

Canadian Consortium of Cancer Survivorship Research

Until recently, fewer individuals diagnosed with cancer became long-term survivors; however, due to advances in prevention, screening, and treatment, an increasing number of people are surviving cancer diagnoses. As the number of cancer survivors increases in Canada and worldwide, it is becoming critical to understand the unique needs of this population and develop a Canadian research agenda that will inform policy and service delivery.

The development of a Canadian Survivorship Research Consortium will establish a national network of research partners to create action to advance the priority setting for cancer survivorship.

Several recent initiatives in Canada, led by Richard Doll and Dr. Arminée Kazanjian, have paved the groundwork for a Canadian Survivorship Research Consortium, including an environmental scan, two 2-day national invitational survivorship workshops, and a national invitational 1-day meeting, all in 2008-2009.

As a strategy to move the previously identified research priority areas forward, develop research partnerships, and further the establishment of a Canadian Consortium of Cancer Survivorship Research, the *"Fostering cancer survivorship research in Canada: Building capacity through a research consortium"* workshop, held on May 6-7th in Vancouver, BC, served as the next step. Funding from the Canadian Institutes of Health Research and LIVESTRONG facilitated the 2-day workshop.

The purpose of the workshop was to bring together researchers from key cancer survivorship programs currently operating in Canada to discuss and develop terms of reference for a Canadian consortium of cancer survivorship research. The workshop facilitated research partnerships and collaborations under the umbrella of a consortium, and ensured an early alignment of research questions with the pre-established research priority areas. The workshop also ensured that knowledge synthesis, dissemination, and exchange considerations will be integrated to the Canadian survivorship research agenda.

The workshop consisted of several presentations and two breakout sessions. Speakers presented on their unique perspective and expertise in the field of survivorship, the value of and contributions to a consortium, and offered lessons learned from their own experience with consortium development. Representatives from national funding organizations and special interest groups across Canada also presented on funding priorities and current research activities in cancer survivorship, and guest attendees shared on the survivorship perspective.

The presentations were followed by two break-out sessions to discuss the structure of the Consortium, as well as identify potential research questions, target groups, collaborations, and a knowledge translation plan within the identified research priority areas.

The final outcome of the two day meeting was a commitment from those who are interested to continue working towards the development of a Pan-Canadian Survivorship Research Consortium that will excel in research, inform clinical practice, and develop research priorities through input from those who have experienced cancer.

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Introducing Fraser Valley's New Professional Practice Leader



Pam Whiting Vickers, MSW, has joined the BC Cancer Agency to work as Professional Practice Leader (PPL) for the Fraser Valley Centre Patient and Family Counseling department as of June 2010.

Pam comes to us with senior leadership experience and a strong track record in strategic

planning, system improvement, change management, professional practice, and coaching and leading teams. Pam has over twenty-five years of experience working in health

care, most recently with PHSA, Simon Fraser University, and Fraser Health Authority.

Her clinical experience includes individual, couples, family and group counselling, both in the health sector and in private practice.

Pam obtained a Certificate in Strategic Leadership from the Sauder School of Business at UBC, a Masters Degree in Social Work from McGill University, and completed an undergraduate degree in Social Work at the University of Victoria.

Please join us in welcoming Pam to the cancer care community in BC!

Supportive Care for the Loved Ones of Cancer Survivors

The BC Cancer Agency Sociobehavioral Research Centre (SRC), under the team leadership of Dr. Amanda Ward, is working on a pilot project funded by the Cancer Journey Action Group of the Canadian Partnership Against Cancer to develop and evaluate a program for the family/support persons of cancer survivors as they enter the early post-treatment phase of survivorship. The program will be delivered at four pilot sites across Canada and evaluated using a pre-and post-intervention questionnaire design.

The intention of the pilot project is to use research evidence to guide clinical practice in educating and supporting the family as they transition into survivorship with their loved ones.

