Quality of Life Research: Pain Management

Pain requiring treatment is experienced by a majority of cancer patients at the end of life. Many family caregivers experience feelings of hopelessness, helplessness, and a sense of loss of control when observing their loved ones in pain. This grounded theory study focuses on the following questions: 1) What is the process used by family caregivers at home to manage the pain of palliative cancer patients? 2) What are the types of pain family caregivers of palliative cancer patients are managing at home? 3) What are the interventions that family caregivers are performing at home? The results of the study will allow us to design an intervention to ensure that family caregivers have the appropriate skills to safely and confidently manage the patient’s pain at home. Preliminary results show that family caregivers seem to be involved in “implementing a pain management regimen” at home. This involves a process whereby they assess pain, intervene to help control what they perceive as pain, and then document the effectiveness of their strategies. It has also been found that family caregivers are managing many different types of pain as they care for palliative cancer patients at home. Although the majority of patients are suffering from pain related directly to their cancer, they are also experiencing pain related to their various treatments, and/or other illnesses. As a result, their family caregivers have the responsibility of managing these different types of pain. Although some family caregivers felt prepared to handle this, and were equipped with a selection of pain control strategies that they tailored to the type of pain the patient was experiencing, others felt unprepared or stated that they had received little or no information on pain management. Other family caregivers did the same intervention, regardless of the type of pain the patient had. Although the most common strategy used for pain relief was medication, family caregivers were also using a variety of non-pharmacological interventions as well. Interestingly, there appears to be a “preparing a pain management regimen” process that precedes “implementing a pain management regimen” and which involves collecting information about the pain/pain management, seeking support, drawing on past experiences with pain management, respecting the relationship with the patient, accepting the responsibility of pain management, and establishing/understanding patterns of communication.

Anita Mehta, RN, MSc(A)

Quality of Life Research: Predicting Bereavement Outcomes

Robin Cohen, together with colleagues from across Canada (Gillian Fyles, Raymond Viola, Julie LaChance, Anne Leis, K. Stephen Brown and Patricia Porterfield), have just completed a longitudinal study of the quality of life of palliative care patients with cancer and that of their family caregivers in the last few months of the patient’s life and in early bereavement. These periods are little studied in a longitudinal design due to data collection difficulties. Analysis is still ongoing. Caregivers were recruited from palliative home care services and/or inpatient units in 6 Canadian cities (Montreal, Ottawa, Kingston, Saskatoon, Kelowna, and Vancouver). They were referred to the study if their physician or nurse believed that the patient the caregiver was providing care for had 3-6 months to live. They were included in the analysis as long as they completed 1 set of questionnaires within 1 month prior to the patient’s death (n = 121). They completed measures of their quality of life (QOL)(our McGill Quality of Life (patient)

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Quality of Life Research: Predicting Bereavement Outcomes

and Quality of Life in Life-Threatening Illness – Family Carer version (QOLI-T:F) questionnaires), generalized sense of self-efficacy, reaction to caregiving, satisfaction with health care, and sense of preparedness for caregiving at various intervals while the patient was alive.

The most important results of the aspect of the study that examined predictors of the bereavement experience can be summarized as follows: Of the 121 participating family carers, 60 went on to participate during bereavement. They were not different demographically than those who did not continue into the bereavement phase. These carers completed a single-item measure of QOL and of depressive symptoms (CES-D) from 1-3 times during the first 6 months of bereavement. Multiple regressions using number of days after death and each predictor variable were used to determine the strength of the relationship between carer data collected during caregiving and those collected during bereavement. The Pearson correlation between Sense of Preparedness to provide care and Generalized Sense of Self-Efficacy was .34 so these are not one and the same.

From this we can see that QOL (especially the carer’s own state and financial concerns) and Preparedness to Provide Care while the patient is alive predict QOL and depressive symptoms in bereavement. Satisfaction with care predicts QOL but not depressive symptoms.

Many of the predictors of the bereavement experience can be modified during the caregiving phase by individual services (e.g., QOL, Preparedness to Provide Care, Satisfaction with Care). Therefore, we will develop interventions to optimize these and test their effectiveness not only during caregiving but during bereavement as well. Some things that worsen the bereavement experience such as financial concerns will need policy changes to ameliorate. Therefore the general population and the government need to recognize that just before and just after the death of a close family member is a financially unstable time that may require temporarily stabilizing interventions.

This study was funded by The National Cancer Institute of Canada (grant #13201) with funds donated to the Canadian Cancer Society.

