

LESSONS LEARNED ABOUT PALLIATIVE CARE IN INDIA

BY GUEST AUTHOR DANIELLE PITTMAN

Pallium India healthcare workers

sophomore in the University of Iowa's College of Nursing, I had the opportunity to take a threeweek course with 11 other students in Trivandrum, Kerala in southern India. The course, Pain, Palliative Medicine, and Hospice, was instructed by Dr. Joann Eland, Dr. M.R.Rajagopal, and various healthcare professionals

working for Pallium India. Pallium India is a palliative care program that helps support the less fortunate throughout their illness. We spent three weeks exploring learning Kerala, from spectacular individuals, and making rounds with Pallium's healthcare teams. I've never learned so much in such a The A patient and her spouse await timeframe. short program we worked with

brought us to patients who opened my eyes in such a way I didn't know was possible.

One patient specifically made a difference in my life. We drove an hour and a half and hiked ten minutes to her home. The woman was suffering

from breast cancer that has metastasized to her lungs and brain. In addition to the struggle of her health, she has been abandoned by her family and left with what little she had of a home with a concrete slab for a bed. This was a common occurrence with some of the families we visited. If a family member became chronically ill,

> occasionally a husband would leave his wife and children to support himself.

> The one thing that really touched me was that even though we did speak not language, we could watch the nonverbal interactions that the healthcare team had with this patient. They found a

way to effectively use touch and silence without any interference. Doctors and nurses were in no rush whatsoever. They had no other patients to rush off to see, and their



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PAGE 2 OUR CENTRAL LINE

FROM THE DESK OF OUR PRESIDENT

A MESSAGE FROM KATHY

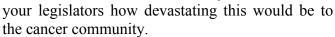
ONS is celebrating 35 years of supporting oncology nursing's future! More than 36,000 registered nurses and other healthcare professionals are committed to excellence in oncology nursing and to leading the transformation of cancer care by initiating and actively supporting educational, legislative, and public awareness efforts to improve the care of people with cancer. ONS provides nurses and healthcare professionals with access to the highest quality educational programs, cancer care resources, research opportunities, and networks for peer support. I have been an oncology nurse for 26 years and one of my most valued experiences has been my association with ONS. As a member for 26 years, I credit my successes as an oncology nurse in part to the incredible

education and leadership opportunities ONS provides. Getting involved in ONS and specifically our local chapter is a great way to advance your career, make professional connections, and improve patient care. Volunteering in the CWSONS chapter is easier than you think and can fit your schedule and your interests. Do you have strong organizational skills? Are you passionate about trends in oncology nursing? Do you love to think outside of the box? Want to take on a short term project? Consider volunteering to help with planning the Fall Symposium. Want to provide your colleagues with practical oncology nursing information while developing your publishing skills? Consider writing a short article for the newsletter. You can even earn cash by recruiting member! We want and need your involvement. Contact a board member (see the newsletter front page) with your idea or contribution and we will commit ourselves to your success!

LEGISLATIVE UPDATE

BY KIM ROHAN

The Federal HR 1 bill will cut funding for screenings including mammography and colonoscopy. It will also cut funding to the NIH for cancer research. Please notify your legislators how devastating this your



Continue to urge your state legislators to not allow smoking in casinos. This would just be opening up holes that could lead to more exceptions. We will be asking legislators to include oral chemotherapy to be under a patient's medical plan, not their prescription plan where their out-of-pocket costs can be unaffordable. We will be looking for patients that will be willing to testify to Congress and the state legislators regarding their experience with oral chemotherapy payment issues. If you have a patient that may be interested, please have them notify me at 630/646-6050 or krohan@edward.org.

NEWS YOU SHOULD KNOW

Colleen O'Leary is leaving Advocate Good Samaritan to be the Head and Neck Clinical Nurse Specialist at The James Cancer Center at Ohio State University.

Judi Bonomi (Rush-Copley) had a poster accepted at an evidence-based practice conference in San Francisco about her research on utilizing the time to administer medications using bedside bar coding.

Katie Opfer (Hematology Oncology Consultants) has been awarded a national Congress Scholarship by the Oncology Nursing Foundation and will be travelling to Boston in April.