The Cancer Journey Action Group of the Canadian Partnership Against Cancer has identified the development

of improved approaches to cancer survivorship care planning as a major priority. Currently, in Canada, there are no evidence-based uniformly available supportive care programs for the family of cancer survivors. It is important to make available supportive care services for the family of cancer survivors, not only to help them improve their own quality of life, but also to enable them to cope and provide optimum support for the cancer survivor as they move beyond active treatment. As cancer becomes more of a chronic disease there will be a growing burden for the family of survivors. The support that family members of cancer survivors provide has social and economic implications that positively impact the Canadian health care system.

The program is called *"EMPOWER: Education and Support for the Family of Cancer Survivors"*, and was developed by Heather Rennie, Provincial Practice Leader for Patient and Family Counselling Services in Abbotsford, and the BCCA SRC team. The program was developed to compliment and run alongside Cancer Transitions, a program for cancer survivors to aid in the transition from active treatment to post-treatment care. *EMPOWER* is a three session group intervention that will consist

of educational material, support and discussion, skill building, social networking, and problem solving.

Examples of topics for the weekly sessions include:

- Defining a Cancer Survivor
- Returning to a New Normal
- Transition: Hospital to Home
- A Survivor-Family Care Plan
- Family Member Role Burden: Tools and Resources for Coping
- Family Member Emotional Well-Being and Self-Care
- Communication in the Family – Family Roles and Shifting Responsibilities
- Managing Side-Effects of Treatment (pain, fatigue, sexuality, fertility, etc)
- Practical Issues: Employment Concerns, Wills, and Financial Planning

The project will provide evidence-based research to support the development of supportive care services for the family of cancer survivors in order to optimize the care giving experience for the family.

For more information about the program, please contact Joanne Magtoto at jmagtoto@bccancer.bc.ca or Dr. Amanda Ward at award2@bccancer.bc.ca

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Survivorship Care Needs of Head and Neck Cancer Patients at Vancouver Island Centre

An inter-disciplinary team of researchers at the BC Cancer Agency Victoria Cancer Centre is undertaking a qualitative study on the survivorship information and care needs of locally advanced head and neck cancer patients living on Vancouver Island and treated with curative intent radiotherapy for locally advanced base of tongue and tonsil. The project is funded by the VIC Catalyst grant.

Patients with cancer of base of tongue and cancer of the tonsil experience long term reductions in quality of life, which impacts on treatment outcomes and survival. Their survivorship information needs are not currently being met, as evidenced by anecdotal self reporting by patients who return to the Cancer Centre for radiation follow-up. Patients living outside of Victoria have less access to supportive



Team members (from left to right):
Helen Wong, Cheri Cosby, Andrea Fimrite

Team members missing from photo:
Tracy Lister, Beverly Gerbis, Sally Smith

resources and information. A sample of 12 patients, 6 living in Victoria and 6 living up island close to Nanaimo will be interviewed on an individual, one-on-one basis.

We hope to get better insight and be able to identify specific issues that survivors of these head and neck patients face as they transition back into their communities.

The project is composed of a multidisciplinary team that includes principle investigator, Cheri Cosby, RD (Nutrition Services) and co-investigators Andréa Fimrite, RD (Nutrition Services), Tracy Lister, RD (Manager of Nutrition Services, VIHA-Nanaimo General Hospital), Dr. Sally Smith (Radiation Oncology), Beverly Gerbis, RN (Nursing), and Helen Wong (Patient & Family Counselling).

Supportive Needs of Cancer Survivors Workshop

A recent Pre-MASCC (Multinational Association of Supportive Care in Cancer) Symposium study group workshop, *"Cancer Survivorship: Creating international collaborations to study the supportive care needs of cancer survivors"*, was held in Vancouver, BC on June 23rd, 2010. The workshop aimed to bring together leading international researchers and clinicians to highlight international work in the field of cancer survivorship, and to explore ways of facilitating collaborative partnerships.

