



What's Poppin'?

Population-Based Palliative Care Research Network

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

Volume III, Issue 2

Summer 2002

KERNEL'S CORNER

Jean S. Kutner, MD, MSPH

The past several months have been an exciting time for PoPCRN. As you'll read in the body of this newsletter, we were honored with receipt of a special "Circle of Life" award, we held a very interesting and helpful strategic planning retreat, the number of participating hospice/palliative care organizations continues to increase, and we have interesting and relevant research results to share. None of this would be possible without the interest and dedication of the hospice and palliative care organizations that comprise PoPCRN. It is your hard work and enthusiasm that sustain this effort. I would like to take this opportunity to offer a very heart-felt THANK YOU to all of you who have and continue to be supportive of the vision of PoPCRN. The Circle of Life Award belongs as much to you as it does to the PoPCRN team. Taking the lead from the Stanley Cup tradition (for those of you who are familiar with hockey), it would be wonderful for each of you to physically share in the beauty of this award.

So, what does all this mean? What should you expect? What happens next? As you may be aware, the Circle of Life Award carries with it a significant financial award (\$25,000). Following the example of other successful research networks, I'd like to use these funds to support a PoPCRN "convocation" – an opportunity for representatives from all participating organizations to come together to share ideas regarding hospice and palliative care research and to learn from each other. I had the privilege of attending the Dartmouth COOP (a primary care research network) annual meeting several years ago and found it to be an incredibly stimulating and interesting experience – something that I'd like to replicate for PoPCRN. This idea is in a very nascent stage currently – expect to hear more over the coming months.

(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 446 people from 174 research sites located in 36 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
- 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

WHERE ARE WE NOW?

- Study 2A: Psychosocial/Spiritual Issues Study in Dept. of Corrections sites
- Study 6: Symptom Study-Phase I, 8/00-12/02
- Study 7: National Hospice Outcomes Project, 4/01-3/03
- 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
- Study 13: Pilot Study: Efficacy of Massage Therapy at the End of Life, 9/02-12/02

WHERE ARE WE GOING?

Under Development:

- ◆ Safety of Hospice Home Care Workers
- ◆ Web-based Pre-hospice program Study

KERNEL'S CORNER, CONTINUED FROM PAGE 1:

Based on the discussion at the strategic planning retreat, we have decided that we need to understand more about our constituents, the participating hospice/palliative care organizations, in order to better meet their (your) needs. As such, we are in the process of developing a survey to help us understand the characteristics of the participating organizations, their research capacities, interests and needs. We are also working to increase our web-based data collection capacity to facilitate communication, uniform data collection and rapid feedback. Concurrently, we are in the process of formalizing our structures and process to make them transparent to participating organizations, potential funders, researchers and others. Our goal is to clarify mechanisms for network and advisory committee membership, study design, communication and further development.

The Circle of Life Award confirms that we have something special in PoPCRN and validates what we are trying to accomplish together. I look forward to the opportunity to continue to work together to improve upon and refine what we have accomplished thus far. I am excited about the future and our (and your) ability to really make a difference in the care of persons with advanced serious illnesses.

RECENT POPCRN PRESENTATIONS

- ◆ Hospice and Palliative Care Association of New York Meeting, 4/02

Upcoming Presentations:

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

POPCRN PUBLICATIONS

- ◆ 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.
- ◆ Nowels DE, Kutner JS, Kassner CT. "Estimation of Prevalence of Confusion in Terminally Ill Hospice Patients." In press, *Journal of Palliative Medicine*. 2002.
- ◆ 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

- ◆ ***The Pharmaceutical Cost Study began May 1, 2002 and has been extended through September 15, 2002! From the PoPCRN webpage (<http://www.uchsc.edu/popcrn>), go to the "Research" link.***

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

CONGRATULATIONS!

Dan Johnson, MD, for his poster recognition award at the Society for General Internal Medicine Conference in May. His poster was titled "Integrating Palliative Care Consultations into an Internal Medicine Residency Training Program".

SPECIAL RECOGNITION!

Over the past several months PoPCRN has expressed our appreciation to one person who has contributed to the growth and development of PoPCRN in extraordinary ways. We want to acknowledge who this special person is and how they have supported PoPCRN:

- ◆ **Larry Goldberg, MD**, *Rainbow Hospice Medical Director*, for his ongoing support of PoPCRN research, particularly with the Natural History of Symptoms in Hospice study.

PoPCRN has provided a gift certificate to Mentor Books (www.mentorbooks.com) in appreciation of his efforts.

Thank You!

