

What's Poppin'?

Population-Based Palliative Care Research Network

NEW WEB ADDRESS: WWW.UCHSC.EDU/POPCRN

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KERNEL'S CORNER

David E. Nowels, MD, MPH

Nearly 15 years has passed since the opening of the assessment and accountability "revolution" in healthcare. This revolution was heralded by reports describing a lack of important information about what providers really do in practice and the effect that has on patients. Studies conveying this information are called effectiveness studies; they are evaluations of the processes and results, or outcomes, of actual healthcare practice rather than those achieved in carefully selected populations under ideal circumstances. We are trying to bring that assessment and improvement revolution to end-of-life care at PoPCRN, along with your help.

Together, we have described the frequency and severity of a variety of symptoms and other problems experienced by hospice patients, along with their quality of life. The current symptom study will eventually identify processes of care designed to improve symptoms and quality of life. However, improving patient outcomes shouldn't always wait for carefully designed systematic research studies. Once baseline data are available, the process of improving care can begin.

Unfortunately, most of us are not taught how to evaluate our practice, or how to integrate summary information – of the type PoPCRN has produced thus far - into data-driven improvement processes. Systematically looking at the care we provide can improve it, and the process can be gratifying. Several steps are important to using information to drive improvement changes in practice.

Working with information, rather than avoiding it, is a necessary first step along this path of data-driven practice improvement.

(Continued, Page 2)

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.

REPRESENTATION:

Our current mailing list includes 253 people from 90 research sites and 30 organizations. The research sites are located in 17 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 3: Bereavement Pilot Study
2/00
- Study 4: Confusion & Delirium Prevalence Study
2/00-3/00

WHERE ARE WE NOW?

- Study 5: Discharge Follow-up Study
7/00-6/01
- Study 6: Symptom Study-Phase I
8/00-12/01

WHERE ARE WE GOING?

- Study 2A: Psychosocial/Spiritual Issues Study in
Dept. of Corrections sites, 7/01-12/01
- Study 7: National Hospice Outcomes Project,
4/01-3/03

Under Development:

- ♦ Safety of Hospice Home Care Workers
- ♦ Hospice Education Survey
- ♦ *Fast Feedback Surveys (see article)*

KERNEL'S CORNER, CONTINUED FROM PAGE 1:

This first step may include critical evaluation of the way the data were obtained, development of clinical and methodological hypotheses about why the data show what they do, and interaction with the producers of the information, when possible, to sharpen the analysis in an iterative way. Working with other providers may enhance the effectiveness of this step. The next step, a key one, is to tie the outcomes of care to the environment and processes of care. Use of clinical practice policies, whether developed nationally, locally, or even personally, is one way to make this tie direct. Elsewhere in this edition of "What's Poppin'?", Pikes Peak Hospice and Palliative Care tells us how they have worked through these first two steps in dealing with the intimacy and sexual issues and needs of their patients. Other PoPCRN affiliates have also begun using PoPCRN data to evaluate their practice.

The final step is to assess the impact of changes made in clinical practices from the first two steps, focusing especially on patient outcomes. Routine monitoring might use the previously established data sets or data collection instruments. Sometimes, though, monitoring requires development of different data collection instruments or even data sources. By adding this final step, a feedback component is introduced into the process improvement cycle. These are essential steps of data-driven quality improvement. They offer the hope of harnessing the power of healthcare effectiveness evaluations in practice settings, while remaining realistic about the limitations of the data.

We should learn to use the information from effectiveness evaluations to better care for patients. This requires willingness to learn new skills, apply them, and work with other caregivers in the improvement process. Taking a proactive approach to use of effectiveness information allows us to remain true to our clinical and ethical imperative of providing the best care we can for our patients.

POPCRN PRESENTATIONS:

- ◆ Colorado Hospice Organization Meeting, 9/99
- ◆ Colorado Hospice Organization Meeting, 5/00
- ◆ Colorado Hospice Organization Meeting, 10/00
- ◆ National Hospice Work Group, 1/01
- ◆ National Hospice and Palliative Care Organization Meeting, 3/01
- ◆ Society of General Internal Medicine Meeting, 5/01
- ◆ American Geriatric Society Meeting, 5/01

***** *POPCRN JOURNAL ARTICLE PUBLICATION:* *****

“Symptom Burden at the End of Life – Hospice Providers’ Perceptions”
by Jean Kutner, Cordt Kassner, and David Nowels
Journal of Pain and Symptom Management
June 2001, Volume 21, Issue 6, Pages 473-480

This article was written from our first study “Symptom Prevalence Card Study” with data YOU provided. Copies of this article are being sent to sites that provided study data. If you are unable to access this journal and would like a copy of the article, please contact Cordt Kassner at cordt.kassner@uchsc.edu or 303-372-9364 and we will mail you a copy.

USING RESEARCH RESULTS: FIRST THE RESEARCH, NOW WHAT?

***Jane Schnell, RN, Vice President Clinical Services
Pikes Peak Hospice & Palliative Care, Colorado Springs, Colorado***

As one of the many sites participating in PoPCRn research studies, we support the importance of the studies and how outcomes will influence the future delivery of end-of-life care.

Often, when staff is asked to participate in another survey, study, or project, there is a refrain of “What, more research?” After initial grumbling, there is the realization that it is important, that their participation is vital, and ultimately – and this is what hooks the clinician every time – it will improve patient care.