Due to advances in screening, prevention, and treatment, an increasing number of people are surviving cancer diagnoses. Embracing survivorship issues has therefore become a priority at both research and practice levels. However, there are challenges to advancing the science and practice work in cancer survivorship, including, a limited number of people working in the area of survivorship, and constraints on funding. At this time, it is essential to consolidate knowledge and expertise internationally.

The collaborative study workshop encouraged experts in cancer survivorship to come together to share information and form alliances to advance international survivorship priorities under a single consortium. This international consortium will provide a platform for researchers and practitioners to communicate regardless of geographic location.

The objectives of the workshop were to highlight existing cancer survivorship initiatives at national and international levels, discuss the benefits and challenges of establishing an international survivorship consortium, identify potential collaborations among researchers, clinicians and funders, and a process for knowledge dissemination, exchange and translation, and establish a commitment to develop partnerships under the umbrella of a cancer survivorship research consortium.

Priority research areas identified for short-term team projects included a catalogue of currently implemented survivorship guidelines, a survey of health care providers, and a survey of cancer survivors and caregivers' unmet needs.

Upcoming Events

International Union against Cancer (UICC). 2010 World Cancer Congress.
August 18-21, 2010. Shenzhen, China.
<http://2010.worldcancercongress.org>

Palliative Care Division, McGill University. 18th International Congress on Palliative Care.
October 5-8, 2010. Montreal, Quebec, Canada.
www.pal2010.com

Oncology Congress. 6th Annual Oncology Congress.
October 15-17, 2010. San Francisco, California, USA.
www.oncologycongress.com

Society for Integrative Oncology (SIO). 7th Annual International Conference of the Society for Integrative Oncology.
November 11-13, 2010. New York, New York, USA.
www.integrativeonc.org

Canadian Interdisciplinary Network for Complementary & Alternative Medicine Research (IN-CAM). 6th Annual IN-CAM Symposium.
November 19-21, 2010. Vancouver, British Columbia, Canada
www.incamresearch.ca

BC Cancer Agency (BCCA). Annual Cancer Conference.
November 24-27, 2010. Vancouver, British Columbia, Canada.
www.bccanceragencyconference.com

Psychosocial Oncology Rounds

Join us from 12:00 p.m. to 1:00 p.m. every second Wednesday of the month for lunch time learning. Videolink to all 5 cancer centres. Location TBA. For more information on upcoming speakers and topics, contact Elaine Shearer: eshearer@bccancer.bc.ca

The next rounds will take place on September 1st and 8th.

Oncology Nutrition Lunch & Learn

Join us on the third Wednesday of every month for lunch time learning from 12:00 p.m. to 1:00 p.m. by teleconference. For information on upcoming speakers and topics, contact Angela Bowman: abowman@bccancer.bc.ca

Staff Updates

Tracey Brickell, D.Psych, was a Research Scientist at the SRC. Tracey has moved to a new position as Senior Scientist with the USA Defense and Veterans Brain Injury Center.

Heather Rennie, MA, MSc, has taken over as the new Professional Practice Leader for the Abbotsford Centre's Patient and Family Counselling department.

Svetlana Ristovski-Slijepcevic, PhD, was a Research Coordinator for the CIHR Team in Supportive Cancer Care at the SRC. Svetlana has accepted a new position with the School of Population & Public Health at UBC.

Kirsten Smillie, MA, is the new Research Coordinator for the CIHR Team in Supportive Cancer Care at the SRC.

Pam Whiting Vickars, MSW, is the new Professional Practice Leader for the Fraser Valley Centre's Patient and Family Counselling department.

Cancer Rehabilitation Network

BCCA's Cancer Rehabilitation Network coordinates regional cancer centre activities for patient and family counselling, psychiatry, and nutrition services. The Rehabilitation Network also works with host hospitals to provide speech pathology and physiotherapy services. Community activities with practitioners are provided through the psychosocial oncology and nutrition oncology networks.

Subscribe

To submit a story idea or to sign up to receive the Connections Newsletter in print or PDF format, please contact:

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More Information

To learn more about the Cancer Rehabilitation Network's activities, please contact:

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