

Palliative Care McGill Research News

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****SPECIAL ISSUE****

Departments of Oncology and Medicine, McGill University
 McGill University Health Centre
 Sir Mortimer B. Davis-Jewish General Hospital
 St. Mary's Hospital Centre
 Mount Sinai Hospital

Palliative Care is a Basic Human Right

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The International Association of Hospice and Palliative Care (IAHPC) and the Worldwide Palliative Care Alliance (WPCA) drafted a *Joint Declaration and Statement of Commitment on Palliative Care and Pain Treatment as Human Rights* (www.hospicecare.com/resources/pain_pallcare_hr/). As palliative care organizations are now mobilizing to encourage international human rights organizations to take up the cause, it seemed an opportune time to put this topic on the agenda at the 2008 International Congress on Palliative Care. Organized and chaired by Dr. Martin Chasen, this all day seminar focused on palliative care delivery around the world.



Table Mountain, Cape Town, South Africa

Dr. Liz Gwyther from the University of Cape Town in South Africa noted that half the countries in the world have no hospice and palliative care services and that 80% of cancer sufferers in the world do not have access to pain relief despite the fact that the palliating drugs they need are on the World Health Organization's (WHO) essential medicines list. She discussed the various barriers which limit access to palliative care such as physician barriers (education of health care

providers), access barriers (policy issues), social factors (death denial in some cultures), and patient factors. She also described ways to address these barriers such as increasing community awareness, increasing drug availability, education of health care workers and policy makers and development of policies.

Diederick Lohman from Human Rights Watch noted that this is the first time a

representative of a major human rights organization has addressed this Congress. He highlighted the importance of collaboration between the palliative care organizations and human rights groups to bring the message to governments around the world that palliative care needs to be a priority. Mr. Lohman described the various human rights groups and how to ultimately encourage the UN Human Rights Council to rally around this cause.

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Selected highlights of the 17th International Congress on Palliative Care September 23-26, 2008.

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Hope and Meaning in Palliative Care for Children

Organized and chaired by Dr. Stephen Liben, this all day seminar took place on the first day of the Congress and focused on communication between palliative care physicians and the families of children in intensive care.

Dr. Brian S. Carter from Vanderbilt Children's Hospital in Nashville talked about palliative care for children in inten-

sive care. The pediatric intensive care unit is a unique place where patients, families and staff can experience a gamut of emotions from intense physical, mental, emotional and spiritual pain to hope, anticipation and expectation of miracles. There are many issues to deal with such as the lack of privacy and quiet, and the necessity to act quickly in many cases. Dr. Carter dis-

cussed the need for the integration of the palliative care team within the intensive care unit to help support patients and families and guide them through the difficult process as end-of-life care becomes a reality. Integration at the point of diagnosis would allow the palliative care team to be more accessible to the families.

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Research Fora

Organized and chaired by Dr. S. Robin Cohen, each of the three Research Fora featured three speakers and a discussant, followed by a question and answer period.

Dr. Susan Cadell from Wilfred Laurier University in Kitchener presented the study she and colleagues have been doing looking at the impact of caregiving on parents of children with life-limiting illness. Preliminary data shows that meaning of caregiving positively correlates with self-esteem and that depression has a weak but significant correlation with growth.

Dr. Sarah Hales from the University Health Network, Toronto is studying the quality of dying and death in metastatic cancer from the perspective of the caregiver. Using the Quality of Dying and Death questionnaire which focuses on six broad domains (symptoms, preparation for death, quality of moment of death, time spent with others, were treatment prefer-

ences followed, whole person concerns), preliminary results show that on average the quality of dying and death is judged quite positively and that a patient's age may be connected to the quality of dying and death.

Dr. Susan McClement from the University of Manitoba presented her study on the experience of health care aides in caring for dying seniors in a personal care home. Through interviews she learned that they often develop close relationships with the people they care for and sometimes feel very frustrated because they are unable to provide the care they would like due to external factors that may arise such as disregard for patient wishes, inadequate pain control, and challenges with resources.

Dr. Sharon Kaasalainen from McMaster University discussed her study looking at the experiences of adults with advanced heart failure, their family caregivers and

formal health care providers. Due to the unpredictable nature of the illness, recruitment proved to be a challenge. Through interviews she learned that there is a great deal of frustration due to the limited access to resources such as transportation barriers and community supports, for people with advanced heart failure. There also seems to be poor transitioning to palliative care. These issues need to be addressed by the health care providers.

