HOT SPOT

The Newsletter of the Rapid Response Radiotherapy Program
of the Odette Cancer Centre

Sunnybrook
ODETTE CANCER CENTRE
A Cancer Care Ontario Partner

Volume 13, Issue 1, February 2011

Editorial

By Dr. Arjun Sahgal, MD, FRCPC

In this fascinating issue of **Hot Spot** we touch base on several key areas pertinent to cancer care. We gain perspective on a cancer patient's journey as a parent, and again an area that we may not be so focused upon when discussing management of the illness itself. There are supports available through the Odette Cancer Centre's Patient and Family Support Program and Denise Bilodeau describes several key issues that patients and families face in a thought-provoking fashion. A list of children's resources for support is provided by Julie Burnett.

At the Sunnybrook Health Sciences Centre and the Odette Cancer Centre, a major advance in cancer treatment is being researched involving the use of MRI-guided ultrasound as a cancer therapy. Drs. Dennis and Czarnota describe the use of this technology in the treatment of bone metastases, and an exciting clinical trial designed to evaluate this therapy as an alternative to radiation therapy. There is no doubt that therapeutic ultrasound will develop into an established cancer therapy. We are lucky at Sunnybrook to have the technology and several world leaders in the field guiding the development of this treatment from which our cancer patients benefit. Stephen Jenkinson shares his thoughts in "It takes a village".

Rosanna Macri describes the issue of informed consent in a way that forces us to remember that not all the information we give to a patient is remembered, and the importance of revisiting key toxicities that can affect a patient's life even more than the cancer itself. It is very interesting to read her perspective, as a student in bioethics, as we often do not interact with students in this discipline. A complete list of CME events for 2011 is also provided by Dr. Ewa Szumacher.

The insert for this issue is by Dr. Urban Emmenegger: "Rapidly changing landscape of systemic therapy for castration-resistant prostate cancer."

We hope you find this issue interesting to read.

In this issue of Hot Spot:

Facilitating parental competencies in the face of cancer

By Denise Bilodeau, MSW, RSW, on behalf of the Patient and Family Support Program, Odette Cancer Centre

The recently published American study estimates that 18 per cent of individuals with a newly diagnosed cancer were the parents of one or more minor children (Weaver, Rowland, Alfano, & McNeel, 2010). Using numbers generated by the Canadian Cancer Society, this percentage would translate to mean 31,300 Canadian parents of young children will be diagnosed with cancer this year. In their article, "On Being an Ill Parent", published in *Clinical Child Psychology and Psychiatry*, Altschuler and Dale (1999) note that, despite the growth of interest and research into the psychological implications of illness for the family, adults are not routinely asked about their children or given the

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Facilitating parental competencies in the face of cancer

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opportunity to talk about the impact of illness on their ability to parent. While this lack of questioning may represent an attempt by health care professionals to protect the division between parent and patient, failing to address the implications of illness for parenting may, in fact, increase the distress experienced by emphasizing their identity as patients and leaving them unaided in their attempts to parent in the face of cancer.

There can be few tasks that prove more challenging, as a parent, than striving to maintain integrity within the parenting role while addressing their own anxieties in the face of a cancer diagnosis. Parenting demands a commitment to caring for others. However, the urgency of self-care demanded by a newly diagnosed or recurrent cancer may mean that a parent's own needs come into direct competition with attending to the needs of their children. Although many parents find a resolution that feels satisfying to them without outside intervention, many other parents struggle with these dual demands and are receptive to the opportunity to receive guidance and support in their parenting role.

The social workers in the Odette Cancer Centre's Patient and Family Support Program are, at times, approached by patients seeking support and information on how to address the needs of their children in the context of this diagnosis. While frequently able to meet directly with patients and their children, for reasons of logistics and, at times, the reluctance of parents to expose their children to the cancer centre environment, we have incorporated a psycho-educational model to enable us to support these parents while fostering and reinforcing their own competency in the parenting role.

