Editorial

By May Tsao, MD, FRCPC, Department of Radiation Oncology, Sunnybrook Odette Cancer Centre, University of Toronto, University of Toronto

Dear Hot Spot readers,

In this article of Hot Spot, the new Sunnybrook CNS Oncology Radiosurgery (SCORS) is highlighted. In addition, articles on ethics (Dr. Monica Branigan), research (Drs. Julie McDonald and Camilla Zimmermann and co-authors), patient and family support (Lina Gagliardi and her team), end-of-treatment workshop (Dr. Janet Ellis et al.) and educational activities (Dr. Ewa Szumacher) are provided. The three inserts are on “Latest Advances in Treatment for MDS” by Dr. Rena Buckstein, “2015 Best of ASCO on Lung Cancer” by Dr. Parneet Cheema, and “ASCO Update on Renal Cell Cancer” by Dr. Xiao Zhu. The editorial board would like to extend our thanks to the contributors and we hope you continue to find these articles useful and interesting.

Announcing the Sunnybrook CNS Oncology RadioSurgery (SCORS) Clinic: A multidisciplinary brain and spine radiosurgery service for your patients

By Dr. Arjun Sahgal, Associate Professor of Radiation Oncology and Surgery, Deputy Chief, Department of Radiation Oncology, Site Group Leader CNS Oncology, Clinician Scientist Sunnybrook Research Institute, Affiliate Scientist – Toronto Western Research Institute, Director of the Cancer Ablation Therapy/MR Linac Program, Department of Radiation Oncology, University of Toronto, Sunnybrook Health Sciences Centre

The Odette Cancer Centre has been a leader in stereotactic radiosurgery for the brain and spine for several years. The latest data presented at ASCO (Paul Brown et al.) have further proved that radiosurgery alone results in better neurocognitive function, as compared to whole brain radiation for patients with limited brain metastases. As a result, we are expanding our program and announce the Sunnybrook CNS Oncology RadioSurgery (SCORS) Clinic, which represents a multidisciplinary neuosurgical, medical and radiation oncology clinic for CNS and spine patients.

This clinic occurs every Wednesday morning and is able to rapidly accommodate patients with brain metastases (typically up to 10 metastases are eligible), functional brain disorders like trigeminal neuralgia, benign brain tumours (for example, acoustics and menigioma) and spine tumours for stereotactic radiosurgery. To make life easier you can put “SCORS clinic” on the referral. Weeks 1 and 3 and 5 will be staffed by radiation oncologists Drs. Arjun Sahgal, Sten Myrheaug; weeks 2 and 4 by Drs. Hany Soliman and May Tsao; and each week from neurosurgery organized by Dr. Todd Mainprize. We are also lucky to have Dr. James Perry, Medical Neuro-Oncology.

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Creating the new normal: Medicine post Carter

By Monica Branigan, MD, MHSc Bioethics, University of Toronto

In our work as health care professionals, we deliver news on a daily basis that changes our patients’ lives profoundly. We then work together to help them create a “new normal”. Our profession has been delivered of such news with the Supreme Court ruling of February 6, 2015. This ruling, known as the Carter decision, struck down the prohibition against physician-assisted dying. After February 6, 2016, the sections of the Criminal Code that prohibit physician-assisted dying will be invalid “for a competent adult person who:”

(1) clearly consents to the termination of life; and

(2) has a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition.”

Carter v. Canada (Attorney General), 2015 SCC 5

What will this “new normal” look like? To begin with, the conversations we have with our patients will change. Previously when we discussed a request to hasten death with a patient, we focused on deeply understanding their suffering. While this will remain our core role, we may be asked to take the role of evaluator or judge. How will we evaluate “grievous” and “irremediable”? And what about “enduring”? We know that patients are particularly vulnerable to emotional distress and hopelessness at certain points in their illness: diagnosis, major functional change, and the reality of mortality. We also know that many patients can accommodate a new normal with time and support.

So how are we, as a profession, accommodating this new normal? Patients are asked to live with the reality of dying. As a profession, we are being called to be healers with the possibility of hastening a profession, we are being called to be asked to live with the reality of dying. As we accommodate this new normal? Patients are

involve all members of the team/community. Elements for success include: formal dedicated time as well as informal conversation, consideration of anticipated level of involvement in physician-assisted death either through a survey or case scenarios, continued feedback and engagement with senior management at your institution.