Report from the Second PoPCRN Strategic Planning Retreat (July 11, 2002)

Jean S. Kutner, MD, MSPH

Now that PoPCRN has grown in size and demonstrated the viability of this model for studying end-of-life care, we felt that it was time to take a critical look at where we are currently, where we want to/should be heading and how best to get there (without the benefit of detailed topographic maps and a GPS). As such, PoPCRN hosted its second strategic planning retreat on July 11, 2002. The first such planning retreat, held in July 2000 focused on initial network development, including agreement on a vision, formulation of a mission statement and creation of a development plan that would best meet these objectives. The goal for the July 2002 retreat was to develop a 5-year strategic plan for PoPCRN, focusing on its mission, goals and vision, infrastructure and organizational processes and, of course, funding. We were honored to benefit from the participation of local and national leaders in hospice and palliative care and network-based research (see list of retreat participants at end of this article).

Major themes which resulted from the often lively discussion were:

- PoPCRN should continue to focus on and refine the goals and processes on which it was developed – conducting clinically relevant studies primarily in the hospice setting – while collaborating with other research networks as needed.
- PoPCRN needs to learn more about the process and content needs of its constituents. That is, understanding better the characteristics of participating sites, what facilitates and what impedes data collection in various settings as well as the capacity of participating sites to participate in various types of studies. Equally important is maintaining familiarity with the areas of investigation that are most relevant and topical to participating sites.
- PoPCRN should collaborate with other national initiatives to enhance the research culture among hospice and palliative care organizations.
- PoPCRN should formalize its structures and process to make them transparent to participating organizations, potential funders, researchers and others. Such a structural framework should clarify mechanisms for network and advisory committee membership, study design, communication and further development, paying careful attention to the culture under which we want to operate.

PoPCRN is grateful to the following participants in the July 2002 planning retreat:

Linda Niebauer, Bill Henderson, Connie Beehler, Lynn Weitzel, Jan Bezuidenhout, Kathy Egan, Wilson Pace, Dan Johnson, Nancy English, Miriam Dickinson, Robin Rawlings, Stephen Connor, Marcia Lattanzi-Licht, Cordt Kassner, Christy Whitney, Marcia Blake, Steve Franey, Al Canner, Cindy Bryant, Denise Hartung, Stacy Fischer, David Nowels, Janet Houser, Donna Roberts, Larry Green, Bill Reiquam, Sean Morrison, John Steiner, Debbie Main, Terri Gould, Jean Kutner

- ◆ Retreat proceedings are available from the PoPCRN staff. We welcome your questions and/or comments.

STUDY SUMMARY – WEB-BASED HOSPICE EDUCATION STUDY

By Stacy Fisher, MD, UCHSC Geriatrics Fellow

While at the 2000 American Geriatrics Society meeting in Chicago, IL, Dr. Jean Kutner and I spent an afternoon visiting Michael Preodor, MD, at Horizon Hospice – a PoPCRN site. During our meeting, we discussed the vital role community hospices play in educating health professions students. However, all agreed that the extent and character of the hospices' investment of staff time and resources was largely unknown. The idea for a web-based questionnaire evolved. The main purpose of the survey was to collect descriptive information describing the nature and span of individual hospices' role in the education of health professions students, interns, residents, and fellows. In addition, it was hypothesized that the hospices rarely received financial compensation from the health professions schools/programs, with whom they have mainly informal arrangements.

With the help of the PoPCRN research team, Dr. Preodor, and Kathy Egan of the NHPCO, Dr. Kutner and I developed a comprehensive questionnaire designed to cover the broad scope of hospice's commitment to education. Dr. Cordt Kassner created a web-based survey and all PoPCRN and NHPCO sites were invited to participate. Between December 2001 through March 2001, the study experienced an excellent response rate of 75 hospices from 25 different states. Seventy-one (95%) sites stated that they participated in education activities for health professions students. While analysis of responses is still ongoing, a wealth of information has been gathered.

As anticipated, hospices provide education to a wide range of health professions students including BSN students (73%), associate nursing students (61%), masters level social work or counseling students (61%), RN students (59%), medical students (58%), and medical residents (57%). Even more significant was the extensive staff time devoted to educating these students (range=11-30 hours/week), while less than 3% received any financial compensation. As expected, less than half of the sites had legal contracts or affiliation agreements with the students' home educational institutions. Fifty-five percent had preceptorship or mentorship training for staff, 51% had a separate education department, and 41% had a dedicated position to coordinate student education. Hospice staff that most frequently participated in education were: patient care nurses (84%), social workers/counselors (75%), bereavement counselors (68%), chaplains/pastoral care (60%), directors of nursing (60%) and medical directors (53%). Perhaps the most interesting findings from this survey were the reasons hospices cited for participating in education which included fulfilling a sense of responsibility, increasing awareness about hospice/palliative care and meeting perceived educational needs. Perceived benefits included: increasing the knowledge and awareness of learners, improving patient care, and training potential future staff. Perceived burdens were time and staff burden.