Parents are, at times, understandably concerned about the effect their illness will have on their children and are usually quite open to exploring ways to approach this apprehension. Parents are encouraged to talk to us about their children—their age, their temperament, their personalities—all of which can provide important insight to us, as practitioners, as well as to the patient about how each child may react to the parent's illness. By reflecting on typical developmental issues outside of the cancer milieu, we are able to provide some perspective on how much of a child's behaviour may be age-appropriate, the goal being to present a balance that respects the adaptability of children without undervaluing the impact of illness. Through a discussion of the ways they and the family have coped with past challenges, we are also able to support parents in their expertise in parenting their children through difficult times.

It is helpful to provide parents with a developmental perspective on how children understand medical illness, as this can assist them in providing age-appropriate information and anticipating some of their informational needs. As an example, pre-school-age children are egocentric and engage in "magical thinking", which may lead them to believe that they can cause the events in their world, including a parent's illness. Parents of pre-school-aged children can be encouraged to invite their children to share their ideas about what caused the cancer so that misconceptions can be identified and dispelled.

Despite the good intentions of parents who hope to protect their children from potentially anxiety-provoking

Children's resources

By Julie Burnett, BA(Hons), BSW, MSW, RSW

Wellspring
www.wellspring.ca

- Support groups at Wellspring locations in Brampton, Halton-Peel and Toronto for children and their parents

Gilda's Club
www.gildasclubtoronto.org; **www.gildasclubbarrie.org**

- Support programs at Gilda's Club locations in Toronto and Barrie for children, teens and their parents in Toronto and Barrie

Hearth Place Cancer Support Centre
www.hearthplace.org

- Kids Connection—support group for children who are coping with the serious illness of a loved one
- Healing Kids Hearts—bereavement support group for children who have lost a loved one to cancer

Max and Beatrice Wolfe Centre for Children's Grief and Palliative Care
Temmy Latner Centre for Palliative Care
www.tlcpc.org

- Dr. Jay Grief Program—educates and supports children who have a loved one who is dying or who has died

Dorothy Ley Hospice
www.dlhospice.org

- Support is available to children and teens whose parent/sibling is dying

Hospice Toronto
www.hospicetoronto.org

- Kit for Kids program—supports children who have a family member living with a serious illness
- Young Carers program—supports young people who are 18 years and younger who provide a substantial amount of care to a family member on a regular basis

Hospice Richmond Hill
www.hospicerh.org

- Support for children who have a loved one who is dying or who has died information, children inevitably become aware of the presence of illness, by overhearing parents or other adults in discussion or by sensing the change in the emotional environment at home. The lack of direct communication heightens the risk of misunderstanding and may also inadvertently imply to the children that either their experience of this event is unimportant or that the news is so distressing that it cannot be shared. In both instances, the child is alone in making sense of upsetting information.

Another common struggle that parents identify is when and how much to tell their children about their diagnosis. Many parents express a reluctance to use the term "cancer", as they view it as a frightening word. However, the use of euphemisms, such as "lump" in the place of the actual term may lead to confusion or anxiety, as it risks them thinking a lump of any nature is, in fact, a bad illness. Parents are encouraged to open the doors of communication with their children by asking their children what they have heard about their parent's cancer or about cancer in general. Worries based on misconceptions can be set aside, or at the least lessened though the knowledge that has been shared.

All of our work with parents is predicated in the belief that parents are the experts in the needs of their own children. We focus on reinforcing their skills and, through support and education, maintaining competence in their parental roles through the course of disease. When additional support for the family is required, we access one of a number of community programs that focus on children's needs when a parent has cancer. A list of these services could be made available on request by contacting the Patient and Family Support Program, 416-480-4623.

References

Altschuler, J., & Dale, B. (1999). On being an ill parent**.** *Clin Child Psychol Psychiatry, 4*(1), 23–37.

Weaver, K.E., Rowland, J.H., Alfano, C.M., & McNeel, T.S. (2010). Parental cancer and the family. *Cancer, 116*(18), 4395–4401.

