By Ewa Szumacher, MD, FRCPC, and Joan Pope, RN, BNSc

Welcome to the February 2002 issue of Hot Spot! This issue of the Hot Spot newsletter celebrates the beginning of our fourth year of publication.

In the psychosocial section, Dr. Mary Vachon discusses denial and minimization in advanced cancer. In this feature article, Dr. Vachon updates readers with a recent literature review on this subject.

Dr. Charles Hayter presents the “Story of Essiac” in the historical vignette. The “Story of Essiac” is about a controversial alternative remedy developed in 1930 which is still being used by cancer patients today.

Dr. Scott Berry addresses important ethical issues in palliative care.

Superior vena cava obstruction (SVCO) is one of the complications of malignant disease. In our research corner, Drs. Rebecca Wong and Paula Wilson examine a new prospective randomized controlled study for SVCO and are currently accruing patients with this medical condition.

Our feature insert is written by Dr. Trey Petty, Chief of the Division of Dentistry and Oral Medicine, from the Calgary Foothills Medical Centre and by Dr. Alex Hammond, Radiation Oncologist from the London Regional Cancer Centre. It focuses on problems and strategies for effective mouth care management.

As guest editors, and on behalf of the Rapid Response Radiotherapy Program at the TSRCC, we are proud to announce that as of October 15, 2001, our associate editor, Dr. Rebecca Wong, Radiation Oncologist at Princess Margaret Hospital, was appointed as co-chair of the National Cancer Institute of Canada Clinical Trial Group - Symptom Control Committee. Dr. Wong was also appointed as a University of Toronto Representative to the Canadian Cochrane Network for a three- to six-year term.

We hope you find this issue of Hot Spot interesting and informative, and as always we welcome your letters with comments and suggestions.

We would like to wish you a successful New Year 2002.

Enjoy!

Advance notice of the ninth annual conference on the science and art of pain and symptom management

The ninth annual conference on the science and art of pain and symptom management is planned for November 15 and 16, 2002, at the Old Mill in Toronto. The conference is aimed at medical and radiation oncologists, palliative care physicians, and other physicians and health care professionals with a specific interest in pain and symptom management. The interactive program is jointly organized by the Interdepartmental Division of Oncology and the Division of Palliative Medicine of the Department of Family and Community Medicine at the University of Toronto, and RRRP at Toronto-Sunnybrook Regional Cancer Centre. For course information, call 416-978-2719.

In this issue: Denial and minimization in advanced cancer; Global health ethics and palliative care; Historical Vignette: The story of Essiac; Research Corner.

Insert - Mouth care for cancer patients
Denial and minimization in advanced cancer

By Mary L.S. Vachon, RN, PhD

Patients who do not accept the prognosis of the treating physician or who are not making appropriate life plans based on a negative prognosis are often said to be denying their illness or its negative impact. Thirty years ago, Dr. Avery Weisman wrote in On Dying and Denying of three orders of denial. In first-order denial the individual denies the main facts of the illness. Second-order denial may appear after the diagnosis is accepted; the individual denies the significance or implications of the illness. In third-order denial there is an inability to believe that the illness will result in death – the person believes he or she will remain in this incapacitated state forever. More recently, Fawzy Fawzy, a psycho-oncologist has contrasted denial with minimization. In contrast to denial, minimization involves acknowledging that one has the problem, but recognizing that one can still do things.

In a study of prognostic indicators in metastatic melanoma (Butow et al. J Clin Onc. 1999:2256-63), feeling that treatment would lead to a cure or long-term survival, minimizing the illness, and anger were independent predictors of survival, controlling for demographic and disease predictors. Other variables associated with improved survival included being married and reporting a better quality of life.

In Kitchen Table Wisdom, Rachel Naomi Remen (1996, Riverhead Books), a physician counselling cancer patients and health care providers at Commonweal, a retreat program in California writes of a farmer whose case was reported as well in Remarkable Recovery (Hirshberg & Barash, 1995, Riverhead Books). He was diagnosed with metastatic lung cancer and sent home to die. When he returned to the clinic several years later for an unrelated problem, everyone was shocked to see him. Hirshberg felt that his outcome was related to his attitude: “he didn’t take it on”, she said. The man took the same attitude towards his doctor’s prognosis that he took towards the opinion of the government soil experts who analyzed his field. As they were learned men, he listened carefully to their opinion as they showed him the findings of their tests and told him that corn would not grow in his field. He valued their opinion but said, “a lot of time the corn grows anyway.”

