



What's Poppin'?

Population-Based Palliative Care Research Network

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

Winter 2000

Kernel's Corner

David Nowels, MD, MPH

We have been doing quite a bit of thinking in recent months about our mission here at PoPCRN. Earlier this year we developed a mission statement that was shared in our last newsletter and is printed on the first page of this edition. Recently we have been asked, appropriately, how we will know when we are fulfilling this mission. That is the question I want to address in this space.

Each of the studies we have conducted thus far has focused on issues or problems that patients experience – physiologically-based symptoms and social, emotional, and spiritual concerns. The data that you collected provide a snapshot, at a single point in time, of these problems and concerns. To our knowledge, each of these studies represents the largest and most generalizable data ever collected about these issues in dying patients.

These accomplishments are substantial and may provide enough understanding to address our mission – we give the data back to you to enhance your understanding of your patients and see opportunities for where care might be improved – but they do not ensure that patients' lives are improved. A snapshot only tells the viewer how things looked at one point in time. A video, by including time in collection of information, can give a much more complete perspective about how things are. We are now beginning the next study in the series dealing with common symptoms. This will be a prospective study and provide data about the symptoms that patients experience over time – more like a video than a snapshot. After that,

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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 173 people representing 81 sites and 18 organizations. Of the 81 sites, 74 (91%) have agreed to participate in at least one of our research studies. These 74 sites are located in 13 states and Canada. Of the 38 Colorado hospices, 34 (89%) participate. Twelve sites are located in Ohio.

Where Have We Been?

- | | |
|--------------|---|
| Study 1: | Symptom Prevalence Card Study
7/99-10/99 |
| Presentation | Colorado Hospice Organization Fall Meeting, 9/99 |
| Study 2: | Psychosocial/Spiritual Issues Study
1/00-9/00 (most sites) |
| Study 3: | Bereavement Pilot Study
2/00 |
| Study 4: | Confusion & Delirium Prevalence Study
2/00-3/00 |
| Presentation | Colorado Hospice Organization Spring Meeting, 5/00 |
| Retreat | Strategic Planning Retreat
7/00 |
| Board | Formation of the PoPCRN Advisory Board, 10/00 |
| Presentation | Colorado Hospice Organization Fall Meeting, 10/00 |

Where Are We Now?

- | | |
|----------|--|
| Study 5: | Discharge Follow-up Study
7/00-6/01 |
| Study 6: | Symptom Study-Phase I
8/00-3/01 |

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we plan a study to systematically introduce changes in care that we hope will improve patient experiences. If we find that those changes do improve care, and are then translated into routine palliative care practice, we will be able to say that PoPCRN is fully meeting its mission.

Great plans, huh? You may be asking yourself – “*But do we really need to go to such trouble – after all, don't we already know the things to do from our clinical experience, and, besides the plans you describe could take years to complete?*”. It's true that a number of issues are already handled appropriately in practice, but our mission is to improve care. Furthermore, the “snapshot” studies have already identified areas where we know too little about our patients. Our goal is to develop an evidentiary basis for clinical practice that we know enhances the lives of dying patients. That implies a scientific approach – one that limits unwanted variation to ensure that the conclusions drawn are most likely correct. Current practice uses more of an authoritarian approach – where expertise is given priority.

So, we are a little like a farmer growing popcorn. We have grown a few test rows of different varieties to get a feel for what they are like. Our next steps are to see if we can grow a field of at least one variety – by doing the prospective symptom study. Finally we will compare one variety against another by growing a field of each – an intervention study to improve symptoms. Just like the farmer our process will take several growing cycles, but we expect the final product to be **great!**

PoPCRN Advisory Committee

In previous PoPCRN research studies we have asked for feedback and comments from key participants regarding study design and study relevance on an ad hoc basis. At our summer planning retreats we agreed it is important for us to formalize this process. In September we extended 16 invitations to key regional participants to provide “scientific” advice concerning study design and methodology or “technical” advice focusing on relevance of study ideas, practical aspects of study implementation at the patient/staff/caregiver level, and implications of study findings for care at the end of life.

