



LG-POP News

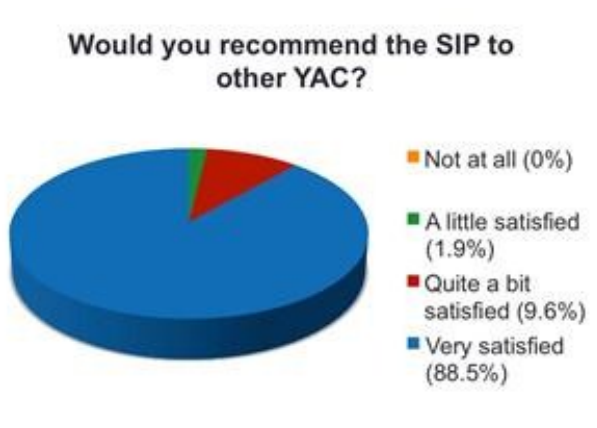
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Addressing the Unique Psychosocial Challenges and Needs of Adolescents and Young Adults with Cancer

Background: For the past 10 years, there has been a steady but dramatic rise in the incidence of cancer in individuals between the ages of 15 and 39, the adolescent and young adult cancer population (AYAC). Despite a small increase in survival rates in the past few years, AYAC constitute an underserved and highly vulnerable population of survivors because of their unique biopsychosocial profiles. In AYAC there is a high incidence of developmental delays in reaching autonomy in several existential areas, increasing the risk of financial hardship, social isolation and psychological distress. Research has also shown that many psychosocial needs of AYAC remain unmet due to the limited

availability of intervention programs and services specialized in AYA oncology, most notably after treatment, during the survivorship phase of the illness trajectory.



Coping Skills Intervention Program (SIP) for Young Adults with Cancer

Research program: The objective of **Dr. Sylvie Aubin's** program is two-fold. First, it is to provide a theoretical framework to better understand and

conceptualize the psychosocial adjustment of AYAC. The program aims to identify the unique developmental, social and sexual repercussions of cancer faced by AYAC and study how they adjust to these impacts across the disease trajectory. Examples of current projects include prospective cohort assessment studies targeting the creation of an AYA psychosocial databank, encompassing issues related to distress screening, mood/emotional, coping style, sexuality, fertility and health-related quality of life. Second, the research program aims to fill the current gaps in psychosocial oncology, specifically to provide interventions designed to address their unique needs and report on empirically-verified data. Attempts to address

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Psychosocial Barriers to Secondary Prevention of Melanoma

Dr. Annett Körner's Health Psychology Research Group seeks to empirically validate interventions that enhance the psychological adjustment, quality of life and health behaviours after a cancer diagnosis. One current project focuses on psychosocial barriers and facilitators of adherence to medical advice regarding the practice of skin self-exams in individuals at high risk for melano-



Health Psychology Research Group

ma. Cutaneous melanoma is the deadliest and fastest growing tumour of the skin, disproportionately affecting younger and middle-aged individuals. Melanomas

can metastasize when only 1mm in depth while most other human cancers start metastasizing after reaching a size of 1cm diameter. While melanomas are visible, recognizable and highly curable in early stages, there are no effective treatments once the tumour has spread. Hence, early detection (and removal of the melanoma) is one of the most effective measures to decrease melanoma-related

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Patient Denial: Family Caregivers Are Frustrated and Angry Too

Objectives: It is widely accepted that cancer impacts the family of a person with cancer, particularly affecting their family caregivers. Patient denial of some aspect of the illness is not uncommon, yet we know little about how patient denial affects these family caregivers. The purpose of this project was to explore the way in which a cancer patient's denial is perceived, experienced, and understood by the patient's family caregivers.

Method: A prospective phenomenological methodology guided the study. Family caregivers of cancer patients who clinical oncology staff believed were in denial were purposefully sampled to achieve a heterogeneous sample in terms of age, gender, and relationship to the patient. Data was collected via semi-structured interviews with 19 family caregivers. Sixteen

were retained, as three did not contain clear evidence of patient denial. Data were analyzed by a team consisting of a social worker, nurse, and psychologist.