Congratulations to Kim Rohan

(Edward Cancer Center) has graduated from St. Francis with a post-Masters Nurse Practitioner degree. Good luck with your boards!

Hope Prasse has accepted a new job in Radiation Therapy at the **Edward Cancer Center** and **Katie Cudzik** is moving from Rad Onc to Medical Oncology.

Jean Unruh is now working as the clinical supervisor for outpatient infusion services at **Dreyer Medical Center**.

PAGE 3

UP CLOSE & PERSONAL (REWORKED!)

KERSTEN SMITH, RN, BSN, OCN®

Just the stats:

CURRENT POSITION: Oncology Nurse Clinician, Hematology

Oncology Consultants

BIRTHDAY: September 24, 1962

BIRTHPLACE: Oak Lawn, IL

CURRENT HOME: Plainfield, IL

FAMILY: single

EDUCATION: BSN, Lewis University



Kersten Smith

DEEP THOUGHTS: If you have to have a regret, regret something you have done instead of something you should have done.

MY IDEA OF A GOOD TIME: Watching the Bears beat the Green Bay Packers (in a Super Bowl!), with all of my friends

WORST JOB I EVER HAD: Moonlighting as a Prison Nurse to make some extra

MY FANTASY: to retire to Hawaii NOW!

IF I COULDN'T BE A NURSE, I'D: be an auto mechanic!

IT'S SATURDAY AFTERNOON, IT'S RAINING, I'M: Mad! The Cubs will be rained out.

| ✓ Ketchup or | ✓ McDreamy or | Winter or |
|----------------|---|--|
| Mustard | McSteamy | √ Summer |
| (EL : I | | _ |
| √ Florida or | ✓ Bacon or | Dogs or |
| Colorado | Croutons | √ Cats |
| | | |
| ✓ Chocolate or | Bike or | √Plain or |
| Vanilla | √ Walk | Peanut |
| | Mustard ✓ Florida or Colorado ✓ Chocolate or | Mustard McSteamy ✓ Florida or ✓ Bacon or Colorado Croutons ✓ Chocolate or Bike or |

PAGE 4

OUR CENTRAL LINE

India—Continued from page 1)

cell phones and pagers were turned off to give her their undivided attention. In the U.S., patience is sometimes hard to find.

It surprised me that even though this woman was suffering from a severe illness, she still welcomed us into her home. She allowed us to photograph her, offered us a place to sit, and even reached out so we could hold her hand in comfort. I'll never understand the impact we had in her life just by visiting and giving her the touch that was missing in her life. I only hope that when visitors come to see me, I can make them feel as welcome.

On one long trek to a patient's home, we stopped on the side of a road to meet a woman who traveled six miles on foot to meet us for medicine for her paralyzed husband. Their home was not accessible for us because there were other patients in need. Pallium supplied his wife with medication, assessed his status the best they could, and set up a date and time that they would meet again. Since there is such a high demand for care, Pallium India has to make do with the time, supplies, and professionals that they have.

Collusion was another cultural difference that was jaw dropping for most of us. In India, patient diagnoses are divulged to the family instead of the



University of lowa nursing students use their "body language" to pay tribute to their school in south India in January during their Winterim '11 course about p alliative care.

individual. Most of the time, patients won't know what illness they have until they go to an "oncology clinic" or until their families tell them. I think it is important that nurses be aware of these practices in order to provide culturally sensitive care despite personal beliefs.

Throughout India, one million people are diagnosed with cancer each year and less than three percent of India's cancer patients have access to adequate pain relief. Many states have no medical facilities that dispense morphine (McDermott, 2007). Adequate care is not provided because physicians do not perceive pain as an issue. Medical students have not seen morphine when they graduate and medical professionals do not have adequate knowledge about pain relief.

The number of people suffering alone and ignorant about their disease is unimaginable. Pallium can only get to so many people. We only visited the state of Kerala. Compared to the rest of India, Kerala is economically well off and has the highest number of educated people. India is in need of help, but they are slowly progressing to change.

In India, 10 U.S. dollars can feed a family of four for an entire month through Pallium India's program. Most of the families we visited were in a struggle for good health, food, and medical support. Standards in the US are viewed by some people from India to be quite extravagant and feel that a lot of things that we do could be cut back on in medicine.

