



What's Poppin'?

Population-Based Palliative Care Research Network

WEBPAGE: WWW.UCHSC.EDU/POPCRN *** Toll Free: 866.372.9417

Volume III, Issue 3

Winter2002

KERNEL'S CORNER

Jean S. Kutner, MD, MSPH

Happy Holidays and Happy New Year from PoPCRN. We wish you all the best in your personal and professional lives for the coming year.

Recently, we sent out a "hold the date" email notice about the first "PoPCRN convocation" to be held in conjunction with the NHPCO Joint Clinical Conference in April, 2003. Judging from several questions that we received, it appears that some clarification is in order. I'd like to spend this "Kernel's Corner" talking about the background and goals for this "convocation" and (hopefully) encouraging you to consider participating.

PoPCRN was modeled on successfully primary care research networks such as the Dartmouth COOP and the Ambulatory Sentinel Practice Network (ASPN). We currently share resources and ideas with two other practice-based research networks housed at the University of Colorado Health Sciences Center, the Colorado Research Network (CaReNet) and the High Plains Research Network (HPRN). A key feature of primary care research networks is an annual "convocation" to which representatives from all participating practice sites are invited. I had the good fortune to participate in a Dartmouth COOP annual convocation several years ago when PoPCRN was first being formed. I came away from that event energized about practice-based research networks and the synergism between front line clinicians and researchers. I was impressed by the enthusiasm and energy (and friendliness) of all whom I met.

It has been one of my goals and dreams since starting PoPCRN to host such an event for participating PoPCRN sites.

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MISSION STATEMENT:

The Population-based Palliative Care Research Network (PoPCRN) is committed to enhancing the care of persons at the end of life and their families through the conduct and dissemination of high-quality research in palliative care settings.

REPRESENTATION:

Our current mailing list includes 488 people from 175 research sites located in 38 States and Canada.

WHERE HAVE WE BEEN?

- Study 1: Symptom Prevalence Card Study, 7/99-10/99
- Study 2: Psychosocial/Spiritual Issues Study, 1/00-9/00
- Study 2A: Psychosocial/Spiritual Issues Study in Dept. of Corrections sites, 12/01-11/02
- Study 3: Bereavement Pilot Study, 2/00
- Study 4: Confusion & Delirium Prevalence Study, 2/00-3/00
- Study 5: Discharge Follow-up Study, 7/00-12/01
- Study 8: Web-based Hospice Fall Rate Study, 10/01
- Study 9: Web-based Hospice Education Study, 12/01-2/02
- Study 10: Palliative Care Guidelines for Symptom Management Study, 3/02-8/02
- Study 11: Hospice Nurses Symptom Management Study, 3/02-8/02
- Study 12: Web-based Pharmacy Cost Study, 5/02-9/02

WHERE ARE WE NOW?

- Study 6: Symptom Study-Phase I, 8/00-12/02
- Study 7: National Hospice Outcomes Project, 4/01-3/03
- Study 13: Pilot Study: Efficacy of Massage Therapy at the End of Life, 9/02-12/02
- Study 15: Research Screening Study, 11/02-2/02
- Study 16: Medication Prescribing Patterns, 12/02

WHERE ARE WE GOING?

Six studies are under development.

KERNEL'S CORNER, CONTINUED FROM PAGE 1:

This has become an even stronger imperative since PoPCRn has grown from several Colorado sites, with whom it was relatively easy for us to maintain personal contact, to over 170 sites spread across the entire country. The convocation format provides a forum for persons from participating sites and the research team to meet one-another face-to-face, share ideas and create the synergy and energy necessary to sustain practice-based research.

With the financial support that came with receipt of the Circle of Life Award and the significant help of Stephen Connor at the NHPCO, I am very pleased that we will be hosting our **first PoPCRn Convocation on the afternoon of April 9, 2003 in Denver, Colorado**. The goals of this convocation are several:

- 1) to recognize participating sites for their role in the successful completion of PoPCRn-based studies;
- 2) to facilitate networking among representatives from participating sites;
- 3) to share results from recent PoPCRn studies; and
- 4) to work together to determine research priorities.