When Pikes Peak Hospice and Palliative Care agreed to participate in PoPCRn’s Symptom Prevalence and Severity study in 1999, I felt fairly confident that I knew what the most prevalent symptoms would be – pain, lethargy, lack of appetite. The study did show these in the top five most prevalent symptoms among all patients, as reported by staff. No surprises! But what was surprising was that among the top five symptoms about which staff is unaware – sexual interest was an issue over 60% of the time.

I took the results of this study to our clinical services management team, and it was as if we, who tout ourselves as caring for the whole person, had missed an entire area that was clearly an important one to patients at the end of life. Although clinical staff had no difficulty assessing bowel and bladder habits, there was general discomfort about who should do the sexuality assessment and then, how would we respond if the patient wanted to discuss his/her concerns. In an effort to reinforce the importance of the data, I had to result to my “pitch” about improved patient care – and all agreed that this was not something that we could ignore. In caring for the whole person, sexuality and intimacy concerns needed to be addressed.

As a result, we have had an outside “sex-pert” do training with staff that informed, desensitized, and provided new skills. We are currently working on adopting an assessment tool that is easy to use and gives the patient “permission” to discuss sexuality and intimacy issues. Additional staff training and finalizing the assessment tool will soon be completed. We continue to have discussion about who is the most appropriate team member to initiate the conversation. This is a clear indicator that this subject matter – although important to the patient – is one that challenges our comfort zone.

Perhaps more research is needed to determine why health care givers are so sensitive to this topic...

KEEPING POPCRN VISIBLE

***Barb Kamlet, Volunteer Coordinator
Exempla Lutheran Hospice, Wheat Ridge, Colorado***

Among the many tasks that our staff does on a daily basis, we are trying to be innovative in keeping PoPCRn visible to our staff on an ongoing basis. By virtue of its name alone, the easiest way has been making popcorn available to the staff...and for several days, bottomless bowls of popcorn appeared in our kitchen surrounded by a popcorn graphic and the reminder, “Think PoPCRn!”

On a more serious note, we have posted “Think PoPCRn!” signs in various areas of our office and attach a “Think PoPCRn!” reminder on all incoming referrals. Our referral nurses have been asked to alert the staff when a new admit is a possible candidate for the PoPCRn study. We also have a PoPCRn update next to our census board listing “PoPCRn’s in Progress” followed by as many blank spaces as we have study books available to advise the staff of our “PoPCRn’s in Waiting”. PoPCRn updates are given at every team and staff meeting and we are beginning to highlight the names of PoPCRn patients on the weekly team report.

Having PoPCRn Staff come to both our homecare and residence staff meetings to talk about PoPCRn in general, and the Pain and Symptom Management Study in particular, has been very helpful. In some ways we wish we had them come earlier in the process. On the other hand, our timing gave staff a chance to experience PoPCRn for a period of time which led to very difficult questions that might not have been asked otherwise.

We continue to look for innovative ways to keep PoPCRn visible and staff motivated. However, if I had to name the most effective motivation for getting staff involved in PoPCRn, it would very simply be an ability to move past the fear of research and getting a patient involved in the study. As those members of our staff who have patients in the PoPCRn Natural History of Symptoms in Hospice Patients Study have found, the study is less intimidating than is perceived by the size of the (symptom study) notebook and the power of the study is seeing it in action.

FEATURED SITE

HOSPICE OF THE WESTERN RESERVE, CLEVELAND, OHIO

David Simpson, Executive Director

Hospice of the Western Reserve, Cleveland, Ohio

Founded in 1978, Hospice of the Western Reserve has grown along with the hospice movement from a very small community base nearly 30 miles from Cleveland to one of the nation's largest providers of end-of-life care. Its current daily census is 640 patients. The organization provides its services through five satellite offices as well as a 42 bed residential facility situated on an eight-acre park overlooking Lake Erie.

Hospice of the Western Reserve distinguishing features include:

- ◆ **Pediatric Team**-initiated in 1993 and now serving a daily census of 25 patients.
- ◆ **AIDS Team**-started in 1992, this team's census rose to fifty patients then dwindled to 8 as medical interventions improved longevity, and has recently seen a resurgence in referrals.
- ◆ **Project Safe Conduct**-a joint endeavor with the Ireland Cancer Center, an NCI designated Comprehensive Cancer Center. The Robert Wood Johnson funded program is part of the Excellence in End-of Life initiative and focuses on moving end-of-life discussions, counseling, and planning up to the time of diagnosis.
- ◆ **Community Bereavement Center**-funded with nearly \$1.5 million from local foundations, the center provided a wide range of bereavement programs and services to the general community including schools, employers, health care workers, and safety forces.
- ◆ **Art and Music Therapy**-expanded from one music therapist in 1985 to six full time art and music therapists in addition to interns in each area.
- ◆ **Medical staff**-includes three full time physicians.
- ◆ **Medical School relationships**-serves geriatrics, family practice, internal medicine, first year students as well as fellows.
- ◆ **Hospice House**-opened in 1995, this 42 bed residential inpatient facility also serves as a center of excellence for teaching and demonstrating quality care in the crowning phase of life's development.
- ◆ **A program for COPD Patients**-initiated four years ago, this disease management approach has been very successful and continues to grow.
- ◆ **Education Team**-includes four staff dedicated to internal staff development and continuing education.
- ◆ **The Hospice Institute**-focus is on academic and professional education. The Institute hosts community seminars and hosts town hall meetings and lectureship program.
- ◆ **Palliative Care Consultation Team**-consists of an advanced practice nurse and a hospice physician with support from other team disciplines.
- ◆ **International Endeavors**-HWR staff members have consulted in Hong Kong, Korea, Slovakia, South Africa, Tanzania, and Canada in addition to hosting visitors from many other nations.

