Issue 2

Spring 2009

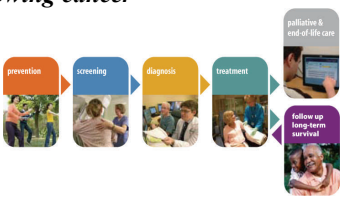
Psychosocial Oncology Program Newsletter

cancer care ontario | action cancer ontario

PSYCHOSOCIAL ONCOLOGY PROGRAM

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

The 2008-2011 Ontario Cancer Plan (OCP) included the launch of the Psychosocial Oncology Program, within Goal 4: Improve the Patient Experience across the Cancer Journey. One of the key goals of the OCP is to: ***meet the realities of the growing cancer burden while improving quality and access and capitalizing on innovation.*** *The intent is to:*



- Span the entire cancer patient journey.
- Set measurable goals and targets and commit to results.
- Ensure access to cancer services throughout the journey.
- Ensure highest quality and safety.

The imperative is to accelerate transformational change and

- Ensure access to services throughout the journey.
- Ensure highest quality and safety.

To meet the goal of the OCP, the Psychosocial Oncology Program Committee spent time meeting to clarify purpose, align goals and begin to define indicators to measure progress. A small group including Scott Sellick, Diane Manii, Pat Brown and Jane Hatton-Bauer met to develop the draft on behalf of the Committee, which formed the basis of discussion and revision by the PSO members. The two long-term goals agreed upon by the members are:

- Improve timely access to quality Psychosocial oncology care; and
- Reduce psychosocial morbidity related to unmet physical, emotional, and practical needs that may include but are not limited to distress, depression & anxiety.

Medium to short term goals included:

- Articulate a model of psychosocial oncology care.
- Implement evidence based guidelines to improve whole person care.
- Increase early and timely detection of psychosocial symptoms.

By articulating the intended goals and objectives of the program, we have provided clarity and focus of the scope of work ahead for the program. We now have the opportunity to develop meaningful measures that can lead to data for planning and reporting across the cancer system.

Esther Green
Provincial Head
Psychosocial Oncology, Nursing
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Update: Psychosocial Oncology Committee

The Psychosocial Oncology Committee (PSO) is "*working collaboratively to improve the patient experience and quality of psychosocial care increasing patient satisfaction scores in all cancer programs*". It has regular monthly teleconference meetings and one face-to-face meeting per year. The group recently had a face-to-face meeting on February 19, 2009. The meeting was well attended and a big success. Sharing information, comparing, standardization and quality improvement are all facilitated through these meetings. Attendance is encouraged with representation from all areas, urban and rural settings and with an interdisciplinary focus..

For more information on the PSO Committee, please contact:

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Inside this issue:

Creating Synergy in the Psychosocial Oncology Program, Ottawa

When The Ottawa Hospital Cancer Center developed the Psychosocial Oncology Program (PSOP) in April 2008, much thought was given to the composition of this multidisciplinary team. The final decision was based on a background document on psychosocial programs of excellence, staff survey, an innovative business plan, and on principles of interprofessional collaboration. In their unique way, each discipline involved in the PSOP strives to provide excellent clinical care, education and participate in research in the cancer field. But central to their work is the focus on the patient experience and improving quality of life for patients and their families throughout the disease continuum.

Consistent with the dyad model of administration at The Ottawa Hospital Cancer Center, the PSOP is comprised of a **Medical Lead** (0.2 FTE) and **Clinical Manager** (1 FTE), who are responsible for the day to day functioning, as well as the overall clinical, academic and research mandates of the program. The role of the **Intake Coordinator** (1 FTE) was created to focus on the referral process and triage, to provide education, as well as crisis and resource counseling. As well as the Intake Coordinator, who is a Social Worker, there are 6.5 FTE **Social Workers** including the Social Work Clinical Practice Leader. This dynamic group provides support services throughout diagnosis, treatment and follow-up. They also provide individual, couple, family and group interventions. The **Psychologist** (1 FTE) provides psychological assessments and interventions, and leads the Research Sub-committee. The **Psychiatrist** (0.6 FTE) treats individuals requiring psychotherapy and/or medications. In future years, we also hope to include a representative from **Spiritual Care**.

To help address the more physical dimensions of psychosocial care, nutritional services are provided by **Clinical Dieticians** (2.4 FTE) to restore or improve nutritional status, help minimize side effects, improve strength and overall quality of life. The **Physiotherapist** (1.0FTE) provides physical assessments and interventions in regards to pain management, increase movement and mobility, restoration of function and education. The **Occupational Therapist** (0.7 FTE) provides functional and cognitive assessments and interventions, and makes home safety recommendations to maximize functional independence. The **Kinesiologist** (0.5 FTE), working directly out of the cancer center's gym, provides fitness evaluations, recommends personalized fitness programs and promotes the importance of exercise during treatment and follow up. The **Speech-Language Pathologist** (0.5 FTE) provides assessment and therapy services to cancer patients with speech, voice and swallowing difficulties. Essential to the professional staff is a 1FTE Clerk who answers phone calls, books appointments and inputs workload for data collection.

