Enhancing culturally sensitive practice when caring for seriously ill patients and their families

By Elizabeth J. Latimer, MD, CCFP, FCFP, Professor, Department of Family Medicine, McMaster University, Palliative Care Consultant Physician, Hamilton Health Sciences Corporation

Leininger has defined culture as “the learned, shared and transmitted values, beliefs, norms and life-way practices of a particular group that guides thinking, decisions and actions in patterned ways”. We are all influenced by our culture of origin and the culture with which we are surrounded in daily life. Societies, communities, groups, organizations, professions, even particular health care teams and programs all have their own “culture” which will influence us in various ways.

Because it is a major life passage accompanied by intense emotion, the process of serious illness and dying is culturally laden. It behooves practicing health professionals and trainees to be aware of and sensitive to this when providing care to all patients and families who are experiencing this life crisis, whether death is occurring unexpectedly, as a result of a progressive illness, or as a natural event at the end of life.

Fortunately, good palliative care is person-centered in nature, providing for effective symptom control, emotional support, decision-making, care planning, and enhancement of quality of life for patient and family in a manner that is consistent with their values and unique personhood. Such a philosophy readily incorporates cultural dimensions.

Culture will influence end-of-life care in many ways. These include: the practice of truth-telling; the process of decision-making about treatment and care; the value and ethics of pain control and the perception of opioid analgesics; personal values and emotional expression; the appropriateness of physical touch between people; the care of the dying person and rituals surrounding the time of death; the nature of family systems in terms of authority, tasks, gender roles and other features; understanding of and expectations of health professionals and health care institutions; comfort level with accepting outside help in the home; and the manner and rituals of grieving.

Continued on page 2...
Quality end-of-life care: What do patients think?

By Scott Berry, MD, FRCPC

Issues surrounding end-of-life care continually challenge physicians and other health care providers who care for patients with cancer. In the last issue of Hot Spot, I reviewed how “advance care planning” could help improve the quality of care we give to our dying patients. Qualitative research methods in the field of advanced care planning have forced us to examine our previous conceptions of the process by providing indepth analysis of patient interview.

Until recently, there have been very few papers published in the medical literature that have used qualitative methods, at least partially due to the fact that these papers were thought to lack the rigour and objectivity of their quantitative counterparts.

The British Medical Journal has recently published a series of review articles describing qualitative research methodology that has helped dispel this myth. By systematically exploring people’s thoughts and opinions through interviews, focus groups and other methods, qualitative researchers can help us reach a deeper understanding of complex social issues like end-of-life care.

Realizing that existing frameworks describing approaches to end-of-life care are derived from the expert medical perspective, Dr. Peter Singer and his colleagues from the University of Toronto Joint Centre for Bioethics analyzed material from interviews with 126 patients to develop a framework that was derived from the patient perspective. The participants of the study were people who were either on dialysis, living with HIV infection or who were residents of a long-term care facility for chronically ill adults. Transcripts of indepth interviews were rigorously analyzed to search for themes relating to patients’ opinions regarding quality end-of-life care.

The analysis of data revealed five dominant themes that were important to patients in achieving quality end-of-life care and these are listed in Table One.

Because this study did not include patients with cancer, one must reflect on how generalizable these data are to oncology patients. Given the diversity of patients studied and the fact that we face very similar issues in caring for people with cancer, it would not be unreasonable to think that cancer patients would have similar concerns. Obviously, exploring these issues in cancer patients would be a meaningful research endeavour.

The aspects of quality end-of-life care highlighted by patients are important for several reasons. Most importantly, this framework can help clinicians focus on the issues that are most important to patients in caring for their dying patients. While clinicians have previously realized the importance of addressing symptom management issues, studies like this help reinforce the importance of dealing with patients’ concerns regarding their families and ensuring patients have an appropriate voice in their end-of-life care. In the academic setting, the framework can help serve as a focus for research into improving quality end-of-life care. Finally, the results of this study should help us educate the next generation of health care providers to be more adept at providing quality end-of-life care.

Enhancing culturally sensitive practice

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From the viewpoint of ethical decision-making in care, the role of the self (individualism), the concept of individual autonomy, and truth-telling about the nature of serious illness and prognosis are very subject to cultural influence. While highly valued in western thought, they may hold a lesser position in other cultures. Truth-telling about serious illness may not be the norm in the culture of the patient who presents for care. When this is the case, the concept of informed consent as the important basis of ethical decision-making with patients is not possible.

