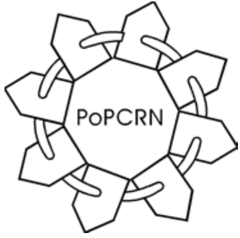

What's Poppin'?

Population-Based Palliative Care Research Network

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

Volume II, Issue 3 *Fall 2001*

KERNEL'S CORNER

Jean S. Kutner, MD, MSPH
Written September 22, 2001

A week-long September backpacking trip has become somewhat of an annual tradition in my household. Each September, we look forward to a the opportunity to explore a beautiful area far away from email, cell phones, pagers and the rush of daily life. It is a chance for the two of us to really take the time to communicate and enjoy each others' company, while engaged in an activity we love. I also cherish the time on the trail as an opportunity to reflect on my current activities and goals, and, ideally, reenter "civilization" and work life with renewed energy, commitment and direction. This year was no different. I spent September 9 – 14 in the backcountry of Rocky Mountain National Park, enjoying an early snow, bright yellow aspens, elk, deer and other high alpine scenery. While I hiked I reflected upon the past three years of PoPCRN – what we and you have accomplished to date, our current projects, and where we are headed over the next few years and beyond. I thought about all the wonderful, dedicated, enthusiastic and supportive people I've met and spoken with since we first started conducting hospice-based research. I concluded that we and you are, indeed, doing meaningful and necessary work. Through our efforts we are addressing relevant questions and providing the data that will help us provide better care to persons with progressive illnesses and their families. On September 14 we emerged from the wilderness into the small town of Grand Lake, Colorado, after 6 days of wonderful hiking and relaxing. I felt renewed both mentally and physically and recommitted to the important work we and you are doing through PoPCRN.

Then, the week's events caught up with us…

(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 293 people from 106 research sites and 30 organizations. The research sites are located in 20 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 8:	Web-based Hospice Fall Rate Study 10/01

WHERE ARE WE NOW?

Study 5:	Discharge Follow-up Study 7/00-12/01
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, 10/01-4/02
Study 7:	National Hospice Outcomes Project, 4/01-3/03

Under Development:

- Safety of Hospice Home Care Workers
- Hospice Education Survey
- Pre-hospice program web-based study

KERNEL'S CORNER, CONTINUED FROM PAGE 1:

(Then, the week's events caught up with us…) We had emerged from our trip into a world changed in ways we still cannot comprehend. Suddenly, our daily work and research seemed to lose their significance. In light of the magnitude of the national crisis, do we really care what happens to patients who are discharged alive from hospice care? Do we really care how symptom distress and quality of life change over time for hospice patients? Over the past week since I've returned from the woods to "civilization", I've heard over and over stories about individual acts of heroism and compassion, how people are interested in volunteering and in caring for their fellow human being. I've also noticed a real yearning for both spiritual and human connectedness – people seeking out friends and family and spiritual foundations that may have become somewhat lost in the rush of day-to-day life. I've spoken to a number of hospice and palliative care people about their role in and reactions to the disaster. We, as a community, have been called upon to support those around us in their (and our) shock, grief and fear. We may not be able to fix the world and return it to how it was when I went into the woods on September 9th. However, we can continue to do good for the world and our own communities and for individuals by renewing and continuing our commitment to doing good for our fellow humans. What better way to do this than to strive to provide the highest quality care possible to persons in one of their greatest times of need – as they approach the end of life? We are doing this through both the clinical care we are currently providing and through participating in research that aims to advance knowledge and improve practice.

While I may not be as relaxed as I was one week ago before I suddenly became aware of current events, I am more convinced than ever that you and we are doing important work through PoPCRN. By your participation in PoPCRN, we can and are making a difference. Thank you. I'm already looking forward to next September's backpacking trip.

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

Upcoming Presentations:

- "Cognitive Impairment in the Terminally Ill" at the *Coleman Institute Workshop*, Aspen, CO, 10/01
- "Discharging Patients from Hospice: One suggestion for process and a look at data for post-discharge clinical course" at the *Colorado Hospice Organization Meeting*, Denver, CO, 10/01
- "Practice-Based Research Networks: Challenges and Opportunities" at the *16th Annual Primary Care Research Methods & Statistics Conference*, San Antonio, TX, 11/01
- "Life after Hospice: Discharge process for and outcomes of hospice patients who 'stabilize'" at the *14th Annual Assembly of the American Academy of Hospice and Palliative Medicine*, Palm Springs, CA, 2/02.