Because of this trip, I've have a new understanding for pain, palliative medicine, and hospice care. Pallium India attempts to help as many people as they can with the resources they have. Pallium doesn't just dispense medications – they are patient advocates and try to help families through the most difficult times of their lives. Pallium India believes in care beyond cure.

Danielle Pittman is a BSN Nursing student at the

- University of lowa and is the daughter of CWSCONS
- member and Program Committee Co-Chair Lisa
- Pittman. Contact the author at Daniellepittman@uiowa.edu.

NOVEMBER MEMBERSHIP MEETING RECAP

BY MARIBETH MANEY, RN, MS, AOCN®

The November membership meeting held in Winfield in a meeting space across the street from Central Dupage Hospital. Krista K. Rubin MS, RN, FNP-BC, from Massachusetts General Hospital in Boston, was the featured speaker for the presentation entitled Clinical Advances with Immunomodulatory Antibodies in the Treatment of Melanoma.

The lecture focused on new advances in the treatment of melanoma that are on the horizon for melanoma patients. Melanoma incidence in the U.S. is 1:50. The survival rate for advanced disease is low. FDA approved drugs for the treatment of melanoma currently includes DTIC and high dose IL-2.

Ipilimumab is a new drug awaiting FDA approval for the treatment of melanoma currently in clinical trials. This drug is a monoclonal antibody that manipulates the body's immune system using the CTLA-4 immune pathway. This acts on the T lymphocytes. Naturally the T lymphocytes kill cancer cells by programmed cell death and the CTLA-4 is an immune check point that puts a natural stop or brake on the actions of the T cells. Ipilimumab is an anti CTLA-4 therapy that blocks the braking action. This up regulates the T cell activation allowing the T cells to continue the cell killing function. Rubin anecdotally reported dramatically increased survival time in patients who had shown a response to the drug, but admitted that approximately 50% of patients had no response.

Ipilimumab is given as an outpatient infusion. Dosing is 3-10 mg/kg IV over 90 minutes every 21 days x 4 doses. Since the drug is fully human, no pre-medication is required. The role of maintenance therapy every three months is being evaluated. Infusion reactions are rare. Side effects include depigmentation of the hair and diarrhea which can be treated with Imodium or Lomotil. Severe diarrhea may represent an autoimmune colitis requiring colonoscopy for diagnosis. If diagnosed, treatment is steroids, (Prednisone 60 mg). There may also be rash with or without itching. Late side effects 12-15 months later include immune related hepatitis and requires monitoring of LFTs. Inflammation can also lead to hypophysitis (inflammation of the pituitary) leading to adrenal crisis. Symptoms include headache, fatigue, memory loss and decreased libido. MRI scans may be helpful, along with cortisol testing and testosterone levels. Treatment would include steroids plus testosterone therapy for 1 year.

The evening including a catered dinner and CEUs. Attendees were encouraged that progress is being made in finding promising treatments for malignant melanoma.

DID YOU MISS THE FALL SYMPOSIUM? LET'S PLAY Jeopardy was the vehicle used to discuss short topics at a quick pace. If you missed it, you can catch up on one of the topics presented in this fun format. Even if you were there, play along and see if you can remember what you learned! The category is: Lung Cancer 101 The answer is: \$100 This chemotherapy doublet is recommended for concurrent chemo and radiation therapy. \$500 What is dyspnea? \$200 This surgery for lung cancer offers less pain and \$400 What is chemotherapy and XRT? shorter length of stay. \$300 What is esophagitis and pneumonitis? These two treatment side effects are often seen \$300 in individuals undergoing XRT for lung cancer. \$200 What is video assisted thoracic surgery (VATS)? \$400 These two treatment options are indicated for \$100 What is cisplatin & etoposide? patients who are not medically fit for surgery. \$500 This symptom is seen in most lung cancer pa-The question is: tients at end of life..

NEWS FROM NATIONALS

In Memory: Rose Mary Carroll-Johnson, Oncology Nursing Forum Editor for 20 yrs.

Rose Mary Carroll-Johnson, RN, MN, noted oncology nurse, researcher, author, and editor of the *Oncology Nursing Forum* for more than 20 years, died at home on Monday, February 21, from gastric cancer. Carroll-Johnson was an active member of the Oncology Nursing Society, serving on the Society's first Council in 1996. She coedited two editions of the popular Psychosocial Nursing Care Along the Cancer Continuum along with Linda M. Gorman and Nancy Jo Bush.