Tension may occur because the team holds one set of values and the patient and family holds another. Often, misunderstanding and lack of information about viewpoints, values, and cultural expectations may form the basis of disagreements and polarization between health teams and family about the best treatment for the patient. This tension can be distressing to everyone involved.

Heightened awareness about the important role that culture plays in illness, combined with genuine openness, a desire to learn and to help will go a long way in fostering mutual understanding. Consider the following approaches to strengthen your culturally sensitive practice:

• Recognize that many human experiences and feelings are universally shared. For example, anxiety, grief, humour, joy and sorrow are common to everyone. We can all connect on these levels.
• Be open in acknowledging and respecting the richness of cultural diversity.
• Emphasize the idea of uniqueness rather than “difference”. What is the unique way in which illness is viewed in a culture?
• Focus on each person as an individual, rather than focusing on the group.
• Be respectful in word and demeanor. Take the time required for detailed assessment and care.
• Inquire about values, beliefs, practices and expectations. “How can we support and help you?”
• Develop sensitive ways to ask questions and gain information. Role-playing is a good way to practise asking what you will need to know. Some areas to pursue include views about: the sanctity of life, the definition of death, religious background and beliefs, causal agents of illness and death, social support systems, who makes decisions about treatment and care, practices at the time of death, what should and should not be done by the team.
• Utilize an interdisciplinary team approach to care. Use team meetings to focus on cultural aspects of care to ensure that these are incorporated in the care plan for the patient.
• Take care in selecting and using interpreters. Ideally, they will have received some training, will be acceptable to the family and patient, and will have a prior orientation from the health care team. Remember that it can be very difficult for children to serve as interpreters, particularly when this activity requires role reversal or when the information to be conveyed is emotionally distressing, for example, about diagnosis and prognosis. Wherever possible, alternatives should be sought.
• Affirm the mutual desire of the health care team and family to do what is best for the patient, acknowledging that viewpoints about what is best may differ. Seek to emphasize shared ground.
• Seek education and knowledge about particular cultures as you care for patients. Acquire resource materials in cross-cultural care.
• Consider ways to celebrate and value culture within your organization, including developing links with cultural communities, developing volunteers and interpreters, inviting participation in educational rounds, encouraging sharing of cultural richness amongst staff members.

Table One: Domains of quality end-of-life care from patients’ perspective

1. Receiving adequate pain and symptom management
2. Avoiding inappropriate prolongation of dying
3. Achieving a sense of control over end-of-life care decisions
4. Relieving burden on loved ones
5. Strengthening relationships

References are available from Dr. Latimer upon request.
Families dealing with advanced cancer

By Mary L.S. Vachon, RN, PhD

The response of a family to advanced cancer is determined by a number of factors including the developmental stage of the family, the cancer illness trajectory, the family responses to cancer, and the relationship with health care staff.

**Developmental stage:** A family that is already struggling with issues such as the developmental changes of adolescence, career change, ill or aging parents or financial hardship may not have the resources that might have otherwise been available to cope with the crisis of advanced disease. While some families pull together to deal with the stress of an ill family member, other families may splinter as the stress of coping with an ill family member may cause increased strain in an already difficult situation.

**Cancer illness trajectory:** A family’s adaptation will be affected by the pattern the disease follows. If there has been time to adjust to the fact that the disease may lead to death there may be somewhat less difficulty than if the family is overwhelmed by a rapidly progressive disease with difficult-to-manage symptoms that allows for little time to process the emotional aspects of what is going on. However, families who have adjusted to cancer as a chronic illness may be shocked to find that there are no longer treatment options to prolong life. Families may become exhausted over the course of the illness, particularly if the disease has had numerous relapses and remissions and the frequent expectation of death. Such families may have a difficult time believing that death will ‘really happen’ at this point. They may also come to hope that the person will either get better or die and stop the chronic uncertainty for all concerned. Of course, this may lead to feelings of guilt during the final illness and bereavement if such feelings are not expressed and family members should be helped to understand that they are normal.