Hospice of the Western Reserve employs 430 paid staff and 750 volunteers. Its budget for FY 2001 budget is \$32 million. It is a not-for-profit organization overseen by a local board providing volunteer leadership. Several of HWR's staff participate in leadership roles for state and national organizations including NHPCO, NCHPCP, AAHPM, HPNA, ELNEC and CAPC.

Additional Information about Hospice of the Western Reserve may be found at www.hospicewr.org.

AIDS IN AFRICA: THE TRAGEDY AND WHAT YOU CAN DO

Bev Sloan, BS, MPH, CEO

Hospice of Metro Denver, Denver, Colorado

“I’m a big believer that if you see a crime being committed and you don’t do something about it, you are as guilty as the criminal. What’s going on in Africa right now is a crime.”

James Kelly
Managing Editor
TIME magazine

It’s the worst humanitarian crisis in the world’s history, a pandemic without precedent. Colin Powell calls it a national security crisis. It is AIDS in Sub-Saharan Africa. As human beings, we grieve when a plane crashes fatally, we shudder in disbelief when an earthquake kills 30,000 people in India, yet the world has stood by nearly mute as the dreadful toll has mounted in Africa:

- ◆ 17,000,000 Africans have died of AIDS a number that will reach 40,000,000 if interventions are not made.
- ◆ One in seven Africans in the Sub-Sahara is HIV+.
- ◆ Thirty percent of women 15-24, and up to 50% of pregnant teens, are infected in some regions.
- ◆ 10 million AIDS orphans struggle for survival, overflowing the extended families’ capacities into the streets of every city.
- ◆ Every day, 5500 Africans die of AIDS and more become infected.

And still, most African governments have maintained a wall of silence about AIDS, reflecting the great stigma of their cultures against speaking about a disease associated with sexual behavior. This degree of denial in the wake of mass mortality is hard for Westerners to comprehend, but is one of the most powerful forces fueling the epidemic. Add to that, lack of resources and education coupled with sexual mores that put many at risk, and the scope of the disease’s spread starts to become comprehensible. But the most important factor that has permitted the tragedy to unfold at such proportions is lack of leadership and lack of action by the African governments certainly, but also by the Western world which has stood by watching.

So, what can you do in the wake of a tragedy of such immense proportions? Plenty! Here are a few suggestions.

- ◆ *Donate to the International Red Cross. Their community nurses are everywhere in the townships and villages giving care and teaching.*
- ◆ *Donate to the Foundation for Hospices in Sub-Saharan Africa (Pсарver@hospicecny.org). They are on the front lines helping patients and families, gaining a foothold where stigma has kept most help away.*
- ◆ *Vitamins are very needed! Donate vitamins to the African Vitamin Program Attn: Kathy Tebbett, Catholic Mission Board, 33-01 11th Street, Long Island City, NY 11106. Take a collection at your workplace or church. Hospice of Metro Denver collected several boxes.*
- ◆ *Donate to the search for an AIDS vaccine, truly the only way the epidemic will be wiped out. Visit www.iavi.com or www.aidsresearch.com*
- ◆ *Write to your U.S. legislators, urging them to support Sen. Bill Frist and others in passage of financial assistance to Africa for AIDS, before these countries’ economic stability is eradicated along with their productive workforce and education systems.*

Just start somewhere ... do something! A little goes a long way in Africa. Your help will make a difference. Then tell a few others to do the same.

Bev Sloan, CEO of Hospice of Metro Denver, recently went to South Africa to visit physicians and hospices working with AIDS.

***PSYCHOSOCIAL AND SPIRITUAL ISSUES AMONG HOSPICE PATIENTS:
QUALITY OF LIFE PERSISTS AT THE END OF LIFE
Jean S. Kutner, MD, MSPH***

We have recently completed analyses of data from the study of psychosocial and spiritual issues among hospice patients. This study was the original impetus for developing the hospice research network that has developed into PoPCRN. As you are well aware, quality end-of-life care requires meeting patients' physical needs and attending to the social, psychological and spiritual dimensions of care. While these are the central tenets of excellent palliative care, little is known about the prevalence and types of psychosocial and spiritual issues experienced by persons at the end of life. The purpose of this study was thus to describe the prevalence and types of psychosocial and spiritual issues among hospice patients.