A special thank you to all the sites and individuals who participated in the planning, orchestration, and completion of this survey. We hope to use these results to further the awareness of the assets and needs of hospices in meeting education requirements through institutional and community support.

Study Summary – Discharge Follow-up Study

Cordt Kassner, PhD

In the spring of 2000, Connie Beehler, MD, then Medical Director at Porter Hospice / Hospice of Peace in Denver, Colorado (now Medical Director at The Hospices of the National Capital Region, Falls Church, VA) was having a discussion with Jean Kutner, MD, MSPH. The discussion focused on what happens to patients after they are discharged alive from hospice. Very little information addressed this topic in the literature, so with the help of Dr. Beehler, PoPCRN designed and implemented a study to learn more about hospice patients who are discharged alive.

PoPCRN sites participating in this study obtained patient consent for this study and completed a 1-page information survey at the time of patient discharge. Site or PoPCRN personnel then conducted monthly prospective, telephone surveys until death or 6-months following hospice discharge.

Eighteen PoPCRN sites enrolled 164 patients into this study between 6/01-5/02. Monthly follow-up data was collected between 7/01-12/02. Demographic characteristics of enrolled patients included: 67% female; diagnosis cancer=29%, heart/lung=22%, neurologic=27%, rapid decline=15%; 46% were discharged home, 39% were discharged to a nursing home. Mean patient age=76 years (range=1-101 years). Mean admission Karnofsky score=37 (range=10-100), mean discharge Karnofsky score=45 (range=20-100). Mean hospice length of stay=128 days (range=1-773 days). Reasons for hospice discharge included: improved or stabilized condition=79%, patient/family decision=12%, to pursue more aggressive treatment=7%, financial reasons=0%, and payment denied by fiscal intermediary=0%.

Follow-up outcomes 6 months after patient discharge from hospice (total n=164) found 56% (n=91) alive, 29% (n=48) deceased, 12% (n=20) lost to follow-up, and 3% (n=5) withdrew consent. For patients who died (n=48), death occurred a mean of 86 days following hospice discharge (range=4-189 days). Of those with follow-up information (n=144), 29% (n=42) were readmitted to hospice (mean=55 days, range=1-175 days). For patients readmitted to hospice (n=42) and who died following readmission (n=32), death occurred a mean of 37 days following hospice readmission (range=2-179). Location of death for patients who died (n=48) included: 33% nursing home or SNF, 25% home, 25% unknown, 15% inpatient hospice, and 2% hospital.

Overall study conclusions include:

- ◆ More non-cancer (vs. cancer) patients are being discharged from hospice
- ◆ Most discharges are due to improvement or stabilization
- ◆ Patients continue to receive hospice care for several weeks to months following stabilization of condition
- ◆ 29% died and 29% were readmitted to hospice within 6 months of discharge
- ◆ Deaths, on average, occurred within 3 months of discharge
- ◆ Hospice readmissions, on average, occurred within 2 months of discharge

Study analysis is currently ongoing. Please contact PoPCRN for additional information regarding this study. We appreciate the 18 sites that participated in this study.

GROWTH HOUSE, INC.

<http://www.growthhouse.org>, <http://iicn.html>

Growth House, Inc., is an international gateway to resources for life-threatening illness and end of life care. Their primary mission is to improve the quality of compassionate care for people who are dying through public education and global professional collaboration.

Their “topic pages” explain major issues, and “what’s new” links you to their reviewed “best of the net” resources around the world.

Growth House, Inc., hosts the Inter-Institutional Collaborating Network On End-of-life Care (IICN) which links major organizations internationally. The IICN can be found on the internet at iicn.html and offers access to the net's most comprehensive collection of reviewed resources for end of life care. Over one hundred health care web sites offer remote access to their search engine, including PoPCRN. International guest editors cover major topics and regions of the world.

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (EAPC)

<http://www.eapcnet.org>

The European Association for Palliative Care (EAPC) was established to promote palliative care in Europe and to act as a focus for all of those who work, or have an interest, in the field of palliative care. Since its foundation in 1988, the EAPC has grown rapidly and today consists of 240 individual members and 27 collective member associations representing about 45,000 people.

The EAPC communicates with members in several ways. They maintain a website with current events,

ACTIVITIES OF THE EAPC

Web Site

Communication is a subject of continuing importance within the EAPC. The EAPC website is crucial in this respect and we encourage all members to visit the site regularly. It is also important that members contribute to the web site and draw attention to events that could be usefully publicised here.

