Psychosocial Oncology Program Newsletter

cancer care ontario | action cancer ontario

Fall 2010

Special points of interest:

- The Psychosocial Oncology Program has a committee made up of regional leaders in Psychosocial Oncology.
- Improve the patient experience through symptom management, coping and stress management strategies
- Regional sites featured in this newsletter are: Sudbury, Credit Valley, North Simcoe Muskoka, Thunder Bay and London
- Get ideas for successful partnerships
- See results from the Regional Lymphedyma Program Survey

Inside this issue:

A Message from Esther Green…

The aim of this newsletter has been to highlight and celebrate the successes and challenges of the fulfilling work we do with our patients. This edition really drives home the fact that Psychosocial Oncology (PSO) has grown to encompass so many strategies to improve the patient experience. Each of these articles illuminates what we can do better, the amount of effort professionals devote to PSO and the potential outcomes that come from that dedication. These stories also demonstrate 'whole person care', incorporating the physical, emotional, functional, and social aspects of care for the person and their families.

I'm also reminded of what amazing things can be accomplished through partnership, from Thunder Bay's Regional Cancer Program, Wellspring & Hospice Northwest collaboration (see page 5) to the interdisciplinary development of the Symptom Management Guides to Practice (see page 2). The PSO Committee has made promising headway on the gathering of data from the various PSO programs at each hospital, which will help us with our understanding of regional resources and planning for the future.

Please take our readership survey http://www.surveymonkey.com/s/MN32NHB or feel free to contact us with ideas for the next edition.

Esther Green
Provincial Head of Nursing & Psychosocial Oncology Programs

'Cancer Transition' Addresses Survivorship Issues in Sudbury

The Supportive Care Program of the Regional Cancer Program at the Hopital Regional Sudbury Regional Hospital (HRSRH) is pleased to provide *Cancer Transitions: Moving Beyond Treatment* for cancer survivors from Northeastern Ontario.

This dynamic group program, offered 2 ½ hours per week over six weeks, is designed to assist cancer survivors with their transition from active treatment to life post treatment. The Cancer Transitions program, is led by a trained facilitator along with interdisciplinary professionals providing their expertise in nutrition, physical rehabilitation, and medicine, and is designed to address the emotional, physical and social obstacles encountered in this transition period, through the following sessions:

1. Get back to wellness: take control of your survivorship
2. Exercise for wellness: customized exercise
3. Emotional health and well being: from patient to survivor
4. Nutrition beyond cancer
5. Medical management beyond cancer: what you need to know
6. Moving beyond treatment: next steps towards survivorship

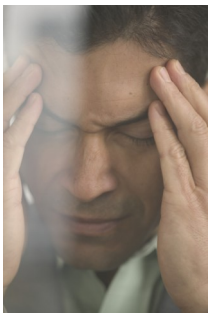
This initiative began in 2009, when I attended a Facilitator's Workshop in Ottawa co-hosted by The Wellness Community in partnership with the BC Cancer Agency.

The program was then promoted within the Regional Cancer Program to recruit participants within 24 months of completing cancer treatment. The first session commenced on September 29th. We look forward to participants' feedback and exploring the possibilities of delivering this program in French and expanding to communities throughout

… continued on page 3

Cancer Care Ontario's Symptom Management Guides to Practice

The Ontario Cancer Symptom Management Collaborative (OCSMC) is a joint initiative of the Palliative Care, Psychosocial Oncology and Nursing Oncology Programs at Cancer Care Ontario. The main goals of this initiative are to improve the management of symptoms experienced by cancer patients and increase the delivery of patient-centered care. To meet this goal guides-to-practice were developed by the Symptom Management Group (SMG), which included interdisciplinary representation from across the province. To date, the SMG has developed guides-to-practice for four symptoms - pain, dyspnea, delirium, and nausea and vomiting. An additional interdisciplinary group was established to develop simultaneously one-page algorithms based on the four guides to practice. While creating comprehensive and user-friendly evidence-informed tools, the algorithm group has been instrumental in bridging the work currently being undertaken by the SMG and the Cancer Journey Action Group (CJAG) at the Canadian Partnership Against Cancer, that is also developing symptom guidelines. The CJAG recently completed a pan-Canadian practice guideline on screening, assessment and care of psychological distress focusing on depression and anxiety in adults with cancer. Similarly to the SMG documents it is comprised of a guide to practice and a two-page algorithm. In the near future the SMG will be developing additional management tools for loss of appetite, bowel care and mouth care, while the Cancer Journey Action Group is working on fatigue and treatment related nausea and vomiting symptom guidelines. Download the Symptom Management Guides to Practice, Algorithms and Pocket Guides from the CCO website www.cancercare.on.ca/symptools



