

HOT SPOT



Editor's corner

By **Rebecca Wong**

Part of the mandate of the Rapid Response Radiotherapy Program is to promote and develop palliative radiotherapy research. Earlier in the year (February 2000) you heard from Dr. Bezjak on the activities at Princess Margaret Hospital. This issue marks the expansion of our collaboration, now to include our colleagues at the Hamilton Regional Cancer Centre. Dr. Wu provides our readers with his thoughts and insights into our first collaborative meeting. Also in this issue Dr. Hayter again takes us back in time, this time to meet Dr. Vera

Peters, a legendary figure in oncology. Dr. Berry gives us useful tips on surfing the net for resources in end-of-life care. This, no doubt, will be helpful to many of us through our daily practice. Dr. Vachon brings our focus to the adolescent in our patients' families. In the research corner, I report to you our results from our survey, to guide us on how we can better fulfil our patients' informational needs. One of the major symptoms of concern, fatigue, is the focus of this issue's insert. We hope this collection of short pieces proves interesting and informative.

Report from the "tri-centre" meeting with Dr. William E. Powers

By: **Jackson Wu, MD, FRCPC,
Radiation Oncologist,
Hamilton Regional Cancer Centre**

On June 27, 2000 the RRRP hosted the first "tri-centre" forum in honour of a special visit by professor emeritus Dr. W. Powers. Radiation oncologists, including members from the RRRP, the Palliative Radiation Oncology Program (PROP) at the Princess Margaret Hospital (PMH), and representatives from the Hamilton Regional Cancer Centre, gathered to discuss current controversial issues in radiotherapy for bone metastases.

Dr. Powers is a legendary character in the development of radiotherapy and cancer care in the United States. He served as advisor to three presidents — Nixon, Carter, and Reagan — for the use of grants in cancer care and research, and won multiple "gold medals" from different cancer societies. His clinical and scientific achievements are too numerous to mention. He is now "retired" in Florida, but his enthusiasm continues as demonstrated by his co-

authorship of an extensive review article of the subject of dose-fractionation for patients with bone metastases.

Dr. Powers' friendly visit to Toronto was prompted by two letters (sent by RRRP & PROP) written in response to his review article. The controversy and discussion involved the question: "Would patients experience greater and more long-lasting pain improvement with higher doses of radiation to painful bone metastases?"

During our discussion with Dr. Powers on this subject we came to appreciate several important differences between the US and Canada in the radiotherapy environment faced by radiation oncologists. In the US, privatized radiotherapy services tend to result in greater selection bias in clinical studies, and some medical oncologists fail to recognize the usefulness of radiotherapy in the early management of painful bone metastases; nevertheless, more radiotherapy resources (machines and technologists) are available to provide

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In this issue: Report from the "Tri-Centre" meeting with Dr. William E. Powers; Adolescents living with a parent with advanced illness; Resources on the Internet for improving end-of-life care - How to get started; Historical vignette – Vera Peters: Canadian pioneer in psychosocial oncology; Seventh annual conference - The science and art of pain and symptom management; Research Corner.

Insert - Management of fatigue

Adolescents living with a parent with advanced illness

Mary L.S. Vachon, RN, PhD

Adolescence is a difficult enough phase of life for both the teens and their family members without simultaneously having to deal with terminal illness in a parent. Teens may wish to be helpful, but not know what to do. They may be expected to help and become overwhelmed dealing with household needs and providing physical care for a parent with advanced disease. They may become withdrawn, angry and resentful that this is happening to them, when the lives of other friends continue uninterrupted.

Parents can tend to rely on adolescents to assume increased responsibility and may wish them to be more available for practical assistance and emotional support at home. If there are difficulties in the relationship between the parents, one or another may tend to use the teen as a confidante, creating a parentified child whose own needs for nurturing are not met. Normal developmental needs for separation and individuation can be interfered with and conflict can result for all concerned.