Carroll-Johnson was employed as a senior research specialist in Nursing Research and Education at the City of Hope Medical Center in Duarte, CA. Previously she had worked for a number of organizations, including UCLA School of Nursing and Williams & Wilkins. She had served as editor for the Journal of Hospice and Palliative Nursing, Nursing Diagnosis, and the International Journal of Nursing Terminologies and Classifications. She received her bachelor's degree in nursing and a minor in psychology from Mount St. Mary's College in Los Angeles and received her master's degree from UCLA.



In 2010, she received the UCLA School of Nursing Distinguished Alumni award, and she is also the recipient of two North American Nursing Diagnosis Association's Unique Contribution Awards. In 2010, ONS awarded the first Rose Mary Carroll-Johnson ONS Distinguished Award for Consistent Contribution to Nursing Literature. Renamed in her honor, the award is given annually to recognize an individual who has made consistent and significant contributions to the oncology nursing literature.

Register for Congress

http://www.ons.org/CNECentral/Conferences/ Congress/2011/learn

Prostate Cancer Awareness

ONS has joined as an advocacy partner in a sportsthemed campaign produced by Edge Health Initiatives, LLC. that will focus on prostate cancer awareness. "On The Line" launched on February 15 with celebrity appearances on ABC's Good Morning America and MSNBC's Morning Joe. ESPN is the main media vehicle for this ongoing campaign that will reach across all sports seasons. Let's share this link with our patients, family members, and colleagues to help men recognize that their health is "On The Line"! http://www.ontheline.com/

World Cancer Declaration

ONS has pledged to gather 1,500 signatures by the first UN Summit for Non Communicable Diseases (NCD's) in September, 2011. Show your support for ONS and this important global initiative by signing the declaration as an ONS member!

http://www.ons.org/International/Declaration

Breast Cancer Biomarkers

Registration for the 36th Annual Congress is now open! Biomarkers are becoming key predictors of cancer out-Join more than 4,000 colleagues in Boston, MA, from comes, particularly in breast cancer. By identifying the April 28-May 1 to get the latest in cancer nursing educa-presence of biomarkers in breast tumors, healthcare protion. Connect with attendees before the conference to viders are better able to prescribe effective, personalized find a roommate, make dinner plans, and get in touch treatments. An article in the December 2010 issue of the with those in your specialty. Register by March 24 to save Clinical Journal of Oncology Nursing discusses the three traditional breast cancer biomarkers and what they mean for breast cancer care. Get the overview in ONS Connect. http://ons.metapress.com/content/h782631737819463/

Forgoing Axillary Dissection

A study published Wednesday in JAMA found that, among a small subset of patients with breast cancer, axillary dissection in patients with sentinel node metastases does not significantly affect survival rates. The study was covered by the mainstream media with a New York *Times* reporter describing it as turning "standard medical practice on its head." Although the findings are exciting for patients with breast cancer, nurses play a key role in helping patients understand the limitations of the findings. http://jama.ama-assn.org/content/305/6/569.full. pdf+html

CWSCONS presents:

Intrathecal Drug Delivery for Effective Management of Intractable Cancer Pain

May 11, 2011 • Oak Brook, IL

This continuing nursing education activity has been approved by the American Association of Critical-Care Nurses (AACN) for 1.5 Contact Hours, CERP Category A, File Number 00015786.

Purpose

To provide oncology and pain management nurses and other clinical staff an overview of the prevalence of cancer pain, and how intractable cancer pain fits into the population of patients with cancer pain. The program covers the role of intrathecal drug delivery as an option in the effective management of intractable cancer pain.

Objectives

This course will allow the participant to:

- Outline considerations when identifying patients with undertreated cancer pain
- Identify the role of interventional pain therapies in cancer pain management
- Identify the role of interventional therapies in the management of cancer pain
- Explain why intrathecal drug delivery is a viable option for the treatment of cancer pain
- Describe the intrathecal drug delivery system
- List patient selection requirements for intrathecal drug delivery as related to cancer pain
- Identify patient management and reimbursement considerations

Audience

This introductory program is intended for clinicians and administrators involved in the treatment and/or management of cancer patients.