Kate Bak
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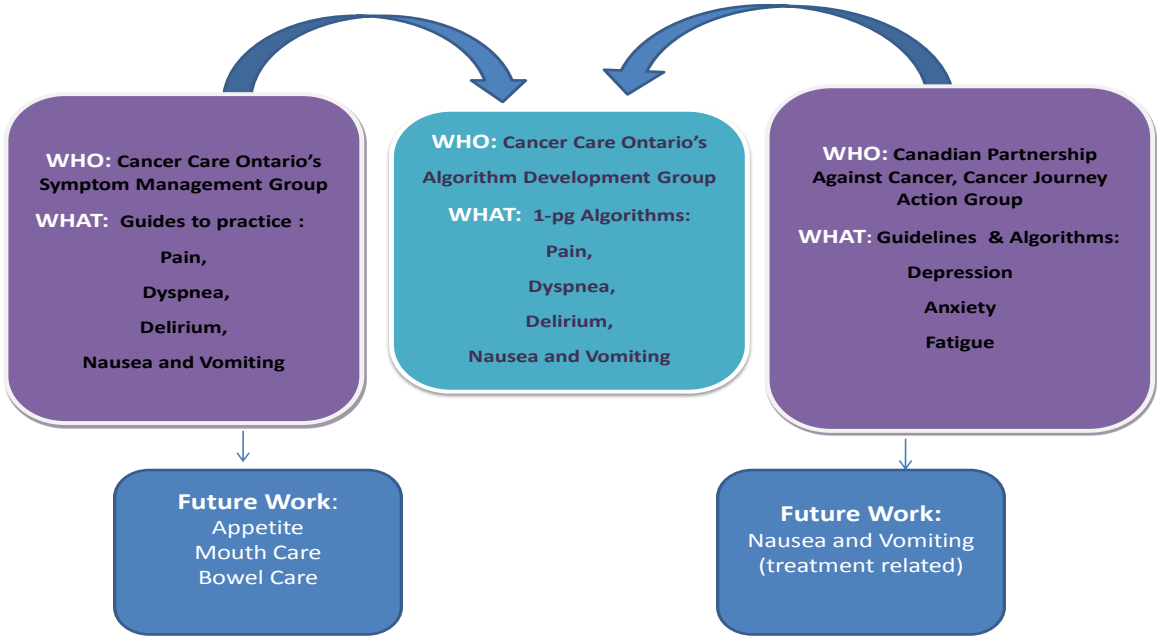
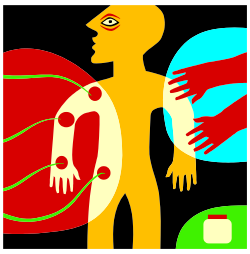
"These resources are the result of the dedication and collaboration of interprofessional groups from across the province reviewing the literature and determining what constituted best practice." Dr Deborah Dudgeon



Regional Program Completes a Stock-take of Ontario Hospital-based Lymphedema Programs

Recently, the Lymphedema service in the Simcoe Muskoka Regional Cancer Program (SMRCP) at the Royal Victoria Hospital evaluated its program. The purpose was to evaluate whether its current program was meeting the needs of the community. To accomplish this task, a questionnaire was developed and sent to various hospitals in Ontario. The results of the survey showed consistency in the challenges faced by hospital-based lymphedema clinics and demonstrated a shortage in lymphedema care across Ontario hospitals. It also confirmed that the SMRCP situation coincides with the majority of hospitals. Unfortunately, a significant number of patients requiring treatments do not have medical insurance to seek out private therapy. We may see the impact of this in the form of long waitlists for treatment in hospitals.

Out of sixteen targeted hospitals, 10 completed the survey. The majority of the lymphedema programs started between 5-9 years ago, highlighting the increase in awareness of lymphedema and the progress in services within the last decade. Program resources range from as little as a few hours each month to 2 full time equivalents (FTE). These programs are staffed by occupational therapists, physiotherapists, or nurses; as single disciplines or as members of a team.



Referrals come from primarily medical or radiation oncologists, surgeons or family physicians. Eight out of the 10 respondents have decided to restrict their referral sources, limiting their services to oncology lymphedema, breast cancer related lymphedema, patients from within their own cancer centre or catchment area. The programs cited the lack of funding, lack of access to health information and low staffing as reasons for restricting referrals.

The programs focus on education, authorization for the assistive devices program (ADP) and exercise instruction. Manual lymphatic drainage (MLD) is provided by half of the programs and is often outsourced to the community.