**The family’s response:** Family status has been correlated with survival in some studies where married patients have been found to have earlier access to treatment, enhanced compliance with treatment regimes, increased social support and access to the caregiving skills of spouses. However, family members may experience significant distress. Studies of family caregivers of persons with advanced disease have shown that most experienced stress in the caregiver role and significant distress in observing their family member suffering. They report significant distress from the uncertainty about the course of the disease, feelings about their difficulty in providing care and effective symptom relief and managing the patient’s symptoms of anxiety and depression.

Family distress may be as great if not greater than that of patients. Family member distress has been found to be associated with patient distress and perceived family burden has been associated with desire for early death in patients with advanced disease. Studies of children whose parent has cancer have found that 20-30% of these children experienced adjustment difficulty. Children’s adjustment was correlated with that of their parents. Poorer prognosis and more extensive surgery were found to be associated with more problems in parent-child relationships.

Family members may have difficulty with the physical demands of caring for a loved one, particularly if the caregiver is older, or already has pre-existing physical problems. There may be concerns about the dying process; difficulty with role changes and life-styles, both during the final illness and after bereavement; finances; whether there will be adequate services to provide care for the person, whether in the hospital or at home; what will happen if the person dies at home; and what will happen to the family after death.

**Relationship with health care staff:** Family members are now being asked to assume increasing responsibility, both in the hospital and home care setting. It has been found that programs for family caregivers to deal with pain were successful in improving knowledge and attitudes about pain as well as improving the pain intensity and overall quality of life for the patient. However, the study also showed the unmet emotional burden of the family arising from the perceived burden of caring for the loved one. Family members need support for the intense roles they assume and they shoulder as they are expected to take on more care of their loved ones. Such support needs to come from hospital and clinic staff as well as family physicians and community caregivers and needs to extend into the bereavement period.

### Percutaneous vertebroplasty/cementoplasty at bone metastases clinic, TSRC
By Edward Chow, MBBS, FRCP<br><br>A new minimally invasive procedure for the treatment of intractable pain and pathological fractures due to osteolytic metastases, myeloma and osteoporotic vertebral collapse is now available. This service is jointly offered by Dr. Gordon Cheung and his colleagues in the radiology department and Dr. Joel Finkelstein in the department of orthopedics at Sunnybrook and Women’s College Health Science Centre to patients with bone metastases.

In percutaneous vertebroplasty/cementoplasty, polymethyl methacrylate (PMMA) is slowly injected into the long bone/vertebral body under fluoroscopic guidance. PMMA is a bone cement commonly used in orthopedics for stabilization of prosthetic implants and vertebral lesions during open surgery. Rapid partial or complete relief of pain (approximately 85%) can usually be achieved with acceptable complication rates.

Eligible patients can be referred to Dr. Joel Finkelstein at (416) 480-6100 ext. 7102, or you can fax in a referral to (416) 480-4705.

### Historical Vignette: Dr. Joseph-Ernest Gendreau and the early use of radium
By Charles Hayter, MA, MD, FRCPC, Radiation Oncologist, T-SRCC

Radium, a naturally occurring radioactive material, was discovered by Pierre and Marie Curie in 1898 and was very quickly found to be useful in the treatment of cancer. Dr. Joseph-Ernest Gendreau of Montreal had studied with Marie Curie and was keenly interested in radium treatment. However, the cost of radium was very high since it took over four and a half tonnes of ore to produce one gram. Citing the increasing mortality from cancer, Gendreau appealed to the premier of Quebec for help. As a result, the government of Quebec allocated $100,000 for the purchase of radium in 1922. Quebec thus became the first province in Canada to recognize the importance of radiotherapy and provide funding for radium.

The radium was kept and used at the Institut du Radium at the University of Montreal, which was officially opened in April 1923. Over the subsequent years, many thousands of patients were treated at the Institut for a wide variety of malignant and benign conditions. In 1927, the Institut moved to more spacious quarters in its own hospital in the east end of Montreal. The use of radium to treat bone metastases at the Institut is of particular interest. Reports show that between 1923 and 1927, 47 patients were treated for bone metastases, and 33 (70%) had improvement in their condition. Thus, even in these early days, radiotherapy had recognized effectiveness for bone metastases.
By Rebecca Wong, MBCChB, FRCPC

For this issue, I bring you some thoughts from the 12th International Symposium in Supportive Care in Cancer, which took place in Washington, D.C., amongst the cherry blossoms, from March 23-25.