While we recognize that many of you may be busy with Joint Clinical Conference-related activities and that there will, of course, be competing priorities, we hope to maximize participation from PoPCRn sites by hosting this event in conjunction with the Joint Clinical Conference. We will send out "official" invitations and the convocation schedule early in 2003. We expect to be able to defer at least some travel expenses for those participating in the convocation.

I look forward to the opportunity to meet you in person, to learn from you, and to personally thank you for believing in and participating in PoPCRn.

RECENT POPCRn PRESENTATIONS

- ◆ National Hospice Work Group Meeting, 8/02
- ◆ Two PoPCRn presentations at the Colorado Hospice Organization Fall Meeting, 10/02

POPCRn PUBLICATIONS

- ◆ Nowels DE, Bublitz C, Kassner CT, Kutner JS. "Estimation of Confusion Prevalence in Hospice Patients." *Journal of Palliative Medicine*. 2002; 5(5):687-695.
- ◆ Kutner JS, Nowels DE, Kassner CT, Houser J, Bryant LL, Main DS. Confirmation of the 'Disability Paradox' Among Hospice Patients: Preservation of Quality of Life Despite Physical Ailments and Psychosocial Concerns. Submitted to *J Pain Symptom Manage*. July 2002.
- ◆ Kutner JS, Blake M, Meyer S. "Predictors of Live Hospice Discharge: Data from the National Home and Hospice Care Survey (NHHCS)." *Am J Hospice and Palliative Care*. 2002; 19(5):1-7.
- ◆ Kutner JS, Kassner CT, Nowels DE. "Symptom Burden at the End of Life – Hospice Providers' Perceptions." *Journal of Pain and Symptom Management* 2001; 21(6):473-480.

WEB-BASED RESEARCH

If you have additional ideas for web-based studies, please let us know!

FEATURED SITE
Exempla Lutheran Hospice
Wheat Ridge, Colorado
by Pat Archer, Director

As the concept of Hospice care has evolved through the years, so has Exempla Lutheran Hospice (ELH). Located in metro Denver, we offer a truly unique, hospital-based program. Being hospital-based means we are able to care for people in a variety of settings and in a variety of care models, from direct patient care, to the education and support of other professional care providers as they care for people with a terminal illness. We offer assistance through every stage of the Hospice care continuum: at the time of diagnosis, through the active care process, for comfort care, as death nears, and to the survivors after the death occurs. In addition, patients may enter and leave the Hospice program as their disease process and care needs change.

Founded in 1985, ELH provides end-of-life care in many different settings. As many hospice programs do, we operate a strong home care program, providing care wherever the patient calls “home” -- in a nursing home, a private home/apartment, a board and care home, or an assisted living center.

In addition, patients may be cared for in our “Residence,” a nine-bed inpatient unit on the 6th floor of Exempla Lutheran Medical Center. This care setting allows the patient to benefit from the focus on and expertise of the skilled staff on that unit for pain and symptom management. In addition, we have the opportunity to access the specialty services available from the hospital system, such as palliative radiation or assistance from specialists in our pain clinic.

Finally, we also provide care in another setting within the Exempla Healthcare system. A patient may be in a bed on the oncology or respiratory care unit and receive “general inpatient care” under the Medicare Hospice benefit. The advantage to this short-term intervention is patient/family comfort with the continuity of care offered within the Exempla Healthcare system. If time/disease process allow, we can provide easy access when a bed becomes available on the Residence unit within the hospital; or a transfer to home hospice services can also be readily accomplished.

Other ways that differentiate our hospital-based Hospice program include our 24-hour availability to assist Exempla system individuals and departments with pain and symptom management. We are called upon to troubleshoot specific questions about pain management for a particular patient. We also offer a “compassionate extubation” program, in which a Hospice team member can be present at an extubation in ISCU. Our team members are also available to assist family members who have experienced a non-Hospice related death in their family; this service includes the same 13 months of bereavement care that Hospice family members receive. We have the capability to extend our services throughout the Exempla system to include the mentally ill who receive treatment at Exempla West Pines, Exempla's behavioral health hospital.