Patients often tell us that when they create their new normal, there are unexpected positive outcomes. I believe this may be possible post Carter. Practising in our new normal may stimulate us to truly pay attention to suffering in a deeper way. Many of us have been taught that detached concern is the appropriate professional stance. When we are faced with this deep suffering, we may be called upon to have another, more effective stance—that of engaged curiosity that seeks to truly understand. This may make us better professionals and make our work more fulfilling, as we experience compassion first hand—for our patients—and ourselves in our challenging new role.

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within the clinic to enhance our ability to deliver multidisciplinary care. Dr. Michael Schwartz will be there for AVM as a Sunnybrook pioneer in the field.

Furthermore, our inter-professional team also includes Lori Holden, who is a dedicated clinical radiation therapist specialist, who manages and also attends each of these clinics, and can be reached at lori.holden@sunnybrook.ca. We are also fortunate to have our other team members, Nurse Practitioners Claire Moroney and Christina Mueller in conjunction with nursing staff from the CNS and radiation sites, as well as the broader allied health care team of social work, nutrition, and pharmacy to support our patients. We also have an expert dedicated CNS medical physics group led by Dr. Young Lee, committed to further the field of SRS. If you have any questions don’t hesitate to email arjun.sahgal@sunnybrook.ca.
Exploring the effects of early palliative care on caregivers of patients with advanced cancer

By Julie McDonald, MBChB, Breffini Hannon, MBChB, Shan Mohammed, RN, PhD, Nadia Swami, BSc, Camilla Zimmermann, MD, PhD

There is now robust evidence that the provision of early palliative care (EPC) can improve outcomes for patients with advanced cancer, including quality of life (QOL), symptom burden, satisfaction with care, and, in some cases, survival.1,2,3,4 This is a positive step for patients, with many cancer centres around the world adopting an EPC approach. Family caregivers of these patients have also shifted into the spotlight, as clinicians and researchers investigate whether the complex needs of caregivers are adequately addressed. We have previously reported in Hot Spot our findings that EPC led to improved QOL, symptom control and satisfaction with care of patients with advanced cancer.1,6 Here we present secondary results of caregiver outcomes for the same trial, which we are in the process of submitting for publication.

Caring for cancer patients can lead to increased anxiety, depression, physical morbidity and mortality in caregivers.2 Current interventions to improve caregiver QOL have been centred on education on symptom management, practical caregiving skills, developing coping strategies, and therapeutic counselling.3 Meta-analyses of these interventions detect improvements in caregivers such as decreased burden, depression and distress; better coping; and improved QOL.4 Despite these benefits, few interventions for caregivers have been implemented widely, mainly due to financial and clinical resource limitations.

We conducted a cluster-randomized controlled trial (RCT) of an EPC intervention versus standard oncology care.7 In addition to 461 patients with advanced cancer, we also recruited 182 family caregivers in order to conduct exploratory analyses regarding the effects of the intervention on caregivers. The sample size for caregivers was not calculated in advance, and the study ended when our target sample size for patients was reached. Caregivers completed validated measures at baseline and monthly for four months, assessing QOL (Caregiver QOL-Cancer and SF-36v2 Health Survey), and satisfaction with care (FAMCARE). Satisfaction with care improved significantly over time in the EPC group compared to controls (p=0.01). There was no significant difference in QOL scores.

To further elucidate the effects of EPC on caregiver QOL, we invited caregivers to participate in qualitative interviews following completion of the RCT. Using a grounded theory approach, we analyzed data from 23 caregivers (14 intervention, nine control) who completed semi-structured interviews. The results revealed themes related to QOL in the intervention versus control group that were not identified in the quantitative measures. These included a greater willingness to discuss mortality and advanced care planning; more prevalent positive coping strategies; increased access to practical supports at home; and a broader life perspective.

We also conducted a subgroup analysis of 13 patient-caregiver pairs (five intervention group pairs, eight control pairs). Intervention pairs showed remarkable congruency in the content of their interviews. They were more likely to report positive changes in shared priorities and strengthened relationships, and described improved communication about the future. In contrast, control group pairs were more likely to report divergent priorities and to be avoidant of end-of-life discussions.