This three-day conference ranged in topics from alternative medicine to the role of genomics in the development of new therapies for cancer.

One of the major advantages of this international meeting is the acknowledgement that supportive care spans a very wide scope. While many of the “new medicines” or “complementary” or “alternative” therapies did not have their foundations built upon conventional western medicine and the research methodologies that came with it, it did not preclude the organizers or conference delegates from trying to study the modalities using languages or methodologies that are more familiar to us, and to open our minds to consider evidence originating from very different paradigms. Such is the nature of the invited presentation by Dr. James Gordon, a professor in psychiatry, and first chair to the NIH office of alternative medicine. As the program director to the Centre for Mind-Body Medicine in Washington, he provided insights on how “mind-body approaches to supportive care of the cancer patient” can be achieved. Theories and possibilities with herbal medicine were tackled by Eron Ben-Ayre from Israel. While no discrete pearls of knowledge could be reported back to you on this front, the need and attractiveness to consider these approaches, and the fact that we are now beginning to have the tools to allow us to do it, were quite convincing for at least this one conference delegate.

Back to more familiar territory, fatigue and its impact on cancer patients were addressed by C.A. Curt from the National Cancer Institute. He reported on results from a survey designed to determine the prevalence and duration of cancer-related fatigue and its impact on patients treated with chemotherapy with or without radiation. Of the 379 patients interviewed, 76% experienced persistent fatigue. This was ranked as the most significant symptom affecting everyday life. The authors refer the readers to an algorithm described by Dr. Portenoy (The Oncologist, 1990; 4:1-10) who provided a good working algorithm for the management of cancer-related fatigue.

Dr. Bezjak of Princess Margaret Hospital conducted an international survey on behalf of MASCC probing into how clinicians view, and their knowledge about, quality of life tools and their applications. Respondents have a good understanding of the type of tools available and describe willingness to incorporate quality of life tools into clinical practice. With the increasing recognition that quality of life information represents an important component of cancer care, this work now suggests that the medical profession has a collective readiness to begin incorporating quality of life information into clinical practice.

Psychosocial issues and quality of life in family caregivers were discussed by Dr. Weitzen. Prognostic factors affecting how family members coped with the burden of illness were explored. Caregivers, when experiencing heavy burdens (no resentful feelings), tend to benefit from supportive measures, while those who experience heavy stress (i.e. resentment) do not benefit particularly from supportive care.

The Rapid Response Radiotherapy Program of Toronto-Sunnybrook Regional Cancer Centre is published through the support of:
# Accessing Palliative Care in Your Community

## Simcoe County (Barrie, Orillia)

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<tr>
<td>Hospice Simcoe (Barrie)</td>
<td>Royal Victoria Hospital (705) 728-9802 x 4704</td>
<td>Palliative Care Pain &amp; Symptom Management (800) 539-1444</td>
<td>Physician teams can be accessed through 1 (800) 539-1444</td>
<td>Canadian Cancer Society: Barrie: (705) 726-8032 Orillia: (705) 326-9587 Reach - Support group for women with breast cancer: 1 (800) 338-6610 Man to Man - Support group for men with prostate cancer: 1 (800) 338-6610</td>
<td>Community nursing, Community Care Access Centre (CCAC) Saint Elizabeth Health Care: 1 (888) 737-5055 CCAC: (705) 721-7444</td>
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<td>Hospice Orillia (705) 327-7797</td>
<td>Orillia Soldiers’ Memorial Hospital (705) 325-2201 x 3426</td>
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<td>Hospice Huronia (705) 549-1034</td>
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## Halton Peel Region (Oakville, Brampton, Mississauga)