The Official Journal (EJPC)

The EAPC's journal, the EJPC, is a fundamental part of the Association's communication strategy. The journal has the potential to reach a much wider audience and the Board will be making every effort to encourage wider readership and more subscriptions. <http://www.eapcnet.org/publications/ejpcdetails.html>

EAPC News and views

The EAPC Newsletter will not be included in the journal, or distributed as a separate document, but it will be available on the web site every quarter. <http://www.eapcnet.org/publications/news.html>

EAPC Congresses

The EAPC organises every two years its European Congresses. <http://www.eapcnet.org/congresses/congresses.html>
The biennial congresses of the EAPC bring members together and have become one of the highlights of the palliative care calendar. The congresses provide opportunities for networking, for keeping in touch with latest developments, and for renewing energy and enthusiasm for the work. However, only a small proportion of the membership is able to attend each congress and the EAPC has developed other initiatives to involve the membership and to promote the discipline.

Projects and Task forces

In the last years, the EAPC Board has proposed that the activity of the EAPC may be organised through specific task forces, which will undertake a particular project with a clearly defined and time-limited objective. Members may propose topics or projects to be undertaken by a task force which will be considered by the Board. Details and an application form are available on the EAPC web site (<http://www.eapcnet.org/projects/projects.html>).

In the field of ethics, the Board proposes to set up a task force to update and revise the position paper on euthanasia that was published in the first edition of the European Journal of Palliative Care (EJPC).

Centre to support the development of Palliative Care in Eastern Europe

Finally, with the collaboration and the support of the Soros Foundation the EAPC has established a centre to facilitate the development of palliative care in Eastern Europe

to facilitate the development of palliative care in Eastern Europe, the two organisations have established a network with the colleagues of Eastern Europe such as ECEPT « East and Central European Palliative Care Taskforce » .

<http://www.eapceast.org/>

Research Network

The Steering Committee has organised various Expert groups who have published a series of papers (information available on the Web) <http://www.eapcnet.org/researchNetwork/research.html>. It furthermore has created a network of collaborating centres around Europe and has recently completed a major study involving a cross-sectional survey of palliative care in 20 different countries. A total of 141 palliative care services took part in the study. The ResNet organises a conference on Research In palliative care in the years in-between the big European Congresses. The next one will be held in Italy Spring 2004.

Additional information about EPAC, including membership information, please see the contact information below:

EAPC Head Office,
National Cancer Institute
Via Venezian 1
20133 Milano
ITALY
Tel. +39-02-23903390
Fax +39-02-70600462,
Email: eapc@istitutotumori.mi.it
Web site: <http://www.eapcnet.org>

Facts About the End-of-Life Nursing Education Consortium (ELNEC)

For more information, refer to the Web site: www.aacn.nche.edu/elnec

- ◆ A national initiative to provide nurse educators with training in end-of-life care so they can teach this essential information to nursing students and practicing nurses to improve end-of-life care in this country
- ◆ Funded by a major grant from the Robert Wood Johnson Foundation
- ◆ 3 ½-year project which began in February 2000
- ◆ Administered by American Association of Colleges of Nursing and City of Hope National Medical Center, in collaboration with curriculum consultants, faculty, and advisory board members
- ◆ Includes eight 3-day courses designed for different target audiences
 - ◆ Baccalaureate and associate degree nursing faculty (five courses)
 - ◆ Nursing continuing education and staff development educators with limited experience in end-of-life care (two courses)
 - ◆ State Board of Nursing representatives (one course)
- ◆ Supports five additional 2-day courses for nursing continuing education and staff development educators who are experienced in end-of-life care. Courses held in conjunction with Last Acts Regional Conferences
- ◆ Course spaces are limited, and application is a competitive process
- ◆ Projected to prepare almost 1400 nurse educators, designated as ELNEC trainers, who will influence end-of-life education and practice in their communities around the country
- ◆ Participants receive a comprehensive syllabus, two new end-of-life nursing textbooks, and a wealth of resources and strategies to teach this content to others
- ◆ Publishes a newsletter for course participants to provide additional information, share successful education strategies, and provide reinforcement for the network of ELNEC trainers
- ◆ If each ELNEC trainer teaches this content to a minimum of 100 others, and they each care for 50 dying patients, the ELNEC project will touch the lives of 7 million people facing the end-of-life within the next few years
- ◆ The current grant will not reach every nursing school in this country, and does not include graduate or practical nursing education

CLINICAL FEATURE

Nebulized Opioids for Dyspnea: Fact or Fiction?

Daniel Johnson MD, University of Colorado Health Sciences Center, Denver, CO.

