



PUGET SOUND QUARTERLY

Oncology Nursing Society

Vol. 24, No. 2

Summer 2001

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THE McCORKLE LECTURE 2001

Patient-Centered Pain Management: Novel Computer Technologies Amplify the Patient's Voice

Diana J. Wilkie, PhD, RN, FAAN

For a long time, in fact my entire 24-year nursing career, I've been hearing voices. No, not those kind of voices. The voices of health professionals debating pain management goals and above all, the voices of patients crying for pain relief. The roar of the voices was deafening and compelled me to conduct pain research focused on amplifying patients' voices so they could be heard and on supporting health professionals to implement effective pain management strategies. In this lecture honoring Ruth McCorkle, I share findings from several of the many studies we have conducted during the past 12 years. These findings led us to create innovative uses for computer technologies to amplify patients' voices and to support clinicians' pain management decisions.

Research Framework

My integrated model of pain for my research (Figure 1), shows pain as a multidimensional phenomenon. Specifically, the neural mechanisms of pain interact within the person influencing the affective, behavioral, cognitive and sensory aspects of pain which in turn can affect pain transduction, transmission and perception. At the core is suffering, which can be nonexistent or engulf the entire person. Through investigation of various elements of this model, I've been able to clarify and

Integrated Model of Pain

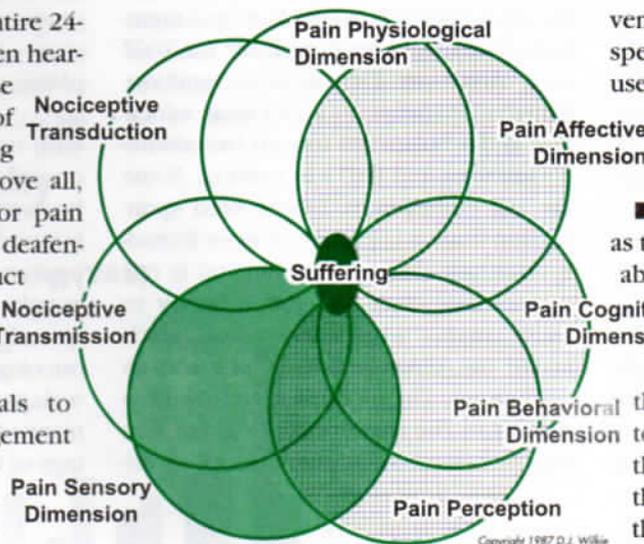


Figure 1
amplify the patient's voice.

Behavioral Dimension

A decade ago, we studied the behavioral correlates of lung cancer pain, focusing on the sensory, behavioral, cognitive and affective dimensions of pain. Early in my clinical practice, I observed that often patients' voices were not heard if their behaviors did not indicate the person was experiencing pain. In this study I videotaped patients in their homes with one camera focused on their bodies and another camera focused on their faces. We scored the videotapes, stopping every 20 seconds to see what behaviors were displayed by the 45 patients who had lung cancer. We found 42 different pain behaviors

that patients used intending to control their pain, either to reduce it or to prevent its onset. From the patients' perspective, these pain behaviors were not used to let other people know they hurt or to get secondary gain. Following are a few examples of some of the pain control behaviors:

- guarded the arm on the same side as their tumor by internally rotating and abducting the arm, holding it in a stiff and a rigid position as they walked; they did not have a normal gait swing. Unfortunately this same behavior caused the patient to have myofascial discomfort from the stiffness this guarding produced in the neck and shoulder region. Then they rotated the affected shoulders and stretched their backs to overcome the new pain caused by a behavior they had intended for pain control.

- braced when shifting from static positions (sit, recline, stand).

- put their thumbs in their pockets or in their waist belt loops to take the weight off of their shoulders if patients had hypertrophic pulmonary osteoarthropathy (HPOA) in their shoulders. HPOA is a paraneoplastic syndrome in lung cancer. Patients with HPOA in their knees shifted their weight from one leg to the other, sometimes as often as every 20 seconds.

- put their hands to their thighs as they shifted from one position to another and in doing so they stabilized their low back when they had vertebral body metastasises.