Results: Caregivers described their experience of the patient's denial in terms of: the strategies they used to understand it (e.g. knowing the patient's usual way of coping and communicating); the various sources of burden it added (e.g. patients endangering themselves by not following medical advice); its emotional impact on them (e.g. feeling frustrated, angry, alone, disenfranchised); and strategies they used to cope with it (e.g. avoiding confronting denial; using nonverbal cues to communicate with doctors).

Conclusions: Cancer patients' denial had an impact on their family caregivers in many

important ways; affecting the caregivers' well-being, as well as undermining their ability to provide care. Our results have implications for strategies health care providers can use [if patients permit] to enable family caregivers to compensate for the barriers to care imposed by patient denial, so they may be better able to fulfill their caregiving roles, and preserve their own well-being.

More detailed information about this study can be found in the published article:

Naomi R. Kogan, Michelle Dumas, Robin Cohen (2012). *The extra burdens patients in denial impose on their family caregivers*. Palliative and Supportive Care Available on CJO doi:10.1017/S1478951512000491.

Empowering Patients to Master Control When Undergoing Uncomfortable Medical and Diagnostic Procedures

Dr. Sylvain Néron, in collaboration with **Dr. Té Vuong** and colleagues in Radiation Oncology, is conducting research studies on the use of non-pharmacological techniques as an adjunct to other symptom management procedures to help patients take agency and control over uncomfortable medical and diagnostic procedures.

A two-year research project developing a descriptive profile

of the emotional, cognitive and physical experience of a novel brachytherapy procedure in rectal cancer patients using a mixed quantitative and qualitative method was conducted by **Dr. Néron**, **Samara Perez**, **Renata Benc**, **Dr. Zeev Rosberger** and **Dr. Té Vuong**. The results showed that the experience of pain and discomfort varied greatly between patients and was linked to their meaning and perception of: the

treatment, time, body's position, penetrating applicator, patient's sense of agency and empowerment.

Dr. Néron is now planning a feasibility project to look at Hypnotic Intervention during rectal brachytherapy (Pilot Randomized Control Trial) measuring several dimensions (physiological, social support, quality of life, depression and anxiety, self-efficacy, self-regulation) prior, during, and after brachytherapy. This study will not

only involve colleagues from Radiation Oncology, but also, **Dr. Céline Gélinas** from the McGill School of Nursing and the JGH Centre for Nursing Research, as well as **Dr. Ghassan El-Baalbaki** from the Department of Psychology at UQAM. **Mrs. Sarah Provencal**, a PhD candidate, will also be involved in this work.

Sylvain Néron, PhD

Overview of LG-POP 2012

The past year was the fourth in our development, since our original organizing retreat in 2008. We have come a long way. Our overriding goal is to bring the timeliest, cutting edge services in psychosocial oncology to our patients and families. In order to achieve our lofty goals, we are constantly reflecting on ways to improve our services through teaching, training, research and innovation in practice. This philosophy is no different from mainstream medicine. The cancer experience is constantly buffeted by the vicissitudes of diagnostics, treatments, and evaluations interacting with the day-to-day of people's lives. Distress may occur at any point in this trajectory and even far into the future, well into the survivorship years that are

thankfully experienced because of treatment advances. Living with cancer and living into the future without cancer are newly emerging challenges for cancer patients and their families.

In the past year our interdisciplinary team of health care professionals has continued to achieve on all fronts, from clinical care providing psychosocial support to cancer patients and their families, to a myriad of academic pursuits in teaching, training and research. Our researchers have been successful in obtaining new operating grants to continue clinical research in the improvement of care, have presented their work at various scientific conferences and have a number of publications in both the scientific literature and the

popular press. Through the McGill Department of Oncology's *Visiting Speaker's Program in Oncology*, LG-POP hosted two visiting professors, one from the US and one Denmark.

We are very proud of our individual and collective accomplishments, but we do not stand on our laurels. We are moving into new programs such as the implementation of a cancer centre-wide screening for distress in order to identify those patients and their families who may be experiencing challenges in their lives exceeding their capacities to cope. Through screening, we will bring opportunities to intervene and support them in the most timely and effective ways.