Ms. Y is an 82 y/o woman admitted to inpatient hospice with advanced metastatic lung cancer and COPD. Despite treatment with steroids, nebulized albuterol and atrovent, IV morphine, lorazepam and oxygen, she remains short of breath at rest. Ms. Y accepts her poor prognosis, and appears at peace both socially and spiritually. She states "I just want to be more comfortable [in her breathing] for whatever days I have left." She complains of fatigue, increasing somnolence and constipation - especially following recent increases in her morphine. Her pain is well controlled. You want to provide her relief, but are concerned about the increasing side effects of the IV opioids. You wonder, "is there a role for nebulized opioids in treating Ms. Y's dyspnea?"

Multiple studies have examined the use of morphine and other narcotics in the treatment of breathlessness in seriously or terminally ill patients. There is a growing interest in the use of nebulized opioids for dyspnea - especially in cases where systemic side effects of oral/ parenteral opioids make further narcotic dosage escalation less desirable. While the physiologic mechanism(s) by which opioids relieve dyspnea are poorly understood, nebulized opioids may provide an advantage over oral/parenteral routes through direct drug delivery to lung opioid receptors with decreased systemic absorption.¹

While numerous authors have reported case series describing the effective relief of dyspnea using nebulized morphine, hydromorphone and fentanyl, few blinded, well-controlled clinical trials exist. A recent Cochrane collaborative systematically reviewed the use of opioids for the palliation of dyspnea in terminal illness. Based on 18 randomized double-blind, controlled trials (9 of which studied nebulized opioids) the group concluded that 1) there was evidence to support the use of oral or parenteral opioids to palliate breathlessness, although the number of patients involved in the studies were small, and 2) there was no evidence to support the use of nebulized opioids. The group recommended further research with larger numbers of patients, using standard protocols and with quality of life measures.²

Is the use of nebulized opioids for the relief of dyspnea safe? While most studies report few or no significant adverse reactions to nebulized opioids, at least one study describes a case of respiratory depression requiring mechanical ventilation following the administration of nebulized morphine.³ Bronchospasm has been reported with the use of nebulized opioids, particularly at higher doses. Fentanyl may be associated with less bronchospasm.⁴ The first dose should be administered in a supervised setting where medical or nursing intervention is available in case of bronchospasm or other adverse effect. When utilizing morphine, the IV formulation should be used rather than the oral elixir.⁵

There is no consensus on the most appropriate starting dose or schedule, the best steps for dose titration, or the optimal design and length of a therapeutic trial. Some suggested doses by one review include:⁵

Drug	Starting dose	Schedule	Titration	Comments
Morphine Sulfate	20 mg diluted to 5 mls w/ saline	Up to 4 times/hr	Up to 100 mg 4 times/hr	Risk of bronchospasm
Fentanyl Citrate	50 mcg diluted to 5 mls w/ saline	Up to 4 times/hr	Up to 100 mcg 2 times/hr	Less risk of bronchospasm

Summary:

1. While increasing anecdotal evidence supports the use of nebulized opioids for the palliation of breathlessness, the current best evidence does not consistently demonstrate beneficial effects. Larger controlled studies should help to clarify which patients are most likely to benefit from nebulized opioids.
2. Rare adverse outcomes associated with nebulized opioids include bronchospasm and respiratory depression. The first dose should always be administered in a supervised setting.
3. There is no consensus on the most appropriate starting dose or schedule, the best steps for dose titration, or on the optimal design and length of a therapeutic trial. Additional clinical trials are needed to better define optimal regimens.

1. Chrubasik J et al. *Absorption and bioavailability of nebulized morphine*. Br J Anaesth. 1988 Aug;61(2):228-30.
2. Jennings L et al. *Systematic review of the use of opioid drugs in the palliative treatment of dyspnoea*. Palliat Med. 1999 Jul;13(4):354.
3. Lang E, Jedeikin R. *Acute respiratory depression as a complication of nebulized morphine*. Can J Anaesth. 1998 Jan;45(1):60-2.
4. Coyne PJ et al. *Nebulized fentanyl citrate improves patients' perceptions of breathing, respiratory rate, and oxygen saturation in dyspnea*. J Pain Symptom Manage. 2002 Feb;23(2):157-60.
5. Ahmedzai S, Davis C. *Nebulized drugs in palliative care*. Thorax. 1997; 52(Suppl 2):S75-S77.

FEATURED SITE

New Statewide Hospice Database Provides Powerful Tool To New York's Hospices

Kathy A. McMahon, President and CEO, Hospice and Palliative Care Association of NYS

The Hospice and Palliative Care Association of New York State (HPCANYS) offers a powerful new service to its members—a web-based statewide database. Known as the New York State Hospice Information Reporting System (NYS – HIRS), the database was developed as a strategic initiative through the generous support of the Verizon Foundation and Project on Death in America (PDIA).