"Unfortunately, a significant number of patients requiring treatments do not have medical insurance"

Some of the take-aways from the survey for the SMRCP helped to adapt the priority system for patients and appointments for ADP authorization, and guidelines for referral and discharge. Because treatment is offered on an individual basis, they are considering offering a group-based education program for patients currently on the waitlist, with potential to expand to include all breast cancer patients. In addition to offering education, MLD, compression therapy, ADP authorization, and exercises and treatment for musculoskeletal issues related to the Lymphedema this underscores the importance of early education in the management of Lymphedema and reducing risk.

Rowena Hill, PT

For more information and Lesley Moody, moodyl@rvh.on.ca

Continued from page 1 HRSRH Cancer Transition

Northeastern Ontario, including the utilization of alternative methods of delivery including telemedicine to remote communities. The implementation of this program in our region is promising for the development of further Supportive Care interventions geared towards cancer survivorship.

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de Souza Institute Uses Innovative Methods to Educate Nurses about Psychosocial Cancer Care

The de Souza Institute, funded by the Ministry of Health and Long Term Care, aims to inspire and empower Ontario nurses through education and mentorship to provide the best cancer care. Since the Institute's inception, educating nurses about psychosocial issues in oncology has been a priority.

In January 2010, de Souza Institute Educator, Ashleigh Pugh delivered a five hour education session to a specialized group of surgical nurses at Toronto General Hospital. The nurses approached Ashleigh to find ways to identify the degree/depth to which patients and their families struggled with the emotional impact of physically disfiguring surgeries so that the nurses could improve the quality of psychosocial care. The goal of the sessions was to educate nurses on ways to screen for distress, ask difficult questions, and intervene or refer as needed. After delivering the session to 36 nurses, confidence increased substantially across the board. The largest increase in confidence was in response to "applying psychological distress screening tools for the early detection of current, severe, and/or sustained distress" in which confidence rose 60% ($p < 0.05$). Participants received a three month follow-up that included qualitative interviews. Nursing participants indicated they felt better equipped to care for this very complex patient population and were implementing tools learned in the sessions. As a result of the success of the session at Toronto General Hospital, a videoconference was held in August 2010 (which can be viewed here: http://bit.ly/bmxpkM) on some of the basic concepts taught in the previous educational session. The Institute plans on continuing to offer support in psychosocial oncology including workshops, videoconferences, and online courses.

"Since the Institute's inception educating nurses about psychosocial issues in oncology has been a priority."

For more information about upcoming events related to psychosocial oncology, please visit Ashleigh's oncology nursing blog: www.desouzanurse.ca/blog_ashleigh.php or the de Souza Institute website at www.desouzanurse.ca .

Ashleigh Pugh-Clarke

Update on Dyspnea Management Projects

Disease Pathway Management (DPM) is CCO's new approach to setting priorities for cancer control, planning cancer services, and improving the quality of care in Ontario. Focusing on one disease site at a time, DPM brings together multidisciplinary experts, including clinicians, allied health, patients and patient advocates relevant to that type of cancer. Together these teams examine the entire patient journey – from prevention, to recovery to end-of-life care – and identify areas for improvement in the areas of quality of care, processes and patient experience.

Lung cancer was the second disease site of focus for DPM. The lung DPM working groups highlighted that dyspnea is a priority symptom for most lung cancer patients. Evidence has shown that active management and counselling , along with providing practical tips for managing day-to-day activities, can help improve patients' functional outcomes and quality of life. Dyspnea management in lung cancer patients was thus identified as a priority for improvement by the lung cancer DPM team.

In response, Cancer Care Ontario's DPM team held a competition and subsequently funded six cancer treatment centres across the province to develop and implement pilot projects in dyspnea management. Each site is required to make use of existing available resources, including CCO's Dyspnea Symptom Management Guide and Algorithm.

Each centre uses a different approach to dyspnea management. The pilot projects will each report their impact on quality of life, functional outcomes and patient satisfaction. The projects are ongoing and results will be available in mid-2011.

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Credit Valley Hospital's Self-Administered Stress Management Program

It started with a donation to help Credit Valley Hospital (CVH) "get closer to the patients." Based on the volume of positive research surrounding it, CVH's Oncology Supportive Care team launched a Self-Administered Stress Management Training initiative to improve the quality of life of patients undergoing chemotherapy.

Research suggests that training can help with control and reduction in the global side effects of systemic therapy. Specifically, baseline and follow-up questionnaires will be used to measure anxiety, perceived stress, and physical symptoms such as nausea and pain.