Zeev Rosberger, PhD
Director, LG-POP

Psychosocial Challenges and Needs of Adolescents and Young Adults with Cancer

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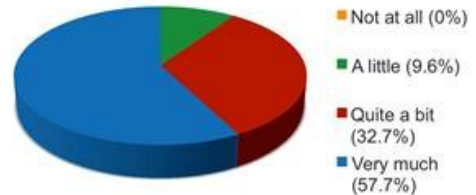
how we should tailor the content and delivery of interventions include a pilot study evaluating the impact of a brief, 3-session intervention (Coping Skills Intervention Program – SIP) specific to young adults with cancer aged between 18 and 39 years and delivered in person or via Skype. This study consists of a randomized control trial (n = 117) with subjects assigned either to the intervention or wait-list group and assessed at 3 time-points (baseline, post and 3-months post-intervention). The study outcomes were measured using a mixed method approach, integrating self-

-report questionnaires with semi-structured interviews. Preliminary data revealed that the majority of participants were satisfied with the intervention and reported that the sessions covered issues that were relevant and useful (90%). These results serve as a basis to design future studies testing the comparative efficacy of the intervention using different clinical modalities and technologies commonly used by AYAC as modes of delivery.

Sylvie Aubin, PhD

What they thought of the SIP (n = 52)

Were the sessions relevant and useful?



LG-POP Members and Their Trainees Present at the 2012 CAPO Conference

The 2012 Canadian Association of Psychosocial Oncology (CAPO) conference: *Shifting Paradigms: New Directions in Psychosocial Oncology*, was held April 25-28th in Vancouver.

Dr. Annett Körner gave an oral presentation on the utilization of information from the fields of dermatology, nursing, health psychology, mental health and education for the secondary prevention of melanoma. Her trainee, **Adina Coroiu**, presented a poster on her research on

skin self-examination behaviours of melanoma patients. **Dr. Alexandra Meyer**, another trainee, presented a poster of her work focusing on the perspective of the volunteer regarding their commitment and role in the support of cancer patients.

Dr. Carmen Loisselle's trainees presented their research studies focusing on: (i) a comparison of the viewpoints between patients and oncology team members regarding the Oncology Interactive Navigator (OIN™)

virtual navigation application (**Kristen Haase**); (ii) the perception of nurse navigators on the use of OIN™ and the development of communities of cancer care practice (**Garnet Lau**); (iii) the use of grounded theory methodology in the study of treatment decision-making of older cancer patients (**Fay Strohschein**).

Dr. Tanya Fitzpatrick presented her work on a pilot study looking at a relaxation intervention to reduce stress of cancer

patients in the oncology waiting room.

Finally, **Dr. Zeev Rosberger** gave an oral presentation on his study of fertility and distress in young men who have recently been diagnosed with cancer. His trainee, **Andrea Krawczyk**, presented her work on parents' decision-making regarding the HPV vaccine for their 9-10 year old daughters.

Gayle A. Shinder, PhD

Psychosocial Barriers to Secondary Prevention of Melanoma

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mortality. Moreover, most melanomas are self-detected and skin self-examination (SSE) results in earlier detection and reduced mortality risk.

Due to the elevated risk of survivors for developing subsequent melanomas, monthly self-exams are strongly recommended by oncology care guidelines. Yet, only a minority of high-risk individuals practices thorough and regular self-exams. Little is known about why individuals avoid self-exams, which is especially surprising as the most

prevalent coping strategies of patients in melanoma follow-up care are "to trust their doctors and to follow medical advice exactly". Despite such contradictions, psychosocial variables like distress, coping, partner and physician support are widely neglected in melanoma research. However, there is first evidence for self-exams triggering tumour fears and for a higher prevalence of avoidant coping behavior in patients with melanoma compared to other cancers.