Ultrasound therapy for bone metastases

Dr. Kristopher Dennis and Dr. Greg Czarnota, Department of Radiation Oncology, Odette Cancer Centre

Bone metastases are a common cause of cancer pain. They cause significant functional limitation and worsen the quality of life of a large proportion of patients with cancer. External beam radiotherapy is the standard localized treatment for uncomplicated bone metastases. However, up to 30% of patients do not respond, 30% of patients who do respond have their pain return at some point following therapy, and re-treatments with radiotherapy can be limited by cumulative doses to critical structures such as the bowel or spinal cord. Thermal and ablative therapies such as radiofrequency ablation, osteoplasty and cryotherapy are alternatives to radiotherapy. However, they are invasive procedures that place patients at risk of various complications.

Magnetic resonance-guided high-intensity focused ultrasound (MR-HIFU) is a new, non-invasive outpatient localized therapy that is being investigated for the treatment of various types of cancer, including bone metastases. In MR-HIFU, a specially designed transducer is used to focus a beam of ultrasound energy into a small volume at a specific target site in the body. In the cancer setting, the focused beam can produce therapeutic hyperthermia at the site of the tumour, but only harmlessly warm the immediately surrounding tissue. MR imaging is used to focus the ultrasound beam on the tumour and to perform real-time thermal mapping at, and around the target site.

MR-HIFU has been used to treat bone metastases in a few small studies. In this setting, the target is the bone metastasis itself, as well as the adjacent periosteum that contains nerves and the vasculature that supplies the tumour. It is believed that MR-HIFU alleviates the pain from bone metastases by causing thermal periosteal denervation and/or thermal ablation of the bone metastasis itself, which subsequently diminishes pressure on the surrounding tissues. Results from these studies have been promising, with significant proportions of patients reporting partial or complete pain relief at the site of their treated bone metastasis. The procedure also appears to be safe, as no device-related serious adverse events have been detected. These studies involved only small numbers of patients, however, so further investigation is needed to more rigorously test the effectiveness and safety of the procedure.

As recently announced here at a press conference attended by Ontario Minister of Health Deb Matthews, Sunnybrook Health Sciences Centre and the Thunder Bay Regional Health Sciences Centre have launched a dual-site program to further investigate the use of MR-HIFU in the treatment of various health disorders. The first clinical trial in patients with cancer will focus on treating patients with bone metastases. This trial will begin in early 2011 and will operate through partnerships with the Rapid Response Radiotherapy Program and the multidisciplinary bone metastases clinic at the Odette Cancer Centre. Patients with bone metastases that have not received any previous localized treatment will be eligible to undergo MR-HIFU within this trial if they meet a number of clinical and radiologic criteria. Patients will be closely monitored prior to, during, and following the procedure for several months to determine the effectiveness of MR-HIFU in decreasing pain and analgesic requirements, and to ensure the safety of the procedure, as well.

It is hoped that MR-HIFU will be proven to be an effective and safe treatment for patients with bone metastases so that it may complement the other localized therapies already available. Additional clinical trials involving patients with recurrent breast cancers, head and neck cancers and rectal cancers are also being implemented and should begin enrolling patients in the coming months. As stated by Minister Matthews, "New technologies like this will not only put Ontario on the world stage as an innovator, but also will improve the quality of health services for patients".

It takes a village

By Stephen Jenkinson, MTS, MSW, RSW

Often, you hear the old adage: It takes a village to raise a child. Anyone who has tried to raise a child knows pretty well how true that is. Raising kids is one place where many people will taste the very limit of what they believe in, what they have inherited, what they once thought was true. We often circle the family wagons, though, when it comes to child rearing, especially when there are hard times. This is one place where our belief in privacy, not in village, is emphatic. We have the saying, but we don't often have the experience.

We don't seem to have any saying that rings with the same ancestral verity when it comes to the rest of our lives. In our way of doing things, here in the dominant culture of North America, the reliance on the village seems to end when the childhood ends, and from then on you are pretty much left to your own devices. We seem to be missing any kind of a saying, something that strong, that would guide us on the 'village' part of things. We seem to take the presence of the village for granted, as if it is part of the natural order of things. If the child comes from the village's care, where does the village come from?