POPCRN PUBLICATIONS:

- 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.
- Nowels DE, Kutner JS, Kassner CT. "Estimation of Prevalence of Confusion in Terminally Ill Hospice Patients." Under review, *Journal of Palliative Medicine*. August 2001.
- Kutner JS, Blake M, Meyer S. "Predictors of Live Hospice Discharge: Data from the National Home and Hospice Care Survey (NHHCS)." Under review, *Am J Hospice and Palliative Care*. September 2001.

Web-based Research!
Results of Hospice Fall Rate Study

The first PoPCRN "fast feedback" web-based survey has been completed! We sent an email to everyone on our mailing list notifying you of this study. In the future, this kind of study notification will only occur via our “PoPCRN Research Email Listserv”, which you can sign up for on our webpage (http://www.uchsc.edu/popcrn).

The goal of these "fast feedback" surveys is to provide quick answers to focused questions that are generated by participating sites, allowing individual sites to compare their experience to that of a number of other organizations. The web-based format allows for rapid sharing of information among many hospice/palliative care organizations. Based on suggested study topics that we received, the focus of the first "fast feedback" survey was fall rates. We asked each site to share their most recently available 12 months of data for number of falls and number of patient days. PoPCRN then summarized these data and calculated fall rates (number of falls / 1,000 patient days), distributing the aggregate findings via the web site, email listservs, and newsletter.

This survey was open for participation between **Monday October 1, 2001 and Friday October 12, 2001**. (Well, OK, a few sites contributed their data the following week…)

Hospice Fall Rates Study Results 10 Sites From 6 States Reported Data October 24, 2001			
Location	**Number of Falls in 12 Months**	**Number of Patient Days for Same 12 Months**	**Number of Falls Per 1,000 Patient Days**
Hospice	576	72,824	**7.9**
Nursing Home / Long Term Care	210	161,650	**1.3**
Assisted Living	0	366	**0.0**
Home	607	451,233	**1.3**
Combined Locations (If data not broken down by individual locations above)	260	225,993	**1.2**
Totals	**1,653**	**911,700**	**1.8**

Thank You to All Sites Participating in this Study!

We are currently developing 2 more web-based studies:

- **Hospice Education Survey**
- **Pre-hospice program web-based study**

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

SPECIAL RECOGNITION!

Over the past several months PoPCRN has expressed our appreciation to four people who have contributed to the growth and development of PoPCRN in extraordinary ways. We want to acknowledge who these special people are and how they have supported PoPCRN:

- **Al Canner**, Colorado Hospice Organization – for promoting PoPCRN at hospices throughout Colorado.
- **Shareefah Sabur**, Hospice of the Western Reserve, Cleveland, Ohio – for promoting PoPCRN at hospices throughout Ohio via Jeff Lycan and the Ohio Hospice and Palliative Care Organization.
- **Jenna Dandar**, Hospice of Northwest Ohio – for enrolling and following over 40 patients in the Hospice Discharge Follow-up Study.
- **Martha Barton**, Pikes Peak Hospice and Palliative Care – for her support of PoPCRN’s research efforts via her site’s participation in our studies and for PoPCRN to present to the National Hospice Work Group.

PoPCRN has provided gift certificates to Mentor Books (www.mentorbooks.com) in appreciation of their efforts.

Thank You!

Participating in the Symptoms at the End of Life: Natural History Study
Julie Noetzelman, Executive Director
West End Family Link Center, Nucla, Colorado

The West End Family Link Center is a nonprofit family resource center that provides a wide array of services / programs to those living in the *west end* of Montrose and San Miguel Counties, located in Southwest Colorado. This is an isolated rural area surrounded in all directions by mountains and canyons. It takes about 2 hours (one way) to reach a hospital, in good weather. The geography of this area plays a large part in the availability and delivery of services.

The staff of West End Family Link Center are para-professional family support workers who go out into the homes and schools to provide services. The Family Link Center is administering a three-year palliative care project from a grant by The Colorado Trust. The palliative care project explains why we are interested in participating with PoPCRN in the Symptoms at the End of Life: Natural History Study.

The difference between our site and others is that we are neither a hospice nor a hospital. We provide advocacy and a support system to patients and their families in their own homes. The family support workers can continue visiting patients even if they are transported away from their homes to the hospital or nursing home, thus providing continuity of care across several health care settings.