Hence, a longitudinal study was launched at the JGH and the MUHC to improve our understanding of psychosocial barriers to skin self-exam practice. The mixed-methods approach complements self-report questionnaires with interviews of melanoma survivors, their spouses and clinicians to gain a most comprehensive picture. Already 100 patients enrolled in this 3-year project, funded by FRQS, RTCC and CIHR. The findings will allow health care professionals to better address patient difficulties in adhering to life-saving health behaviour

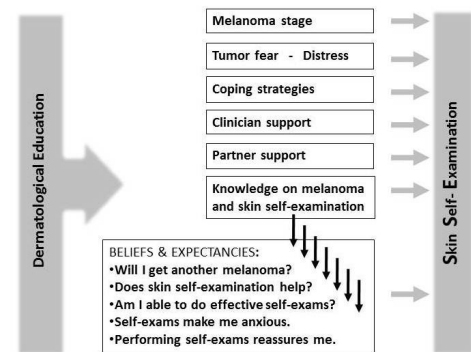


Figure 1. Barriers and facilitators of adherence to medical advice on skin self-examination for early detection of melanoma

and guide secondary prevention strategies for other high-risk populations, i.e., persons with dysplastic nevi, a family history of melanoma or non-melanoma skin cancer, the most prevalent cancer worldwide.

Annett Körner, PhD

Standardized Screening for Distress for Women with Gynecological Cancer: A Review of Trends in Patients' Concerns

N. Drummond, S. Lau, L. Gold, R. Caplan, Z. Rosberger, W. Gotllieb, E. Stephenson

Background: Cancer and its treatments have more than a physical impact, with emotional, psychosocial, spiritual and practical consequences. Distress is a common response across the cancer journey for both patients and their families. Distress is conceptualized as an unpleasant experience of an emotional, psychological, social or spiritual nature that interferes with the ability to cope with cancer. Distress is a dynamic phenomenon, rising and falling over time, as events unfold. In particular it can be elevated for cancer patients at points of transition. These include such times as the initial diagnosis, start of treatment, end of treatment, at the point of recurrence and during the last days of living. Identifying and responding to distress is considered a critical aspect of quality care.

Methods: In a busy clinical setting, computerized tablets with the standardized Distress Thermometer, Edmonton Symptom Assessment System (ESAS) and Canadian Problem Checklist were used to capture data regarding a broad range of physical, psychosocial and practical concerns in order to better understand, respond to and provide patient-centered care.

Results: A review and analysis of data collected after one year of implementation of standardized screening identifies trends in patients' concerns.

Conclusions: (i) Tablet computers linked to a database and patient profile allows for effective analysis of patient concerns. (ii) Analysis of overall trends of concerns for women with gynecological cancer provides direction for resource allocation. In this pilot study fear/worry about self and family as well as physical problems related to sleep/tiredness are examples of where interventions could be targeted at the program level. (iii) The ability to collect patient information from visit to visit and to trend individual patient profiles over time could allow for more targeted conversations and interventions from the health care team. (iv) Improvements in database design to allow for immediate patient profile trending could allow for more tailored cost and time-efficient care.

Conferences

CAPO 2013: *Connecting with Intention in Psychosocial Oncology*, April 24-26, Ottawa, Ontario

IPOS - 15th World Congress of Psycho-Oncology, *Innovation in Psycho-Oncology*, November 4-8, 2013, Rotterdam, The Netherlands

First International Congress on Whole Person Care *Transforming the Healthcare Mandate*

October 17-20, 2013, Montreal, Quebec

Tom A. Hutchinson, MB, FRCPC(C)

What would it be like to participate in a conference that nurtured you, stimulated you, educated you, and sent you home with a new sense of what the practice of healthcare could be, and how you can begin to bring these insights into your own work as a physician, nurse or other healthcare professional?

Whole person care is healthcare that relates to the recipient of care as a whole person (as opposed to a relationship limited to a disease, an organ system, or even a whole body). The intention is to synergize the power of modern biomedicine with the potential for healing of every person who seeks the help of a healthcare practitioner. In this first international congress on the subject we will explore what this means for individual practitioners, patients and the health-



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www.martin-hill.com

care system by bringing together from around the world experts on mindful medical practice, narrative medicine, medical professionalism, and healing in the context of clinical practice.

The meeting will combine plenary sessions, workshops, oral papers and posters to explore the cognitive dimensions of this approach. There will also be a social program designed to encourage rewarding interaction and reflection. In addition, since effective whole person care mandates adequate self-care for the healthcare practitioner, we will provide participants with an experience of self-care and nurturance during the congress (through meditation, music, writing and yoga) that they will be able to take back to their home bases when they leave the conference.

For more information about the program and deadlines for abstract submission please go to www.wpc2013.ca.