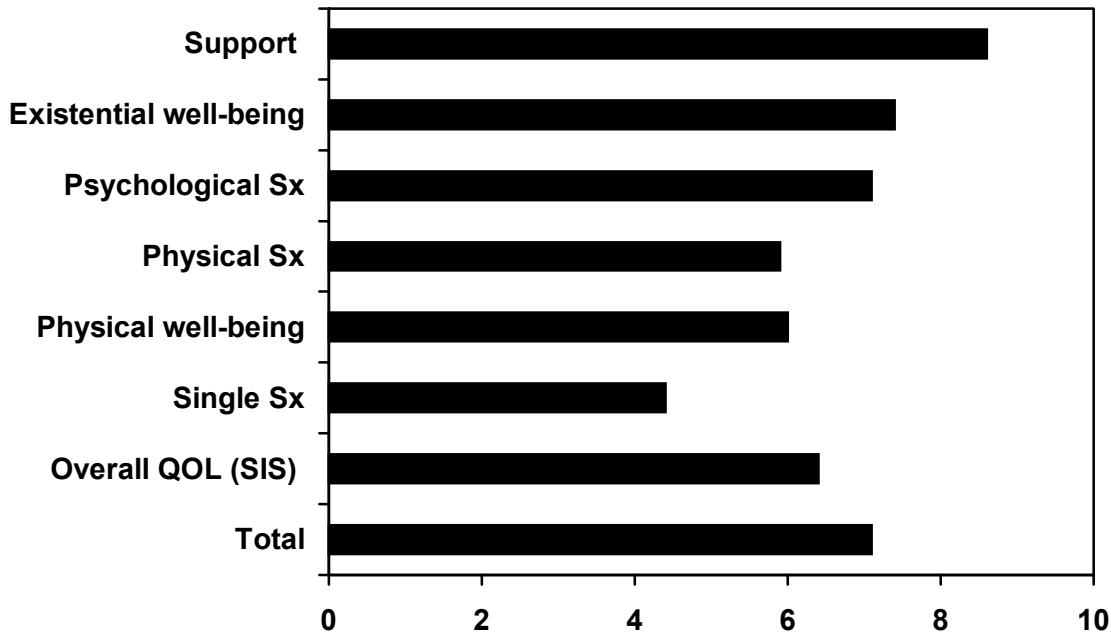
Fourteen PoPCRN hospices participated in this study, which consisted of an interviewer-administered questionnaire:

- ◆ Horizon Hospice
- ◆ Hospice & Palliative Care of Northern Colorado
- ◆ Hospice of Boulder County
- ◆ Hospice of Mercy
- ◆ Hospice of Metro Denver
- ◆ Hospice of Montezuma, Inc.
- ◆ Hospice of St. John
- ◆ Hospice of the Comforter of Colorado
- ◆ Hospice of the Plains, Inc.
- ◆ Life Source Services
- ◆ Namaste Comfort Care
- ◆ Pikes Peak Hospice & Palliative Care
- ◆ Porter Hospice / Hospice of Peace
- ◆ San Diego Hospice

Hospice and PoPCRN staff administered the survey to English-speaking adults who were cognitively intact and willing to participate in the study.

Sixty-six hospice patients participated in this study. Fifty-six percent of these patients were female, 89% were white, 39% were cared for at home, and 53% had a cancer diagnosis. The median age of the patients was 76 years. The participating patients had a relatively high functional status (average Karnofsky score of 50) and had been under hospice care for a prolonged period of time (median time between hospice admit and interview of 49 days).

Study patients completed the McGill Quality of Life Questionnaire (MQOL), which was developed and validated in the palliative care setting among cancer patients. It consists of 17 items that are scored on a 0 – 10 scale (score of 0 indicates the least desirable and 10 the most desirable situation). Scoring of the MQOL allows for calculating a Single item scale (SIS) measuring overall QOL, a Total score, and 4 subscales: Physical Symptoms, Psychological Symptoms, Existential Well-being, and Support. Study participants' MQOL scores indicate that they had few physical symptoms (single troublesome symptom score=4.4). These patients were less troubled by psychosocial and existential issues than by physical symptoms (see figure below). Diagnosis, functional status, and care location were associated with QOL. Patients with a cancer diagnosis had a greater sense of Existential Well-being (7.8 vs. 6.9, $p=0.047$) and a greater sense of support (9.0 vs. 8.1, $p=0.042$) than patients with other diagnoses. Patients with worse functional status (Karnofsky score < 50%) had a worse sense of Existential Well-being (6.9 vs. 7.9, $p=0.017$) than patients with better functional status. Finally, patients who were receiving care at home had a greater sense of Support (9.2 vs. 8.2, $p=0.005$) than patients in other care settings. There were no significant associations between age, marital status, gender or length of hospice care and any of the QOL scores



Respondents had a strong spiritual connection: 85% had a personal relationship with a power greater than themselves; 84% felt connected to something greater than themselves; 82% agreed that spiritual health contributes to physical health; and 77% felt that a spiritual force influenced events in their life. There was also a strong sense of hope: 90% believed that life has value and worth; 87% believed that each day has potential; 82% agreed that they had a positive outlook on life; and 80% were *not* scared about the future.

These hospice patients did not express anxiety or fear about death. Seventy-two percent agreed that they were looking forward to a new life after they died. There were concerns about the dying process: 33% were afraid of a long, slow dying; 33% worried about being helpless; and 28% feared dying a painful death. While 63% felt at ease with their current situation 68% were concerned about how their illness was affecting their family. Twenty-seven percent were bothered by the loss of their usual role. Twenty-one percent of these patients indicated that they were currently suffering. Despite being under hospice care, twenty percent thought that their illness was going to get better. Financial and legal issues did not concern most of these individuals (27% and 18% expressed concern, respectively).

The findings of this study are limited by the small sample size and the fact that they may not be representative of all patients receiving hospice care. That is, the patients who participated in this study had a relatively long hospice length of stay, relatively high Karnofsky scores. Nevertheless, these findings speak to the strength of the human spirit. Among this older, terminally ill population receiving hospice care, there was a strong spiritual connection, hope and quality of life persisted, and death was not feared. This may reflect self-selection of those who enter hospice care or, perhaps, hospice care itself.