I have taught groups of palliative care workers and caregivers all over North America, and I am most frequently asked to give guidance on how to survive doing the work. These same people report over and over again how alone and isolated they feel trying to do a job that once was the thing that gave deep meaning and purpose and direction to their personal and professional lives. They are alone with their peers often, commonly remote from the agency mandates and the supervisory structure, and frequently at odds with much of the dominant culture's strange aloofness and illiteracy when it comes to dying and grief, a poverty that shows up with exhausting frequency at the deathbed.

Something that has struck me over the years is how much the plight of the reflective palliative care worker resembles the plight of the reflective person with a terminal diagnosis. Dying people often talk about feeling a profound alienation from the family and friends around them. For the dying person it seems that with the terminal diagnosis everything has changed—everything—except their ordinary social and family lives. It is as if the people around them either don't get it, or don't want to. We've all bumped up against the strange etiquette around dying: don't bring it up, don't act like it's true, find every euphemism you can find in the name of being compassionate. Dying people are encouraged, not infrequently, by paid health care practitioners to keep as much of their lives untouched by their dying as they can: as normal a life as possible, under the circumstances.

What might dying people and those trying their best to care for them have in common? What makes these feelings of isolation, loneliness and a deep uncertainty about how to keep going? It may be that they have each come to see how skittish, unreliable or insubstantial their village is when it comes to dying. I know that often a terminal diagnosis will have the effect of making families more tightly knit, at least temporarily more emotionally available and cooperative. It is true that friends often come closer at such times. But anyone who has lived a village life knows emphatically that friends and family do not a village make. You could say that a village is a place where the people serve the village and the village serves life, a place where people are kin not by blood, but by having a shared understanding of the hard things of life. Village people are such not because of preference—those are friends—but because of a willingness to be differently together. One place this shows up almost unfailingly: village people die the same kind of death, their dying recognizable and familiar to each other, in each other's presence. In our part of the world, we pride ourselves on each of us dying our own unique, never-to-be-repeated way of dying, just as we sought to live our singular lives. We circle the wagons of family and friends when we are dying precisely because we have no village coming to gather around us in our leaving—just as it was when we were born. In this way, our beginning and our end often have a sorry resemblance.

I taught in a small town near Ottawa recently. I was talking about the death phobia that often passes for common sense inside and outside of the helping professions, and about how fugitive a thing this idea of village is when it comes to the care of dying people. When the teaching day was done a social worker of East Asian descent and culture came to speak with me, when she was sure there would be no one to overhear. She said, "My God, I've just realized how crazy it is for me to do something I do almost every day on the job. We have a check box on our intake form that says: Cultural Issues. Every time that the patient is white, you know, a typical anglo Canadian, I automatically check: None."

One way to translate this is to say that the social worker has been poorly trained and needs some 'cultural sensitivity' classes. Another way is to say that this is what happens in our part of the world whenever the giver of care and the recipient of care are of the same culture: culture disappears as a conscious thing to be assessed, understood and contended with. Culture only shows up when the issue is 'cultural difference'. Perhaps the most useful way is to say that the social worker has grown accustomed to the dominant culture's unwillingness or inability to understand the need for a village sensibility. Our villagelessness is normal.

Anyone's dying can be a time when the old, austere uniqueness of our personal life can be traded for something older, more inclusive, whether we ourselves are dying or not. Dying has proven itself to me emphatically to be an occasion for village making, something that offers a kind of 'in common-ness' that could have an enduring influence over the whole of one's life. I have also so often seen dying be a time of village breaking, where it becomes solitary, private, secretive. It takes a village to bring a person well into their dying time. It isn't often sought, but it is deeply deserved.