Studies comparing the perception of parents and teens about the experience of parental illness have found that parents tended to report little or no evidence of emotional distress or disruptive behaviour in their children regardless of the child's age, sex, or which parent was ill. However, the children's reports differed significantly from the parents. Adolescent girls reported the highest levels of anxiety and depression and aggressive behaviour. Girls whose mothers were sick reported significantly more anxious-depressed symptoms than girls whose fathers were ill or boys whose mothers or fathers had cancer. These girls reported more stressful

life events reflecting increased family responsibilities. Grace Christ and her colleagues from Memorial Sloan Kettering Cancer Center studied 120 adolescents whose parents had terminal cancer. Compared with younger children, the adolescents' greater cognitive and empathic capacities allowed them to be more aware of losses and of the parent's physical and emotional pain. The adolescents coped with illness and impending death through intellectual defenses, search for meaning, deeper understanding, and seeking help.

This study illustrated the difficulty adolescents face as they deal with the conflicting tasks of re-engaging with their parents because of their illness and undergoing developmentally appropriate separation. Most of the adolescents were able to discuss the facts and circumstances associated with their parent's illness, but many were unable to communicate their emotional responses. They often dealt with the illness and impending death with emotional detachment. At times they appeared to be unconcerned about their parent's illness or were preoccupied with their own daily activities unless the parent was in acute medical crisis. If acute crises evoked an intense emotional response, the adolescent was often apologetic about this. **Five problems and concerns** characterized the adolescent's reaction to the parent's deteriorating condition: empathy for the parent's suffering, increased involvement with the ill parent, need to help at home, reactions to specific parental relationships, and guilt. Factors that influenced how much parents should help their adolescents to confront their powerful feelings included: the imminence of the parent's death, the adolescent's relationship with the parent, the degree of

the adolescent's resistance, and the family's practical needs, preoccupations, strengths and vulnerabilities. The adolescents were often put into the position of needing to provide significant support to the healthy parent who was dealing with his or her own impending loss. The majority of adolescents interviewed coped with the difficulties inherent in their parent's impending death without the significant acting out behaviour that has commonly been reported in studies of adolescents whose parents are dying or have died, but some of these other studies involved those referred for mental health counselling during the illness or after the death. In this study the adolescents who had the most significant acting out had a history of pre-existing psychological disturbance or other family members with a history of acting out. Symptoms of depression were common in the group. Depressed adolescents generally did not have a history or pre-existing psychopathology.

Intervention to assist teens might include providing guidance and support for parents to help them to understand the normal developmental needs of their children and to balance the needs of the adolescent with those of other family members. The pediatrician, family physician, or staff at the treating hospital might seek out the opportunity to ask the adolescent if he or she has questions about the parent's illness and to provide support. A support group for teens whose parents have cancer is held at Wellspring, at the downtown Toronto location at 81 Wellesley St. East.

Phone (416) 961-1928 for details.

"Tri-centre" meeting
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opportunities to explore alternative radiotherapy treatment strategies such as treating patients with smaller amounts of radiation twice a day (for less side effects during large-field radiation).

Respecting the fact that there are always differences in opinions, what I found most reaffirming from our half-day meeting with Dr. Powers is the common recognition that this group of patients with advanced cancers is often under-served and poorly understood. Basic questions, such as how metastases cause pain, how radiotherapy helps pain, how much pain relief radiotherapy

actually provides, how much improvement in mobility and quality of life can be achieved, how to select patients for treatment according to their estimated life expectancy, and what patients expect of their treatments, remain challenging issues yet to be addressed in order to better provide true palliative benefits to the patients without compromising patients' time with families, convenience, and quality of life.

Dr. Powers' visit helped to introduce a "new member" to the currently existing "University of Toronto Palliative Radiotherapy Group", which up until now included radiation oncologists from TSRCC and PMH. Beginning in September 2000, interested radiation

oncologists from the Hamilton Regional Cancer Centre joined the group to form a "tri-centre" palliative radiation oncology group. Through monthly video conferences members from the three cancer centres will discuss and update research topics related to palliative radiotherapy. With a strong spirit of collaboration, the new tri-centre forum will be an exciting avenue through which previously unanswered questions and new patient-care ideas can be translated into research studies and treatment guidelines. Through education and research, the collaboration will enhance effective and efficient palliative radiotherapy services to communities along the "Golden Horseshoe".