These data do not inform us about the trajectory of psychosocial and spiritual issues throughout the course of a terminal illness. Study of these issues from the time of diagnosis of a life-threatening illness through its terminal stages is necessary to provide context for findings from this study.

If you are interested in additional information about or findings from this study, please contact Jean Kutner, MD, MSPH (Jean.Kutner@uchsc.edu) or Cordt Kassner, MA (Cordt.Kassner@uchsc.edu), or visit the PoPCRN web site.

EDUCATION IN PALLIATIVE CARE

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

Palliative Care Education and Practice¹ is the name of a wonderfully designed course held recently in Boston and sponsored by Harvard University. The course had two main objectives: to enhance the care and attention to suffering of the critically ill and dying, and to promote personal growth and self-reflection in the care giver.

My dictionary says that we might look at palliation as “to ease without curing”. Or then as another take, “to cover by excuses and apologies”. With our contemporary love affair with technology and all its hopes and promises for relief of our maladies, we must still acknowledge that to ease without curing is the big player in our quest for quality health care. Curing become an imperative, yet the search continues and failures are inevitable. Excuses have no place and apologies become gestures in communicating our helplessness. Palliations, the easing and caring without curing, must sustain us and seek to relieve us of sufferings of abandonment.

It is with these attitudes in mind that Harvard Medical School sponsored this course. Aware that “hidden and informal curricula of academic medical centers, in addition to deep cultural influences” often undermines palliative care teaching and practice, this immersion in palliative care sought to wash us clean and expose those obstacles. Not only were the barriers of ever expanding barnacles laid bare, but the challenge to overcoming reluctance to take a change or two was addressed.

Through days of immersion in adult learning techniques, as role playing and being led by Pied Pipers of facilitation, participants explored thoughtful approaches to institutional change, personal reflection, and growth. Patience turned up as a prime value and guide in confronting change.

Fortunately, I made the effort to become part of this group of 25 M.D.’s, 14 nurses, 1 pharmacist, 1 lawyer (also a nurse), and 2 clergy (17 women and 25 men).

Focusing on attitudes and communication skills took precedence over conveying fundamental knowledge about palliative care, though there were plenty of opportunities for “how-to-do-it” learning.

The program content and the instructors/facilitators were superb in the conveyance of these attitudes, as outlined in the program brochure:

- ◆ that clinicians have great potential for being enormously helpful to patients and families despite common feelings of aversion to suffering and “medical failure”
- ◆ that health care workers can be awakened to a readiness to bear with all the uncertainties, ambiguities, and helplessness posed by terminal illness
- ◆ that clinical workers become adept in curiosity, wonder, and tolerance about how others – including patients, families, and health professionals – face the end of life
- ◆ recognition of the values of “just being there” rather than avoiding or trying aggressively to overcome a fatal disease
- ◆ of valuing an interdisciplinary approach to end-of-life sufferings and the clinician’s role in promoting such care

Participants in this first half of the course will return to Boston in November 2001 to examine what has happened to them and their patients between April and November. A second week of exploring attitudes about suffering and end-of-life care should bring rewards in being able to deliver a quality laden kind of patient care. Feelings of personal fulfillment in a better understanding of palliative care is a special added benefit.

Reference

¹ Billings, J.A. What is Palliative Care. J. Palliative Care 1998; 1:73-81.

POPCRN PARTICIPATING IN THE NATIONAL HOSPICE OUTCOMES PROJECT

Jean S. Kutner, MD, MSPH

We are proud to announce that Colorado PoPCRN hospices have been invited to participate in the 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.

Fifteen hospices nationwide (including Colorado) have been selected to participate in this important project. Nationally, the study will include 1800 hospice patients, 120 of which will come from Colorado. Staff from participating hospices will receive training in the Hospice of the Florida Suncoast's documentation training program "Reflecting Excellence and Quality Care: The Hospice Documentation Process". Participating sites have agreed to incorporate the standard documentation tools for dyspnea and pain assessment into their routine clinical care, beginning in November 2001. In December 2002, we (PoPCRN staff for the Colorado hospices) will collect data from chart reviews of selected patients (based on diagnosis and length of stay). These data will then be combined with the national data to evaluate the relationship between various treatment modalities and patient outcomes.

The following Colorado hospices have volunteered to participate in this project:

- ◆ Hospice of Mercy, Durango
- ◆ Hospice of Montezuma, Cortez
- ◆ Hospice of St. John, Lakewood
- ◆ Hospice of the Plains, Wray.
- ◆ Lamar Area Hospice Association, Lamar
- ◆ Pikes Peak Hospice and Palliative Care, Colorado Springs
- ◆ Porter Hospice/Hospice of Peace, Denver

These Colorado hospices join the following hospice nationwide that are participating in this project:

- ◆ Adventist Health Hospice, Portland, OR
- ◆ Alive Hospice, Nashville, TN
- ◆ Family Hospice and Palliative Care, Pittsburgh, PA
- ◆ Franciscan Hospice, Tacoma, WA
- ◆ Home Health and Hospice Care of Nashua, NH
- ◆ Hospice of Michigan, Southfield, MI
- ◆ Hospice of the Florida Suncoast, Largo, FL
- ◆ Houston Hospice, Houston, TX
- ◆ Lutheran Hospice, Columbia, SC
- ◆ Ministry Home Care – Hospice Program of St. Joseph's, Marshfield, WI
- ◆ Palliative Care Center and Hospice of the North Shore, Evanston, IL
- ◆ San Diego Hospice, San Diego, CA
- ◆ Trinity Care Hospice, Torrance, CA
- ◆ UAB Hospice, Birmingham, AL.