By working collaboratively, we hope to create a synergy in which the total collective contribution will be greater than the sum of individual contributions provided in isolation.

And as a team, we are united by our newly developed vision: "The Ottawa Hospital Psychosocial Oncology Program will lead the country in the provision of excellent interprofessional care to improve the experience of people living with cancer and establish this field as an equal partner in oncology".

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Forever Bears: Royal Victoria Hospital, Barrie

A Forever Bear is a real teddy bear that is clothed using material from the clothing or belongings of a loved one who is terminally ill or who has died. The bear's clothing can be made from other material, if that is preferred. When people are grieving it can be comforting to have a warm friend to hug or to talk to and a Forever Bear can be that companion that offers a sense of security to a child at times of sadness and loneliness. The idea for the Forever Bear was taken from the Memory Bear which is offered through an American palliative care corporation and has been adopted to suit the needs of our patients and their families. The Forever Bear is available to children of the Royal Victoria Hospital's Cancer Program and recently has expanded to other programs in the hospital. There is no cost for the bear and 100 teddy bears were donated by Ty Canada to get the project going. We have two dedicated volunteers who passionately craft the clothing for the bears and since it's beginning in May 2008 fourteen bears have been clothed and given to children. The response has been wonderful and parents inform us that the bears have a very special place in their children's lives. Talking about the Forever Bear and planning the making of the bears is therapeutic for dying patients as well as they work on building legacies for their children and families. In May 2009 we plan to celebrate the anniversary of the program by providing a thank you tea to our volunteers who are so dedicated to their work on the bears at the Royal Victoria Hospital in Barrie, Ontario.

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Supportive Care at Juravinski Cancer Centre, Hamilton

The Juravinski Cancer Centre (JCC) at Hamilton Health Sciences serves the Hamilton Niagara Haldimand Brant (HNHB) Region and sees over 5,000 new patients each year. The JCC's Supportive Care professionals represent a variety of health disciplines, working collaboratively to meet their patients' medical, physical emotional, social and spiritual needs. Team members are committed to an interdisciplinary approach to care which is evidence-based and patient and family-centered.

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The Centre's Supportive Care team includes: Aboriginal Patient Navigator, Chaplain, Genetic Counsellor, Mental Health Advanced Practice Nurse and Psychiatrist, Pain and Symptom Management Team: Advanced Practice Nurse, Registered Nurses and Palliative Care Physician, Registered Dietitians and Social Workers.

Some of Supportive Care's innovative programs and initiatives are:

Aboriginal Population: The HNHB Local Health Integration Network (LHIN) has provided base funding for the Aboriginal Navigator position beginning in the fiscal year 2009/2010. JCC will be one of two cancer centers in the province to participate in the Aboriginal Cancer Care Unit's Aboriginal Indicators Pilot.

Evidence-Based Practice: Under the auspices of the Canadian Partnership Against Cancer, one of the JCC staff dietitians is co-leading the development of Tube Feeding and Nutritional Screening Guidelines.

Genetics: With the recruitment to the JCC of a second oncologist with expertise in cancer genetics, planning for a comprehensive Cancer Genetics Program is underway.

Ontario Cancer Symptom Management Collaborative: The Centre's part-time Regional Improvement Coordinator supports this provincial initiative and a number of staff are engaged in related projects: a review of the psychosocial referral needs of patients with ESAS scores of seven or greater for depression and/or anxiety; a detailed chart audit of documented assessments and interventions in response to ESAS pain scores of four or higher; and development of a training program for ESAS volunteers.

Post-Treatment and Survivorship: "Out of the Shadows" is a highly successful psycho-educational wellness program for women completing treatment for early-stage breast cancer. The JCC's healthy eating class for people who have completed cancer treatment has recently been revitalized and re-launched to better meet the needs of patients.

Public Education: Several staff members contribute to *House Calls*, a weekly *Hamilton Spectator* column written by Hamilton Health Sciences experts — recently writing on such topics as genetics and colon cancer risk, nutrition during treatment and spouses supporting ill partners.

Regional Supportive Care Network: There are inequities in access to psychosocial care across the LHIN. The Network will focus on opportunities to collaborate with Family Health Teams and community oncology clinics to enhance the quality and continuity of care.

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Research Initiatives at Princess Margaret Hospital, Toronto

Researchers in the Department of Psychosocial Oncology and Palliative Care at PMH currently hold more than 8 million in research grants from major granting agencies, including CIHR, NCIC, and CBCRA. The department's research activities are subsumed under three, over-arching themes.

Quality of Life and Survivorship. Gerald Devins is leading research on cancer-induced lifestyle disruptions and their effects on quality of life and self-concept as these are shaped by culture, age, sex, and coping in two cancer populations: head and neck cancers and bone marrow transplantation. Mary Jane Esplen is leading research on the psychological implications of genetic testing for breast cancer and psychological interventions to relieve distress and promote well-being of individuals at genetic risk for cancer. Jennifer Jones is evaluating the impact of interventions to assist men in providing effective social support for their wives with breast cancer and is evaluating the validity of proxy caregivers' quality-of-life assessments. Andrew Matthew is studying the impact of screening and interventions to improve psychological adjustment and sexual health in prostate cancer. Norma D'Agostino is undertaking research to facilitate the transition of childhood-cancer patients to the adult setting.

