Welcome to the October Edition of the MASCC Society News

Message from Editors Anna Ugalde and Anna Boltong

This month we profile a new and unique cancer empowerment measure called the Health Education Impact Questionnaire, which we anticipate will be of interest to MASCC Members. This novel measure allows researchers to assess the benefits of programs designed to support and enhance patient empowerment. We also present good news that MASCC Member Alex Chan and his team have received funding to continue important work into cancer-related fatigue. Three upcoming international conferences are also profiled (including the MASCC Annual Meeting in 2015!). As in prior issues it is our pleasure to introduce you to some new MASCC members. Finally, we include a list of some recent publications from members. We look forward to hearing from you about any publications, presentations, awards, conferences, funding or other achievements.

From your editors, Anna & Anna

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New validated cancer empowerment measure published in Cancer

Cancer support services are now able to measure the benefits of their programs in empowering patients to manage their illness, thanks to the work of Australian and Canadian researchers. Two validation studies of the Health Education Impact Questionnaire (heiQ) as a tool for measuring the impact of support programs on cancer patients’ feelings of empowerment were recently published in Cancer.

Two studies were conducted; one validated the heiQ with cancer patients overall; and the other used heiQ to test if current evaluation tools used in Australia and Canada capture patients’ sense of empowerment – allowing community-based cancer organisations understand and improve their programs. The results are described in these publications:

- Lauzier S, Campbell HS, Livingston, PM, Maunsell, E (2014), Indicators for evaluating cancer organizations’ support services: Performance and associations with empowerment, Cancer, first published online: 2 JUL 2014, DOI: 10.1002/cncr.28846

heiQ assesses key elements of empowerment from the cancer patient’s perspective, including social integration, confidence in help-seeking, navigating the healthcare system, constructive attitudes and approaches, use of adequate coping skills and techniques, and managing emotional distress.

The studies involved researchers from the Université Laval, University of Waterloo and Deakin University and received funding from the Canadian Institutes of Health Research, Propel Centre for Population Health Impact and the Canadian Cancer Society Research Institute.

This new measure goes helps to fill a global gap in the ability to demonstrate the health impact of cancer information and support services in a way that moves beyond assessment of customer satisfaction.
This month we present our interview with Alex Chan (pictured). Alex is leading a program of work concerning fatigue in cancer patients. Recently Alex won a grant to further this work, and a postdoctoral position with his team is now available.

What is your job & where do you work?
I am an Assistant Head and Associate Professor at the Department of Pharmacy, National University of Singapore. I am also appointed as a Specialist Pharmacist at the National Cancer Centre Singapore, to provide patient care and to conduct clinical research. I am also a member of the Board of Directors for MASCC.

Tell us a little bit about this grant?
The project is funded by the National Medical Research Council (NMRC), which is a national funding body in Singapore. The NMRC oversees the development and advancement of medical research in Singapore. It provides research funds to healthcare institutions and awards competitive research funds for individual projects. The co-investigators working with me on this study form a multidisciplinary team comprising pharmacists, medical oncologists, a toxicologist, a nurse and a statistician.

What do you hope to accomplish with this work?
Through this study, we aim to evaluate the prevalence and severity of cancer-related fatigue among Asian breast cancer patients and to identify the biological and clinical determinants of cancer-related fatigue among such patients. We hypothesize that variations in clinical and biological determinants contribute to different severities of cancer-related fatigue among Asian breast cancer patients. The findings will advance our understanding of the presence and severity of symptoms experienced by cancer patients, which will in turn improve current symptom management strategies.

Our ultimate goal is to create a national program to improve the survivorship care provided to cancer survivors. Currently, research effort and services dedicated to cancer survivorship care is severely lacking in Singapore. It is important to note that there is a paucity of studies focusing on the management of symptoms, including fatigue, in cancer patients in Singapore, particularly the clinical effects of cancer-related fatigue that are experienced by cancer survivors. Symptom burden can also be a useful decision-making endpoint for clinicians when choosing treatments and ultimately contribute to the development of quality cancer survivorship care.

Is there any opportunity to work with this team?
We are actively recruiting a post-doctoral fellow to join our research team. This is a 2-year fellowship. The fellow will join a recently funded multidisciplinary research program of cancer supportive care and toxicities management, with a focus on chemotherapy-associated fatigue and cognitive impairment. The focus of this fellowship is to develop the candidate’s ability to conduct clinical research in cancer supportive care. Research responsibilities include development of research protocols, grant writing, data collection in clinical areas, biostatistics, manuscript preparation and submission. Fellows will also supervise undergraduate and postgraduate students. Didactic lecturing opportunities are available, depending on the fellow’s career interest. Interested individuals with a doctoral degree in health-related disciplines are welcome to apply.

