



What's Poppin'?

Population-Based Palliative Care Research Network

<http://www.uchsc.edu/sm/hospice>
Summer 2000

Kernel's Corner

Jean Kutner, MD, MSPH

Welcome to the inaugural edition of "What's Poppin", the official newsletter of the Population-based Palliative Care Research Network (PoPCRN). Our goal with this newsletter is to provide a forum for PoPCRN to share results from completed studies, provide updates on current studies, and preview future studies. In addition to PoPCRN-specific information, we have included a discussion of recent palliative care literature, a section highlighting one of the participating sites, and a listing of upcoming events relevant to palliative care.

PoPCRN has grown from little more than an idea slightly over two years ago to its current status, in which 53 hospice/palliative care sites have agreed to participate in up to 5 studies, and funding has been secured for ongoing studies (see "Information on Current and Upcoming Studies"). This growth and success would not have been possible without the enthusiasm of the organizations and individuals who have provided advice on study ideas and design, collected data, and been advocates for PoPCRN within the hospice/palliative care community. We continue to be inspired by the interest in and support of PoPCRN activities among hospice and palliative care professionals. We, and you by participating, are truly on the forefront of hospice and palliative care innovation and research.

We hope that you find "What's Poppin" interesting and informative, and we welcome your comments and contributions. We look forward to ongoing communication with you.

Mission Statement:

The Population-based Palliative Care Research Network (PoPCRN) is committed to improving care for persons at the end of life by conducting rigorous, high-quality end-of-life research in settings where palliative care is provided.

Where Have We Been?

7/99-10/99	Symptom Prevalence Card Study: data collection
12/99	Symptom Prevalence Card Study: reported results
1/00-9/00	Psychosocial/Spiritual Issues Study: data collection
2/00	Bereavement Pilot Study: data collection
2/00-3/00	Confusion & Delirium Prevalence Study: data collection
5/00	Bereavement Pilot Study: reported results

Where Are We Now?

7/00	Confusion & Delirium Prevalence Study: reported results
7/00	Strategic Planning Retreat with consultants for future PoPCRN development
8/00	Formation of the PoPCRN Advisory Board
7/00-6/01	Discharge Follow-up Study: recruit sites and data collection

Where Are We Going?

Through 9/00	Psychosocial/Spiritual Issues Study: complete data collection
8/00-10/00	Symptom Study- Phase I: recruit sites and begin data collection
12/00	Psychosocial/Spiritual Issues Study: report results
Through 6/01	Discharge Follow-up Study: complete data collection

Strategic Planning Retreats

On June 15, 2000, the staff of PoPCRN met to update and define the PoPCRN mission and goals. Discussions included current research projects, personal and network research interest areas, and a review of the proposed PoPCRN mission statement. Following much thought and interaction, we agreed upon the following mission statement:

The Population-based Palliative Care Research Network (PoPCRN) is committed to improving care for persons at the end of life by conducting rigorous, high-quality end-of-life research in settings where palliative care is provided.

Following the June retreat and recognizing the importance of input from everyone involved in PoPCRN, several expert consultants were invited to attend a Strategic Planning Retreat on July 5, 2000. With input from many people (including Donna Roberts, Wilma Collins, Al Canner, Don Iverson, and others), we discussed the organizational structure and maintenance/growth plans for PoPCRN. We discussed many useful resources – from PoPCRN as a resource for others to other resources that may be helpful to PoPCRN. We agreed that PoPCRN already has “population-based” coverage in Colorado – ***33/37 Colorado Hospice’s have participated in at least one PoPCRN study.*** Our goal is to involve 100% of the Colorado hospices and palliative care sites, while continuing national growth (***organizations from 13 states participate in and/or support PoPCRN research studies***) and international expansion (***1 site in Canada – Palliative Care Services in Regina, Saskatchewan, participates in PoPCRN research studies.***)

PoPCRN wishes to again extend our appreciation to everyone who participated and contributed ideas toward these planning retreats. THANKS!

Book Review

By Jean Kutner, MD, MSPH

Abrahm JL. *A Physician’s Guide to Pain and Symptom Management in Cancer Patients.* Baltimore, The Johns Hopkins University Press, 2000.

Available via: www.press.jhu.edu \$55.00

A Physician’s Guide to Pain and Symptom Management in Cancer Patients is designed as a complement to traditional oncology texts, concentrating on symptom-oriented, patient-focused treatment. The text provides the information busy clinicians need to address the concerns of patients and their loved ones, assess pain and other causes of distress, and design effective treatment regimens. Part I, “Hidden Concerns, Unanswered Questions”, discusses the issues that may be unique to cancer patients, including the proximity of death and the specter of helplessness, grief, suffering, and loss of dignity. Part II, “Pain Control and Symptom Management”, is a detailed presentation of the technical aspects of symptom assessment and management, including therapeutic protocols for the most common symptoms experienced by patients with cancer. Clinical scenarios, tables, and figures illustrate the key points throughout the text. The book also includes two annotated bibliographies, one directed toward health care professionals and the other towards patients and families.