Bill Finn, COO of the Center for Hospice and Palliative Care, Cheektowaga, NY, chaired the Association's Data Task Force. According to Finn, "This database will provide hospices with real-time in-depth data analysis and benchmarking on hospice care, access, and cost of care. In addition, the database will automatically create state-required reports. It is the single most significant advancement in hospice data analysis since the creation of the Hospice Medicare Benefit."

Over two years in planning and development, the system will provide HPCANYS and its members more comprehensive information regarding hospice services than are available anywhere else in the U.S. It includes all patients, regardless of age, payer, diagnosis, or type of hospice.

Functions

NYS – HIRS, developed by Rapid Application Developers (now CGI), is designed to perform the following major functions:

- Automatic completion of both hard copy and electronic versions of a key regulatory report and summaries for all hospices in the same format as traditionally developed by the New York State Department of Health;
- Providing operational management benchmarks and comparisons. Benchmarks compare each hospice to others grouped by region, type hospice, and urban/rural density. Benchmarks include, among others, several measures of lengths-of-stay, charges, payments and visits per episode and per day, payments as a percentage of charges. Each benchmark report can be re-generated for subsets of a wide variety of parameters such as period, age group, gender, marital status, diagnosis, primary payer, and discharge type;
- Program planning support based on reports that incorporate Vital Statistics mortality data. Reports are generated for each county, zip and diagnosis showing percentages of all who died who were served by hospice; and,
- Support of policy analysis and advocacy. Because of the system's design, the Association will be able to conduct ad hoc studies quickly and easily. For example, the system would enable a study comparing the distribution of individual lengths-of-stay by diagnosis as well as traditional averages.

The Data

In numerous ways, NYS – HIRS will enable hospice leaders to improve their services and encourage participation in research activities. From the user perspective, NYS – HIRS, which is HIPAA compliant, has four major sub-systems:

- Patient data;
- Hospice data;
- System management, including security; and,
- Reports generation and analyses

NYS – HIRS uses four types of data regarding individual patients:

- Demographic data, such as gender, age (calculated based on birth date);
- Level of care data
- Data regarding episodes of care. Such data include admission and discharge dates, referral sources, payers, and diagnoses; and,
- Visit data

(Continued, Page 10)

(FEATURED SITE, CONTINUED FROM PAGE 9:)

User-Friendly

NYS – HIRS is designed for flexibility and ease of use:

- The entire application is web-based. There is only one installation and maintenance is handled centrally. Access to input or upload data and to view the results are all accomplished through a web browser;
- Hospices with only limited technical capacity may enter data over Internet using a web browser. More technically sophisticated organizations may use simple batch uploads;
- Basic On Line Analytical Processing (OLAP) capability providing multi-dimensional and highly flexible ability to analyze patient distributions; and,
- It includes a tiered security system that allows the creation of an unlimited number of groups and assignment of privileges for using the system for each group and assignment of individual users to groups.

John Rodat, of CGI, is enthusiastic about the program's capabilities: "Outside of government, we're not aware of any multi-provider data base for *any* type of health care service organizations, much less for hospice providers, that combines the comprehensiveness, ease of use, and technological foundation, and promise and potential that HIRS does."

The database was designed so that it can be replicated in other states and tailored to meet their specific needs. For more information contact, Kathy McMahon, President and CEO, Hospice and Palliative Care Association of New York State, 21 Aviation Road, Suite 9, Albany, NY 12205; 518/446-1483; e-mail kmcmahon@hpcanys.org.

BOOK REVIEWS

Clinical Dimensions of Anticipatory Mourning: Theory and Practice in Working With the Dying, Their Loved Ones, and Their Caregivers.

Editor: Therese A. Rando. Publisher: Research Press, Champaign, IL, 2000 (ISBN 0-87822-380-0); 601 pages, softcover.

Review by: Robin M. Rawlings, MA, PhD student, PoPCRN Volunteer

Clinical Dimensions of Anticipatory Mourning: Theory and Practice in Working With the Dying, Their Loved Ones, and Their Caregivers, edited by bereavement expert Therese Rando, offers a collection of work from numerous end-of-life experts. The book is divided into three parts for a total of 19 chapters. The sections provide basic knowledge, theory, and a wide variety of perspectives with examples of specific applications.

The first section provides a review of the knowledge base and theory of anticipatory mourning. This section is thorough and while it may not be new material to seasoned practitioners, it provides a good review for those who work "in the trenches" and thus experience anticipatory grief on a daily basis. The second section of the book offers perspectives from the dying individual, challenges for professional and volunteer caregivers, and ideas for promoting healthy anticipatory mourning. For example, one article mentions burnout, personal distress, and vicarious traumatization--validating those aspects that hospice caregivers must continually face. Finally, the last section provides meaningful illustrations for those dealing with specific losses such as prenatal, death of a child, HIV/AIDS, Alzheimer's, ALS and irreversible coma. This section concludes with articles on the relationship between the anticipatory mourning process and aspects such as advance directives and organ donation.