Resources on the Internet for improving end-of-life care - How to get started

By Scott Berry, MD, FRCPC

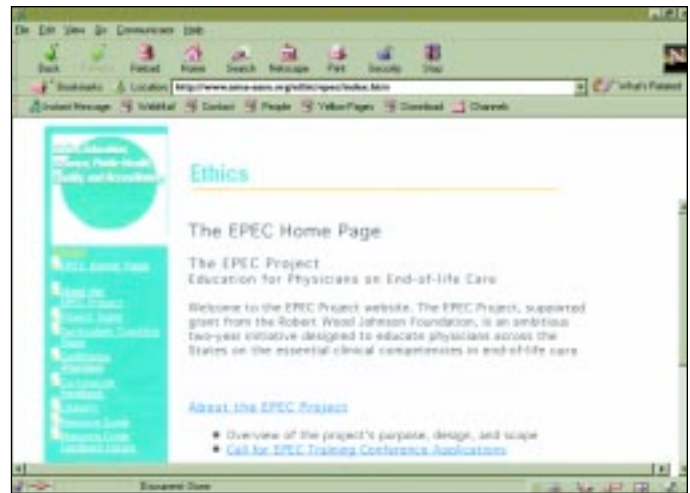
The Internet has become the meeting place of the global village. People chat, play, and exchange ideas with other computer users from around the world. It is a powerful tool for recreation, for business and for education. Although it's great to have fun on the Internet, it is gratifying to know that such a powerful tool is not used only for online casino games and online shopping.

People who care about improving the care of dying people have also been able to produce excellent sites to provide valuable information, resources and forums for discussion. I would like to review just a few of the innovative and informative websites that might be able to help you find information on improving the end-of-life care that you provide for your patients.

You don't have to stray far from home. The University of Toronto Joint Centre for Bioethics website is full of useful information on end-of-life care as well as other topical ethical issues. The "end of life" web page is found at http://www.utoronto.ca/jcb/Resources/end_of_life.htm. This is an excellent place to find a listing of a wide variety of resources and is a great place to start surfing. You could jump to a site on the management of cancer pain or perhaps head off to look at a full-text copy of a relevant article from the CMAJ's "Bioethics for Clinicians Series". There is information on important legal cases, policies of different medical organizations and links to important articles dealing with issues in end-of-life care from many journals. This site should be bookmarked and re-visited because the contents of the site are updated as new links become available.

One of the interesting places you can venture from the Joint Centre's site is the American Medical Association's site on the "Education of Physicians on End-of-Life Care" or "EPEC" project (<http://www.ama-assn.org/ethic/epec/index.htm>). This is an ambitious project to provide broad-based training to physicians across America in caring for dying patients. A Canadian project with similar goals is also being developed. The EPEC site contains the entire curriculum handbook in convenient "PDF" format so it can be downloaded and printed for your reference files. The curriculum contains modules on many pertinent topics in end-of-life care including advance care planning, pain management and communicating bad news. The curriculum materials in themselves make a trip to this site worthwhile, but there is also an "EPEC Resource Guide" available for download. This comprehensive guide provides information on a wide range of materials available that might help you learn more about improving end-of-life care for your patients.

There are many more interesting and informative web resources on end-of-life care. The websites discussed are just a few to help you get started, but don't stop there. Type a topic of interest into a search engine or start at a central site like the Joint Centre's and follow the links that interest you. You never know where you might end up, but you will surely be impressed by the wealth of information available to you on the Internet about end-of-life care.



Historical Vignette:

Vera Peters: Canadian pioneer in psychosocial oncology

By Charles Hayter, MA, MD, FRCPC, Radiation Oncologist, T-SRCC

Mildred Vera Peters was born in Rexdale, Ontario in 1911, and obtained her MD from the University of Toronto at the age of 23. She entered a surgical residency program but was inspired to switch to radiotherapy by Dr. Gordon Richards, who treated her mother for breast cancer. After an apprenticeship with Richards, she was appointed to the radiotherapy staff at Toronto General Hospital in 1937. She was a member of the founding staff of the Princess Margaret Hospital in 1958.