I would like to share two interesting situations that have occurred since we began participating in this PoPCRN study. First, one patient's spouse insisted on completing the study forms even though her husband had died. She believed it was important to contribute to research trying to improve end-of-life care. Second, we have had several caregivers agree to complete the study forms at the patient's admission to our program, and then later become resistant to participating in the study. We believed their resistance stemmed from the study forms making their loved one's disease too real and final for them. Even if they resist participating in the study, the study has helped identify important areas for our staff to work with these caregivers. For the most part, our patients have agreed to participate in this PoPCRN study and have enjoyed telling their stories.

National Home and Hospice Care Survey Data Provides Insights into Predictors of Hospice Discharge
Jean S. Kutner, MD, MSPH

In the context of the current regulatory environment, patients may be discharged from hospice care if their condition stabilizes or improves over time and the certifying physician is unable to conscientiously recertify the 6-month prognosis. Little is known about the characteristics or outcomes of patients who are determined to no longer be eligible for hospice care. To help address these issues, PoPCRN has conducted analyses of the combined 1996 and 1998 National Home and Hospice Care data to characterize rates and predictors of live hospice discharge.

Of the 807,733 patients in the combined 1996 and 1998 NHHCS Discharge Patient file who met study inclusion criteria, 761,858 (94%) were deceased and 45,875 (6%) were discharged alive. Those who were discharged alive were more likely to be female, have received hospice care for more than 60 days and to have a non-cancer diagnosis, particularly advanced cardiopulmonary or neurologic disease. Mean age and total number of aids used did not significantly differ between patients who were discharged alive and those who were deceased. Length of service > 60 days, cardiopulmonary diagnosis, neurologic diagnosis, female gender, worse functional status, and living in an institutional setting were independently associated with live hospice discharge.

Given the demonstrated differences between these patients and those who died while receiving hospice care, these data provide further impetus for careful study of the appropriateness of current hospice eligibility criteria, the determinants of hospice discharge and, most importantly, the outcomes of patients who are discharged alive from hospice and the impact of hospice discharge on patients and their families. PoPCRN's current discharge study, in which patients are being followed monthly for 6 months after hospice discharge, should contribute to our understanding of the outcomes of these patients. We expect to complete 6 month data collection for all study participants by the end of December, and to have preliminary results available in time for the Spring edition of "What's Poppin?".

Learning Opportunities in Palliative Care During Medical School

Sue Meyer
3rd Year Medical Student and PoPCRN Research Team Member
University of Colorado Health Sciences Center

The Curriculum

Traditionally, the first two years of medical school have concentrated on teaching the basic sciences and are mainly classroom-based and have limited patient contact. Across the United States, revisions have been made in the curriculum to encourage more patient interactions earlier in medical education. At the University of Colorado School of Medicine, such changes include spending one afternoon a week with a physician preceptor during part of the first two years. In addition to actually seeing patients, some electives are offered that address patient care issues.

One elective in palliative care is offered, "Issues in Terminal Illness and Palliative Care", for freshmen or sophomore students. This elective consists of four two-hour sessions and one Saturday trip to the Hospice of St. John. The course is open to medical and nursing students, and utilizes a seminar format to introduce the care of the dying patient, and hospice care to healthcare students.

There are also two required courses that discuss issues surrounding patient care. During the spring of freshmen year, "Ethics in the Health Professions" discusses ethical decision-making and the illness experience of the patient. Human Behavior is taught throughout the entire sophomore year. Topics in addition to psychiatric issues are addressed in this course, such as grieving and how people cope with illness.

My Experience

There are many opportunities made available to medical students, depending on individual interest. During the summer between freshmen and sophomore year, I decided from among the many options available to us in the last free summer of medical school to participate in a summer research internship program that was offered to freshmen medical students at the University of Colorado. I had stated on my application that I was interested in Geriatric medicine and was very fortunate to be assigned to Dr. Kutner as my mentor. Not only did I learn about the more technical aspect of academic research from Dr. Kutner, but was able to participate in various aspects of the discharge study with Dr. Kutner and Cordt Kassner that is ongoing at this time. I also interviewed some patients during the Psychosocial/Spiritual study and learned many pointers from Cordt that have helped me to become better at these skills.

I had chosen to continue to make some of the phone calls every month for the discharge study during my sophomore year. Those phone calls to follow-up on patients that had been discharged from hospice really were a welcome break from all of the studying. In that instant, when I could talk to someone about the health issues of their loved one, I was reminded of why I was working so hard and was instantly renewed. I did not realize how much talking to those family members meant to me until one month when Cordt told me that he had no calls for me to make. I think I emailed him three times asking if he was sure that he didn't have just a few!