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PRESIDENT'S MESSAGE

Opportunities Available

Margot Hill, BSN, RN, OCN

The Oncology Nursing Society Mentorship Weekend was held at the end of March. I had the privilege of attending as the PSONS new president. As with other oncology nursing conferences or any gathering of oncology nurses, for that matter, I am reminded there is a special quality about oncology nurses you identify immediately. There seems to be a bonding and being on the same wavelength. For instance, after Saturday's dinner, a group of us walked along the river. None of us had met before but a stranger would have thought we were long time friends, all of us talking and laughing.

I learned more about ONS, who the staff and volunteers are and what they do. There is a complete list in the back of each issue of the ONS Forum magazine which includes all the Board of Directors, Steering Council, and all Chapter Presidents. There is also a list of all ONS staff voice mail extensions. The telephone number for ONS is 412-9211-7373. When you call that number you actually reach a person from customer service who will help you reach the right person.

There are new things happening at

ONS. Everyone was pleased to hear more medical continuing education credits will be accepted for Oncology Nursing Certification. New to the ONS web page, www.ons.org, is the ability to be politically active in the time it takes for a few "point and clicks." Try clicking on to the Government Relations link, put in your zip code, and appropriate bills will appear with opportunity to notify your Legislative Representative or Senator of your opinion on a specific bill. Lastly, everyone was very enthusiastic about plans for a beautiful new building that will house all ONS business.

What impressed me the most were the number of awards available to our members. The cash awards available for 2002 vary. Some are for special recognition, Congress expenses, continuing education and scholarships toward baccalaureate, masters, and PhD's in nursing. Some are self nominations, others need sponsorship from a colleague or more formally from our chapter. Pat Buchsel is our nominations chair and she is happy to assist anyone who is interested. Each award has separate instructions and an application. The problem is getting information to the membership. There is a one inch stack of applications all in dif-



Margot Hill

ferent bright, attractive colors waiting for the asking. Please call myself, Pat or the Oncology Nursing Foundation directly if you are interested. Please note: because of lack of interest or awareness many of these opportunities are unclaimed. I recommend each member keep in mind these awards and scholarships when planning your professional goals.

ONS is a national organization with its offices on the other side of the country in Pittsburgh. There are difficulties with communication and distributing information, but it does exist to offer opportunities for local chapters and their members. It also provides an opportunity to learn directly from each other as oncology nurses through its periodicals, web page and conferences. I hope to see many of you taking advantage of the offerings of ONS!

GUEST EDITORIAL

Jormain Cady

Linda Hobengarten

Co-Chairs, 2001 Symposium Committee

The 2001 PSONS Cancer Nursing Symposium held on March 9th and 10th was, by all accounts, a rousing success. We had equal distribution of attendance between the 2 days with 174 on Friday and 172 on Saturday. The evaluation scores of program content and facility were identical for both days at 4.6 on a scale of 1 - 5.

Our conference objectives were:

1. Identify ways chapter members have promoted oncology nursing in multiple practice settings.
2. Describe best practice in the care and treatment of patients with lymphoma.

3. List three ways in which genetics will impact oncology care.

In support of achieving these three stated goals, we held a wide variety of instructional sessions from lymphoma and genetics to information technology, reimbursement issues, how to have those tough transitional discussions, and metastasis. Our opening and closing speakers were not only informative but inspirational from the perspective of the patient.

Perhaps more important were the non-tangible gains: those hugs in the hallway between sessions when old friendships were renewed or the "ah-ha!" of inspiration when nurses learned something that could be applied to their own practice site.

This issue highlights four of the presentations - the keynote address by Marilyn Patterson, the McCorkle Lecture by Diana Wilkie, the closing remarks by Diana Shapiro, and an overview of the panel discussion on discussing end of life issues with patients. Each has its own unique flavor, and we hope that they provide you with a good taste of what was available this year.

We hope that in reading some of what was presented you will achieve some secondary gains - whether through revisiting key learning moments, encouraging your professional education, or reminding you of times forgotten. We look forward to your attendance at the 2002 PSONS Symposium.