About the author

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Wading through the questions: A journey into bioethics

By Rosanna Macri, MRT(T), MHSc, Department of Radiation Therapy, Sunnybrook Odette Cancer Centre

Envision the following: a 38-year-old newlywed has just received a horrible diagnosis of Stage II cervical cancer. The past few weeks have been a blur for her and, as I call her from the atrium for her fifth day of radiation treatment, she starts to confide in me. She tells me about her life and family. By the twelfth treatment I am introduced to her husband and a couple of her closest friends. By her fifteenth treatment she is overwhelmed by the reality of her barren womb. I take her aside and the words "adoption" and "foster parent" seem to leave a bad taste in her mouth, as her face contorts into a frown. She never imagined a life without offspring. When asked if she had considered any fertility protection options, her eyes widen and sink almost simultaneously. During the chaos of what she describes as *a diagnosis of imminent death*, she vaguely recalls the mention of fertility, but is unable to remember any suggested options and fertility, or the lack of it never occurred to her. This encounter was disconcerting and I could not help but wonder if there were any other ways we could have supported her during the informed decision-making process?

What entails true informed consent and why does a consent form carry so much weight? Is VIP preferential treatment permissible in a publicly funded system? Why are certain chemotherapies insured by some provincial governments and not by others? Should we administer privately funded chemotherapies in a public cancer centre? Where's the line between innovative radiation treatment and experimentation, and when should the research ethics board be involved? Are our non-English-speaking patients receiving all the information they require? These are just a sample of some of the issues I encountered within the first few months of my career as a radiation therapist that began seven years ago. However, it has only been since I initiated formal ethics participation and education that I began to recognize that these issues contained a significant ethical component. As I write this, I am midway through my Academic Fellowship in Clinical and Organizational Ethics. In retrospect, it is difficult to imagine these types of issues as ever being divorced from ethics. Now, it is impossible for me to not recognize the numerous ethical issues that plague cancer care. While this new lens gives me added pause for thought, I believe it provides an excellent complement to my clinical perspective.

Reconsidering the case above with an ethics lens, I would frame the issues as pertaining to enabling patient autonomy through informed decision-making, considering how enhanced interprofessional dialogue might redress this issue and finally, examining what system-level organizational supports might preventatively address this issue so that it does not recur. Instead of viewing it as an isolated clinical ethics issue, I view it in a systems context.

My journey into acquiring my new-found ethics lens began when I started to ask questions and recognized that medicine and its practice were not value neutral. The more I learned about bioethics, the more questions boiled to the surface and, ultimately, led me to embark on this journey of answer-seeking. My first realization was that a clinical ethics centre existed at our hospital and employed two qualified "ethicists". Once I met these individuals and became acquainted with the ethics services of the hospital, I started by volunteering on the hospital ethics committee. This experience continued to expand my awareness of the unique issues experienced by various departments and professions along with the many issues that the entire hospital faces. As I scratched the surface of this field, opportunities seemed to pour out. I eventually became a member of the ethics committee and contributed to policy revisions and the creation of ethics education materials. I quickly came to the realization that ethical issues span from bedside to boardroom and that ethics is an integral part of health care delivery. My ethics involvement snowballed into courses, workshops, conferences, retreats, and the role of co-chair of Odette's Ethics Advisory Group. I entered a universe of interprofessional enthusiasts who evolved from a common interest in critically reflecting on moral issues arising in the areas of health care and research. While, at times, I felt like an outsider who accidentally stumbled on foreign soil, fear and confusion along with excitement and curiosity took hostage of my emotions and the more I learned, the more I longed to be part of the ethics community. This group consisted of a patchwork of many professionals who welcomed me and were eager to teach.

Once I started on this path, it became impossible to turn around. I was now seeing the world through a different lens and even though at times I felt it would be easier if I could return to a simpler time, it was now out of reach. I have grown to recognize that expanding awareness, dispersing knowledge through education, practice and public engagement and building on research in the field is every health care professional's responsibility. While this path has not been free of obstacles, my aspirations to help bring awareness to these issues so that we can collectively begin to reflect on the 'ought' as opposed to the 'what' has grown. Heightened self-awareness of one's own value system and sensitivity towards the multiple value systems that others hold is vital in a health care environment. As much as I have chosen to pursue this field, there seems to be a gravitational pull that has chosen me, as well. Since the questions continue to multiply as I proceed along this journey, I do not see an end in sight but, rather, a continued path of discovery. After all, to quote Socrates via Plato's *The Republic* in 360 B.C., "We are discussing no small matter but how we ought to live our lives."