I think one of the most rewarding experiences I have had so far in my training has been interviewing a hospice patient for the Human Behavior course. A class requirement was to interview a patient from our preceptor's office, but since my preceptor's office was in Elizabeth, which was a little far to ask a patient to drive, I decided to be a little creative and interview a hospice patient and tape record the interview for my class. While in the lobby of the hospice waiting to talk to the social worker to gain permission for an interview, an elderly woman and her husband began telling their story to me. I couldn't believe how lucky I was to not have to search for an interviewee. I told them of my assignment, and they gave consent to tape the interview and play the tape for the class. The woman told me of her diagnosis, her trouble accepting her terminal illness because she had lived through so much, including a cardiac arrest, and she shared her happiness with her life but also her sadness and anger with dying. She was so candid, one moment tearful, the next happy and joking, and then angry, all in 30 minutes with her husband adding bits and pieces. We learned so much in those 30 minutes, including how she needed her husband to tell her he was sad about her dying, which taught us that we may need to tell our patients that what they feel is okay. What was also so amazing was how happy it made her, to give something back by giving that education to us.

While I have learned a lot from my hours in class and from my hours and hours of reading, I have learned much from minutes spent with patients. I hope I always remember to spend those minutes.

Featured Site

Hospices of the National Capital Region, Fairfax, VA

Bradley Beukema, MS, NCC, PhD Candidate Pastoral Counseling

The Hospices of the National Capital Region constitute the largest family of hospices in the Washington Metropolitan Area and serve Maryland, Virginia, and Washington, DC. Since 1977, we have sustained our commitment to the community to provide expert comfort and care to individuals and families facing loss and the end of life. Our hospices have served more than 30,000 patients, and we continue to care for more than 700 patients, their families and loved ones each day. We are non-profit organizations and provide care to anyone in need regardless of the nature of their life-limiting illness or their ability to pay for our services.

Along with the conventional interdisciplinary hospice care team including physician, nurse, social worker, chaplain, certified nursing assistants, and specially trained volunteers, we also offer physical, occupational, speech, and other therapies as needed. Our art therapy program helps children and teens cope with terminal illness and loss. Approximately ninety percent of the hospice care we provide is in patients' homes, but we also deliver care in nursing homes, assisted living facilities, retirement centers and hospitals.

Our Halquist Memorial Inpatient Hospice Center in Arlington, Va., provides around-the-clock symptom management and respite care when needed by patients and families. Established in 1982 and housed in a remodeled elementary school building, The Hospice Center provides the highest standards of palliative care in an unusually warm and homelike setting.

The Hospices' extensive bereavement program offers counseling, support groups, and workshops for individuals and families coping with loss. During the year, we also offer special weekend camps for children, adolescents, and adults who have experienced the loss a loved one.

The Hospices have also developed a community-oriented grief and loss program based at The Point of Hope Grief Counseling Center. Services include individual and group counseling, bereavement training, and support of local schools, area businesses, and corporations. Grief and loss services now include individual and group counseling in Spanish, as well as English.

Since the terrorist incidents of 11 September, the staff of the Grief and Loss Center have responded with support for individuals and organizations that have directly experienced a loss or trauma from these incidents, support for individuals in the community who have felt affected, and training for counselors and human resources staff who also wish to offer support for trauma from these critical incidents.

Recognizing the responsibilities that accrue with our regional growth amidst richly diverse populations, The Hospices have begun a program to take an active role in advancing evidence-based palliative care, both in developing original research and in joining with other regional and national projects. This emerging effort intends to encourage a culture of curiosity and dedication to expanding knowledge both within the organization and in the fields of related professions serving palliative care.

Inquiries may be directed to:
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AFRICA and AIDS
<u>On the Edge of Despair . . . Hope Prevails</u>

Christy Whitney, President of Hospice and Palliative Care of Western Colorado in Grand Junction, reflects on recent journey across Sub Saharan Africa to Hospices struggling to cope with the impact of the AIDS pandemic.

> ***"There is no medicine like hope, no incentive so great, and no tonic so powerful as expectation of something better tomorrow."***
> -- Orison Marden quoted in "Abounding Grace: An Anthology of Wisdom" by M. Scott Peck

I thought I was mentally prepared . . . I expected to see overwhelming poverty and many young dying patients. But there was nothing in my previous life experiences that could have really prepared me for what I encountered.