Dr. Kathy Webb, working with Dr. Deborah Dudgeon and colleagues at Queen's University, presented their study on dyspnea in cancer patients. They found that the "cancer with dyspnea" patients differed from cancer controls and healthy controls in exercise responses. They had greater exertional dyspnea and exercise limitations and showed a rapid and shallow breathing pattern.

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Pain and Symptom Control (Clinical Master Class)

The Clinical Master Class, organized by Dr. Robin Love, covered a wide range of topics on pain and symptom management.

Dr. Carla Ripamonti from the Istituto Nazionale dei Tumori in Milan, Italy discussed the causes, symptoms and ways to assess diagnose and treat malignant bowel obstruction, and presented clinical studies on the use of octreotide in patients with low level obstruction.

Dr. Sean Morrison from the Mount Sinai School of Medicine in New York discussed pain assessment and management for cognitively impaired seniors. Seniors with cognitive impairments often do not get adequate pain treatment because of their inability to self-report the pain they are experiencing. Studies have shown that

contrary to the fears of some members of the medical community, patients are actually more at risk of delirium if their pain is left untreated than if they are treated with opioids.

Dr. Neil MacDonald from McGill University gave a summary of anorexia cachexia outlining its pathophysiology, symptoms, assessment methods and treatment. Monitoring C-reactive protein levels gives some indication of the prognosis of patients. He also described the McGill Cancer Nutrition Rehabilitation Program and the treatments the Program offers to cancer patients.

Dr. Paul Daeninck from the University of Manitoba discussed the use of cannabinoids in the treatment of pain, nausea and loss of appetite experienced by chronically ill pa-

tients. He also presented research findings on the use of cannabinoids in pain and symptom control

Dr. José Pereira from Hôpital Nestlé CHUV in Lausanne, Switzerland presented on delirium. He discussed the importance of being able to recognize and treat hypoactive delirium, which unlike hyperactive delirium, is not always obvious to caregivers.

Dr. Sam Ahmedzai from the University of Sheffield in the UK gave a lengthy discussion about the physiology, causes, and assessments and treatments for dyspnea.

Dr. Charles Von Gunten from San Diego Hospice and Palliative Care presented a case study of a woman with intractable abdominal pain and opened up the floor to a discussion on the best course of treatment.

Healing and Whole Person Care

This all day seminar was organized by Dr. Tom Hutchinson and brought to the forefront the notion that palliative care becomes more than just another specialty when the physician or other healthcare worker puts him or herself at least partly in the shoes of the person who is ill and possibly dying. This is a challenging step to take but changes the relationship of patient and caregiver in a profound way – one that fosters healing.

Dr. Michael Kearney from Santa Barbara Cottage Hospital gave an overview of the topic and highlighted the fact that palliative care should not only be task-oriented through therapeutic interventions

(Biomedical Model) but also people-oriented (Healing Model) which would allow the patient to come to terms with the notion of dying. He also reviewed various ways to train medical students to look at the importance of emotional healing in addition to physical healing.

Dr. Sheldon Solomon from Skidmore College in Saratoga, New York, reviewed research done on death anxiety and terror management theory. In controlled studies it was found that reminders of one's own mortality can have dramatic effects on how a person reacts in situations which test tolerance to others who have different cultural, religious or political beliefs. Dr. Solomon

highlighted the fact that the self esteem of a person is tied in with cultural social norms as well as with their belief that they are a person of value in a world that has meaning. Within the context of palliative care, if a person believes that life has meaning and they have value, they tend to fare better when dealing with a life threatening illness.

Dr. Gregory Fricchione from Harvard Medical School discussed Separation Attachment Theory and the notion that palliative care patients search for attachment solutions in order to overcome the separation anxiety inherent with knowledge of illness and impending death. Attachment solutions

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Palliative Care is a Basic Human Right (continued from page 1)

Dr. Kathy Foley from Memorial Sloan-Kettering Cancer Center in New York summarized the international efforts being done to drive home the message that palliative care is not only a public health and global health issue but also a human rights issue. Many international organizations such as The International Palliative Care Initiative of the Open Society Institute (OSI), the World Health Organization and the International Atomic Energy Agency have developed assessment, education, training, research and advocacy initiatives to improve drug availability and access to palliative care in low and medium resource countries.

Dr. Nathan Cherney from the Shaare Zedek Medical Center in Jerusalem talked about his experience providing palliative care in a medical centre which has patients and health care providers from both sides of the Palestinian-Israeli conflict. He highlighted the challenges faced on a day-to-

day basis such as availability of resources, lack of free movement of goods, bias issues which can affect both patients and health care providers, distrust and enmity, shortage of health care providers and abuse of the health care system. Dr. Cherney described how bridges have been built between patients and health care providers on both sides of the conflict as a result of the universality of the illness experience.