A recent paper reviewing 24 studies of survival prediction in patients admitted to hospice (Vigano et al, Palliative Medicine 2000:363-74) found that clinical predictions of survival are only one of a few important criteria on which to base therapeutic interventions or health care programs in the terminal phase, and the magnitude of the association with clinical prediction was small. Given that clinical prediction is as yet an inexact science, how should the physician and or other health care team members respond when patients and their family members appear to be denying their prognosis?

According to Connor (in Rando, ed. Clinical Dimensions of Anticipatory Mourning. Research Press, 2000) the clinician has three options:

1. Support the client’s avoidant coping style and join the person in hoping for a very unlikely improvement
2. Attempt to confront the client with the reality of the seriousness of the illness
3. Support the client’s need for hope while gradually helping him/her to face the reality of current losses and the likelihood of impending death.

Maguire (Handbook of Psychiatry in Palliative Medicine Chochinov & Breitbart, eds, Oxford University Press, 2000) states that “Patients use denial as a defense when the truth is too painful to bear. So, it should not be challenged unless it has created serious problems for the patient or relative. In challenging denial, it is important to be gentle so that the fragile defenses are not disrupted, but to be firm enough, that any awareness can be explored and developed”.

• Ask the patient to give an account of what has happened since the illness was first discovered. Explore how the person felt at each key point - when the first symptom developed, saw a specialist, were tested, and were informed about the results.
• Explore their perceptions about what is wrong. This may provide glimpses of doubt… Sometimes patients are ambivalent about whether they want to face reality. It is useful to confront this by saying, “It looks as though part of you prefers to believe that it is not serious, but another part of you is willing to consider your cancer is back and not responding to treatment. Which part of you should I relate to?”
• If that strategy fails, gently challenge inconsistencies.
• If that doesn’t work, check whether there is a “window” i.e. “I can understand that you think that it is an infection. Is there any time, even a moment, when you consider it might not be so simple?” If the person says “no”, accept that he or she finds it too painful to accept what is happening. If “yes”, explore what makes the individual think there might be something more serious.

Patients and families who do not want to accept the clinical reality of the illness must also be supported and often, as the evidence of deterioration becomes more evident, they will be willing to discuss and deal with the issues with caregivers who have stuck with them during the earlier phases of the illness.

Mary Vachon, RN, PhD, is a psycho-therapist in private practice. She can be reached at maryvachon@sympatico.ca.
Global health ethics and palliative care

By Scott Berry, MD, FRCPC

The members of the University of Toronto Joint Centre for Bioethics have been re-evaluating their priorities over the last few months as they have been assessing their collective goals for the year 2006. One of the emerging priorities for the centre will be addressing the ethical issues that stem from the staggering inequities in the provision of health care worldwide. As we struggle to provide better end-of-life care in Canada, we should all be aware of the global challenges in providing quality palliative care, especially in Third World nations.

A recent Lancet editorial highlighted some of the problems: 80% of the 50 million deaths that occur each year happen in less-developed countries; by 2020, 70% of the world’s 20 million cancer cases will occur in the Third World, deaths from HIV in sub-Saharan Africa and other developing regions continue to climb.

Some of the problems are ethical — how do you allocate resources to palliative care when funds to provide even basic medical care are scarce? Other problems are more practical — how do we provide adequate palliative care when oral morphine is not available in most African countries because of legal and administrative problems?

The answers are obviously not easy, but there are some practical steps. The Lancet article described specific funding initiatives that have been developed to provide a “model” hospice in Uganda that can serve as a starting point for other nations. The Ugandan government has been supportive of this initiative and has started to address some of the bureaucratic issues in getting appropriate analgesics to the people who need them. There is a long way to go but the Ugandan initiative is a great start. The University of Toronto Joint Centre for Bioethics has started to recruit and support international students from developing countries (including Uganda) in its MHSc program to develop bioethics capacity in these nations. These individuals should be able to provide local support in addressing the difficult ethical issues that will arise.

As we work to provide better palliative care for our patients in North America, we should be mindful of the challenges of providing this care in less-developed nations. For those of us interested in providing better care for our dying patients, we should start to think how we can contribute to this challenge globally.

Historical Vignette: The story of Essiac

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

Recent studies have shown that a large proportion of cancer patients use unproven and alternative remedies in addition to standard medical treatments such as chemotherapy and radiotherapy. Among the most popular alternative remedies are vitamins, herbal remedies, relaxation techniques, and special diets. Patients are attracted to such treatments because of the limitations and side effects of conventional treatment, the desire to maintain hope, and the need to maintain control over their situation.