Overall, this book is a good blend of theoretical models, personal stories, vignettes, and case illustration. It covers a multitude of perspectives from the dying patient, to loved ones, to hired professionals and volunteers, while exploring those tasks that must be addressed by everyone involved in end-of-life issues. The beauty of an edited book is that it not only covers a broad range of content but it also gives the reader the freedom to address specific topics of interest and skip those that aren't. This book provides just that and is a valuable resource for all disciplines involved in end-of-life care.

The Cocktail Cart

By Edward Bear

Review by: Cordt Kassner, PhD

This book was written by a hospice volunteer from a PoPCRN site. When the Director and Assistant Director of Nursing at this site told me about the book, I asked to read it and offered to review it for our newsletter.

The title of this book is taken from the primary responsibility of Mr. Bear, who offers hospice patients and visitors a variety of mixed drinks, soft drinks, and snacks from the hospice cocktail cart every afternoon. Mr. Bear describes some of his activities, experiences, and relationships developed during his 7 years of experience as a hospice volunteer. Starting the book on a light note, Mr. Bear explains that the hospice is located at the end of a street, and how the street signs were changed from "Dead End" to "Not a Through Street". Further into the book, he explores the depths of human relationships and the healing power they sometimes possess. Spirituality is woven into the plot, sometimes providing answers but more often provoking deeper questions. I enjoyed reading this book and would recommend it to those who appreciate viewing relationships and hospice from the valuable hospice volunteer's perspective.

This book is currently being used for a part of volunteer training at the author's hospice. It has been enjoyed by hospice staff, patients, and family members, as well as those without a direct hospice connection. Additional information about the book, the author, and purchases may be directed to the author's web site at <http://www.edwardbear.net> or email edbear01@aol.com.

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.

The American Board of Hospice and Palliative Medicine: Physician Certification Exam

Next Exam Date: November 2002. The American Board of Hospice and Palliative Medicine (ABHPM) seeks to increase competencies in skilled end-of-life medical care by promoting voluntary, periodic examination and certification in hospice and palliative medicine. For additional information: contact the American Board of Hospice and Palliative Medicine, phone: 301-439-8001, email: mail@abhpm.org, webpage: <http://www.abhpm.org>. (Information from the Journal of Palliative Medicine, 2001, Volume 4, Number 4.)

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.

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 additional information, contact Sandy Muchka, RN, MS, OCN at 414-805-4607.

INFORMATION ON CURRENT AND UPCOMING POPCRN STUDIES

Study 2A: 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, 5 hospices located in various Department of Corrections systems have agreed to conduct this same survey in their hospices. We have received IRB approval and data collection is ongoing.

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. To date, 96/100 patients have been enrolled into this study from 11 sites. Although this study has been closed to enrollment for most sites, we appreciate the efforts of Hospice of St. John, Exempla Lutheran Hospice, Hospice of Metro Denver, and Rainbow Hospice to continue enrolling patients until our sample size is met.

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 10: Palliative Care Guidelines for Symptom Management Study:

This is a study to describe the current use of protocols or guidelines for the management of patients' physical symptoms. Data collection for this study has concluded, and we appreciate the 69 PoPCRN sites who participated! Results from this study will be available soon.

Study 11: Hospice Nurses Symptom Management Study:

This is a study to identify barriers to physical symptom management from the perspective of hospice nurses. Data collection for this study will continue through Fall 2002. Please contact us if you would like to participate in this study. To date, 676 nurse surveys have been returned from 48 sites. Study results of this study will be available soon.

Study 12: Hospice Pharmacy Cost Study:

This study will attempt to identify current trends in hospice pharmacy costs. This web-based study can be accessed from the PoPCRN web site (<http://www.uchsc.edu/popcrn>) and is open for participation through September 15, 2002. To date, 18 PoPCRN hospice sites have participated in this study.

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 will be collected from 2 PoPCRN sites and used for an NIH grant proposal.

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.

CALENDAR OF EVENTS

August

- 17 *10th World Congress – International Association for the Study of Pain*, San Diego, CA. For additional information: contact Ellen Wilson at email iasp@locke.hs.washington.edu or phone 206-547-1703. See their webpage at <http://www.halcyon.com/iasp/02cong.html>.