Anorexia-Cachexia: Nutritional Intervention

Do most newly diagnosed advanced NSCLC patients need nutritional intervention? N. Swintor, G. Kazymjanova, T. Steinberg, L. Lajeunesse, E. Dajcerman, H. Kreisman, D. Small, J. S. Agulnik, J. Kawado, N. MacDonald

Methods: We determined the prevalence of malnutrition in 82 newly diagnosed advanced Non-Small Cell Lung Cancer (NSCLC) patients (stages 3/4) in an outpatient clinic who had completed a baseline Patient Generated-Subjective Global Assessment (PG-SGA). We also investigated the association between C-Reactive Protein (CRP; an inflammatory marker which correlates with poor prognosis) and the PG-SGA. PG-SGA score was based on the sum of 4 scales: symptoms, weight history, food intake and functional status. Results: 92 patients (M 48, F 44) aged 65 ± 11 years were studied. 81 (23%) patients had a PG-SGA score of 0-3, 23 (26%) 4-8, and 48 (52%) of 9 or greater. The most common symptoms accounting for a high PG-SGA score were: appetite change (47%), pain (29%), constipation (28%), feeling full (26%), dry mouth (24%), and taste changes (21%). Of those (85%) patients lost 4.9% of their body weight in the past month. 17 (19%) had a weight loss of 5-9.9% and 24 (28%) had a weight loss ≥10%

In patients with a PG-SGA score of 0-3 the median CRP was 7.0 mg/L (range: 0.7-68.0), in those with a score of 4-8 the median CRP was 41.8 mg/L (0.8-256.1) and in those with a score of ≥9 the median CRP was 135 mg/L (0.3-219.0) (p=0.02). Conclusion: At time of diagnosis, 77% of advanced NSCLC patients were in need of nutritional intervention; 52% required urgent intervention. The PG-SGA is a simple screening tool which should be incorporated into patient care in outpatient oncology clinics.

Pediatric Palliative Care: Pediatric Intensive Care Unit (PICU)

Office or bedroom? A disconnect between family culture and professional culture in the PICU. Mary Ellen MacDonald, Stephen Liben, Franco A. Carnevale, Janet E Rennick, S. Robin Cohen

Methods: Over a 12-month period investigators prospectively identified children in a 12-bed Canadian pediatric intensive care unit who had a significant risk of mortality during their admission. Data was collected from a prospective sample of families (N = 24 families) using daily participant observation (fieldnotes, informal and formal interviewing), which allowed for case-by-case and cross-case analysis. Observation and interviews with PICU staff provided additional data for contextual analysis. Results: A major theme emerged that reflected a disconnect between "family culture" and "professional culture" in the PICU. Interpreting these cultural differences using the metaphor of a child's bedroom versus that of a professional office culture makes it apparent that while the PICU is neither an office nor a bedroom, there are protocols and practices that both structurally and symbolically make the PICU seem more office-like than bedroom-like for its staff and families. Using this frame of bedroom versus office, it becomes apparent that protocols and policies around such issues as noise levels, visitation, parents' access to the bedside, confidentiality, privacy and hygiene may be structured such that they favor staff comfort and convenience (the office culture) over that of the child and family (a child's bedroom). This potential double standard has important repercussions for how families experience their child's PICU care. Conclusion: Comparing family and professional cultures in the PICU allows for a critical examination of PICU practices and values, including novel ways of deconstructing the philosophy of "family-centred care" and its application in the PICU.
Anorexia Cachexia: Exercise

Exercise in Patients with Advanced Non-Small Cell Lung Cancer (NSCLC): Compliance and Population Characteristics

MA Dalzell, H Kreisman, S Dobson, G Kasymjanova, E Roudaja, J Agulnik, D Small, N MacDonald