> **"Prior to departure,** each delegate prepared for the trip to the best of his or her ability. Photos, news stories and other research provided a factual context for the mission But, in the end, the preparation failed to adequately personalize the epidemic. While participants knew the situation would be grim, many feared finding absolute hopelessness...What no one **expected to find was hope."**
>
> *Keith Montgomery*
> *VITAS - Miami*

We were quite enthusiastic, my colleague Abigail and me, when we climbed into the Toyota 4 x 4 with "Mabuyi", South Coast Hospice's clinical director, and two hospice trained "caregivers". We headed first to the area's village hospital where we picked up "Eric", a young patient fighting TB and AIDS, who was headed back to his village. (really, I only gulped once when I realized I was riding in the bush of Africa with a patient with active TB) We turned off the main road onto the red packed clay trails of the village. We jostled along past huts constructed of mud bricks dug from the soil with roofs of thatched grass. We dropped Eric off at the village "store" where his TB medication would be monitored by the shop owner, and continued down the bumpy road to meet our hospice patients of the day.

As I looked out the window, just taking it all in, I saw an elderly woman in a tattered dress and frilly apron running barefoot down the road toward us. I was soon introduced to her as the mother of our patient "Victoria". She was coming to greet us from the neighbor's where she had been to beg porridge for their one meal that day. She waved us over to the clay building down the slope of the road. As we entered the yard we saw chickens and several new puppies wandering about the yard. We walked through the opening of the house—there was no door. A partially built house was being constructed by the neighboring women about 30 feet away that we learned was being constructed to shelter friends and relatives coming for funerals.

There we met Victoria, the patient with the pleading eyes that would stay etched on my soul for a very long time. The sun's rays streamed through the tiny dirty window onto her face. She lay curled up on the floor of mud cushioned only by several thin wool blankets. Her mouth was filled with "thrush" to the point she could no longer swallow. She grimaced as the caregiver's tried to position her a little more comfortably. The only furniture in the room was a handmade wooden bench, that was dusted off with a cloth for us -- the guests – who must have seemed more like aliens in our travel garb from LL Bean and a Main Street Boutique.

We were not part of the conversation, as it was held mostly in Zulu. But, we didn't miss the communication: the fear and despair of a 70 year old woman facing the loss of her second remaining child; the resolution of her voice when she explained her daughter must not be taken to the hospital for pain control because she would have no way to bring her body home for burial when she died; the pain that emoted from Victoria whose young body had wasted away to less than fifty pounds who would be leaving behind two little children in a matter of days.

We asked for water to bathe the patient, and were told they had very little. The mother brought in a large jug she had carried from about a mile away and poured a small amount in a dirty wash basin. Mabuyi gently cleansed the patient. She drew up an injection for pain and delivered it, telling me they had no access to morphine to leave for the patient. There would be no way to provide pain medicine without a prescription from a doctor, and even then there

was not much access. The hospice workers are only able to see patients once a week, they typically had over 10 a day to see, so they would not be able to visit again until likely after Victoria died.

We went on to see others… mother's whose children were HIV positive… a mother who had sold her valuable livestock to buy bicycles so that her children could ride the three miles to school over the hilly roads of the village. We saw the children with bloated tummies in need of worm medicine. We saw TB wards filled with patients who were hospitalized for their first few days of treatment. We saw people with nothing . . . little food, little water … in a village of what seemed like mostly women-- overcome with poverty, abandonment, resignation, confusion and pain.

This was my introduction to Africa and AIDS, the deadly virus that has killed over 22 million people in the last twenty years. How do I adequately put my experience into words that will be understood? Africa… a continent filled with contrasts and contradictions. Africa … a place with many faces where hope and despair stand together, side by side.

I met the faces of despair:

Stoic perseverance best describes the plight of millions of women in Africa. Women, often the victims of their husbands promiscuity, women who walk miles for water, build houses from bricks they have dug from red clay, women still subjected to female circumcision, women feeding porridge to their dying children and caring for the millions of orphans left behind by this dread disease.

Women who don't have the luxury of owning their own bodies and lives. Masai women whose round grass huts surround the husband they share. Prostitutes who only know one way to put food in their mouths. Women who never even had a prayer of a chance of schooling past elementary grades who still do not understand why they won't be cured of AIDS. Little girls who are raped by HIV positive men who actually believe they will be cured by sleeping with a virgin.
Women abandoned to die alone and penniless by the husband who infected them.