While the focus of the text and the clinical scenarios is on patients with cancer, the information provided in this book is applicable across diagnoses. I recommend this book as an easy-to-read, practical approach to care of patients with serious, progressive illnesses. *A Physician’s Guide to Pain and Symptom Management in Cancer Patients* is both a comprehensive introduction to palliative care for health care providers just becoming familiar with this field and a valuable reference book for seasoned palliative care professionals.

Featured Site: Hospice Of The Plains, Wray, Colorado

By Jim Hoganson, Hospice of the Plains

Hospice for Yuma County began as a dream for Sandy Crossland back in 1993 when she began working as a case manager for the Wray hospital. In that capacity, she saw a great need for services to the terminally ill. However, after doing some preliminary research, she decided that this was not something that could be done at the time.

Two years later, as the need became more apparent, a Wray doctor approached Sandy to try to put the dream into reality. At the same time, Teresa Peterson, also a nurse at the hospital, expressed a desire to start a hospice. Together, Sandy and Teresa worked at gathering information from several hospices on the front range. In May of 1995 a steering committee was formed.

In September of 1996, after over a year of tremendous teamwork of those who had caught the hospice vision, Hospice of the Plains was granted state licensing! Our first patient was received early the next month. Throughout the intensity of pushing long and hard for over a year, we felt a great sense of accomplishment to be up and running. But this sense was soon to overshadowed by the deep sense of fulfillment that came from assisting others face one of life's most challenging situations - terminal illness. The joy of finally offering services was soon met with tears after the death of our first patient.

Hospice of the Plains has embraced a County of 2400 sq. miles with a population of almost 10,000. Farming and ranching are the center of business in our county. We are the home of one of the largest feedlots in the world and one of the largest corn producing counties in the nation! Center pivot irrigation has turned somewhat barren, parched grassland into highly productive farmland with thousands of acres under irrigation in an area that receives 10-12 inches of moisture annually.

Hospice of the Plains is governed by a ten-member board of directors representing the four corners of the County. Board meetings, fundraising events, and other functions are regularly rotated among towns in the southern, eastern and western parts of the county. We have served an average of 17 patients each of the last three years with an average length of stay of 52 days. A recent patient was a drive of 62 miles one way from the office in Wray.

Hospice of the Plains is a nonprofit organization established to provide quality end-of-life care for the terminally ill and their families. Hospice of the Plains is committed to respond to the needs of the community we serve. We recognize quality of life encompasses physical, emotional, and spiritual well being. To fulfill this mission, we will preserve the dignity of each individual regardless of race, national origin, religion, gender, age, disability, diagnosis, social status, or ability to pay. We strive to achieve and maintain standards of excellence in all aspects of hospice care through an interdisciplinary approach, to provide bereavement support services, and to operate the organization in a financially responsible manner.

Calendar of Events

August

September

25-29 *The 13th International Congress on the Care of the Terminally Ill*, Montreal Canada. For more information, email: info@eventsintl.com.

October

11-14 *The First International Geriatric Palliative Care Congress*, New York, NY. For more information, email info@eventsintl.com.

12-14 *Colorado Hospice Organization Meeting*, Vail, Colorado. For more information, contact Al Canner at 303-449-1142 or email at CoHospOrg@aol.com.

November

December

2-4 *The Center to Advance Palliative Care – Palliative Care Fall Forum 2000*, Washington, D.C. For more information, call the Center to Advance Palliative Care at Mount Sinai School of Medicine @ 212-241-7885.

Cookies From Heaven?

An elderly man lay dying in his bed. In death's agony, he suddenly smelled the aroma of his favorite chocolate chip cookies wafting up the stairs. He gathered his remaining strength, and lifted himself from the bed. Leaning against the wall, he slowly made his way out of the bedroom, and with even greater effort forced himself down the stairs, gripping the railing with both hands. With labored breath, he leaned against the doorframe, gazing into the kitchen. Were it not for death's agony, he would have thought himself already in heaven: There, spread out upon newspapers on the kitchen table were literally hundreds of his favorite chocolate chip cookies. Was it heaven? Or was it one final act of heroic love from his devoted wife, seeing to it that he left this world a happy man? Mustering one great final effort, he threw himself toward the table, landing on his knees in a rumpled posture. His parched lips parted; the wondrous taste of the cookie was already in his mouth, seemingly bringing him back to life. The aged and withered hand made its way to a cookie at the edge of the table, when it was suddenly smacked with a spatula by his wife.

"Stay out of those," she said, "they're for the funeral."

Of Note...

Do, every day, something nobody else would do.

Think, every day, something nobody else would think.

Say, every day, something nobody else would say.

It is bad for the mind to be always part of a unanimity.

- Christopher Morely

Information on Current and Upcoming Studies

Psychosocial and Spiritual Symptoms Among Hospice Patients Study:

This patient interview study examines what psychological, social, and spiritual issues are important to hospice patients. With initial funding from the Centers for Excellence and the Division of General Internal Medicine at the University of Colorado Health Sciences Center, we are now entering the final months of the data collection period. Data collection will end September 30, 2000.