Two new services have been added within the past year for care to people who are not yet ready to accept the full spectrum of services that Hospice has to offer.

“Transitions” is a volunteer-driven program that provides assistance in the form of support and companionship to patients who are managing a life-limiting illness but who may still be obtaining active treatment for that illness and /or are not ready for Hospice care. The support for family members available through this program has proven to be invaluable. Respite care, light housekeeping and companionship at physician appointments are just some of the services provided by our specially trained Transitions volunteers.

Our “Progressive Disease” program provides assistance to patients who are enrolled in a home care program that is not Hospice oriented. Again, these patients may not be ready for the full spectrum of Hospice care but could benefit from the knowledge and expertise in pain and symptom management that a Hospice nurse can provide. Under the direction of the patient’s physician, we contract one of our Hospice nurses to work with the home care nurse to provide medication management that will maximize the patient’s comfort.

At Exempla Lutheran Hospice, we are constantly striving to understand what our patients and their families want and need in end-of-life care, and to provide the types of services and programs that meet their needs beyond the traditional models of Hospice care.

For more information about Exempla Lutheran Hospice, please contact:

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CLINICAL FEATURE

Terminal Agitation – Clinical Review

David Nowels, MD, MSPH, University of Colorado Health Sciences Center

I saw Ms. H during a palliative care consult last week. The consult request indicated that she had been obtunded for a few days before I saw her, probably as a result of her multiple problems – CO₂ retention with encephalopathy, hypoxia, infection, and chronic opioid and benzodiazepine use. However, when I visited the next day she had awakened and become very agitated. Her family was extremely upset and indicated that “nothing” was being done for her despite their being told that she would be kept comfortable. I learned that she had not received any opioids or benzodiazepines for about 24 hours due to her poor mentation.

Ms H. was lying down when I first saw her and immediately asked if I could help her sit up. Her family indicated that she had been asking to sit up or get out of bed, then whenever she did get up within 30 seconds she was asking to go back to bed and lay down. I did try to help her up – but she began to slip off the edge of the bed as I gave her a hand. Due to her immense size (over 450 lbs) I was concerned about her safety and encouraged her to lie back down until we could get adequate help. Ms. H. became very upset with this plan, insisting on getting up, as she was “uncomfortable.” She could not tell me more about how she was feeling, but agreed that she was not having pain. She could not answer any other questions I asked – she simply could not focus on the question. Her speech was pressured and she was mildly confused when telling me about events of the last few hours.

Ms. H. was severely agitated, however, that was only part of the picture. She met DSM-IV criteria for an agitated delirium: 1) acute onset and fluctuating course, 2) reduced clarity of awareness of the environment, 3) perceptual disturbance, disorientation, or memory disturbance, and 4) underlying general medical condition. When this occurs in patients who have a very limited lifespan it often is best referred to as an *agitated terminal delirium*, though *terminal agitation* or *terminal restlessness* are terms frequently used. These latter terms focus on the behavioral component of the clinical syndrome. Severely agitated patient can be very challenging. Clinicians are concerned that their patient will not be safe, that families will “burn out” in trying to provide care for these patients, and that they will be unsuccessful in trying to relieve, or even evaluate, the other problems of the patient. As distressing as the behavioral disturbance can be, usually the root problem is a cognitive one. Recognizing and addressing the cognitive impairment in agitated delirium is usually a more effective way of helping the patient and family.

Delirium is present in 50% of hospice patients at any time and probably occurs in 80-90% overall. Up to 1/2 of patients with delirium are misidentified because of a focus on the neurobehavioral components of the syndrome. Delirium is associated with worse outcomes for the patient and their loved ones. Overall 80% of episodes of confusion in hospice are thought to cause problems for the patient, their loved ones, or the care team.

