their role as next of kin for someone who died in Nova Scotia from June 2009 to May 2011, less than thirty of the interviews relate to a person who died of breast cancer. Further structured interviews, or new qualitative interviews, might be worthwhile to investigate the situation more fully for persons dying of breast cancer. Jillian Demmons was one of the two interviewers for this study. Further details are in NELS News 5 at: nels.dal.ca/nelsnews.html. Fred is also the co-Principal Investigator for a major new cross-Canada multi-year research proposal of community based primary care for persons at end of life called PINNACLE, which has just been successful at the Letter of Intent stage for the Canadian Institutes of Health Research (CIHR). This new research includes Robin Urquhart and Grace Johnston as well as many others.

Dr Geoff Porter is a surgical oncologist who directs the Cancer Outcomes Research (COR) unit where Robin Urquhart coordinates knowledge exchange. COR leads the NET ACCESS linked database study on colorectal cancer, and has recently started a parallel study on pancreatic cancer. Thereby, COR has gained much expertise in linked administrative data which examines disparities in and quality of care for cancer services. A new large breast cancer linked database study is of interest but would need a focused research question to guide protocol development. There are challenges in not having comprehensive data on chemotherapy. However, there is an increasing body of research looking at surgery for metastatic breast cancer so there may be an issue in that literature which could be addressed.

Dr Judith Fisher is no longer a post-doctoral fellow with the College of Pharmacy and NELS ICE. She is now at the provincial Department of Health and Wellness (DOHW) as Manager of Drug Technology Assessment. Therefore, she has become a user of research since DOHW pays for many drugs. ABC-SC research could be relevant in a new way in the evaluation of what drugs should be funded. The systematic literature review that had been planned is no longer viable. However, there may be an opportunity to work with **Dr Ingrid Sketris** and others using Prescription Monitoring Program data linked to OPIS cancer data to better understand pain medication use in Nova Scotia for women with breast cancer.

Lynn Lethbridge carried out an analysis of care-giving hours using cross-Canada costing data collected by a team lead by Dr Serge Dumont. Lynn could also examine 3x3 NELS data for women who died of breast cancer to understand their use of palliative care and place of death by a range of covariates including socio-demographic factors and their co-morbidities. She would be able to provide ABC-SC work-in-progress sessions on both of these analyses.

Lynn may work with **Dr Tallal Younis** and **Chris Skedgel** on a new costing study using the Dumont data. **Dr David Haardt** is also interested in costing issues particularly for the elderly.

Robin Urquhart's primary area of expertise is knowledge translation. Through ABC-SC she wants to enable others in their research as well as evaluate the PAR process for building research and research teams to study supportive care for women with advanced breast cancer. As and after she finishes her PhD thesis, she is sure to have additional ideas to share.

For **Dr Grace Johnston**, with the NELS ICE project coming to an end, she saw ABC-SC as a way to bridge to new projects. New proposals need to demonstrate the potential of an emerging research team, so ABC-SC was a good fit. From her experience leading interdisciplinary research, she knows it is demanding, but believes that interdisciplinary research has advantages including the emergence of innovative thinking. However, little is yet known as yet about best practices for interdisciplinary research team development and productivity. Grace believes that interdisciplinary research works best when new projects are based on individual interests and strengths. Another reason that motivated her to apply for funding for ABC-SC was that many people have data that they haven't had time to fully analyze. She is interested in seeing win-wins emerge across co-investigators. ABC-SC also connects with her previous work on breast cancer as well as end of life care.

SEPTEMBER MEETING

Date: September 27th, 2012

Time: 12-4:30

Location: Room 544,
Bethune Building, VG Site,
Capital District Health Authority