Discharge Follow-up Study:

This study will follow up on people discharged alive from hospice sites. We hope that information from this study will help justify continuing hospice/palliative care for patients who may not meet current criteria for continued hospice eligibility. Information will be gathered on patients discharged alive from hospice sites between July 1, 2000 and June 30, 2001. Six-month follow-up data will be gathered between August 1, 2000 and December 31, 2001. Please contact us if you would like to participate in this study.

Symptom Study:

This is a study of symptoms in hospice/palliative care patients funded for 4-years by the Robert Wood Johnson Foundation and the Beeson Award. The first of four study phases begins this Fall by describing the time course of and distress due to common symptoms among hospice/palliative care patients. Site identification will begin in August 2000 and data collection will begin in October 2000.

Safety of Home Care Workers Study:

Initiated by concerns from hospice home care workers, this study examines safety issues and concerns relevant to those visiting patients in their homes. Study planning is currently in progress.

Brief Results From Previous Studies*

Symptom Prevalence and Severity at the End of Life Study (N=348, 16 Sites):

Five most prevalent symptoms

- 90% Lack of Energy
- 79% Pain
- 67% Difficulty Concentrating
- 67% Feeling Drowsy
- 66% Lack of Appetite

Five most severe symptoms (among those with the symptom)

- 46% Lack of Energy
- 36% Hair Loss
- 35% Change in Self Image
- 34% Changes in Skin
- 32% Problems with Urination

Five symptoms about which staff is least aware

- 64% Sexual Interest
- 32% Change in Self Image
- 27% Worrying
- 23% Feeling Sad
- 23% Change in Food Taste

Bereavement Pilot Study (N=48, 3 Sites):

- Several respondents described the influence of spirituality, caregiving burden, multiple losses, financial issues, regret and guilt on their bereavement experience.
- 75% of respondents replied they would be likely or very likely to participate and complete the study.

Confusion & Delirium Prevalence Study (N=303, 19 Sites):

- 50% of patients were confused
- over 1/3 of those confused were severely confused or disabled
- altered sleep/wake cycle, impaired short term memory, misinterpretation of events, disorientation to time or place, drowsiness, agitation, and being easily distracted were common in the confused
- the confusion caused problems for the patient or others most of the time

* Please either contact us or see our website, <http://www.uchsc.edu/sm/hospice>, for additional details.

PoPCRN Is...

Co-Directors:

Jean S. Kutner, MD, MSPH
General Internal Medicine
University of Colorado Health Sciences Center
Campus Box B180
4200 East 9th Avenue
Denver, CO 80262
(O) 303-372-9086
(F) 303-372-9082
(E) Jean.Kutner@UCHSC.edu

David E. Nowels, MD, MPH
Department of Family Medicine
University of Colorado Health Sciences Center
Campus Box B155
4200 East 9th Avenue
Denver, CO 80262
(O) 303-315-9700
(F) 303-315-9746
(E) David.Nowels@UCHSC.edu

Staff:

Cordt T. Kassner, MA
General Internal Medicine
University of Colorado Health Sciences Center
Campus Box B180
4200 East 9th Avenue
Denver, CO 80262
(O) 303-372-9364
(F) 303-372-9082
(E) Cordt.Kassner@UCHSC.edu

Volunteers:

Marcia Blake, MA
General Internal Medicine
University of Colorado Health Sciences Center

Lucinda Bryant, PhD, MSHA, MBA
Dept. of Prev. Med. & Biometrics, Postdoctoral Fellow
University of Colorado Health Sciences Center

Jennifer Jeans, MD
General Internal Medicine Resident
University of Colorado Health Sciences Center

Sue A. Meyer
Medical Student
University of Colorado Health Sciences Center

Jean Petri, ND
Director of Nursing
Namaste Comfort Care

William Reiquam, MD, MHum
Assistant Medical Director, Clinical Laboratory
University of Colorado Hospital

Population-based Palliative Care Research Network (PoPCRN)
Information / Study Sign-up Form

YES, I am interested in participating in the following *Population-based Palliative Care Research Network* studies and/or opportunities:

- Discharge Follow-up Study
- Symptom Study funded by RWJ and Beeson grants
- PoPCRN email listserv – discussion and articles pertinent to palliative care
- PoPCRN newsletter

NO, I am not interested in participating in the Population-based Palliative Care Research Network Studies, but please notify me of your progress on current projects and upcoming events.

NO, I am not interested in the Population-based Palliative Care Research Network and please remove me from your mailing list.

Please send materials to:

Contact Person: _____
Position: _____
Site: _____
Address: _____

Phone: _____
Fax: _____
Email: _____

Thank you for taking the time to complete and return this form!
Please Fax or Mail This Form To:

Cordt T. Kassner, MA
University of Colorado Health Sciences Center
Campus Box B180
4200 East 9th Avenue
Denver, CO 80262

(F) 303-372-9082