The program is based on the work of Dr. Paul Jacobsen, professor of Psychology and Interdisciplinary Oncology at the Moffitt Cancer Center, University of South Florida. Dr. Jacobsen generously donated his copyright and materials which include an instructional DVD and a "Coping with Chemotherapy" participant booklet that outline coping strategies to assist patients in maximizing their mental and physical well-being. The CVH team also professionally recorded an accompanying relaxation CD. Currently, the materials are only available in English but, translation to other languages to serve CVH's ethnically diverse patient population will be considered as needed. Ideally, patients are encouraged to practice the techniques prior to starting their chemotherapy, at least once a day, and are encouraged to keep a practice log. Program participants will be recruited through the weekly interdisciplinary Chemotherapy Education classes starting October 2010.

Despite the body of research that supports this type of programming and the enthusiasm of the clinical community, stress management programs are still rarely available for cancer patients. This may be due to the perception that these interventions are resource intensive. However, the CVH team hopes, as the research suggests, that better access to these programs will offset costs downstream in the form of less calls to nurses, less referrals to psychologists, less trips to the ER with panic attacks, fewer prescriptions for anti-anxiety medications – not to mention better outcomes for patients. The team hopes to gather data to evaluate the effectiveness of this "self-administered" intervention in the Canadian context, publish the results, and eventually consider integrating it into routine care.

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Skills for Coping with Cancer Support Group: Creating Successful Partnerships

In Spring of 2009, The Supportive and Palliative Care program (SPCP) in Thunder Bay, Ontario became involved in a new initiative. The Toronto based, Wellspring Cancer Support Network, entered into collaboration with Hospice Northwest, a local palliative care volunteer agency, to offer support services to cancer patients in Thunder Bay. In consultation with the SPCP, the need for a psycho-educational group for cancer patients and their caregivers, to provide them with tools to assist them in coping with cancer was identified. A group was offered on a weekly basis for people to attend as needed. The group material was prepared by a Supportive Care student, which involved information on breathing, relaxation, visualization and other important topic areas and was organized into four modules. The "Skills for Coping with Cancer Support group" was led by Supportive Care counsellors, which involved an educational component, as well as a hands-on active component (eg. relaxation exercises) that was used throughout the 1.5 hour long sessions. The group attendance was quite low throughout the piloted time frame, however, feedback from members revealed that they very much enjoyed the opportunity to learn and practice these useful skills.

As the Wellspring pilot was coming to an end, this prompted the decision to proceed with the continuation of a similar group. The Wellspring Cancer Support Network fully endorsed our continuing efforts. SPCP and Hospice Northwest joined forces to offer a newly designed group for cancer patients, caregivers, and others with chronic disease. Members can be referred to the six week sessions by referral. The first group will run as a continuation of Wellspring and will be offered October 14- November 18, 2010. Although this will conclude Wellspring's involvement with the program, collaborative efforts will continue both at Thunder Bay Hospital and Hospice Northwest.

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Virtual Tour Assists Newly Diagnosed

London Regional Cancer Program recently launched a virtual orientation at http://lrcp.tours.lhsc.on.ca to assist people who are newly diagnosed with cancer prepare for their first appointment. The site was prepared after consultation with patients and families to ensure that the site included not only helpful information, but also the information that would help to alleviate anxieties around coming to LRCP for the first time.

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"When I found out that I had cancer a couple of years ago, I was terrified. I couldn't believe that it was happening to me," says former LRCP patient Judy Lambers, who hosts the virtual patient orientation. "I had many questions about how my life would change, what I had to do, where I had to go and how long everything would take."

Judy Lambers conducts a virtual tour for LRCP patients. Our goal is to take this a step further, creating similar videos for chemotherapy and radiation therapy patients.

Plans are underway to develop complementary programs to help people who are going to have radiation and /or chemotherapy.

CCO's Patient Experience Upcoming Workstreams

As the Ontario Cancer Plan (OCP III) is launched for 2012-2015, stay tuned for opportunities to join in on new initiatives aimed at improving the Patient Experience along the trajectory of the cancer journey. Specifically, work streams dealing with understanding and measuring the patient experience, improving navigation of the cancer system and increasing patient engagement are being developed, in addition to the already existing CCO Psychosocial Oncology Program and the Ontario Cancer Symptom Management Collaborative.

If you are interested in learning more about the program workstreams please contact:
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We want to hear from you!
Please take our readership survey:
http://www.surveymonkey.com/s/MN32NHB

Working collaboratively to improve the patient experience, and quality of psychosocial care increasing patient satisfaction scores in all cancer programs.

Cancer Care Ontario is the provincial agency responsible for continually improving cancer services. As the government's cancer advisor, Cancer Care Ontario works to reduce the number of people diagnosed with cancer and make sure that patients receive better care every step of the way.