Delirious patients experience worse pain management, more skin problems, more falls, and a shortened lifespan. Moreover, they can neither participate in their care nor address the tasks and issues around dying. Families are often upset by the patients’ behaviors and loss of function, and there is a widespread belief that the experience carries a higher risk for complicated grief, especially if the deceased displayed an agitated form of delirium.

The first step in helping these individuals is to accurately identify the syndrome. Agitated delirium is often difficult to distinguish from other syndromes in which agitation is evident – delirium, dementia, depression, grief, primary anxiety disorders and psychotic illness. Delirium with somnolent behaviors may even be more difficult to identify. Simple diagnostic tools such as the mini-mental status exam and the Confusion Assessment Method are important to use to correctly identify delirium.

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TERMINAL AGITATION, CONTINUED FROM PAGE 4:

After the “diagnosis” of delirium is made an evaluation of some of potentially reversible causes of the episode should be undertaken. This evaluation should especially focus on pain, minor infections, constipation, incomplete emptying of the bladder, drug toxicities (most commonly opioids and benzodiazepines), drug withdrawal, dehydration, elevated calcium, hypoxemia, and accumulation of CO₂ (in patients who hypoventilate). Several published series of patients with advanced cancer who became acutely confused while receiving care in palliative situations have reported reversal of up to 50% of episodes of delirium with a change in medications (opioid reduction or rotation and benzodiazepine reduction or removal) or with hydration.

Non-pharmacologic interventions should be performed next. These include educating and supporting the family, creating a calm, safe environment that supports re-orienting the patient (calendar, clock, etc), and providing the patient with needed aids such as eyeglasses and hearing aids.

Clinicians frequently give benzodiazepines to patients with agitated delirium. This approach may temporarily address the behavioral aspect to the presentation by sedating the patient. Unfortunately benzodiazepines do nothing to clear the patient sensorium; they typically cloud thinking even more, sometimes leading to paradoxical worsening. Because short acting preparations are frequently used, the cycle of confusion, agitation, treatment, sedation, worse confusion, agitation, etc is created. Typically it is better to use a neuroleptic first, when the decision to medicate is made. This class of drugs calms patients without interfering with cognition. A randomized trial comparing haloperidol with lorazepam revealed the benefit of using the neuroleptic. Serious side effects associated with using major tranquilizers are uncommon. Dose escalation similar to that seen in pain management is often useful, as sometimes are more sedating major tranquilizers such as chlorpromazine (Thorazine).

Some patients who are very agitated and actively dying might have their delirium better managed by sedation rather than by trying to improve their cognition. When the goal of treatment is shifted to sedation, benzodiazepines given regularly and routinely may be used. A midazolam infusion is usually very effective. I view the management goal of sedation for agitated terminal delirium as one for which I obtain special informed consent since the treatment may lead to shortened lifespan.

Ms. H. had multiple potential reasons for her acute, agitated confusion. Her infection was being treated with appropriate antibiotics, treatment of her CO₂ retention was addressed, and her opioids and intermediate acting benzodiazepines were re-started at a lower dose. We felt that the major cause of her delirium was her opioid withdrawal. Within 12 hours of restarting her medication her agitation resolved and her cognition had cleared considerably. Because she has experienced delirium once, she has a higher chance of again developing confusion, though both the cause and the treatment plan will probably differ from this episode. An important aspect to her hospice care will be to monitor her medication and cognition carefully and educate the patient and family about possible recurrence.

Selected References:

- Nowels et al. Estimation of confusion prevalence in hospice patients. *Jr Pall Med* 2002; 5(5):687-695.
- Breitbart W, Strout D. Delirium in the terminally ill. *Clin Geriatr Med* 2000; 16:357-372.
- Barraclough J. ABC of palliative care: depression, anxiety, and confusion. *BMJ* 1997;315:1365-1368.
- Lawlor et al. Occurrence, causes, and outcome of delirium inpatients with advanced cancer. *Arch Intern Med* 2000; 160:786-794.
- Casarett DJ, Inouye SK. Diagnosis and management of delirium near the end of life. *Ann Intern Med* 2001;135:32-40.