Men who still bear the scars of Apartheid violence and remember all too ell being ripped from home and sentenced to a life in shanty town. Men, whose eyes show resignation, confusion and chaos. Men who are just starting "to get" that traditions must change in order to save the very existence of their villages. Young men, many now orphaned, not knowing what lies ahead in the next hour or days—more or less their life. Street boys who find solace in huffing drugs, hustling tourists or putting money in their pocket with petty theft. Men in government who breed corruption and crime as they attempt to assume some control over their lives and others.

Death by AIDS is devastating. Equally sad is the fear that pervades the lives of so many millions of people every day from corruption, crime and abuse. The manufacturing of Iron Gates and Caskets have both evolved to be fine art forms in African cities.

Personal protection is paramount for many. We visited the beautiful home of the British, female physician who is the Medical Director of Hospice Uganda overlooking Lake Victoria. 12 foot walls held the iron gate. Three large guard dogs greeted us, and we were shown the tree house in the back yard where the night watchman slept at night.

Millions of city street orphans with no hope of affording the money to attend public school past grade 5 or 6 create a desperate, scary environment.

Did I feel afraid? You bet. When I did, I said a prayer of thanksgiving… that I was blessed through no merit of my own to have been born in the United States…. adopted by loving parents who provided shelter from most any storm….. a far cry from the storms of violence my hospice colleagues in Africa awaken to each morning.

I also met the faces of hope :

I saw the face of hope—albeit sometimes through a mirror dimly. Perhaps my friend Greg described this kind of hope best when he said he believed in the capacity of human beings to turn their greatest weaknesses into their

greatest strengths. Hope, yes glimmers of hope… testament to the capacity of just one person to make a difference. I witnessed hope being extended one human being to one human being. I found myself marveling at the small corners of the world brightened by:

Sister Paulina, nurse and Hospice Director, with twinkling eyes and a broad smile that beamed with pride as she greeted each of us with a rose and led us to the tiny beds at Selian Lutheran Hospital in Tanzania…. she gently touched the shoulder of a stoic, vacant-eyed Masai mother who sat on a bed with a plastic mattress across from the identical bed that held her three year old son with his head covered with a stained blanket—his small, still hand all that was visible since his death several hours before.

Sister Denise, nurse and British Sister of Mercy at Mildmay HIV Center in Uganda, who could truly pass for Julie Andrews as "Maria" in Sound of Music anyday—whose eyes connected with us with such love and ease we thought we'd known her forever. Her laughter was infectious when Greg – a hospice director from Birmingham, Alabama—donned a grass skirt to join the children in the HIV Day Care program in a song and dance routine.

Justin, a young Masai man in Tanzania our group grew to love in a few short days as he capably guided us through the African jungle on Safari to witness unharnessed nature at its best. Justin, whose smile often overtook his face when teaching us Swahili and Masai words, quizzed us on identification of acacia and ebony trees… who introduced us to his proud, beautiful mother as we drove through the bustling streets of his village … who simultaneously dreams of coming to America and is proud of his return to his Masai village following his graduation from college with his degrees in botany and biology. Justin, who ended his long day with us by visiting his neighbors who are dying of AIDS and wonders… where will it end?

Mabuyi, the nurse practitioner at South Coast Hospice, whose community health nursing skills were exceptional. Zulu, she lives close to the village where she grew up. She, her husband and children feel blessed to live safely and securely despite long days spent teaching, supervising, inspiring and lovingly caring for the one of four rural villagers now dying of AIDS.

Kath, the CEO of South Coast Hospice—a white South African woman who has spent the last 20 years building a Hospice program—never dreaming she would be responsible for transforming a program caring for a few cancer patients in the town of Port Shepstone, to one that cares for hundreds impacted by the epidemic in the surrounding thousands of miles. Kath… who unassumingly inspires volunteers, staff, patients with her clear acceptance, patience and leadership.

David, the Peace Corps worker in Old Town Mombassa, Kenya…. David who shrugs off any self sacrifice … who teaches and guides the "twenty-something" kids living in huts and riding public buses for hours to the surrounding remote villages. . . who fosters the personal growth of a young peace corps worker. . . or simply puts a broader smile for the day on shopkeeper Kassim's face when he oohs and awes over his "goat bone soup".

Heroes, really… each of them… *way* to busy to question if whether what they do each day will change the world. It is enough for them that they might change the life – or even death – of just one.