Cancer and the Brain. Lori Bernstein and Kim Edelstein are examining the effects of radiotherapy and chemotherapy on cognitive functioning in adult survivors of childhood cancer and in adults with brain and other cancers treated with chemotherapy. With Norma D'Agostino, they are evaluating the impact of these cognitive effects on quality of life.

Advanced and Terminal Disease. Camilla Zimmermann is evaluating the impact of palliative-care team interventions on patient and family outcomes in a large, cluster-randomized controlled trials of early palliative-care referral. Camilla Zimmermann and Gary Rodin are examining the palliative-care needs and psychological impact of acute myelogenous leukemia. Gary Rodin is investigating predictors of adjustment in advanced and terminal disease and, with Sarah Hales, bereavement morbidity and the quality of death and dying as appraised by the spouses of metastatic cancer patients. Lucia Gagliese is conducting research on measuring cancer pain and clarifying age-related differences in the experience and communication of pain symptoms postoperatively and in advanced disease. Madeline Li is examining the reciprocal interactions among cytokines, biological illness responses, and depression; she is also examining the effectiveness of distress screening for the detection and amelioration of emotional distress. Doris Howell is examining relations between symptomatic distress and illness representations in metastatic cancer. Linda McLean is evaluating an emotion-focused marital intervention for people affected by metastatic cancer.

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If there are topics or issues you would like us to address in the newsletter, let us know!
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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.

National Guidelines: Psychosocial Assessment

Extensive research shows that individuals with cancer experience a myriad of physical, informational, emotional, psychological, social, spiritual, and practical needs in response to cancer that vary at specific time points in the cancer continuum and according to patient and disease factors (Ashbury et al., 1998; Boberg et al., 2003, Fitch, 1994; Gustafson et al., 1993; Richardson et al, 2005, 2007; Sanson-Fisher et al., 2000). The Institute of Medicine reported that many of these needs are not fully acknowledged across cancer systems leading to a high prevalence of unmet needs (IOM, 2008). Unmet needs contribute to physical and psychological morbidity, poor quality of life and increased health care use (Wen & Gustfason, 2004). A national panel of psychosocial oncology and supportive care experts are leading the way to ensure clinicians have the tools they need to reduce unmet needs and improve the experience of living with cancer in the cancer system.

Unmet needs contribute to physical and psychological morbidity, poor quality of life and increased health care use .

The Cancer Journey Action Group of the Canadian Partnership Against Cancer is committed to fostering a person-focused cancer system that is responsive to the full range of psychosocial and support needs of Canadians and their families. In partnership with the Canadian Association of Psychosocial Oncology and the Guidelines Action Group of the Canadian Partnership, we are moving one step closer to this vision with the soon to be released Clinical Practice Guideline for Psychosocial Health Care Needs Screening and Assessment. A national expert panel led by Dr. Doris Howell (Lead, Standards and Guidelines, Cancer Journey Action Group) and Shelley Currie (Lead, Clinical Guidelines, CAPO), reviewed the many international guidelines on the psychosocial care of adult cancer patients and using a systematic adaptation methodology (CANADAPTE) have developed a practice guideline to guide clinicians in psychosocial health care needs screening and assessment. To our surprise most of the existing international guidelines do not make specific recommendations regarding routine psychosocial health care needs assessment, in spite of its importance as an essential precursor to appropriate interventions and access to relevant psychosocial and supportive care services. Consequently, we combined the adaptation methodology with a denova guideline development process based on a systematic review of the empirical evidence. One of the most important findings of the review of existing guidelines, randomized trials and cohort studies, is that screening and assessment alone does not improve patient outcomes unless accompanied by changes in care processes or the actions taken by providers to respond effectively to assessment findings.

The expert panel comprised of an interdisciplinary psychosocial and supportive care experts will make recommendations in this guideline regarding the parameters that should be assessed as part of routine psychosocial health care needs assessment. We have also reviewed assessment and screening instruments and their psychometric qualities to make recommendations about tools that might facilitate screening and assessment. Most important, the guideline supports national and international consensus and empirical findings that screening and assessment alone without preparation of point of care providers to respond effectively in meeting needs will fall short in meeting our goals for a responsive patient-centered care system that can reduce unmet needs and improve quality of life for cancer populations.

The guideline will be posted on the knowledge portal of the Canadian Partnership Against Cancer and will be disseminated as part of the national distress screening initiative toolkit and through knowledge translation strategies to be developed by CAPO as the steward for the guideline. A second part of the guideline that will include recommendations on distress management will soon be released by Cancer Care Nova Scotia in partnership with the Cancer Journey Action Group.

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On behalf of the Expert Panel: Cancer Journey Action Group (CPAC) and Clinical Guidelines (CAPO)