Continuing Medical Education 2011

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**

- **February 10–12, 2011**
  17th Annual Network of Oncology Clinicians and Researchers Meeting, Las Vegas, NV
  www.nocrannualmeeting.com/2011/index.asp
- **February 17–29, 2011**
  2011 Genitourinary Cancers Symposium, Orlando, FL
  www.gucasymposium.org
- **February 24–27, 2011**
  11th Annual Canadian Oncology Winter Conference, Sun Peaks, BC, Canada
  www.eventcare.ca/clients/cowc/index.html
- **March 10–12, 2011**
  Palliative Medicine & Supportive Oncology 2011—The 14th International Symposium, Fort Lauderdale, FL
  www.clevelandclinicmeded.com/live/courses/2011/pallmed11/overview.htm
- **April 2–6, 2011**
  American Association for Cancer Research (AACR) 102nd Annual Meeting, Orlando, FL
  www.aacr.org/home/scientists/meetings--workshops/aacr-102nd-annual-meeting-2011.aspx
- **April 10–11, 2011**
  2011 Hospice Palliative Care Conference, Toronto, ON, Canada
  http://hpcconference.on.ca
- **April 28, 2011**
  2011 Canadian Association of Medical Oncologists (CAMO) Annual Scientific Symposium, Toronto, ON, Canada
  www.cos.ca/camo/meeting.asp
- **April 29–30, 2011**
  Cancer Imaging and Radiation Therapy Symposium: A Multidisciplinary Approach, Atlanta, GA
  www.cancerimagingandrtsymposium.org
- **May 4–6, 2011**
  International Conference in Community Health Nursing Research Symposium, Edmonton, AB, Canada.
  www.nurs.ualberta.ca/icchnr
- **May 19–21, 2011**
  30th Annual Scientific Meeting of the American Pain Society, Austin, TX
  www.ampainsoc.org/meeting/annual_11
- **May 19–21, 2011**
  12th Congress of the European Association for Palliative Care, Lisbon, Portugal
  www.eapcnet.org/Lisbon2011
- **June 3–7, 2011**
  47th American Society of Clinical Oncology (ASCO) Annual Meeting, Chicago, IL
  http://chicago2011.asco.org
- **June 21–25, 2011**
  9th International Conference on Grief and Bereavement in Contemporary Society and Association for Death Education and Counseling 33rd Annual Conference, Miami, FL
  www.adec.org/conf
- **June 23–25, 2011**
  15th Annual Atlantic Canada Oncology Group (ACOG) Symposium, Charlottetown, PE, Canada
  www.acon-atlantic.ca/pages/15th-annual-atlantic-canada-oncology-group-acog-symposium
- **September 8–10, 2011**
  2011 Breast Cancer Symposium, San Francisco, CA
  www.breastcasymposium.org
- **September 14–17, 2011**
  25th Canadian Association of Radiation Oncology (CARO) Annual Scientific Meeting, Winnipeg, MB, Canada
  www.caro-acro.ca/Meetings___Education/Annual_Scientific_Meetings.htm

Correction notice

In the Systemic therapy for metastatic Renal Cell Carcinoma (mRCC) insert by Drs. Sonal Gandhi and Georg Bjarnason, included in the last issue of **Hot Spot**, the second bullet point in the Everolimus section should have read: Heavily pretreated patients randomized within six months of TKI failure to everolimus versus placebo showed PFS of 4.9 versus 1.9 months with a HR of 0.3 (95% CI: 0.22–0.40 Log rank $P < .0001$) (*not* …PFS of 4.0 versus 1.9 months with a HR of 0.3…).

We apologize for the error.

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