The Contradictions of Racism and Tolerance

To describe Africa and avoid the subject of diversity and racism would be a lie. But startlingly, I witnessed more celebration of diversity than I expected. Oh sure, there are some places one cannot miss it. As the sole white person waiting in the Dar Es Salaam Airport on my way to Kenya one evening, I wasn't exactly comfortable. And, I was aware that I could not have safely left our hotel in Dar as a white woman and been safe. I heard resentment of Indian merchants from Black Africans, and I felt embarrassed to be white as I listened to the atrocities of apartheid in Capetown's District Six.

At the same time, I laughed as I found myself oblivious to skin color while watching an amateur production of Sound of Music in Kampala, Uganda. Blacks played German soldiers and the seven children represented three races! I noted with significance that Indians, Blacks and Whites seemed to be equally represented in leadership, service and patients at the South Coast Hospice Annual General Meeting.

Our hospice group was diverse itself—in age (from 20 to 70), in race (African American, Asian and White), and in culture (rural to inner city New York & Miami). We emerged from this trip a family… connected in miraculous ways to each other.

Lessons from the Journey

I learned a lot about the difference between what we Americans describe as "needs" and what real "need" is.

I couldn't help but be constantly aware of the hospice workers who found joy in caring and serving with so few resources, so little help and such enormous need. As I looked upon the patients hospitalized in their dirty street clothes, lying on thin plastic mattresses without sheets, I thought of the times I whined when as a nurse I didn't have enough help to deliver a complete bed bath with a backrub to every patient within my charge.

I thought about our hospice's dedication to conquering terminal pain, and our standard of no patient having pain greater than a 4 on a 10 point scale, as I looked into the eyes of Victoria who had only one injection to hold her for a few hours during the final days of her dying.

I felt a hollowness in the pit of my stomach as I caught myself annoyed at airplane food just days after leaving the rest of my lunch with a family that had not eaten that day, and had no idea how they would eat the next.

I wondered just how long it would take for me to redefine my everyday "needs" to the "wants" they really are.

I learned there were Hospices with very few monetary resources who were extraordinarily resourceful. I visited hospices with unbelievable volunteer programs, far advanced palliative education programs for physicians, supporting businesses like tea kiosks and thrift shops, integrated programs with public health agencies.

I learned what a "small world" really is. I couldn't really miss it. How could I stand in the midst of this worldwide crisis, and not be convinced that "idly standing by" is simply not an option?

I could not sit in a case conference at Hospice Uganda and confer with physicians-- who will for the first time in their professional career have access to oral morphine to treat terminal pain next October -- and not be reminded it was just 20 years ago I was hanging the very first IV morphine infusion calculated from a journal article at a hospital in Durango, Colorado (having convinced the attending physician the patient would not become addicted!)

I could not witness the extraordinary dedication and courage of people like Sister Denise, Mabuyi, and Sister Pauline and not feel compelled to say, "Here… Let *me help."*

I left some incredible company in the airport at Dar Es Salaam as we parted. Caring colleagues from Miami, New York City, Illinois and Upstate New York. We shared life experiences that few ever will. We held the hands of dying children and touched the shoulders of mourning grandmothers. We witnessed courage and hope in the face of despair. We laughed till we cried and cried till we laughed.

And we learned what we had come to learn: "We are one". We may be different colors, with different traditions, different histories—but still, we are one. We are one global village who faces the most devastating disease known to mankind since the dawn of civilization. It is in Africa that we learned . . . "there is here".

"Ashay" (Masai for "thank you") to the many of you who made this trip possible. To my friends who cheered me on, to the Hospice Board of Directors who had the courage to send me, to the Hospice staff who so capably managed my office, Ashay. Ashay to those of you who contributed acetaminophen and vitamins left in South Africa, Uganda and Zimbabwe. Ashay to those of you who gave dollars that bought food for starving families in South Africa and Tanzania. And Ashay to those of you who have taken the time to read these words and reflect on them, who I know will join me in deciding not to stand idly by. Ashay for raising hope from despair, and bringing us all closer as a global village.

INFORMATION ON CURRENT AND UPCOMING POPCRN 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. ***Patient enrollment for this study ended June 30, 2001. Follow-up information will be collected on patients discharged alive from hospice through December 31, 2001.*** Eighteen sites nationally have enrolled 164 patients into this study. Look for results from this study in spring 2002.

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, 23 sites nationally have agreed to participate. Of the 23 participating sites, 8 have contributed data on 46 patients. Our sample size goal is 100 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, 4 hospices located in various Department of Corrections systems have agreed to conduct this same survey in their hospices. *We have received IRB approval and plan to begin collecting data this fall!*

National Hospice Outcomes Project:
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.