ESTIMATION OF CONFUSION PREVALENCE IN HOSPICE PATIENTS

**BY DAVID E. NOWELS, MD, MPH, CAROLINE BUBLITZ, MS,
CORDT T. KASSNER, MA, AND JEAN S. KUTNER, MD, MSPH**

JOURNAL OF PALLIATIVE MEDICINE

VOLUME 5, NUMBER 5, OCTOBER 2002, PAGES 687-695

ABSTRACT

Background: Confusion is common among ill patients and has broad consequences for their care and well being. The prevalence of confusion in hospice patients is unknown.

Objectives: Describe the prevalence, severity, and manifestations of nurse-identified confusion and estimate the prevalence of delirium in hospice patients.

Design: Cross-sectional descriptive study.

Setting: Nineteen hospices in the Population-based Palliative Care Research Network (PoPCRN).

Patients: Adult patients receiving care from participating hospices, February 15 to April 1, 2000.

Measurement/Analysis: Hospice nurses estimated prevalence, severity, behavioral manifestations, and consequences of confusion during the preceding week. Confused and not-confused patients were compared using standard bivariate and stratification techniques. Logistic regression identified manifestations associated with problematic confusion.

Results: Median age of the 299 patients was 78 years, 59% were female, 52% lived at home, and cancer was the most common diagnosis (54%). Fifty percent were confused during the preceding week, 36% of those were severely confused or disabled by confusion. Compared with non-confused patients, confused patients were less likely to have cancer (64% vs. 43%, $p \leq 0.001$) and more likely to live in nursing home/assisted living (21% vs. 33%, $p \leq 0.01$). Disorientation to time or place, impaired short-term memory, drowsiness, and easy distractibility were common manifestations of confusion. When present, confusion caused a problem for the patient, someone else, or both 79% of the time. Inappropriate mood, cancer diagnosis, agitation, and age were the variables predicting problematic confusion. Only 14% of confused patients met criteria for delirium.

Conclusions: Confusion among hospice patients was common, frequently severe, and usually problematic.

Thank you to the 19 PoPCRN sites that participated in this study. Please contact Cordt Kassner for reprints of this article.

BOOK REVIEW

***Mortally Wounded: Stories of Soul Pain, Death, and Healing, by Michael Kearney, MD,
Foreword by Dame Cicely Saunders (1996).***

Review by Cordt Kassner, PhD

Kearney, a palliative care consultant and university lecturer in Dublin, Ireland, reflects on his experiences with the dying to contribute to our understanding of holistic health and the dying experience. Psychological and mythological models – similar to James Hillman and Thomas Moore – are used to explore the author's concept of "soul pain". Soul pain is "the experience of an individual who has become disconnected and alienated from the deepest and most fundamental aspects of himself or herself" (p. 63). Soul pain may be described as "suffering", it may take the form of symptoms unresponsive to standard treatments, it may appear similar to terminal agitation, or it may result in a profound sense of meaninglessness. I found this to be an interesting book, challenging professionals working with the terminally ill to explore areas of suffering and soul pain within themselves as well as with the people they serve.

Results of the PoPCRN Hospice Pharmacy Cost Study

Conducted between May 1, 2002 – September 30, 2002, a web-based study was designed by PoPCRN, in collaboration with The Hospices of the National Capital Region, to identify current trends in hospice pharmacy costs. Thirty-four PoPCRN hospices from 17 States participated in this study. Key findings include:

- ♦ Average daily census for routine care = 192 patients (range = 10-680).
- ♦ Average daily census for General Inpatient Care = 23 patients (range = 1-304).
- ♦ Mean FTE: physician = 1.6; nurse = 37.3; pharmacist = 0.8.
- ♦ Mean current satisfaction with current pharmacy = 7.4 (1 = terrible, 10 = couldn't be happier).
- ♦ Mean drug cost (per patient / per day) by patient care location:
 - ♦ Hospice inpatient care = \$22.46
 - ♦ Home care = \$11.26
 - ♦ Long term care = \$9.95
- ♦ Mean drug cost (per patient / per day) by care level:
 - ♦ Routine care = \$11.04
 - ♦ General inpatient care = \$16.96
- ♦ Sixty-seven percent of responding hospices report increasing drug costs since 1998.
- ♦ Top 5 factors most significantly contributing to inpatient care settings pharmaceutical costs:
 1. Continuous infusion plus bolus drug delivery systems (73%)
 2. Opioids – long acting (e.g., Oxycontin, transdermal opioids) (67%)
 3. Parenteral medications (53%)
 4. Antibiotics (27%)
 5. Cell line stimulants (e.g., epoetin or Procrit, G-CSF or filgrastim or Neupogen) (20%)
- ♦ Top 5 factors most significantly contributing to routine care settings pharmaceutical costs:
 1. Opioids – long acting (e.g., Oxycontin, transdermal opioids) (78%)
 2. Continuous infusion plus bolus drug delivery systems (44%)
 3. Cell line stimulants (e.g., epoetin or Procrit, G-CSF or filgrastim or Neupogen) (34%)
 4. Bisphosphonate (e.g., paridronate or Aredia) (28%)
 5. Antibiotics (22%)

A 10-page summary of aggregate results is available on our webpage or by emailing Cordt Kassner (Cordt.Kassner@uchsc.edu).

ANNOUNCEMENTS

Harvard Medical School, Program in Palliative Care Education and Practice 2003

The Harvard Medical School Center for Palliative Care offers the Program in Palliative Care Education and Practice on April 29-May 6 and November 11-18, 2003 in Boston, Massachusetts. Co-directed by J. Andrew Billings, MD and Susan D. Block, MD, the course provides intensive training for physician- and nurse-educators who wish to become experts in the clinical practice and teaching of palliative care. Participants will deepen their clinical skills in various aspects of end-of-life care, extend their repertoire of teaching methods and curricular design, and learn approaches to program development and institutional change. Faculty who complete the course will be prepared to teach others about end-of-life care, create innovative educational programs, and lead clinical service reform, including building palliative care services. During the 6-month interim between course blocks, participants work on an individual project and contribute to weekly e-mail exchanges about problematic cases presented by other participants. For more information or application materials, please call 617-724-9509, e-mail pallcare@partners.org, or visit www.hms.harvard.edu/cdi/pallcare.

Palliative Care Fellowship

The Massachusetts General Hospital Palliative Care Service offers BE/BC physicians a 1-year fellowship in palliative care. For additional information: contact J. Andrew Billings, MD, at 617-724-9196 or email jbillings@partners.org.

The Butterfly Program:
A Pediatric Palliative Care and Hospice Service
The Children's Hospital, Denver, Colorado
By Brian Greffe, MD, and Nancy King, CRNP

The Butterfly Program was developed in 1999 as a collaborative effort between The Children's Hospital, The Children's Hospital Home Care, Centura Home Care and Hospice and the Porter Foundation to address the needs of children with life-limiting illnesses and their families. The Butterfly Program believes that appropriate pediatric palliative/hospice care does not follow the same guidelines as adult end-of-life care. The life expectancy of a child is generally more difficult to predict than that of an adult and children are often resilient enough to live for a long time even with devastating conditions. The definition of supportive and comfort care is different for children and their families. Children with life-limiting conditions are more often dependent upon technological means such as ventilators, feeding tubes, and IV nutrition for normally maintaining their life. Parents have difficulty stopping treatment modalities they perceive to be helpful or hopeful. They may want to continue measures that enhance quality of life such as medications, transfusions, nutritional support, and occasionally even surgical intervention. Parents may find themselves unable to consent to a "Do Not Resuscitate" order initially, although most parents will come to that decision after much thought and with good information provided by their care team. Few adult hospice agencies are currently equipped to manage children much less those with advanced technological needs. Additionally, we believe it is important to parents and children to maintain relationships with their primary care team. Rather than replace the primary care team, the Butterfly service works with the primary physician and/or inpatient care teams to provide the family with optimal care.