Peters was one of the first oncologists to take an interest in the psychosocial impact of treatments for cancer. In the early part of the twentieth century, mastectomy was the standard treatment for early breast cancer.

Recognizing the emotional impact of mastectomy on women, Peters challenged conventional medical thinking. She wrote: "Quite apart from the medical disadvantages of mastectomy is the associated emotional trauma, frequently raw and bleeding long after the physical wound becomes a scar." She became an advocate for breast-conserving therapy (excision of the tumour followed by radiotherapy) for early breast cancer, long before it became standard treatment, and supported her opinion through careful studies of patients treated at PMH that showed that breast-conserving therapy was not detrimental to survival.

Her contributions to health care in Canada were recognized by the Order of Canada (1975), and her memory is preserved in the name of the Peters-Boyd Academy of the Faculty of Medicine at U of T which is located at Sunnybrook.

Research Corner

Informational needs assessment on patients receiving palliative radiotherapy

By Rebecca Wong, MBChB, FRCPC

The Rapid Response Radiotherapy Group conducted an informational needs assessment on patients receiving palliative radiotherapy. The motivation behind this project stems from the fact that patients living with advanced cancer have very different informational needs than those living with earlier stage disease. During this time, very few things are certain with the exception that the illness will ultimately lead to death. Despite the heavy burden of illness, this health issue is not frequently

addressed in the public education arena for a variety of reasons. The negative connotations of talking about palliative care, and the many practical limitations are perceived potential areas. We therefore conducted the needs assessment to ask the question: Is a public patient educational event an appropriate strategy to facilitate the informational needs of our patients?

Between November 1999 and March 2000, 101 patients and/or their caregivers participated in our survey. The Advanced Cancer Informational Needs Questionnaire (ACIN-Q) was specifically designed and previously pretested for this project.

Our patient sample appears to be representative of all the patients receiving palliative radiotherapy at the time of the study, based on comparison of baseline characteristics including demographics, time since diagnosis of metastatic disease and radiotherapy dose fractionation received.

Of all the potential informational need areas studied, management of pain, fatigue, and availability of home care services to look after patients were most highly ranked by our participants (78, 72 and 52% respectively). It is worthy to note that 50% of respondents (over 45% patients and 50% caregivers) continue to seek answers to questions such as "What causes cancer?", and "Why are some cancers not curable?".

Out of nine different ways to receive information, (in which participants are to select three most preferred), one-on-one medium was most highly ranked, being endorsed by 70% of respondents. This is followed by pamphlets with 50%. Patient education events ranked third, together with books. At least in our patient population, Internet ranked least preferred, likely reflecting the average age of our patients.

Thirty per cent of respondents say they will (40% maybe) attend a patient education event on issues pertaining to living with advanced cancer. Of the reasons cited as potential barriers to attendance, physical condition (for patients) and lack of alternative caregiver (for caregiver) were by far the most important reasons.

Our results: a) suggest that interest in additional information beyond our patients' (and caregivers') clinical encounter(s) remains high, and; b) pointed to areas where the greatest needs exist. A patient educational event as an information delivery tool can only reach a minority of its intended audience, although its potential impact on heightening public awareness in a more general way cannot be evaluated based on our survey. Plans to incorporate patient education into the standard clinical encounter, supplemented by short written material, is likely a more effective strategy.

As a result of this work, we are now planning our next step: the development of an information counseling intervention for patients living with advanced cancer. Its effectiveness and impact on our patients and carers will be evaluated.

Results were presented at the International Palliative Radiotherapy Consensus Meeting, London, UK, 2000 and Canadian Association Radiation Oncologist Annual Meeting, Edmonton, 2000.