Patient-Centered Pain Management: Novel Computer Technologies Amplify the Patient's Voice

Continued from page 1

- crossed their arms to stabilize thoracic spine lesions by holding their arms crossed over their chest.
- positioned body parts or reclined in special positions.
- applied pressure to particular body areas.
- self-manipulated by rubbing, squeezing, and touching the hand and arm that was affected by brachioplexopathy.
- massaged other painful areas.
- had very few of the facial expressions associated with pain (grimaces) but lower eye-lid movement (squint) was common.

In this study we gave voice to the meaning or intent of patients' pain behavior. Patients were clear that their behaviors were attempts to control or reduce their pain, not to communicate

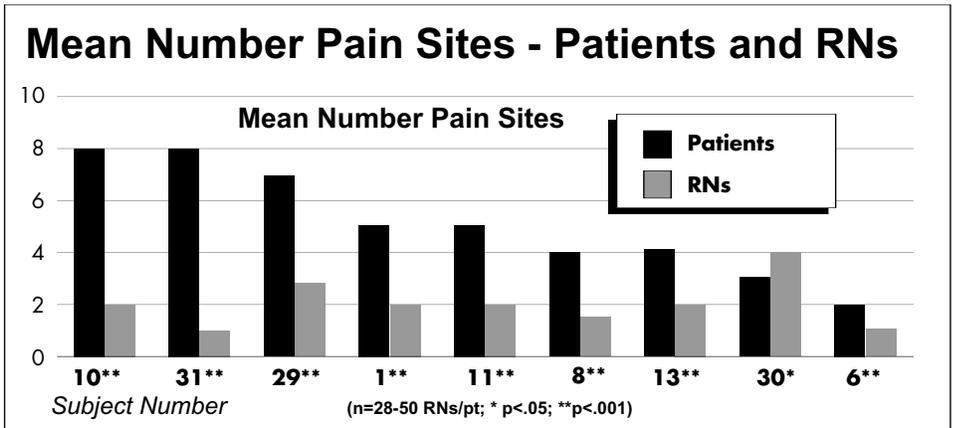


Figure 2a

their pain to others. Overall we found that many of these behaviors can be beneficial but some of them might be harmful. We still need to identify all the harmful and beneficial behaviors related to pain. Then we need to teach

As Figure 2a shows, the nurses tended to underestimate how many places the patients hurt, but for patient #30, the nurses indicated the patient had more pain sites than the patient reported. As Figure 2b shows, the nurses overestimated the intensity of pain compared to the patients' ratings, except for patient #29 who rated his pain as 93 and the nurses rated his pain as 29 on average. Figure 2c shows that nurses underestimated or overestimated the number of behaviors related to pain as were reported by the patient and that few of the same behaviors were noted by both the nurses and the patients. Patient #30, an 80 year old gentleman, used 13 different behaviors to control his pain but the nurses didn't recognized many of those behaviors as an indicator of pain. Patient 29, an African American man with excruciating pain, engaged in many pain control behaviors that nurses often attributed to a pain free state. This African American gentleman only had cough syrup prescribed to control his severe lung cancer pain. The results of this study show how important it is that we amplify patients' voices to help them be heard and get pain relief.

Telling Others about Pain. In several studies, we also found that about half of the patients say that they try not to let others know when they hurt. The other patients say that when they hurt, they just tell other people. For those patients who say they tell others, it is not clear if they tell efficiently. We have not studied

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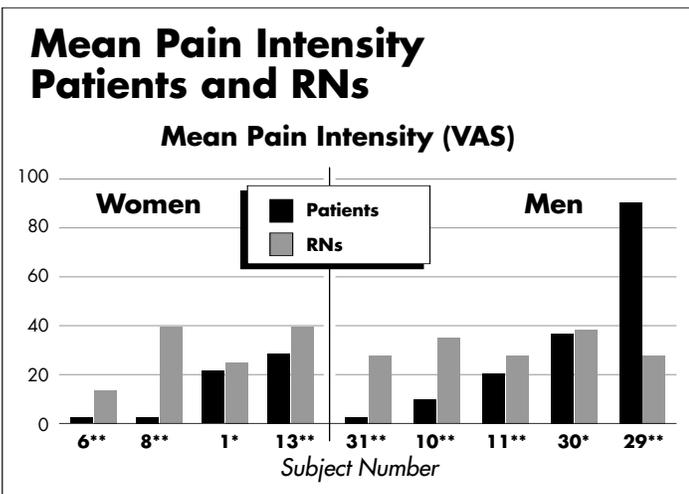