Congratulations to these hospices for their commitment to improving patient care at the end of life. For more information about the National Hospice Outcomes Project, contact Susan Horn, PhD, ISIS/ICOR (shorn@isisicor.com), Stephen Connor, PhD, NHPCO, (sconnor@nhpco.org), or Julie Gassaway, RN, MS, ISIS/ICOR (jgassaway@isisicor.com).

COMPLEMENTARY AND ALTERNATIVE MEDICINE (CAM) AT THE END OF LIFE

Jean S. Kutner, MD, MSPH

Complementary and alternative medicine (CAM) can be defined as health care practices that are not an integral part of conventional medicine. Most people who use CAM do so for chronic, incurable, non-life-threatening conditions, although its use is also common among patients with cancer (7-64%) and with HIV/AIDS (27-100%). Commonly used CAM modalities among these patients include herbs and herbal teas, vitamins and minerals, mind-body approaches, biologics (e.g. shark cartilage), massage and acupuncture. Both palliative care and CAM address the needs of chronically ill patients for whom there is no curative conventional therapy and emphasize the relief of symptoms (physical, psychological and spiritual) and maintenance or improvement of function.

Dying patients experience a heavy symptom burden. Treatment of these symptoms may be associated with troublesome side effects (e.g. opioid-induced constipation, delirium, or sedation). Some CAM therapies may have fewer adverse effects than traditional treatments or may offer therapies that are more consistent with patients' cultural or health care beliefs. If effective, CAM therapies may serve as useful alternatives or adjuncts in the care of terminally ill patients.

Despite the paucity of controlled trials, there are data that support the use of some CAM modalities in terminally ill patients. Relaxation techniques, acupuncture, and TENS may improve intractable pain in dying patients. Acupuncture and breathing retraining may ease dyspnea in moderately to severely impaired COPD patients who have a limited prognosis.

In preparation for writing a proposal in response to the recent NIH RFA, "Complementary/Alternative Medicine (CAM) at the End of Life for Cancer and/or HIV/AIDS", we conducted an informal survey via the PoPCRN list serve regarding use of acupuncture and massage in the hospice setting. Specifically, we asked whether hospices were using acupuncture and/or massage and, if so, who was providing these services. We inquired specifically about these two modalities as we proposed to study the efficacy of acupuncture for the treatment of nausea and of massage for the treatment of pain and anxiety. Sixteen hospices responded to our inquiry, from Colorado (9), Florida (1), Illinois (1), Virginia (1), Ohio (1), Michigan (1), California (1), and Montana (1). Eleven of the 16 sites offered massage therapy for patients, provided primarily by volunteers (8). The other three sites used paid staff (2) and prn staff (1). Five of the 16 sites offered acupuncture for patients, provided by volunteers (3), a medical director (1) and an arrangement with an acupuncture school.

Many CAM modalities have a favorable risk/benefit ratio and may be useful adjunctive therapies to conventional medicine. Future studies of CAM and palliative care require sound designs, larger sample sizes, reliable blinding, and specific and clinically relevant outcomes measures, including the effect on the concomitant use of conventional therapies. As the evidence evolves, those CAM therapies that prove beneficial may be integrated into interdisciplinary health care, thus expanding the therapeutic armamentarium and better addressing the physical, psychological, and spiritual needs of patients at the end of life.

We welcome descriptions of your experiences with CAM in your care setting.

References

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NIH Guide: *Complementary/Alternative Medicine (CAM) at the End of Life for Cancer and/or HIV/AIDS*. <http://grants.nih.gov/grants/guide/rfa-files/RFA-AT-01-002.htm>.

National Hospice and Palliative Care Organization. *Complementary Therapies in End-of-Life Care*. 2001. (<http://www.nhpco.org>)

VITAL BONDS: ETHICAL PRINCIPLES AND GUIDELINES FOR ORGANIZATIONAL CONDUCT
NATIONAL HOSPICE AND PALLIATIVE CARE ORGANIZATION

NPHCO has recently published a model of guidelines for ethical business and organizational conduct to the hospice and palliative care community. The context of these guidelines and detailed definitions and examples of each of the principles can be found in the booklet. To obtain further information about the guidelines or copies of the booklet, call the NPHCO Marketplace at 800-646-6460 (item #700270) or see their webpage at www.nhpco.org. The following "Overview of Principles" is used with permission.

The National Hospice and Palliative Care Organization's Ethical Principles
Hospice and palliative care organizations ought to uphold the following principles:

- ◆ **Access** – Promote universal access to comprehensive hospice and palliative care services.
- ◆ **Admissions** – Offer open access and care for hospice and palliative care patients and their families.
- ◆ **Conflicts of Interest** – Avoid activities that conflict with their responsibilities to patients and their families.
- ◆ **Development and Fundraising** – Be open and transparent in soliciting and accepting support.
- ◆ **Discontinuation of Care** – Discontinue care only upon the voluntary consent of the patient or when the hospice and palliative care provider can no longer provide competent care or provide care without compromising the ethical or professional integrity of the caregivers.
- ◆ **External Collegial Relationships** – Work cooperatively with others to provide compassionate and high-quality end-of-life care.
- ◆ **Governance** – Adhere to governance structures that ensure that hospice and palliative care providers fulfill their mission and purpose.
- ◆ **Information Management, Confidentiality and Privacy** – Respect and protect confidential information.
- ◆ **Marketing and Referrals** – Follow marketing and referral practices that promote compassionate, high quality care for patients and their families.
- ◆ **Public Information** – Disseminate accurate, fair and timely information.
- ◆ **Research** – Support the advancement of knowledge to improve the practice of hospice and palliative care.
- ◆ **Staff and Volunteer Relations** – Ensure that hospice and palliative care staff and volunteers are treated with respect and fairness.