Seventh Annual Conference –

The Science and Art of Pain and Symptom Management

November 17 & 18, 2000.
The Old Mill,
21 Old Mill Rd.,
Toronto, Ontario

Plenary speakers:

Dr. Bruera, Dr. Emanuel,
Dr. Watanabe and Dr. Chaban.
• Seven workshops, one debate
and one drama presentation
• Update on gastro-intestinal
malignancy

• satellite radiotherapy
workshop for radiation
therapists





Course directors:

Dr. Chow and Dr. Goldman

Consultant: Dr. Librach

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Definition

“Significant tiredness, diminished energy or increased need to rest, disproportionate to any recent change in activity level.” *Cella et al*

Some facts

- Fatigue is a symptom and is multidimensional. It is fundamentally subjective.
- The prevalence relates to the definition, how it is identified. It is generally accepted that when sought, the prevalence is higher than expected.
- Fatigue is reported in 75% of cancer patients who have received treatment within the last two years, 96% of patients receiving chemotherapy/radiotherapy, >75% with metastatic disease.
- Fatigue ranked second to pain, as the most important symptom of concern to patients living with advanced cancer.

“Measuring” fatigue

There are many validated multidimensional fatigue assessment tools available. The routine use of the following three questions may be adequate for bedside use.

- *Are you experiencing fatigue?*
- *How severe has your fatigue been?*

0 1 2 3 4 5 6 7 8 9 10

Not fatigued at all

The most severe fatigue imaginable

- *How is fatigue interfering with your ability to function?*

Prepared by Rebecca Wong, MBChB FRCPC (Radiation Oncologist, Rapid Response Radiotherapy Program Toronto Sunnybrook Regional Cancer Centre) and Nina Horvath, MD CCFP (Palliative care consultant, Sunnybrook & Women’s College Health Science Centre).

Algorithm adapted from: Cancer-Related Fatigue: Guidelines for evaluation and management. Portenoy, R.K., Itri, L.M. *The Oncologist*; 4:1-10.

Additional References:

Erythropoietin in the management of cancer patients with non-hematologic malignancies receiving chemotherapy (http://hiru.mcmaster.ca/ccopgi/guidelines/sys/cpg12_1.html)

A Canadian survey of cancer patients’ experiences: are their needs being met? *J Pain Symptom Management* 1998;298-306
Measuring Fatigue in patients with cancer. *Support Care Cancer* 1998;6:94-100.

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HOT SPOT

ALGORITHM FOR MANAGING CANCER-RELATED FATIGUE

Evaluation of fatigue

Severity; Pattern; Impact on function
Assess related construct; Overall quality of life;
Symptom distress; Goals of care



Evaluation for predisposing factors/etiologies

Physiological

Active cancer; Treatment-related; Infection; Anemia; Metabolic;
Sleep; Pain; Side effects of drugs; Malnutrition

Psychological

Mood disorder; Stress



Management of fatigue

- *establish reasonable expectations*
- *plan to assess repeatedly*
- *correct potential etiologies and/or symptomatic therapies*

Specific recommendations

Depression Selective serotonin - reuptake inhibitors
Pain control Optimize analgesics

Correct anemia For patients with non hematologic malignancies receiving chemotherapy, in whom symptoms of anemia sufficient to require red cell transfusion are anticipated, and where transfusion is not considered an acceptable treatment option, EPO can be recommended.* The optimal use of EPO for other indications such as impact on QoL is currently under active investigation and should be individualized.

Sleep disorder Careful use of hypnotics
Metabolic disturbances Don't forget thyroid function test

Symptomatic therapies

Pharmacologic treatment Corticosteroid (e.g. prednisone 2-20mg/day or prednisone 10-40mg/day)
Methyphenidate (e.g. 2.5-5mg, up to 10-20mg qam & qnoon)
Dextroamphetamine (e.g. 5-10mg qam)
Progestins (e.g. Megace 160-800mg/day) could improve overall sense of well-being through appetite stimulation

Non-pharmacologic treatment Patient education (may be the most effective strategy in some patients)
Exercise (individualize and regular, rhythmic and repetitive movements, e.g. walking)
Modify activity, rest pattern, and teach energy conservation
Stress management and cognitive therapies (e.g. referral to psychologist for relaxation therapy, hypnosis, guided imagery)
Adequate nutrition, hydration

* If EPO is used the following guidelines for use are recommended: 10,000 units sc 3 times weekly, or 40,000IU once per week sc.

If Hgb increased $\geq 1\text{g/dl}$, continue. If Hgb increased $< 1\text{g/dl}$, increase dose to 20,000 units 3 times weekly. If no response, discontinue epoetin alfa