The results of these qualitative analyses highlight important aspects of caregiver QOL that are not currently captured by existing quantitative tools, and suggest potential reasons why the quantitative QOL analyses did not detect a difference. The inclusion of topics elucidated as themes in our qualitative analyses (such as confronting mortality, coping strategies, and aligned priorities) should be considered for future caregiver QOL quantitative measures.

We also conducted further qualitative interviews with 61 caregivers of patients who completed the RCT (30 intervention, 31 control) six months to five years after the patient’s death, to establish a more complete picture of the experience of caregiving. Themes corresponding to the care coordination roles of caregivers across phases of a home death included: structuring the home as a place for dying; negotiating relationships with health care providers; ensuring supports for the active dying phase; and managing bureaucratic challenges after death. Caregivers of patients who received palliative homecare described receiving more support. This study highlights the administrative and organizational challenges faced by caregivers while also enduring emotional strain.

The results of the above studies contribute to the emerging evidence that EPC can have a positive impact on caregivers across multiple facets, from improving satisfaction with care to strengthening patient-caregiver relationships. It is more difficult to assess the effects of EPC on caregiver QOL, particularly as this study was not powered for caregiver analyses. As others have suggested, specific interventions directed at caregivers may be needed to demonstrate an impact on their QOL.5,10 However, our qualitative data showed improvement in areas that were missing in current quantitative QOL measures, which may be useful for future measure development. Overall, early, sustained palliative care may help fill the gaps in cancer care through a holistic approach to the care of both patients with advanced cancer and their families.

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REFERENCES

Advance Care Planning—Let’s start the conversation…

Why are we talking about Advance Care Planning now?

By Lina Gagliardi, Tracey Das Gupta and Dr. Jeff Myers, Sunnybrook Odette Cancer Centre

Advance Care Planning is emerging as a Quality Care Initiative in Ontario and across Canada. At the local level, here at Sunnybrook, we are integrating Quality Dying Best Practices into our day-to-day care. Our Quality Dying Initiative has three areas of priority: Comfort Measures for end-of-life care, Goals of Care for current care, and Advance Care Planning (ACP) for future care.

We are currently focusing on ACP so that our patients, their decision makers, and our health care providers can close the gap in conversations about future care that is too often unspoken. As a health care provider, substitute decision maker and person, having discussions about what is important at the end of life when decisions need to be made is often perceived as a “depressing thought”. Many are uncomfortable to talk about death and dying. Advance Care Planning offers the opportunity for patients and their substitute decision makers (SDM) to discuss important information while they are able to help guide future health care decisions.

For the most part, these early conversations are not happening. This is why we often end up focusing on life sustaining measures or code status in a crisis situation or when death is imminent. Without understanding the whole person, what is important to them, and the persons’ prior expressed wishes, substitute decision makers often find it challenging to make decisions on the person’s behalf, when needed. Imagine if we were able to have these conversations with our family or decision maker at home, when we are calm and could think or imagine the future without pressure. In this way, we could really reflect on what our wishes would be for future health care decisions. Since it is difficult to influence people’s personal environment, we are beginning to have these conversations here in hospital. One of the key purposes of ACP conversations is to enable patients time to reflect on their beliefs and what they define as “quality of life” for themselves with support, guidance and information from their health care team. Ideally these conversations would happen at home or at a primary care providers’ appointment. However, we are starting the conversation at Sunnybrook.

So what is ACP?

• A process an individual undertakes to reflect on and discuss their values, as they relate to their health
• A way to express wishes and preferences for future care
• Based on current health care context, but refers to potential care needs in the future
• Giving the substitute decision maker information to help guide decision-making if the person is incapable
• Must occur while a patient still has capacity
• An iterative process — conversations happen over a period of time and can happen across care settings
• A written plan does not need to be produced as a product of this process

Research has shown that when ACP conversations take place, the impact and outcome can be significant. A study conducted in a large urban hospital in the U.S. by Detering et al. in 2010 concluded that:

• End-of-life wishes were known and respected for those who died
• Overall patient and family satisfaction was positively impacted when patient/SDM were involved in decision-making
• The level of distress of the SDM and family members who were charged in making those decisions decreased.