***We appreciate the following people who have agreed to participate
in the first PoPCRN Advisory Committee:***

*Michelle Appenzeller, RN, Hospice of Mercy, Durango, CO
Martha Barton, Pikes Peak Hospice & Palliative Care, Colorado Springs, CO
Jan Bezuidenhout, MSW, CHP, Namaste Comfort Care, Denver, CO
Al Canner, JD, Colorado Hospice Organization, Boulder, CO
Liz Craig, Guiding Responsive Action in Corrections at the End-of-life (GRACE) Project, Boulder, CO
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Jane Schnell, RN, Pikes Peak Hospice & Palliative Care, Colorado Springs, CO
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Christy Whitney, RN, Hospice of the Grand Valley, Grand Junction, CO*

Book Review By Jean Kutner, MD, MSPH

Innovations in End-of-Life Care: Practical Strategies and International Perspectives. Edited by: Mildred Z. Solomon, Anna L. Romer, Karen S. Heller; foreword by David E. Weissman. Mary Ann Liebert, Inc., publisher (ISBN 0-913113-87-5); 240 pages, softcover, \$69; Available from: Mary Ann Liebert, Inc. (www.liebertpub.com/jpm) or (800) M-LIEBERT).

Innovations in End-of-Life Care is a compendium of material that first appeared in the on-line journal of the same name. The online journal (www.edc.org/lastacts) is a source of information for health care professionals who are interested in strengthening the capacity of the organizations in which they work to care better for dying patients and their families. The purpose of *Innovations* is to improve the quality of care provided to patients near the end of life and to their families, through the dissemination and critical examination of innovative practices being implemented throughout the world. *Innovations'* special niche is in focusing on the social and political processes, administrative actions, and organizational steps that are necessary for initiating and maintaining these improvements.

The published volume, a compendium of the best of *Innovations* online journal articles, is full of promising practices and helpful insights from people who have succeeded in changing practices and policies in their own institutions and communities. Four topics are covered in this collection: truth-telling and advance care planning; family-centered care (empowering patients and families to become fuller partners in setting the goals of care); cancer pain management; and improving care and maintaining connection with people with advanced dementia.

According to Ira Byock, MD, "*Innovations* looks behind the curtain of statistical findings and published results, enabling readers to observe the creative process of innovation. Here you will find the thought process of the innovators, their strategies, challenges, missteps and lessons learned. *Innovations in End-of-Life Care* will prove invaluable to leaders across America and in communities around the world as they strive to reframe life's end and build systems of care and support for people to live, age and die well."

Kathleen Foley, MD states, "*Innovations* is a great asset for physicians, nurses, social workers, hospital clergy – any health care professionals who want to take a leadership role in redesigning systems of care for dying patients."

Book Review By William Reiquam, MD, Mhum

As We Are Now. By Mary Sarton (W.W. Norton, paperback)

This short novel (133 pages), copyrighted in 1972, now in 2000 is as readable and provoking as ever. Caroline Spencer describes her life in a nursing home, "a small red farmhouse sinking into the mud for years." She finds the place "a concentration camp for the old, a place where people dump their parents or relatives as though it were a trash can". At 76, here she is plunked into a "home" without having been truly consulted about her destiny. From the beginning she is determined to make herself "whole here in this hell". Her "path inward", as she calls her story, begins with a journal so "I know where I'm at". "Then when I forget things later, I can always go back and read them here."

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Book Review, continued from page 3

Caroline rages and rationalizes; in subtle and blatant terms she defines her case and lays bare clichés about the decrepit and the ugly packaging of the elderly. She finds some solace in building a friendship with Reverend Richard Thornbill. He understands her plight and sees her as a suffering human being. Gradually he helps supplant her despair with hopes that she might remain compassionate even when barely coping amidst the humiliations and pettiness that engulf her.

In the end, Caroline triumphs as a person; her pyrrhic victory is startling and her story lays bare what some may yet encounter in their end-of-life experiences.

Twenty-eight years have passed since this book was written. Millions of public and private dollars have gone into “reform” in nursing homes to improve their management and raise public expectations as caring refuges for the elderly. Public attitudes have moved from seeing nursing home care as a near-death repository to a form of wellness maintenance resource. Is that change reflected in the day-to-day relationships that sustain and nourish one at 36 and yet at 86?

And what about all the Caroline’s – the uprooted, the lonely and disenfranchised, the powerless, unwanted and indigent elderly? Are they being truly consulted as to what their needs are, are their sufferings being recognized, does their real life still stop at the latch key to the nursing home door? Perhaps we are yet only beginning to understand T.S. Eliot’s message in *Four Quartets*, IV.2:

... the rending pain of re-enactment.
Of things ill done and done to others’ harm,
which once you took for exercise of virtue.

Hospice Around the World – Hospice in Sub-Saharan Africa

- 5,500 Persons a day dying from AIDS
- 10 Million AIDS orphans
- Seventy percent of the 34 million people infected with HIV live in Sub-Saharan Africa, where more than two million people died of AIDS last year (Rocky Mountain News, 7/10/00).
- A child born in Botswana, Namibia, Swaziland, or Zimbabwe can expect to die before the age of 35 (Denver Post, 7/11/00).

What can be done?