Background: Few studies focus on exercise in advanced NSCLC. We evaluated compliance with exercise prescription in stages 3/4 NSCLC. Methods: Patients (n=298) referred to the Cancer Nutrition-Rehabilitation Program (CNRP), a multidisciplinary clinic for weight/fat balance loss, were evaluated for participation in a supervised exercise program. Compliance with exercise was scored as 0 (refused/home exercise), 1 (<9 sessions in 2 mo), and 2 (≥ 6 sessions in 2 mo). Gender, age, PS, stage, C-Reactive Protein (CRP), weight loss, and Edmonton Symptom Assessment System (ESAS) were assessed by univariate and multivariate analyses. Survival from the time of exercise prescription was calculated using the Kaplan-Meier method and compared using log-rank. Results: 186 patients were referred to the CNRP from April 2002 to September 2005. 92/186 (50%) were prescribed exercise. Of the 76 remaining patients, 3 (4%) refused, and 8 (8%) were on an exercise trial. Others were excluded due to bone metastasis/severe pain (50 pts, 66%), cardiovascular instability (13 pts, 17%) or poor PS (4 pts, 5%). Of the 92 who were prescribed exercise, the compliance score was 1 in 42 (41%), 2 in 37 (40%) and 2 in 17 (18%). There were no significant differences in gender, age, PS, stage, ESAS, and weight loss at the time of referral among the three compliance groups. Most patients (15/17) with a compliance score of 2 were referred prior to or during initial treatment, whereas those with compliance scores of 0 and 1 were referred later in the course of treatment. Compliance with exercise correlated with survival (p<0.001). The median survival from time of exercise prescription for patients with a compliance score of 2 was 22 mo (95% CI 13.9, 30.2); compared with 8 mo (95% CI 3.7, 8.8) and 7 mo (95% CI 3.5, 11.5) for those with compliance scores of 0 and 1 respectively. No serious adverse events occurred. Conclusion: A select group of advanced NSCLC patients can exercise safely at a moderate-high level. Those referred earlier tended to be more compliant, and their longer survival may reflect a selection bias. Clinical trials are needed to evaluate efficacy of exercise in newly diagnosed NSCLC.

McGill Lymphedema Research Program

Our Canadian group (U. Saskatchewan, URC, U. Manitoba, Dalhouse, McGill) has preliminary data on our CIHR-funded arm morbidity study (PI: Roanne Thomas MacLean) that aims to chart the incidence and course of three types of arm morbidity - pain, range of motion (ROM) restrictions and Lymphedema - in 1000 women during the first five years post-surgery. The first-year data (gathered 6-12 months post surgery) on 347 breast cancer patients shows that 39.4% have pain, 12% experienced swelling and ROM restrictions were observed in over half the sample. Little overlap in the three types of morbidity was observed. Pain and ROM restrictions were significantly correlated with disability, but most women did not discuss arm morbidity with health care professionals.

Our qualitative study on the psychosocial effects of cancer-related lymphedema (Anna Towers and Franco Carnevali) has closed and has reported results. We adopted a phenomenological methodology to explore the experience of patients with cancer-related lymphedema and their psychosocial stressors. We wished to assess patients with a variety of cancer diagnoses and to interview spouses to investigate the experience of spousal involvement and support. We conducted biweekly semi-structured interviews with 19 subjects. Our data sources were: transcripts of interviews, medical records, and field notes (observations of subject's environment, behaviours and demeanours). We found that participants expressed frustration with lack of financial support from government and insurance companies. There was also frustration with physicians for their lack of knowledge and apparent lack of interest. This lack of awareness was perceived as being in society in general, with the burden of having chronic lymphedema being unrecognized. This study supports the findings of qualitative studies published to date from other countries. Participants in our study, however, highlighted financial stresses and views.

Anorexia Cachexia: Blood Counts, Albumin and C-Reactive Protein (CRP)


Methods: An inception and representative cohort of 300 patients 18 years or older, recently diagnosed with advanced Non-Small Cell Lung Cancer (NSCLC) and gastrointestinal cancer was investigated within the McGill University Health Centre. Baseline profiling of cancer cachexia included the Patient Generated Subjective Global Assessment (PG-SCA), Edmonton Symptom Assessment System (ESAS), hand-grip dynamometry and blood counts, including lymphocyte percentage, lymphocyte/white blood cell count, albumin and CRP. Results: Characteristics of the sample were: median age 65 (28-93 yrs), male/ female (123/89), NSCLC was the most common primary. Significant associations were found for: a) high (>10 ng/mL, prevalence: 53.1%) vs. < 10 ng/mL CRP with weight loss (medians: 3.2 kg vs. 0), weight loss/INZ (11.4 vs. 3.7), PC-SCA (13.3 vs. 8.0), weakness (6 vs. 5), appetite (5 vs. 3), and Quality of life (QOL) (5 vs. 3); b) low (<20%, prevalence 34.9%) vs. >20% lymphocyte percentage with weight loss/lmo (3.8 vs. 0), PC-SCA (11 vs. 7), weakness (5 vs. 5), and appetite (5 vs. 3); c) low (<120 g/L, prevalence: 30.7%) vs. >120 g/L hemoglobin with handgrip measures (53.7 vs. 65.3), and appetite (5 vs. 4); d) low (<35 g/L, 40.3%) vs. >35 g/L albumin with weight loss/1mo (3.7 vs. 0), PC-SCA (14 vs. 6), handgrip measures (33.7 vs. 86.9), weakness (6 vs. 5), appetite (5 vs. 4), and QOL (5 vs. 4). Conclusion: Blood counts, albumin and CRP were found to be significantly associated with signs and symptoms of Cancer Cachexia and could help with monitoring the presence and severity of this syndrome. Further studies are needed to confirm the prognostic importance of these blood tests and to suggest their routine use in assessing advanced cancer patients for specific treatments and care programs.