**** FAST FEEDBACK STUDIES! ****

PoPCRN plans to develop a mechanism for sites to generate *FAST FEEDBACK!* for particular hospice issues. It generally takes books 2-3 years to be published, and 12 months for journal articles. With particular straightforward questions, however, we think *FAST FEEDBACK!* is possible – results within 2 weeks, and published in our seasonal *What's Poppin'* Newsletter.

- ◆ **How?** Announcements will be emailed on a new listserv.
- ◆ **Who?** Emails will be sent to one person at sites participating in *FAST FEEDBACK!*
- ◆ **What?** Quick questions for which little comparative data is available – **for example, fall rates, presence absence of hospice ethics committees, and staffing mix/ratio.**
- ◆ **Feedback?** We will ask for feedback via email, web-based survey form, or mail, depending on the nature of the study.
- ◆ **Results?** Survey results will be emailed to this new listserv and published in our newsletter.

Expect to hear from us soon with additional details and sign-up information!

INFORMATION ON CURRENT AND UPCOMING STUDIES

Discharge Follow-up Study:

What happens to people after they are discharged alive from hospice? This study will provide information helpful in answering this question by conducting monthly follow-up phone calls for 6-months following discharge. 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 through June 30, 2001.*** Monthly follow-up data will be gathered on patients for up to six months following discharge. To date, 40 sites nationally have agreed to participate. Of the 40 participating sites, 17 have contributed data on 139 patients.

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. Phase II of the study will develop treatment protocols for at least one symptom described from the first phase. Phase III of the study will then test the effectiveness of the treatment protocol developed in the second phase. ***Data collection for Phase I will continue through December 2001.*** To date, 21 sites nationally have agreed to participate. Of the 21 participating sites, 6 have contributed data on 22 patients. ***Please contact us if you would like to participate in this study.***

Psychosocial/Spiritual Issues Study in the Department of Corrections:

Last year PoPCRN conducted a patient interview study assessing psychosocial and spiritual issues in community hospice patients. Thanks to the work of Liz Craig, Resource Coordinator for the GRACE Project, 3 hospices located in various Department of Corrections systems have agreed to conduct this same survey in their hospices. Data collection for this study will begin this summer.

National Hospice Outcomes Project:

Please see article in this newsletter for details.

Safety of Home Care Workers Study (under development):

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.

Hospice Education Survey (under development):

To what extent and in what ways are hospices providing educational experiences for health professions students and/or residents? PoPCRN is designing a brief study to examine this issue and plans to send out surveys mid-summer.

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

BOOK REVIEW – A VERY EASY DEATH, BY SIMONE DE BEAUVOIR

By Peter Mayerson, MD

This autobiographical essay by Simone de Beauvoir, the famous French feminist and existentialist, was published in 1964 under the title "Une Mort Tres Douce". It is a profoundly moving, day-by-day account of the death of the author's mother from a cancerous "tumour blocking the small intestine". Although Mme. de Beauvoir is internally aware that her "Maman" has incurable cancer, she is unable to talk about her dread with her sister, mother, or the doctors in the hospital and passively consents to an operation by the curatively oriented attending physician.

Although this palliatively oriented reader felt outraged and sad about the consent, the objectively useless operation seemed to have a positive function for the de Beauvoir family. It enables Maman to deny that she has a terminal illness and believe that she is just suffering from curable peritonitis. Although consciously knowing the diagnosis and prognosis, Simone's sister, Poupette, is able to join Maman's frail hope. The operation temporarily prolongs Maman's life and allows the previously alienated mother and sisters to emotionally come together in sharing the prolonged agony of death.

In the March Ethics Community Meeting in Denver, we had an engaging debate about the pros and cons of supporting or confronting denial of death, and whether the book's title expressed a statement of belief or irony. We all felt sad – feeling that the De Beauvoir family suffered a missed opportunity to talk about dying and that Simone perhaps needed to write the book to work through her unexpressed grief. We were outraged at the description of the hospital medical staff who typically focused on procedures rather than empathy.

I would strongly recommend this (short-106 pp.) book to all health care providers involved in end of life care. In the last paragraph of the book, de Beauvoir makes a profound existential statement for us to consider: "There is no such thing as a natural death: nothing that happens to a man is ever natural, since his presence calls the world into question. All men must die: but for every man his death is an accident and, even if he knows it and consents to it, and unjustifiable violation."

NEW BOOKS

- ♦ *Caring for Patients at the End of Life: Facing an Uncertain Future Together*, by Dr. Timothy Quill. Published by Oxford Press. Book review in Journal of Palliative Medicine.
- ♦ *Dying: A Guide for Helping and Coping*, by Martin Shepard, MD. Published by Sag Harbor, \$24.