The Foundation for Hospices in Sub-Saharan Africa (FHSSA) has been established to help channel critical dollars to hospices struggling with meager resources and overwhelming demands. The Foundation has grown out of a series of professional seminar tours by American Hospice and AIDS Care professionals. The personal contacts have enabled a number of hospice-to-hospice partnerships. If your hospice would consider a “twinning” relationship with a Sister program in Sub-Saharan Africa, or you would like to correspond or make a contribution to FHSSA, contact Peter Sarver, Secretary of FHSSA, at email psarver@hospiceny.org or by mail at 19 Manning Blvd., Albany, NY, 12203. Also, **Christy Whitney** (President, Hospice of the Grand Valley, Grand Junction, CO) provides a Colorado connection with this group – she can be reached at 970-257-2360 for additional information.

Information on Current and Upcoming Studies

Discharge Follow-up Study:

This study will follow 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 through June 30, 2001. Six-month follow-up data will be gathered between August 1, 2000 and December 31, 2001. *To date, 37 sites nationally have agreed to participate. Of the 37 participating sites, 9 have contributed data on 51 patients.* Please contact us if you would like to participate in this study.

Natural History of Symptoms 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. Study materials were sent out mid-November and data collection will continue through March 2001. Please contact us if you would like to participate in this study.

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.

- ♦ 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.

Featured Site: San Diego Hospice

By Charles von Gunten, MD, PhD

San Diego Hospice was founded on February 14, 1977 with a grant from the Macomber Fund of the American Cancer Society. In 1980, San Diego Hospice was one of 24 organizations selected for the Hospice Pilot Project that formed the basis for the Medicare Hospice Benefit. In 1988, Joan B. Kroc gave \$18 million to build a multi-purpose facility that would provide short-term acute palliative care for patients as well as house the administrative, educational, and research activities of the agency. Mrs. Kroc's expectation was that San Diego Hospice would be a world-class center of patient care, education, research, and advocacy in hospice and palliative care.

Clinical Program

The Inpatient Care Center is a 24-bed acute care center licensed as a special hospital in the State of California. Average length of stay is six days. There are nearly 1300 admissions per year. Onsite radiology and pharmacy services are available. Patients may be admitted either under hospice insurance benefits or under other health care insurance. No patient is turned away because of inability to pay. The unit runs at 98% occupancy.

The Home Hospice Program of San Diego Hospice Corporation cares for patients throughout San Diego County. Patients are cared for both at home and in extended care facilities. Average daily census in the year 2000 runs at more than 400 patients per day. Average length of stay is about 40 days. More than 2500 patients are cared for each year.

Patients are also cared for in the San Diego Palliative Home Health Care Program. Started in 1999, the program cares for patients with advanced disease with palliative care needs. Their needs are best met under a home health care license rather than in a hospice program. Special teams care for patients with AIDS, cancer, cardiac, and pulmonary disease. Average daily census is currently about 80 patients, and continues to grow.

Physicians in the medical department of San Diego Hospice Corporation also see consultations in any of the major hospitals referring patients to the program. These include University of California, San Diego-Hillcrest Hospital, University of California, San Diego- Thornton Hospital, and Scripps Health System Hospitals (seven).

Education and Research

The Center for Palliative Studies (CPS) was established at San Diego Hospice in 1987 with a \$1.135 million grant from the W.M. Keck Foundation to foster education and research in hospice and palliative care. CPS is a teaching and research affiliate of the School of Medicine, University of California, San Diego. The 8 full-time physician faculty and three part-time physician faculty hold academic appointments in appropriate departments.

CPS coordinates education programs for more than 250 medical students, residents, fellows, and visiting physicians each year. This includes a required rotation for 3rd year medical students from the UCSD School of Medicine. Five primary care residencies send their residents for rotations as well. In addition, CPS coordinates education for nursing, social work, nurse practitioner, pharmacy and complementary medicine students.

CPS coordinates research projects including Phase I, II, III, and IV studies. Studies have been conducted in pain and symptom management, quality of life, complementary and alternative therapies, education and outcome studies. There is an independent Institutional Review Board (IRB) for The Center. The number of protocols that our investigators initiated in cooperation with other institutions continues to grow.

Calendar of Events

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.
- 7-8 Marion General Hospital's Hospice and Home Health Departments in Marion, Ohio will sponsor a seminar featuring Sister Carol Taylor, CSFN, who will discuss issues concerning healthcare ethics, decision-making and reform. Sister Taylor is senior research scholar at the Center for Clinical Bioethics and Kennedy Institute of Ethics as well as assistant professor of nursing at Georgetown University.
- 7-9 *The Fourth Conference on Pain Management and Chemical Dependency*, Washington, D.C. For more information, call Imedex, USA, Inc. @770-751-7332.
- 7-9 “*Research and Development in Palliative Care*” 1st Congress of the Research Network of the European Association for Palliative Care – EAPC Onlus, Berlin, Germany. For more information call the European Association for Palliative Care @ +41 22 732 1188 or see their website @ www.kenes.com/eapcresearch.