Presenter

Dr. John Gashkoff, MD

Registration Form



5:30pm May 11, 2011 The Clubhouse 298 Oakbrook Center Oak Brook, IL

Please print or type and fax to Marlene Nelles at 866-253-4009 before May 4, 2011.

| Name | |
|-------------------------|-----|
| "RN "NP "PA "Other | |
| Clinic or Hospital Name | |
| Street Address | |
| City, State, Zip | |
| Phone | Fax |
| Email | |

PAGE 8 OUR CENTRAL LINE

WHAT'S ON THE CALENDAR?



APRIL 2011

| Su | Мо | Tu | We | Th | Fri | Sat |
|----|----|----|----|----|-----|-----|
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| 10 | 11 | 12 | 13 | 14 | 15 | 16 |
| 17 | 18 | 19 | 20 | 21 | 22 | 23 |
| 24 | 25 | 26 | 27 | 28 | 29 | 30 |

April 28-May 1

36th Annual ONS Congress Boston, MA

Make your reservations today!!

May 11, 2011

Quarterly Membership
Intrathecal Drug Delivery for Effective
Management of Intractable Cancer Pain

Dr. John Gashkoff, MD

The Clubhouse, Oakbrook Center RSVP: Marlene Nelles (866-253-4009) before May 4, 2011.

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MAY 2011

| Su | Мо | Tu | We | Th | Fri | Sat |
|----|----|----|----------|----|-----|-----|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 8 | 9 | 10 | 1 | 12 | 13 | 14 |
| 15 | 16 | 17 | 18 | 19 | 20 | 21 |
| 22 | 23 | 24 | 25 | 26 | 27 | 28 |
| 29 | 30 | 31 | | | | |

Disclaimer:

The Chicago Western Suburbs Chapter of ONS (CWSCONS) respects your opinions.

However, we reserve the right not to publish any submission that our editor or Board of Directors deem inappropriate. *Our Central Line* is produced by members of CWSCONS and is not a peer-reviewed publication. Opinions expressed do not necessary reflect the opinions of the CWSCONS or of the Oncology Nursing Society and its affiliates. Contributions to the CWSCONS and the Oncology Nursing Society are not deductible as charitable contributions for federal income tax purposes.

Looking Ahead

Future meetings are being planned for:

September 7, 2011—Topic: Benign Hematology

November 2, 2011—Genetics

Speakers and locations are yet to be determined. Mark your calendars and plan to attend!

VOLUME 19, ISSUE 1 PAGE 9

IT'S TIME TO RENEW YOUR MEMBERSHIP!

Mail this coupon and a check for \$20 payable to CWSCONS to: Caroline Mangan, 4900 Northcott, Downers Grove, IL 60515

| Name (with credentials) | | | | National Membership Number & Expiration | | | | |
|---|----------------------|-------------------------|--|---|---------------------------------|---------------------|----------------------|--|
| Address | | | | Membership: o New o Renewing | | | ving | |
| City & Zip | | | | Certification: o AOCNP | o OCN [©] o Other _ | o AOCN [©] | o AOCNS [©] | |
| Place of Employment | | | | | | | | |
| Email Address | | | | Newsletters are delivered electronically by email. If you have no access to email please check here □ to receive printed copies by US Mail. | | | | |
| Home Phone | | Work Phone | | Prefer calls: | o Home, af | ter | o Work | |
| Areas of Expertise/Interest: (Check all that apply) | ☐ Inpatient☐ Hospice | ☐ Outpatient☐ Home Care | | notherapy [nistration/Mana | ☐ Radiation | • • | | |

(Closing thoughts—Continued from page 10)

north of Mumbai with a friend of my husband's from medical school. Dr. Alan is an internist from a Mumbai suburb, but has established a medical clinic in a remote village where the locals live in mud huts, there is only one spigot of running water for 39 "homes", and the diet consists of only lentils and rice for 10 months of the year. We watched as Dr. Alan "saw" 220 patients in 3 hours, dispensing medications from a tabletop full of donated pharmaceutical samples and meds purchased in bulk.