To apply, go to http://www.pharmacy.nus.edu.sg/staff/positions/Full-time_research_fellow_position_2014%20AC.pdf

Meet a new MASCC Member, Ann Fonfa

I am the founder and president for a non-profit organisation based in South Florida, USA, called Annie Appleseed Project. Our all-volunteer cancer advocacy nonprofit went online with a website in June 1999 and to date 13 million people have viewed the site. The Annie Appleseed Project organisation is a board member of the National Breast Cancer Coalition and I serve as the volunteer Field Coordinator in the state of Florida. I also am an active Consumer with the Cochrane Collaboration, have done many grant reviews, served on a variety of boards and committees to better represent the patient/advocate perspective. I travel extensively for my work and it is a joy to network and work in collaboration with every group sharing our interests, including MASCC. We had a poster at the MASCC annual meetings in Athens and New York City, and recently in Miami as well. We feel we can help make a difference and offer a patient perspective at the meetings, which is our mission.
Upcoming International Conferences

Two very exciting international oncology conferences that are pertinent to supportive care in cancer are on the horizon for the remainder of 2014.

The International PsychoOncology Society (IPOS) 16th World Congress will be held later this month in Lisbon, Portugal. This meeting marks the 30th anniversary for IPOS and the theme will be: Integrating PsychOncology into Mainstream Cancer Care; from Research to Action. The conference runs from 20 – 24 October, with the first two days dedicated to a series of pre-conference workshops. For more information go to [http://www.ipos2014.com/](http://www.ipos2014.com/) and onsite registrations are available.

In addition, please don’t forget to save the date for the 2015 MASCC/ISOO Annual Meeting on Supportive Care in Cancer which will be held in Copenhagen 25-27 June, 2015. Register your contact details on the conference webpage to receive updates and information about the conference as it comes to hand [http://kenesforms.kenes.com/mailing/mascc2015/](http://kenesforms.kenes.com/mailing/mascc2015/).

Meet a new MASCC Member, Marie Flannery

I am an Assistant Professor at the University of Rochester Medical Center in Rochester, New York. My primary appointment is in the School of Nursing, and I have secondary appointments in the Wilmot Cancer Institute and Department of Surgery. My current role is primarily as a researcher focused on the supportive care of patients with cancer. I study the multiple symptoms that are experienced by individuals with advanced solid tumors, and explore potential interventions that can decrease the burden of their symptoms and improve the quality of their lives. We recently completed a descriptive study of over 5000 telephone calls made by cancer patients when reporting their symptoms to the ambulatory centre (published in Oncology Nursing Forum 2013, 40, 464-471), finding that pain is the most common symptom reported. I have also just completed a pilot, randomized clinical trial of a telephone-based intervention for individuals with advanced lung cancer who are experiencing pain and other symptoms. This analysis is ongoing, and I plan for the results to provide preliminary data to support funding of a phase II RCT. The focus of MASCC and the quality of the science at the meetings, and published within the journal Supportive Care in Cancer, is an excellent match to my personal research interests. After attending and presenting at the recent Miami meeting, I am convinced I have found an organization I want to be involved with throughout my professional career.
I am an Associate Professor at the Department of Health Outcomes and Policy and Institute for Child Health Policy, College of Medicine, University of Florida, Gainesville, Florida, since 2005. I am also a graduate faculty member at the University of Florida. Starting in September 2014, I have become a new faculty member at the Department of Epidemiology & Cancer Control, St. Jude Children's Research Hospital in Memphis, Tennessee. I will dedicate my research efforts in pediatric cancer survivorship at St. Jude. I completed my PhD and a Post-Doctoral Fellowship at Johns Hopkins University in health services and outcomes research, with a special emphasis on measuring patient-reported outcomes (PROs; typically health-related quality of life) using advanced methodologies. I was trained to assess provider and patient factors that contribute to PROs, and use psychometric methods to develop and validate PROs instruments. Given the limitations of PROs instruments in pediatrics, I apply modern test theory (e.g., item response theory; IRT) alongside qualitative methods to improve PROs for pediatric clinical uses. My most recent exciting research has been published in the Journal of Clinical Oncology; this study investigated the associations of 12 different symptom classes with health-related quality of life in long-term survivors of childhood cancer (Citation: Huang et al., Journal of Clinical Oncology 2013; 31(33): 4242-51.). I attended my first MASCC annual meeting 2 years ago in New York and presented a study at this conference. I realize the MASCC annual meeting really focuses on the topics that I want to pursue and I had an opportunity to present a proffered paper/study in a plenary section of this year’s meeting.

**Publications from MASCC members**

2. Bourion-Bédès S, Schwan R, Epstein J, Laprevote V, Bédès A, Bonnet JL, Baumann C. Combination of classical test theory (CTT) and item response theory (IRT) analysis to study the psychometric properties of the French version of the Quality of Life Enjoyment and Satisfaction Questionnaire-Short Form (Q-LES-Q-SF). Qual Life Res. 2014 Aug 12.
Publications from MASCC members, continued


Have any news items to share?

Please send contributions for the MASCC News to MASCCnews@mascc.org or the co-editors:

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