The Butterfly Program is currently funded by a grant from the Program for All-Inclusive Care for Children and Families (PACC), administered through Children's Hospice International as well as by a grant received from The Colorado Trust, and private donations. These funds cover the costs for all supportive services except nursing, dietician, and OT/PT offered by The Butterfly Program and enabled the creation of the inpatient service in 2002. As part of the PACC grant, The Butterfly Program has also created an Outreach Education Program. The team regularly provides in-service education to hospices in the states served by The Children's Hospital and offers consultative services at any time to any hospice or home care agency that may be caring for a child. The program is also actively working with The Children's Hospital to pursue an 1115 waiver application with the Colorado State Medicaid Program. This waiver would expand the definition and scope of hospice services for children, thereby improving both access to and reimbursability for appropriate services.

The Butterfly service consists of a medical director (Brian Greffe, MD), inpatient coordinator (Nancy King, CRNP), outpatient coordinator (Michelle Fillios-Cox, MSW), two outpatient social workers, and inpatient and outpatient chaplains. Bereavement services are provided by a bereavement counselor and through programs available at The Children's Hospital. Volunteer support for families is available through Centura Hospice. Volunteers who work with children are trained through The Children's Hospital volunteer department. Home nursing and other services such as OT and PT and dietary consultation are primarily provided through Children's Pharmaceutical Services, however we can sometimes provide supportive services to families whose nursing is provided through other agencies. Nearly 100 children have received services from the Butterfly Program to date.

To contact the Butterfly Program for more information or to make a referral, please call Nancy King, CRNP at 303-764-8569 or Dr. Brian Greffe at 303-861-6787.

INFORMATION ON CURRENT AND UPCOMING PoPCRN STUDIES

Study 6: Natural History of Symptoms Study:

This is a study of symptoms and quality of life in hospice/palliative care patients funded for 4-years by the Robert Wood Johnson Foundation and the Beeson Award. The first phase of this study describes the time course of and distress due to common symptoms among hospice/palliative care patients. Eleven sites have completed patient enrollment (n=100) for this study. Data analysis is being conducted and results will be available soon.

Study 7: National Hospice Outcomes Project:

This two year research project, supported by the Robert Wood Johnson Foundation Chronic Care Initiative, is being conducted by the Institute for Clinical Outcomes Research in conjunction with the National Hospice and Palliative Care Organization. The overall objective of this project is to conduct a Clinical Practice Improvement study of pain control, dyspnea control, and self-determined life closure to determine which treatment modalities are associated with better outcomes of hospice care. The ultimate goal of this project is to develop research-based dynamic protocols for better pain control, dyspnea control, and self-determined life closure. This goal fits well with the current focus of PoPCRN studies on symptom management and quality of life at the end of life. Five PoPCRN sites are participating in this study. Project tools were integrated into the hospice systems beginning in March 2002.

Study 11: Hospice Nurses Symptom Management Study:

This is a study to identify barriers to physical symptom management from the perspective of hospice nurses. A total of 867 nurse surveys have been returned from 64 sites. Results from this study will be available soon.

Study 13: Massage Therapy Pilot Study:

This study will collect pilot data demonstrating the efficacy of Massage Therapy for decreasing pain, improving quality of life, and lessening physical and emotional symptom distress among cancer patients at the end of life. Pilot data are being collected at 2 PoPCRN sites and have been used for an NIH grant proposal.

Study 15: Research Screening Study:

This study will assess the hospice patients' and caregivers' potential interest in participating in hospice-based research at the time of a patient's enrollment in hospice. This information will help hospice staff identify those willing (and those not willing) to be approached about research participation. Two PoPCRN sites are participating in this study.

Study 16: Medication Prescribing Patterns:

This study examines the medication prescribing by hospice medical directors. We are interested in learning about how hospice medical directors make decisions about continuing or discontinuing particular medications within the first week following a patient's admission to hospice care. ***We are currently collecting data for this study – we encourage all hospice medical directors to respond. Contact Cordt Kassner (E: Cordt.Kassner@uchsc.edu) for a copy of the survey.***

Please either contact us or see our website, <http://www.uchsc.edu/popcrn>, for additional details regarding current studies and results of previous studies.