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

THE DYING PROCESS: PATIENTS' EXPERIENCES OF PALLIATIVE CARE, BY JULIA LAWTON

By Cordt Kassner, MA

Julia Lawton, a Research Fellow at Newnham College, University of Cambridge, wrote this book describing her ethnographic research study in a London hospice. The purpose of the book, published in 2000, is to contextualize and challenge theoretical concepts of personhood, particularly focusing on the importance of physical capacities and boundaries to maintain the integrity of the person. As a researcher, she assumed the position of a hospice volunteer in order to work closely with patients and staff. She volunteered for 10 months, coming in contact with 280 patients in both inpatient and outpatient environments. Lawton challenges the hospice notion of "living until they die" by exploring the loss of personhood associated with bodily deterioration.

> "One of the central and fundamentally important arguments of the book which arises from this approach is that during the course of their illness and bodily deterioration, patients may lose various aspects of their selfhood and identity which qualify them for the status of a 'person'. In other words, it is possible for a patient to die socially – that is, to enter the realms of non-personhood – prior to his or her physical cessation." (p. 2)

Lawton argues that suffering extends beyond physical pain to include the "humiliation of physical dependence, loss of continence, and the distress of ceasing to be able to engage in meaningful relationships with others" (p. 178). She notes that it is common for patients whose pain has been brought under control to experience more intense suffering in areas regarding the of loss of bodily control. It is this loss of personhood, and the suffering accompanied by it, that present a formidable challenge for palliative care.

I found this book to be an interesting description of hospice care in England and an insightful analysis of how physical properties of "bodily intactness" profoundly affect the experience of suffering at the end of life. Her theory of a "social death" occurring prior to "physical death" is worth consideration as one seeks to improve the delivery of palliative care and alleviate suffering at the end of life.

CALENDAR OF EVENTS

October

21-23 *Colorado Hospice Organization Annual Fall Conference & Exposition "At the Crossroads: Surviving or Thriving".* For more information, contact Al Canner, Executive Director CHO at 303-449-1142 or email CoHospOrg@aol.com.

November

14-20 *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.

27-29 *Last Acts Regional Meeting/ELNEC Training*, Philadelphia, PA. Last Acts is hosting a series of five regional meetings over the next year. The one-and-a-half day Last Acts meeting, the second in the series, will be preceded by a two-day ELNEC (End-of-Life Nursing Education Consortium) train-the-trainer precourse for continuing education/staff development educators. For full description, access the web link PDF file of the brochure. To register, contact Diane Cohn by e-mail at dianec@stewcommltd.com or by phone at 312-751-0147.

30-12/2 16th Annual Primary Care Research Methods & Statistics Conference, San Antonio, TX. For more information, see their webpage at http://famp33.uthscsa.edu:81/.

January 2002

31-2/3 *14th Annual Assembly of the American Academy of Hospice and Palliative Medicine Conference*, Palm Springs, CA. For more information, see their webpage at http://www.aahpm.

February 2002

21-23 *The Center to Advance Palliative Care (CAPC) Management Training Seminar: Planning a Hospital-based Palliative Care Program*, Tampa, FL. For more information, see their webpage at http://www.capcmssm.org.

Announcements

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.

Carmel Corn (A Sweet Ending…)

What are those Pink Flamingos doing overlooking Garden of the Gods and Pikes Peak?

You might have to ask Donna Roberts, Administrator of Hospice of the Plains, Inc., in Wray, Colorado. The Flamingus Hospicus Plasticus fundraiser occurred across 3 ½ rural Colorado counties this year, raising $17,456. The general idea is that the birds land in your yard, and a $5 donation will remove them, a $10 donation will remove them and allow you to designate where they land next, and a $20 donation provides insurance to prevent re-roosting in your yard! This is one of two primary fundraisers for Hospice of the Plains, Inc., which are essential for its fiscal survival. Congratulations on a fun fundraiser!

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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 participating in PoPCRN research studies
_____ PoPCRN general email listserv – discussion pertinent to palliative care
_____ PoPCRN research email listserv – designed to announce studies / results
_____ 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:

Cordt T. Kassner, MA
University of Colorado Health Sciences Center
4200 East 9th Avenue, Campus Box B180
Denver, CO 80262
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What's Poppin?
Newsletter of the Population-based Palliative Care Research Network
Volume II, Issue 3, Fall 2001

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