The use of unproven remedies is not a new phenomenon. In the 1930s, nurse Rene Caisse of Bracebridge, Ontario, developed a herbal remedy for cancer based on a recipe formulated by an Ojibwa healer. She named the remedy “Essiac” (“Caisse” spelt backwards). A compound of burdock root, Indian rhubarb, sheep sorrel, and slippery elm bark, Essiac became a popular remedy which was administered by Caisse to hundreds of cancer patients. Although its constituent herbs have been shown to have effects on cancer cells in the laboratory, the compound has not yet been shown to improve cancer survival in human experiments. A 1998 review concluded that there was some weak evidence of its effectiveness and that “high-quality and open-minded research into the effects of this popular unconventional therapy is needed” (Kaegi, Canadian Medical Association Journal 1998: 158, pp. 897-902).

Essiac was only one of many therapies introduced in the ‘30s. Indeed, there were so many unproven cancer treatments that the Ontario government established a Cancer Remedies Commission in 1938 to evaluate various remedies and make recommendations regarding their use. The use of alternative treatments such as Essiac remains controversial. Conventional health practitioners are disturbed by the lack of proof, cost, and side effects of alternative treatments, and by marketing strategies that exploit cancer patients’ vulnerability. Nonetheless, it should not be forgotten that much of conventional medicine is based on natural substances whose effectiveness was discovered through experience and not in the scientific laboratory. The history of medicine is filled with countless examples of substances such as morphine, aspirin, and digitalis derived from plant or animal products which later proved to be of benefit. Recent reports that the herbal compound PC-SPES can lower PSA levels in men with advanced prostate cancer show that such alternative remedies should not be dismissed without an adequate evaluation of their possible benefit.
"Superior vena cava obstruction" – we need patients!

Superior vena cava obstruction (SVCO) is a not uncommon complication of malignant disease. The compression of the SVC can occur acutely or chronically and give rise to a classic collection of symptoms such as neck and facial swelling, headache, syncope, dyspnea and difficulty lying flat. It used to be considered an oncological emergency and the treatment of choice was radiotherapy to the mediastinum.

Over the last few years there have been significant advances in interventional radiology, and stent insertion into the SVC is now possible. This has the theoretical advantage of providing symptom relief within hours, rather than the days and weeks over which radiotherapy usually exerts its effect. There is, however, no randomized data to support this theory.

Two complementary studies have been set up to help improve our understanding and management of this condition.

Randomized trial

Patients will be randomized to receive either radiation therapy to the mediastinum (a five-day course of treatment) or immediate stent insertion followed by radiation therapy to the mediastinum (also a five-day course of treatment). The relative benefits of the two treatment arms will be evaluated by comparing improvement in symptoms.

Eligibility criteria:
- Malignant symptomatic SVCO
- Patients should be deemed suitable for palliative radiation
- Life expectancy greater than six weeks
- ECOG performance status 0-3
- Ability to give informed consent

Ineligibility criteria:
- Previous radiotherapy to the mediastinum

Investigations:
- CXR and CT chest with contrast enhancement

Follow-up:
Symptom diary before treatment and then daily for the first month after treatment. Follow-up hospital visit at one month is suggested, although this can be substituted for a telephone call if appropriate. Further investigations are only done if deemed clinically appropriate.

Prospective longitudinal study

This companion study has been set up to document the symptom profile of patients treated as indicated. It is ideally suited to include patients who refuse to participate in or are ineligible for the randomized study.

Eligibility criteria:
- Any patients with malignant SVCO deemed suitable for palliative treatment
- ECOG performance status of 0-3
- Informed consent

Investigations:
- Investigations if clinically indicated

Follow-up:
Symptom diary as above.

These studies represent a great deal of collaborative effort between many individuals based at Princess Margaret Hospital, Mount Sinai Hospital, Sunnybrook Health Sciences Centre and Toronto Sunnybrook Regional Cancer Centre. These studies are open to accrual through Princess Margaret Hospital and soon at Toronto Sunnybrook Regional Cancer Centre. Please help the investigators work towards identifying better ways to improve the quality of life of your patients with SVCO. The investigators are more than happy to work up potential candidates.

If you have a patient with SVCO requiring assessment, please call Princess Margaret Hospital new patients referral at: 416-946-4575, fax: 416-946-2900, or Toronto Sunnybrook Regional Cancer Centre new patient referral 416-480-4205, fax: 416-480-6812.

Questions regarding the protocol? Please contact Dr. Andrea Bezjak, (PI at Princess Margaret Hospital), 416-946-2132, Dr. Murray Asch (Mount Sinai Hospital), 416-586-5186 or Dr. Yee Ung, (PI at Toronto Sunnybrook Regional Cancer Centre) 416-480-4951.
Oral health care in the patient with cancer*

By Trey L. Petty, DDS, Division Head, Oral Medicine & Surgery, Tom Baker Cancer Centre, Regional Division Chief, Dentistry and Oral Medicine, Calgary Health Region, Associate Professor, Surgery, Faculty of Medicine, University of Calgary.