CALENDAR OF EVENTS

December 14, 2002

14 *Spirituality and Healing*, Harvard Medical School, GWish, The George Washington University, and The Mind/Body Medical Institute, Boston, MA. For additional information, call 617-384-8600.

January 2003

23-24 *Missoula-VITAS Quality of Life Index Implementation Training*, Palm Harbor, FL. For additional information, call Susan Bruno, Hospice of the Florida Suncoast, at 727-773-2530.

- 24-26 *EPEC Conference: The EPEC Project – Education for Physicians on End of Life Care: Become an EPEC Trainer*, Tampa, FL. For additional information, see their webpage at <http://www.epec.net>.
- 31-2/1 *7th Multidisciplinary Approach to Palliative Care, Pain, and Symptom Management Conference*, The University of Texas, MD Anderson Cancer Center, Houston, TX. For additional information, see their webpage at <http://www.mdanderson.org/~meetings>.

February 2003

- 27-3/2 *CAPC Conference: Planning, Funding and Sustaining a Hospital-based Palliative Care Program: Tools and Strategies for Success*, Center to Advance Palliative Care, Philadelphia, PA. For additional information, see their webpage at <http://capcmssm.org>.

March 2003

- 13-15 *Enhancing Communication Skills in Palliative Care*, Harvard Medical School, Boston, MA. For additional information, see their webpage at <http://www.hms.harvard.edu/cdi/pallcare> or call 617-724-9509.

April 2003

- 1-3 *6th International Conference Integrating Research on Spirituality and Health and Well-being into Service Delivery*, The Natcher Center, National Institutes of Health, Bethesda, MD. For additional information, see webpage at <http://www.icihs.org>.
- 2-5 *8th Congress of The European Association For Palliative Care*, The Hague, The Netherlands. For additional information, email eapc03@kenes.com or see their webpage at <http://kenes.com/eapc>.
- 9 *First PoPCRN Convocation*. Denver, Colorado. Further information forthcoming.
- 10-12 *4th Joint Clinical Conference and Exposition on Hospice and Palliative Care*, National Hospice and Palliative Care Organization, Denver, CO. For additional information, see their webpage at <http://www.nhpco.org>.

August 2003

- 2-4 *4th National Conference on Hospice and Palliative Care Volunteerism: Passionate Volunteers: New Horizons in End of Life Care*, National Hospice and Palliative Care Organization, Columbus, OH. For additional information, see their webpage at <http://www.nhpco.org>.

September 2003

- 2-6 *European Federation of IASP Chapters, Pain in Europe IV*, Prague, Czech Republic. For additional information, email Pain2003@cbttravel.cz or call 42-2-2494-8708.

March 2004

- 23-25 *5th Joint Clinical Conference and Exposition on Hospice and Palliative Care*, National Hospice and Palliative Care Organization, Las Vegas, NV. For additional information, see their webpage at <http://www.nhpco.org>.

JOINING AND ADDITIONAL INFORMATION ABOUT PoPCRN

If you are interested in additional information about PoPCRN or being added to the PoPCRN mailing list and/or email listservs, please contact Cordt Kassner, PhD, at (P) 303.372.9364 or (E) Cordt.Kassner@uchsc.edu

Carmel Corn (A Sweet Ending...)

When we learn to fall, we learn that only by letting our grip on all that we ordinarily find most precious – our achievements, our plans, our loved ones, our very selves – can we find, ultimately, the most profound freedom. In the act of letting go of our lives, we return more fully to them.

Learning to Fall: The Blessings of an Imperfect Life, by Philip Simmons, p. xi.

Happy Holidays From PoPCRN

POPCRN Is...

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What's Poppin?
Newsletter of the Population-based Palliative Care Research Network
Volume III, Issue 3, Winter 2002

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