As of July 2, 2015, our Electronic Medical Record, in SunnyCare, will have available an “ACP/Goals of Care” note so that teams caring for patients regardless of prognosis? These conversations can now be documented in SunnyCare in the new “ACP/Goals of Care” note so that teams caring for patients can access this information and have a more holistic understanding of what is important to patients: a foundation of Person-Centred Care.

A Patient Advisor at the Odette Cancer Centre offered this reflection: “We all share the living and dying journey. I know that people who work here do excellent work, but talking about what is important and meaningful, as we journey towards the end of life, is hard.”

Do you reflect on your future health care decisions? Do you know who your health care decision maker is? Is this person who you would want to make your decisions in the future? If not, have you considered appointing a power of attorney for personal care? If yes, do they know what is important to you and your wishes?

If you have not considered any of the above, STOP and consider... WHY? Let’s start the conversation for ourselves and those we care for.

REFERENCE

Each cancer journey is unique to the cancer and the person, but the peaks of stress are often predictable. Diagnosis brings shock and enforces changes in work, roles, and family life, as well as self-concept with a loss of health. In some ways, treatment can be likened to being given a job, albeit unwanted, with clear instructions, expectations and itinerary. There is often a sense of “fighting the cancer” together with the oncology team with some relief from the initial shock with adaptation to the threat and life changes. Most people assume that if they have managed to go through treatment feeling strong, they will sail through the end of treatment. However, the end of treatment has its hidden stressors.

First, there is a loss of the treatment structure and the regular contact with the oncology team. This is disorienting for some and there may be a sense of abandonment, as a result. Hopes and expectations to return back to “normal” have also been shown to increase distress, suggesting a need for proactive education on potential difficulties with transitioning at the end of treatment. Without education, expectations from self and others may be that “normal life should resume” after treatment. The person is often expected to get on with the business of living, as if their life threatening diagnosis and treatment had not occurred. The problem with this is that the person may not feel back to normal emotionally or physically. They may still need to make adjustments in sense of self, recover from side effects of treatment and, in some cases, adapt to permanent changes such as a mastectomy, menopause or anti-androgen therapy from prostate cancer.

Most of us live with the illusion of control—so a diagnosis of cancer and having to go through recommended treatment pathways can be associated with a sense of powerlessness and an awareness of a lack of control. People who like to plan or who have significant death anxiety may have more difficulty adapting to the “dual reality”, which describes the ability to live fully despite the knowledge of one’s own mortality; the human condition we all share. Death anxiety can be paralyzing. It can be measured by the DADDS, which examines the fears and anxiety surrounding loss of time, opportunity, and impact on loved ones. A good book on this subject is *Staring at the Sun* by Yalom. If someone fears that their cancer will shorten their life, they may experience anticipatory grief for perceived loss of future. This is very painful at first, which may cause the person to try to avoid such thoughts. If this strategy fails, the person may become sad, anxious and have disturbed sleep due to these ruminations and fears. “Living with uncertainty” may result in an urge to “wait for the next CT scan” before making any plans. This may be a necessary or reasonable during the first three months, but it can become a habit, keeping the person’s life on hold. One of the greatest distress burdens among breast cancer survivors post treatment is the fear of cancer recurrence. This might result in preoccupation with bodily symptoms and sensations, fearing the return of cancer.

It is important for people to know that these issues and feelings are common and that they can seek support if they experience ongoing or increasing distress or a sense of remaining in limbo. Information should be provided about online peer support groups, community support, such as Wellington and Gilda’s Club and our Patient and Family Support Program. It may only take a couple of visits to make a difference. Coping skills can be augmented, simply having someone to talk to can be helpful. If necessary, anxiety or depression can be treated. Sunnybrook’s department of psychiatry now offers Mindfulness Based Group Therapy, which helps to feel present in the moment, rather than to ruminate about the past or worry about the future. To prepare our patients and family members for the end of treatment, the Odette Cancer Centre will offer two education and support opportunities from the fall: “Coping with the End of Treatment” and “How to get on with the Business of Living” drop in group 5:00-6:30pm on the second Thursday of the month (with psychiatrist Dr. Janet Ellis), as well as Angela Leahey’s “Now what?: Life After Breast Cancer” class offered monthly on a Thursday morning from 11:00-12:30 in the Louise Temerty Breast Cancer Centre (M wing; 6th floor M6-412). Contact number is 416-480-5000 ext. 1004.