September

- 7-9 *National Hospice and Palliative Care Organization (NHPCO) Hospice Administrator's Certificate Program (HACP)*, Washington, DC. For additional information: see their webpage at <http://www.nhpc.org>.
- 10-12 *National Hospice and Palliative Care Organization (NHPCO) 17th Management and Leadership Conference*, Washington, DC. For additional information: see their webpage at <http://www.nhpc.org>.
- 12-14 *Spirituality, Culture, and End-of-Life Conference*, Kansas City, MO. This conference is sponsored by the Association of American Medical Colleges (AAMC), George Washington Institute for Spirituality and Health (GWish), George Washington University School of Medicine, and Harvard Medical School, Department of Continuing Education. For additional information, contact Debra Hollins at phone 202-828-0671 or email dhollins@aamc.org.
- 17-18 *End-of-Life Nursing Education Consortium (ELNEC) Training for Nurse Educators*, St. Louis, MO or Chicago, IL. For additional information: contact Susan Taylor at email susantaylor@thehospice.org or phone 727-588-2864.
- 26 *American Academy of Pain Management 13th Annual Clinical Meeting / Renewing Our Commitment to Multi-disciplinary Pain Management*, Sonoma, CA. For additional information, contact the American Academy of Pain Management at phone 209-533-9744, web: <http://www.aapainmanage.org>.

October

- 5-10 *14th International Congress on Care of the Terminally Ill*, McGill University, Montreal, Canada. For additional information: phone 514-286-0855 or email info@eventsintl.com.
- 10-12 *Colorado Hospice Organization Annual Fall Conference & Exposition*, Marriott Mountain Resort, Vail, CO.
For additional information: contact the Colorado Hospice Organization at CoHospOrg@aol.com.
- 10-12 *The Center to Advance Palliative Care (CAPC) Palliative Care Fall Forum*, New Orleans, LA. For additional information: see their webpage at <http://www.capcmssm.org>.
- 18-19 *Advanced Palliative Medicine: Current Concepts and Certification Board Review Course*, San Francisco, CA. For additional information: contact the American Academy of Hospice and Palliative Medicine at 847-375-4712.
- 24 *American Society for Bioethics and Humanities, 5th Annual Meeting*, Baltimore, MD. For additional information, contact ASBH, web: <http://www.asbh.org>.

January 2003

- 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>.

April 2003

- 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 website at <http://kenes.com/eapc>.
- 10-12 *National Hospice and Palliative Care Organization's 4th Joint Clinical Conference and Exposition on Hospice and Palliative Care*, Denver, CO. For additional information, contact NHPCO, web: <http://www.nhpc.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.

JOINING 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...)

I believe that imagination is stronger than knowledge...
That myth is more potent than history.
I believe that dreams are more powerful than facts...
That hope always triumphs over experience...
That laughter is the only cure for grief.
And I believe that love is stronger than death.

Poster at Exempla Lutheran Hospice, From
An Evening with Robert Fulghum
October 5, 1993

"It is not strange that early love of the heart should come back, as it so often does when the dim eye is brightening with its last light. It is not strange that the freshest fountains the heart has ever known in its wastes should bubble up anew when the lifeblood is growing stagnant. It is not strange that a bright memory should come to a dying old man, as the sunshine breaks across the hills at the close of a stormy day; nor that in the light of that ray, the very clouds that made the day dark should grow gloriously beautiful."

Hawthorne

PoPCRN Is...

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What's Poppin?
Newsletter of the Population-based Palliative Care Research Network
Volume III, Issue 2, Summer 2002

Table of Contents

<i>Feature</i>	<i>Page</i>
<i>Kernal's Corner, Jean Kutner, MD, MSPH</i>	1
<i>Mission Statement, Overview of Studies</i>	1
<i>Presentations, Publications, & Web-based Research</i>	2
<i>Special Recognition</i>	3
<i>Report from the Strategic Planning Retreat</i>	3
<i>Summary – Web-based Hospice Education Study</i>	4
<i>Summary – Discharge Follow-up Study</i>	5
<i>Growth House, Inc.</i>	5
<i>European Association for Palliative Care (EAPC)</i>	6-7
<i>End-of-Life Nursing Education Consortium (ELNEC)</i>	7
<i>Clinical Feature: Nebulized Opioids for Dyspnea: Fact or Fiction?</i>	8
<i>Daniel Johnson, MD</i>	
<i>Featured Site: Hospice and Palliative Care Association of New York State,</i>	9-10
<i>Kathy McMahan</i>	
<i>Book Reviews</i>	10-11
<i>Announcements</i>	11
<i>Information on Current and Upcoming Studies</i>	12
<i>Calendar of Events</i>	13
<i>Join PoPCRN!</i>	14
<i>Carmel Corn</i>	14
<i>PoPCRN Is...</i>	15

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