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McGill Lymphedema Research Program
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suggest further investigation regarding funding of treatments under government or other insurance schemes. Our research findings will inform educational initiatives and help justify the development of cancer rehabilitation programs to serve those who suffer from the long-term sequela of cancer treatment.

Upcoming Conferences

5th Research Forum of the European Association for Palliative Care
Trondheim, Norway.
www.capc.net.org/research2008/
index.html

17th International Congress on Palliative Care
September 21-26, 2008.
Montreal
www.pal2008.com

17th International Congress on Palliative Care
www.pal2008.com

TEACHING AND TRAINING
Research Trainees

With Robín Cohen

Anita Mehta, PhD (Candidate), Nursing, McGill. Family caregivers of palliative care patients at home: The pain management process.


Régis Dupuis, PhD (Candidate), Psychology, York University. Co-supervised with Dr. Paul Ryan. Nursing leadership in palliative care in Quebec.

Lisa Chan, PhD (Doctoral Program), Nursing, McGill. The experience of end-of-life care on an end-stage medical in-patient unit.

Christopher Mackinnon, PhD (Doctoral Program), Counselling Psychology, McGill. Co-supervised with Ada Simacore. Culture and spirituality at the end of life.

Melissa Henry, PhD. Postdoctoral Fellowship, Psychology. Meaning making intervention for women with newly diagnosed advanced ovarian cancer.

Mary Rykov, PhD. Postdoctoral Fellowship, Adult Education. The impact of music therapy on patients in inpatient palliative care units and their families.

Javad Shahidi, MD, Diploma in Experimental Medicine. Social functioning of Iranian immigrants in Canada with advanced cancer.

Trang T. Rozer, Visiting Professor for research from Munich Germany. Spiritual care and meaning of life at the end of life.

With Diane O'Sullivan and Anna Torres

Marie Eve Lessard, PhD (Doctoral Program), School of Physical and Occupational Therapy, McGill. Arm morbidity following breast cancer.

S Robín Cohen, Allard F, Gagnon P, Blondeau D, Dobbins P, Dumont S, Fillion L, Forster/Gill-Bourbonnais F, Hail P, Mayo NE, Wilson K, Gagnon B, and MacDonald, ME. CIHR/NCIC Strategic Training Program in Palliative Care Cancer Research. This infrastructure funding is to provide research training at the master's, doctoral, and postdoctoral levels in interdisciplinary palliative care cancer research. This is a joint project between McGill University, Laval University and the University of Ottawa. www.mcgill.ca/cihr-pcrresearch/

The 17th Montreal International Congress will continue to promote the exchange of leading edge ideas in our rapidly growing discipline of palliative care. Since its beginnings over 30 years ago this biennial Congress has seen increasing agreement in the field that palliative care should be provided from diagnosis, hence the shift to "Palliative Care" from "Care of the Terminally Ill" in its title. Presentations increasingly cover non-malignant diseases, rehabilitation and supportive care issues, as well as the ever important terminally ill person with cancer. For the first time we are offering a trilingual Congress. We are making a positive effort to include our Spanish-speaking colleagues from around the world by offering them the possibility of presenting in Spanish and also simultaneous translation in that language as well as in French for many presentations. We present a forum for discussion of issues that affect our colleagues in Africa and in other resource-constrained areas and settings. We will explore important questions such as: how can developed and developing nations collaborate in palliative care development, to make palliative care available to all as a basic human right? We continue to support a holistic orientation and an emphasis on self-reflection, spiritual and cultural issues, and the inclusion of the family in the unit of care. Nursing education, in both the developed and the developing world, is an area of increasing focus. We need discussions on the status of palliative medicine as a specialty or subspeciality. How do we evaluate our new clinical and education programs? For experienced and new practitioners alike, the program offers the latest evidence-based overview of pain and symptom control issues in a special Clinical Day. New and seasoned researchers will have the opportunity to present their work in oral presentations or in interactive poster sessions. Research Forums will allow the best research paper submissions to be presented with commentary and discussion led by renowned faculty: Serge Dumont, Laval University, Québec; Priscilla Koo, University of Alberta, Edmonton; and Kathleen Foley, Memorial Sloan-Kettering Cancer Institute, New York. As always, participation of the conference delegates during discussions is a valued contribution from which we all learn. Whether as a new or a seasoned participant, you are welcome to attend the 17th International Congress on Palliative Care at the Palais des Congrès in September 2008.

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