Sponsored by an educational grant from Biotène Canada, Division of Bolton Dental Mfg. Inc. biotène

*or, the mouth is (surprisingly) connected to the rest of the body

Introduction
Oral health care is not optional, but is a part of basic patient care. Optimizing oral health will improve the oncology patient’s general health and quality of life while reducing their risk of septicemia, dehydration and nutritional deficiencies. And, that’s the whole tooth.

Oral complications of chemotherapy
• stomatotoxicity (Latin: stoma = mouth)

Direct effect of the drug on the oral mucosa:
Decreased renewal rate of basal epithelium in oral mucosa → result in mucositis

Decreased platelet formation/thrombocytopenia
Spontaneous oral bleeding if PLT < 30K
Possible sepsis from chronic tooth or periodontal infection

Biologic Response Modifiers (BRM) can also cause mucositis:
Interleukin-2, lymphenkine-activated killer (LAK) cells, tumour necrosis factor (TNF), interferons

Pre-chemotherapy dental evaluation is vital. Most general dentists in community unfamiliar with oncology patients. Issues include:
• Oral effects of chemotherapeutic agents
• Potentially fatal consequences of ignoring or under-treated
• Acute or chronic odontogenic (tooth-related) infection
• E.g. root canal treatment may fail (10% of ALL cases)

Extraction of any abscessed or questionable teeth → treatment of choice

Oral Infection
“The quantity and diversity of microorganisms in the mouth is rivaled only by stool.” - Dr. Richard G. Mathias, Regional Head of Inf. Disease, Vancouver, B.C.

Odontogenic infections - dental caries (“toothache”), periodontal disease (“gum boils”) -
• Localized oral pain/interference with function
• Immediate referral for dental management
• Tooth extraction is definitive treatment
Antibiotic prophylaxis if WBC < 2.0, ANC < 500
Excessive bleeding if PLT < 50K

Antibiotics of choice for odontogenic infections (adult dose):
Clindamycin 300mg p.o. qid for 7 - 10d, or Amoxicillin 500mg p.o. qid with metronidazole 500mg p.o. tid X 7-10d

Oral candidiasis common in neutopenic or xerostomie patient
Typically, complain of burning mouth, metallic taste
Topical anti-fungals (e.g. nystatin “swish ‘n swallow”)
Poorly effective in severely immunocompromised patients
Compliance generally poor
All commercial preparations 50% sucrose, “feeds” re-growth
Recurrence common
Systemic ketoconazole or fluconazole more effective
Soak dentures or other oral appliances in vinegar overnight

Oral viral infections Herpes species (HSV, HZV - shingles) Multiple, erythematous, erosive, painful ulcerations on oral mucosa
Treatment acyclovir or other anti-viral
Good oral hygiene to prevent secondary bacterial infection

Oral pain management
Ice chips, club soda, frozen juices, pineapple chunks, capsaicin (cayenne pepper) formulations. Most centres have own favourite “cocktails” for topical oral pain control

Odontogenic pain -
Primary dental care typically necessary
Consultation with a dental department familiar with oncology patients
If palliative, consider serial injections with long-lasting local anesthetics
Bupivacaine (Marcaine) definitive treatment often not realistic during final stages of care

Good oral hygiene of lips, teeth, mucosa vital - reduces number and diversity of microorganisms in the mouth

Oral health care
The goals of basic mouth care:
1. Remove bacterial plaque from the teeth, gingiva, tongue
2. Prevent collection of decaying food
3. Increase appetite, general comfort, prevent illness

“Sacred cows” of mouth care proven ineffective
• Toothettes (sponges on a stick) - no better than swishing water
• Lemon glycerin swabs - dehydrating
• Hydrogen peroxide - foaming, damages granulating/healing tissue
• Sodium bicarbonate (baking soda) - dehydrating, abrasive

Brushing teeth with toothbrush - basic minimum of care
• Soft bristle, small head - requires degree of compliance, dexterity
• Collis-Curve toothbrush if limited range of motion/dexterity

Esp. if caregiver is brushing patient’s teeth
• Children’s toothbrush may provide best access - Requires good dexterity

Nothing magic about toothpaste
• Flavouring and sudsing agents only
• Minimal abrasive or enamel strengthening fluoride content
• Children’s toothpastes have mildest flavouring
• Dipping toothbrush in mouthrinse/club soda as clinically effective