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<td>Hospice of Palliative Care (905) 712-8119</td>
<td>Credit Valley Hospital (905) 813-2200</td>
<td>Halton Peel Palliative Care Initiatives (905) 827-8111 or 1 (800) 426-9666</td>
<td>Resource teams only: Consult and Support for Family Physicians 1 (800) 426-9666</td>
<td>Canadian Cancer Society: Mississauga: (905) 896-3200 Brampton: (905) 451-4640 Wellspring - Oakville, opening in May 2000, bereavement support services Aborcare (905) 451-1100</td>
<td>Community nursing, Community Care Access Centre (CCAC) St. Elizabeth Health Care: (905) 275-2956 Halton CCAC: 1 (805) 810-0000 Halton VON: (905) 827-8800 Peel CCAC: (905) 796-0040 Peel VON: (905) 821-3242</td>
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<td>Ian Anderson House (905) 337-8004</td>
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## Durham Region (Pickering, Ajax, Whitby, Oshawa)

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<td>Hospice Durham (905) 435-5242</td>
<td>Lakeridge Health Corporation (Oshawa site for Palliative Care Units) (905) 576-8711</td>
<td>Palliative care and symptom management program: (905) 721-4703 1 (800) 826-3860</td>
<td>Physician team can be accessed through 1 (800) 826-3860</td>
<td>Canadian Cancer Society: East Durham: (905) 725-1166 West Durham: (905) 686-1516 Health Place: (905) 579-4833</td>
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<td>North Durham Hospice (905) 852-4461</td>
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By: Joan Pope, RN, BScN; Lourdes Andersson, RN, MA  
Acknowledgement: A special thank-you to Catherine Freer for her valuable assistance with this project. Catherine is coordinator of the Palliative Care Information Centre (PCIC) for Metropolitan Toronto. PCIC is located in L-Wing of Sunnybrook & Women’s College Health Sciences Centre. Visit the PCIC website at www.palliativecareinfo.com (mid-May, 2000).
### Metropolitan Toronto (Etobicoke, York, North York, Toronto, East York, Scarborough)

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<td>Temmy Latner Centre for Palliative Care (416) 586-4800 x 7884</td>
<td>Cancer Connection telephone peer support for patient and family (1) 800) 263-6750 x 611</td>
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<td>Hazel Burns Hospice (416) 782-5912</td>
<td>Baycrest Hospital (416) 789-5131 x 2917</td>
<td>Cancer Information Centre 1 (888) 939-3333 Canadian Cancer Society (head office) (416) 440-3330</td>
<td>Sunnybrook &amp; Women’s Palliative Care Initiative Consult Team (416) 480-6100 x 7255</td>
<td>Bereaved Families of Ontario (416) 440-0290</td>
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<td>Jewish Hospice Program (416) 638-7800 x 260</td>
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<td>The Toronto Hospital &amp; Princess Margaret Hospital Collaborative Program (416) 946-2135</td>
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<td>Trinity Home Hospice (416) 363-1666</td>
<td>Sunnybrook &amp; Women’s College Health Sciences Centre (416) 480-6100 x 2445</td>
<td>Cancer and Palliative Services at Yee Hong Centre. Physicians speak Cantonese, Mandarin, and English (416) 321-0458</td>
<td>Canadian Cancer Society (416) 261-6942</td>
<td>Wellspring - two locations: 1. Wellesley/Church (416) 961-1928</td>
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<td>The Scarborough Hospital (Grace Site) (416) 495-2461</td>
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### York Region (Newmarket, Richmond Hill, Markham, Stouffville)

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<td>Hill House Hospice (905) 737-9308</td>
<td>York County Hospital (905) 895-4521 x 2515</td>
<td>Regional Pain and Symptom Management Consultation Program (905) 895-4623 or (905) 895-3628 x 233</td>
<td>Physicians’ teams are organized for families through regional consultation program (905) 895-4623</td>
<td>Canadian Cancer Society: Living With Cancer (905) 830-0447 AIDS Committee of York Region (905) 895-4511 x 4048</td>
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<td>Hospice Newmarket (905) 895-3628 x 291</td>
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<td>Evergreen Hospice Markham, Stouffville (905) 472-5014</td>
<td>Markham Stouffville Hospital (905) 472-7000</td>
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### Community care

- **Community nursing, Community Care Access Centre (CCAC)**
  - Interlink Community Cancer Nurses (416) 599-5465
  - St. Elizabeth Health Care: (416) 498-8600
  - East York CCAC: (416) 423-3559
  - Etobicoke CCAC: (416) 229-5803
  - Scarborough CCAC: (416) 780-1919
  - Toronto CCAC: (416) 780-1919
  - VON: (416) 499-2009