In turn, oncology and transitional care teams should be aware of who might be at greater risk of developing significant distress (depression [15%], anxiety [10%] and social difficulty [30%]). Those with a past psychiatric history, substance use disorder, medical comorbidity; additional life events or lack of social support should be screened carefully for distress and offered specialized psychosocial support. We know that less than half of those with significant distress access extra support and that untreated distress leads to delayed or disrupted treatment, hospital admissions, increased length of stay and worse outcomes, as well as unnecessary suffering to the patient and their family.

However, those who work in this area witness how amazingly resilient most people are, whatever the demands or trajectory of their cancer journey. Whilst adaptation to many of these feelings and fears is often painful initially, most people do come through; even if they need extra help. Many experience what is described as “post traumatic growth”—a true appreciation for each day, for being alive (previously taken for granted), a clearer sense of priority, of what is important and not ‘sweating the small stuff’, a greater sense of spiritual well being and increased connection to loved ones.

*References available on request to Dr. Janet Ellis at Janet.Ellis@sunnybrook.ca*
Continuing Medical Education 2015
By Ewa Szumacher, MD, FRCP(C)

Continuing Medical Education (CME) can update health care professionals on the latest advances for modifications to their clinical practice. At the request of the CME organizers, Hot Spot will list the national and international CME activities in palliative medicine that are of interest to our readers. Please forward details of the CME activities to: Ewa.Szumacher@sunnybrook.ca

- **October 30th, 2015.** Immuno-Oncology and Best of Lung Summits 2015 – Held at the Evergreen Brickworks in Toronto, Canada. Both summits will present the most significant data from the ASCO 2015 and ESMO 2015 annual conferences, with presenters providing expert, in-depth analysis and discussion to update attendees on improvements to the current standard of cancer care. http://www.oncologyeducation.com/events/upcoming-events/

- **November 6th-8th, 2015.** ESMO Summit Americas 2015 – Held at the Fontainebleau Hotel in Miami Beach, Florida, USA. This international meeting is licensed by the European Society for Medical Oncology (ESMO), and will highlight the most significant, practice-changing data to emerge from the ESMO 2015 Annual Conference and put it into context for an anticipated audience of more than 200 oncology professionals from across the Americas. http://www.oncologyeducation.com/events/upcoming-events/esmo-americas-summit/conference-home/

- **November 20th, 2015.** Best of Oncology East Conference 2015. Held at the Westin Harbour Castle in Toronto, Canada. This meeting is organized by OncologyEducation.com and the Community Oncologists of Metropolitan Toronto (COMET), and is co-chaired by Dr. Robert El-Maraghi, Dr. Dorothy Lo, Dr. Sunil Verma and Dr. Scott Berry. This meeting will highlight the top 3-4 most clinically relevant achievements of 2015 for nine different tumour sites. http://www.oncologyeducation.com/events/upcoming-events/best-of-oncology-east-2015/conference-home/

CME courses:

Navigating Later Lines of Treatment for Advanced Colorectal Cancer: Optimizing Targeted Therapies to Improve Outcomes. This case-based course presents systemic therapy options available for metastatic colorectal cancer beyond the first-line setting, as well as the current utility of predictive biomarkers in the disease. This activity is an Accredited Group Learning Activity (Section 1) as defined by the Maintenance of Certification program of The Royal College of Physicians and Surgeons of Canada, for 1.0 MOC. This activity was approved by the Canadian Society of Internal Medicine. Register and visit our CME portal for more information. http://cme.oncologyeducation.com


- **February 12–14, 2016.** The 23rd International Conference of the Indian Association of Palliative Care (IAPCON 2016), Hotel Hyatt Regency, Pune, India. http://iapcon2016pune.in/welcome.html


- **October 17–21, 2016.** The 21st International Congress on Palliative Care, McGill University, Montreal, QC. https://www.mcgill.ca/palliativecare/congress

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