Agents known to cause direct stomatotoxicity:
Antimetabolites: 5-fluorouracil, methotrexate
Anti-tumour antibiotics: dactinomycin, doxorubicin, daunorubicin
Secondary infection often occurs, resulting in possible sepsis

Indirect stomatotoxicity due to drug’s myelosuppressive action
Reduced myeloproliferation
Leukocytes and oral mucosal cells have similar renewal rates

Agents known to cause indirect stomatotoxicity:
Antimetabolites: 5-fluorouracil, methotrexate
Anti-tumour antibiotics: dactinomycin, doxorubicin, daunorubicin
Secondary infection often occurs, resulting in possible sepsis

Therefore, the full text continues over...
Mouthrinse solutions
- Chlorhexidine gluconate (0.12 - 0.2%)
  - antiseptic qualities
  - Reduce bacteria and yeast microorganisms
  - Prescription: Perixid, Periogard, formulary preparations
  - May be only oral care modality available if PLT < 50K
- Phenolic mouthrinses, e.g. Listerine antiseptic available
  - over-the-counter (OTC)
  - Tend to have a high alcohol content
  - painful burning sensation

Management of a dry mouth (Xerostomia) - post-radiation, chemotheraphy, or GVHD
- Frequent sips of water, club soda
- Sugarless gum or mints - neurogenic
- Chlorhexidine gluconate solution
  - reduce volume of saliva
  - Objectionable taste, high cost

Xerostomia - permanent
- Xerostomia - loss or lack of taste
- Dysgeusia (↓ taste) – hypogeusia
  - (loss or lack of taste)
- Osteoradionecrosis
  - (rare) – requires special treatment
- Soft tissue necrosis
- Osteoradionecrosis (rare) – requires special treatment

Mouth care for radiation patients
By Dr. Alex Hammond, London Regional Cancer Centre
- Sponsored by an educational grant from Biotène Canada, Division of Bolton Dental Mfg. Inc.

Patient assessment by multidisciplinary team
- Age
- General condition
- Medical history - Alcohol/drug abuse
  - Nutritional status
  - Cardiovascular disease
  - Coagulopathy
  - Immunosuppression
  - Neurologic impairment
  - Psychiatric disorder
  - Drug allergy
  - Current medications
  - Presenting history
  - Examination
    - T Primary site/size/extension/invasion
    - N Nodal site/position/size/number
    - M Metastases (Chest x-ray)
      - Clinical
      - Palpation
      - Fibre-optic scope
      - Imaging (CT, MRI, PET)
      - Biopsy ± panendoscopy
  - Recommended treatment
    - Radical surgery ± irradiation
    - Radical irradiation ± chemotherapy, surgery for salvage
    - Palliation (irradiation/chemotherapy/surgery)
  - Dental assessment - prophylactic

Irradiation effects
- Depends on:
  - Dentate/edentulous
  - Irradiation dose
    (usually 60 – 70 Gray over six to seven weeks, 30 – 35 fractions)
    - Volume
    - Technique
  - Usually x-rays 4 MV / Cobalt 60
    - Electron boost/in combination with x-rays

Acute effects: two to four weeks on
- Serous glands ↑ sticky saliva
- Mucous glands ↑ dry mouth
- Skin erythema
- Mucosa - erythema
  - superficial slough
  - ulceration
- Candidiasis
- Xerostomia
- Dysgeusia (↓ taste) – hypogeusia
- Odynophagia
- Dysphagia

Chronic effects: three to six months on
- Xerostomia - permanent
  - ↑ risk caries
  - ↑ risk mucosal trauma
  - ↓ healing
- Trismus – fibrosis temporo-mandibular joint
- Soft tissue necrosis
- Osteoradionecrosis (rare) – requires specialized treatment

Care of head and neck cancer patients multidisciplinary team
- Radiation oncologist
- Head and neck surgeon
- Medical oncologist
- Dentist - in-hospital and community
  - oral and maxillofacial surgeon
  - prosthodontist
  - endodontist
  - periodontist
- Speech pathology
- Dietitian
- Social work
- Family doctor
- Registered nurse

Management
- Prophylactic dental care and topical fluoride life-long
- Adequate fluid intake and nutrition
- Prophylactic Pilocarpine (Salagen)
  - 5mg tid/qid. to ↓ xerostomia
- Mouth rinses
  - baking soda and water
  - Nystatin suspension
  - topical 0.02% hydrocortisone solution
  - xylcocaine viscous
- Carry water bottle
- Nutritional support
  - Ensure/Boost etc
- Gastro-jejunal tube
- Analgesics

Post-treatment caries/extractions
- Contact radiation oncologist to plan treatment so as to avoid/minimize further complications.