Not surprising, the people were somewhat short in stature and Dr. Alan prescribed nearly every person who appeared at the clinic an IM injection of Calcium, Vitamin D and Vitamin B complex in attempt to minimize malnutrition. Many were given IM injections of Gentamycin as prophylaxis for skin infections related to lack of hygiene.

The "medical record" consisted of a sheet of notepaper for each patient where their meds are recorded. They are stacked in alphabetical order on benches in the waiting area (no HIPAA there!). The injections were given by a nun from a nearby convent that Dr. Alan has trained to assist him. She used the same two syringes over and over again for the two different injections but I was somewhat relieved to see that she used a new needle for each patient. The only time I saw the use of disposable gloves was when the doctor lanced a badly infected foot of a small boy, prepped only with a squirt from a very old bottle of Betadine.

On this particular day, we saw three new cases of leprosy and many other cases that were successfully being

treated. Scabies and skin infections were also common. People were obviously grateful for the medical attention and the children cheerfully accepted shortbread cookies Dr. Alan had brought with him that were dispersed following their injections.

My emotions ran the gamut that day. I was amazed by how patiently each person waited in line, first come, first served. They were grateful for the few minutes that they spent with Dr. Alan, although it was discouraging to me that so little was really available to them. It was heartwarming that local folks welcomed us into their huts, and astonishing how they live—an open fire in the corner to cook their meals, a stall at one end inside for the family's cow (if they had one), and no furniture whatsoever. Yet happy children ran in small groups from hut to hut announcing our arrival and giggling with delight as they saw their images replayed for them on our cameras.

I guess there isn't a real moral to this story but it seems worth telling. I was frustrated that I wasn't able to speak the local language spoken in this village, but the universal language of a smile and comforting hand on a shoulder surpassed the boundaries of language. This proved to be the common denominator between my experience and that of Danielle Pittman's (see pg. 1). Whether a 2nd yr. nursing student like Danielle or a 34 yr. veteran like me, a caring touch and a warm smile carry the same power.

We need reminding that healthcare needs are globally deficient and there are Americans without access to medical attention. Regardless of what type of medical care we are providing, it is the demeanor in which it is provided that makes a vast difference, and I think that's what nurses do best.



CLOSING THOUGHTS: WHAT WE DO BEST

BY BARB BARHAMAND, RN, MS, AOCN

My husband and I recently spent 3 weeks vacationing and traveling in India. My husband grew up in India and went to medical school there, so this was not my first visit. We did plenty of touring, seeing familiar sites around Mumbai (formerly Bombay) but also traveled to two areas of India that I had not visited before.

Mumbai is a bustling cosmopolitan city not unlike Chicago in many ways. Most people live in apartments (some are high-rises), there are wonderful museums, the shopping is fabulous, and the waterfront boulevard called Marine Drive along the coast of the Arabian Sea looks quite similar to Lake Shore Drive.

Differences between the two cities however, are negligible. Public transportation is not well-developed

with the exceptions of buses, so the streets are bumper-to-bumper with taxis of every type including vans, small cars, and rickshaws (motorscooters with a two-person cab on the back). Traffic iams are common during rush hour periods, but interestingly, road rage, obscene gesturing, and traffic accidents are rare. Honking, which would be considered rude and obnoxious on the streets of Chicago, is interpreted differently in India. Cars and cabs drive three or four abreast in streets intended for two lanes of traffic and honk simply to say "I am beside you", or "please let me cut in front of you". Amazing. Traffic is so tightly packed that most cabs no longer have side-view mirrors. I was quickly reminded of this as I mistakenly rested my elbow out the open window of a cab only to have it brushed by another cab beside ours.

Like Chicago, the socioeconomic spread is vast, with areas of poverty and squalor that are impossible to ignore. Homeless people beg from the sidewalks but some, including small children, will walk amongst traffic, dodging the cars in pursuit of a few rupees (\$).

Leaving Mumbai we visited a colorful city named Goa, settled by the Portuguese in the 1600's. Houses there are commonly painted purple, orange, lime green or yellow, reminding how boring we are with homes of beiges and grays. A vacation and honeymoon destination for Europeans and nationals, the area has numerous resorts with beautifully appointed hotels, quite similar to Hawaii. The socioeconomic spread in Goa, was again, very obvious.

One Sunday, we ventured (Closing thoughts—Continued on page 9)