Dr. Dirk Schrijvers from ZNA-Middelheim in Antwerp, Belgium gave a description of the European Society for Medical Oncology (ESMO) and a summary of its mandate to encourage medical oncologists to play a central role in coordinating the care of cancer patients. He described the ESMO policy paper on supportive and palliative care which advocated for the establishment of a special relationship between medical oncologists and palliative care providers. He also described the ESMO program for designated centres for

integrated oncology and palliative care and noted that the Jewish General Hospital met the stringent criteria and is the only centre in North America to have this designation.

Dr. Julie Lachance from Health Canada was unable to present and therefore her talk was presented by Dr. Chasen. It focused on how the Canadian government's commitment to palliative care has resulted in a rapid expansion of services, national quality standards, educational initiatives and research support.

Dr. William Breitbart from Memorial Sloan-Kettering Cancer Center discussed the universal issues facing people with a terminal illness such as spirituality and the concept of belief and hope. He also talked about how patients deal with the notion of death, some denying it, some having a peaceful awareness of it and some fully accepting it.

Hope and Meaning in Palliative Care for Children (continued from page 1)

Dr. Mary Ellen MacDonald from McGill University presented a case study she had worked on as a postdoctoral fellow regarding a family's experience when their child was brought to the pediatric intensive care unit following an accident. The study highlighted the importance of clear communication between the health care team and the family so that the family fully understands the situation and can make informed and timely decisions on matters of care and closure at end of life.

Dr. Elaine C. Meyer from the Children's Hospital Boston discussed the parent perspectives and priorities at end of life. Dr.

Meyer stressed the importance of sound communication between the health care team and the parents. Health care professionals should not only talk to the families but should also listen, ask questions, make sure they understand the issues and take into consideration their preferences. Moreover, health care professionals should also be aware of any non-verbal cues they may be giving when interacting with the parents. In addition to sound communication with the health care team, families also highly value an emotional and affective component, for example, a health care team member showing rather than hiding sadness is often very

touching for the family members.

Dr. Chris Feudtner from the Children's Hospital of Philadelphia continued on the same theme of how to talk to families and referred to collaborative communication. He discussed the idea that families talk in the language of "hope" and that the families need to express what they are hoping for at each stage. He also talked about the transition from talking about living to talking about dying – reframing and re-anchoring the discussion with the families.

The final hour of the session was devoted to open dialogue regarding various topics in palliative care.

Volunteer Training

This three hour special seminar was organized by The Council on Palliative Care (represented by Kappy Flanders) together with the McGill Medical Simulation Centre (represented by Linda Crelinsten). The session was moderated by Suzanne O'Brien, Executive Director of Hope & Cope at the Sir Mortimer B. Davis-Jewish General Hospital.

Participants viewed four videos which depicted dramatizations of actual situations volunteers had experienced when working with palliative care patients, and the emotional and ethical issues encountered. These videos served as a springboard for small group discussions on training, chal-

lenges and opportunities. The objectives were to identify the role of the volunteer in the different settings, describe the common challenges related to family dynamics, identify the communication issues between patients and families and between the team members and finally, to recognize ongoing opportunities for training.

Challenges depicted in the videos include a patient requesting a favour from the volunteer which goes above and beyond reasonable expectation; how much information a volunteer should impart to a family member regarding the patient's condition; dealing with complicated family dynamics; and being mindful of cultural differences.

Some of the key points regarding the role of the volunteer that were highlighted during the group discussions include: the importance of validating the needs of the patient even if they are unable to comply with the request; volunteers need to ensure they are giving enough space to the family members; the role of the volunteer is not always clear and can change from situation to situation; and cultural sensitivity is important in the home setting and can be a challenge.

The videos are an excellent training tool for volunteers as they provide an opportunity for learning and reflection about key issues and challenges in providing support to palliative care patients and their families.

Healing and Whole Person Care

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can be in the form of a connection to their inner selves, having deeper connections with others, a deeper religious connection, connections to childhood memories or connections to memories of a deceased loved one. The healthcare worker plays a role in this process by functioning as a transitional object for patients caught in the space between separation and attachment. Through a detailed explanation of brain physiology, Dr. Fricchione highlighted how humans are wired to deal with these difficult transitions.