April

- 1-5 7th Congress of the European Association for Palliative Care, Palermo, Sicily. For more information, call K&K Congress @ +41 22 908 1188 or see their website @ www.kenes.com/eapc.

May

- 12-16 *The 19th King's College Conference on Death and Bereavement*, London, Ontario. For more information, call Dr. John D. Morgan @ 519-432-7946.

June

- 21-24 *AAHPM 13th Annual Assembly*, Phoenix, AZ. For more information, call 847-375-4712 or see their website @ www.aahpm.org.

Announcements

Roxane Visiting Nurse Scholar Program in Palliative Care, Medical College of Wisconsin. The Palliative Care Program of the Medical College of Wisconsin is pleased to offer a visiting scholar program designed for nurses. The program provides an opportunity for nurses to enhance their skills in symptom management and end-of-life decision making for patients with terminal illness. The 3-day core content includes discussion on palliative care, pain assessment and pain management, analgesic pharmacology, and management of end-of-life symptoms. For more information, call Sandy Muchka, RN, MS, OCN @ 414-805-4608.

Update from the International Hospice Institute and College (IHIC). The monthly IHIC Newsletter is now available to anyone with e-mail access interested in the international aspects of the development of palliative care. To receive, send your e-mail address to the editor at wmfarr@aol.com. Additional information now available on the IHIC website (<http://www.hospicecare.com>) includes the following:

- ♦ The IHIC Traveling Fellowships are awarded to palliative care professionals who are members of the IHIC and who are interested to visit a developing country to assist in the development of palliative care.
- ♦ A number of essays on Ethical Issues in Palliative Care, including euthanasia and physician assistant suicide are displayed on the Ethics page.
- ♦ An on-line bibliography of the current palliative care / hospice literature is available in the IHIC Currents section.

The Program in Palliative Care Education and Practice. Sponsored by the Harvard Medical School Center for Palliative Care and the Robert Wood Johnson Foundation offers intensive learning experiences for physician- and nurse-educators who wish to become expert in the clinical practice and teaching of comprehensive, interdisciplinary palliative care. April 24 – May 1, 2001 and November 14-20, 2001. For more information, call 617-724-4597 or see their website @ www.harvard.edu/cdi/pallcare.

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Carmel Corn (a sweet ending...)

Favorite answers to some of our Psychosocial / Spiritual Issues Study interview questions:

Interviewer: You focus on what needs to be changed in yourself, not on what needs to be changed in others.
Patient: *(Smiling) Absolutely NOT! Why would I do that?*

Interviewer: On a scale from 1-10, please rate how your life has been over the past 2 days – from 0, being utterly meaningless and without purpose to 10, being very purposeful and meaningful.

Patient: *Over the past 2 days?*

Interviewer: Yes.

Patient: *(Laughing) Well, yesterday I had a good crap! Mark me down as a 10!*

Interviewer: Is there anything else you would like us to know?

Patient: *I have given all of my problems to the Lord. There is not much else I can say. I was told to go home and die, but I married a Swede and she won't let me.*

The Weight of Nothing

“Tell me the weight of a snowflake,” a coal-mouse asked a wild dove.

“Nothing more than nothing,” was the answer.

“In that case I must tell you a marvelous story,” the coal-mouse said. “I sat on the branch of a fir, close to its trunk, when it began to snow, not heavily, not in a raging blizzard, no, just like in a dream, without any violence. Since I didn't have anything better to do, I counted the snowflakes settling on the twigs and needles of my branch. Their number was exactly 3,741,952. When the next snowflake dropped onto the branch – nothing more than nothing, as you say – the branch broke off.”

Having said that, the coal-mouse flew away.

The dove, since Noah's time an authority on the matter, thought about the story for a while and finally said to herself: “Perhaps there is only one person's voice lacking for peace to come about in the world.”

Author unknown

“Nature never repeats herself, and the possibilities of one human soul will never be found in another.”
Elizabeth C. Stanton

Success Is...

At age 4, success is ... not peeing in your pants.

At age 12, success is ... having friends.

At age 20, success is ... having sex.

At age 35, success is ... making money.

At age 60, success is ... having sex.

At age 70, success is ... having friends.

At age 80, success is ... not peeing in your pants.

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
- The Natural History of Symptoms in Hospice / Palliative Care Patients
- 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:

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