CALENDAR OF EVENTS

June

21-24 *American Academy of Hospice and Palliative Medicine (AAHPM) 13th Annual Assembly*, Phoenix, AZ. For more information, call 847-375-4712 or see their website @ www.aahpm.org.

July

13-15 *Center to Advance Palliative Care (CACP) Regional Training Session*, San Francisco, CA. For more information, see their website @ www.capcmssm.org.

August

4-7 *Missoula Demonstration Project Training*, Missoula County, Montana. For more information, call Jason Kurtz at 406-728-1613 or see their website @ www.missoulademonstration.org.

October

- TBA *Center to Advance Palliative Care (CACP) Regional Training Session*, Chicago, IL. For more information, see their website @ www.capcmssm.org.
- 13 *The American Board of Hospice and Palliative Medicine Exam*. For more information, see their website @ www.ptcny.com.

November

Harvard Medical School Center for Palliative Care Program in Palliative Care Education and Practice, Boston, Massachusetts. For more information, email pallcare@partners.org, call 617-724-4597, or see the website at www.hms.harvard.edu/cdi/pallcare.

ANNOUNCEMENTS

Missoula Demonstration Project Training

The Missoula Demonstration Project (MDP) will be hosting Tools for Action, a three-day retreat from August 4-7. The retreat is for people and organizations interested in working to improve the quality of the end-of-life experience. The Missoula Demonstration Project, begun in 1996, has combined community-based action with extensive research on living with life-limiting illness, dying, death, caregiving, and grief in Missoula County, Montana. The project has achieved significant results. For more information and project results, go to www.missoulademonstration.org, and click on "About the Project" and then "Current Newsletter". To register on line for the MDP retreat, click on Tools for Action from the home page or call Jason Kurtz at 406-728-1613.

Stanford Faculty Development Program: End-of-Life Care

September 4-28, 2001. The Stanford Faculty Development Program is accepting applications for this facilitator-training program. The month-long training at Stanford prepares faculty to conduct a faculty-development course in End-of-Life Care for faculty and residents at their home institutions. For more information, please contact: Georgette Stratos, PhD, Co-Director, Stanford Faculty Development Program, 700 Welch Road, Suite 310B, Palo Alto, CA 94304-1809. Phone: 650-725-8802. E-mail: gstratos@stanford.edu. Website: www.stanford.edu/group/sfdp.

American Board of Hospice and Palliative Medicine: Exam Dates

Exam date is October 13, 2001. For more information, contact ABHPM at 301-439-8001 or see the website at www.abhpm.org.

Palliative Care Fellowship

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

Roxane Visiting Nurse Scholar Program in Palliative Care

The Palliative Care Program of the Medical College of Wisconsin is pleased to offer a visiting scholar program designed for nurses. For more information, contact Sandy Muchka, RN, MS, OCN at 414-805-4607.

Project to Improve Residency Training in End-of-Life Care

The Robert Wood Johnson Foundation has funded a 3-year project coordinated by David Weissman, MD, Director of Palliative Care at the Medical College of Wisconsin, to improve training in end-of-life care at 180 internal medicine or family practice residency programs. For more information, contact Lisa Pelzek-Braun at 414-805-4605 or email lpelzek@mcw.edu.

***** New Webpage Address: www.uchsc.edu/popcrn *****

***** New Email Listserv Address: popcrn@uchsc.edu *****

***** Coming Soon – 1-800 Number *****

CARMEL CORN (A SWEET ENDING...)

On May 28, 2001, Pikes Peak Hospice & Palliative Care (Colorado Springs, CO) presented the “Commemorative Celebration 2001”. This 1-hour ceremony was held in a local park for families in bereavement. After several “Readings for Remembrance” and the “Reading of the Names”, the celebration concluded with a live butterfly release. The following story was the last reading:

The Chrysalis Original by Nikos Kazanstakis

Once a man found the cocoon of a butterfly. One day a small opening appeared. He sat and watched the butterfly for several hours as it struggled to force its body through that little hole. Then it seemed to stop making any progress. It appeared as if it had gotten as far as it could and could go no further.

In the spirit of compassion the man decided to help the butterfly. He took a pair of scissors and snipped off the remaining bit of the cocoon. The butterfly then emerged easily. But, it had a swollen body and small, shriveled wings.

The man continued to watch the butterfly because he expected that, at any moment, the wings would enlarge and expand to be able to support the body, which could contract. Neither happened. In fact, the butterfly spent the rest of its life crawling around with a swollen body and shriveled wings. It was never able to fly.

What the man in his kindness and haste did not understand was that the restricting cocoon, and the struggle nature required for the butterfly to get through that tiny opening, were The Creator’s way of forcing fluid from the body of the butterfly into its wings. Once the fluid was forced from the body into the butterfly’s wings, by its struggle through the small opening in the cocoon, it would be ready for flight.

Sometimes struggles are exactly what we need in our life. If The Creator allowed us to go through our life without any obstacles or restrictions, it would cripple us. We would not be as strong as we could have been. We would never have wings to fly, and, without those wings, we could not leave behind the beauty of our flight.

From Barb Kamlet, Exempla Lutheran Hospice, Wheat Ridge, Colorado

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**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 (PoPCRN)* opportunities:

- I would like more information about PoPCRN research studies
- PoPCRN email listserv – discussion and articles pertinent to palliative care
- PoPCRN newsletter / research results / mailing list

No, please remove me from your mailing list.

PoPCRN, please contact:

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:***

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