Dr. Franco Carnevale from McGill University presented a case study of an Inuit boy who was treated for extensive burns at the Montreal Children's hospital. This was used as springboard to discuss the importance of the continued presence of the clinical team and their meaningful personal engagement with the patient during the course of illness.

MARK YOUR AGENDAS

**18th International
Congress on Palliative Care
October 5-8, 2010
Montreal, Quebec**

Research Fora (continued from page 2)

Dr. Tomasz Okon from the Marshfield Clinic and Saint Joseph's Hospital in Wisconsin presented a system implemented at his centre to improve medical error in the form of pain mismanagement. This system, which involves electronic tracking of administration of pain medication, results in an alert popping up on the computer screen 65 minutes after the last documentation of pain treatment. In this way the health care provider is prompted to assess the patient for pain control. Implementation of this system has indeed resulted in a reduction in the error rate and improvement of pain control.

Dr. Joakim Öhlén from the Sahlgrenska Academy at University of Gothenburg, Sweden discussed patient learning in patients with GI cancer. He found that there can be a shift in patient learning and processing of information as their focus of interest changes based on their understanding of the course their disease is taking.

Dr. Melissa Henry from McGill University discussed her pilot study on Meaning Making Intervention (MMi) in people newly diagnosed with advanced ovarian cancer. This intervention focuses patients on the present, past and future in order to help them find ways to cope with the illness. She found that the intervention was indeed very beneficial for these patients.

Dr. Peter Hudson from St. Vincent's Hospital in Melbourne, Australia presented his group education program which helps family caregivers prepare themselves for the role of supporting a dying relative at home. Participants found that it was a useful program which provided resources and practical advice thus increasing preparedness and competence for their role. In addition it allowed them to meet and form friendships with others in the same situation.

Canadian Virtual Hospice (www.virtualhospice.ca/)

An internet-based network created by Dr. Harvey Chochinov and colleagues which provides support for people dealing with life threatening illness. This website features pages specifically geared towards the patient, family/friends and volunteers, including online support and "Ask a Professional", as well as pages for health care professionals such as "Connect with Colleagues".

Family Caregivers

The Family Caregivers special seminar was organized and co-chaired by Drs. S. Robin Cohen, Serge Dumont and Johanne de Montigny. The four speakers were Dr. Kelli Stajduhar from the University of Victoria, Dr. Nancy Guberman from the Université du Québec à Montréal, Dr. Jean-Pierre Gagnier from the Université du Québec à Trois-Rivières and Dr. David W. Kissane from Memorial Sloan-Kettering Cancer Center in New York.

Drs. Stajduhar and Guberman discussed the needs of caregivers to people at end of life from the standpoint of whether they view themselves as partners with the health care professionals or clients of the health care system.

Dr. Stajduhar focused on the caregivers as partners. These people saw themselves as taking a lead role in the primary care of the patient with the clinicians taking a secondary role. Caregivers who viewed themselves as partners had increased confidence in what they were doing. However, they sometimes felt this decision-making responsibility was not always acknowledged by the clinicians and they had

to be more assertive when clinicians could not deal with this change in dynamic. Some of the caregivers who viewed themselves as partners did not take on that role willingly but felt they were positioned into it as a result of cutbacks in the health care system. Some resented being in that role and worried over pain management issues. The decision for care at home should not be a one-time discussion but should be re-opened at different points throughout the course of illness.

Dr. Guberman focused on the caregivers as potential clients because of their need for support as they deal with the issues involved in caring for a dying patient. The caregiver as a client is very ambiguous in the health care system because there is no file open on that person. There are also not very many intervention-based (as opposed to research-based) instruments for evaluating the specific needs of the caregivers. Dr. Guberman is working on an evaluation instrument to evaluate the family caregivers. This will help document their needs and change the rapport between the caregivers and the health care system to better service those needs.

In addition it will help in monitoring the family caregivers to see how well they are coping and whether or not they are at risk for burnout.

Dr. Gagnier discussed the fears and changes that patients and families deal with during the cancer trajectory. He highlighted the fact that professionals must take the concerns and needs of family caregivers into consideration.

Dr. Kissane addressed key issues and challenges that need to be considered during a routine family meeting. These include understanding where the family members are at in their understanding of the illness and whether or not they are comfortable talking about death and dying. He also described at length, a training program to teach health care professionals how to conduct a family meeting. The skills taught are the following: establishing an agenda, question asking skills, checking skills (ascertaining family understanding, knowledge and preferences), information organization, empathic communication and shared decision-making skills.