Figure 2b

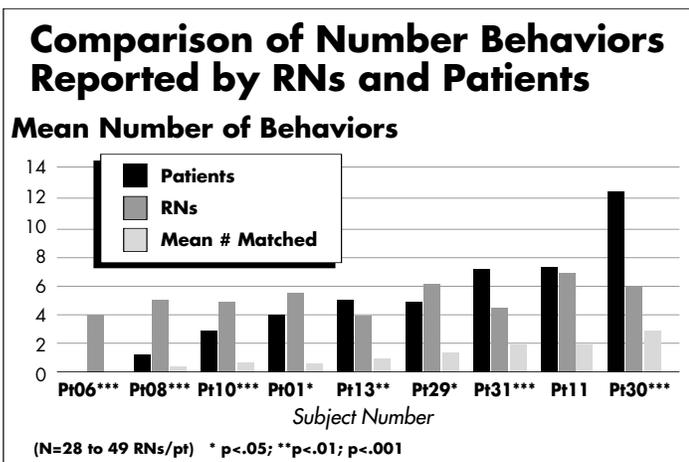


Figure 2c

Patient-Centered Pain Management

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the efficiency of telling, but we have studied ways to help patients communicate their pain to other people, especially their oncology clinicians.

Coaching Patients. Because so many people tended not to tell others about their pain, we started coaching patients to tell others about their pain in 1990. Dr. Donna Berry joined our group in 1994 and together we worked with 9

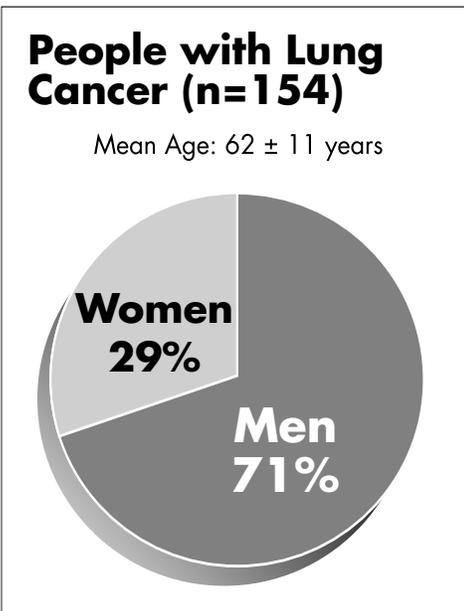


Figure 3

different cancer clinics here in the Puget Sound area to recruit patients with lung cancer. We coached them how to monitor their pain and then to tell their doctors and nurses about their pain. We hoped to make patients' voices heard and that clinicians would then prescribe analgesics to relieve patients' pain. We completed the five-year study with 154 lung cancer patients. Figure 3 shows that we studied an elderly sample. We randomly assigned the patients to an experimental group that we coached and a control group that received usual cancer care. The people we coached saw a 12 minute videotape teaching them why and how to tell their doctors and nurses about the pain. We also showed them how to self monitor their pain using a grease pencil to mark their pain on laminated McGill Pain Questionnaire pages. If the pain changed, they could rub off the mark and make a new one. We also gave them

weekly coaching reinforcements, either in person or on the telephone weekly for the next 3 weeks. The focus of the coaching reinforcements was tailored to the pain information the patient told the clinician, which we obtained by listening to an audiotape of the interaction between the patient and the clinician at the previous clinic visit. Based on what they told the provider, we acknowledged and praised them for the information they had shared and encouraged them to share any missing information so that their doctor or nurse would know about the pattern, area, intensity and nature of the pain that they had reported using a McGill Pain Questionnaire. We also role modeled to those people who hadn't told their doctor or nurse — how to do so at the next clinic visit. We continued to audiotape clinic visits, measure their pain and record the analgesic prescriptions given to these patients.

As Figure 4a shows, with the combined efforts of the patients telling and the clinicians' assessing pain, at baseline about 70% to 90% of the patients told their doctor or nurse about the location, intensity, quality and pattern of their pain. This finding was good news from a clinical perspective and bad news for a study, because there were high rates of telling when both

Results of Patient-Provider Communication at Baseline

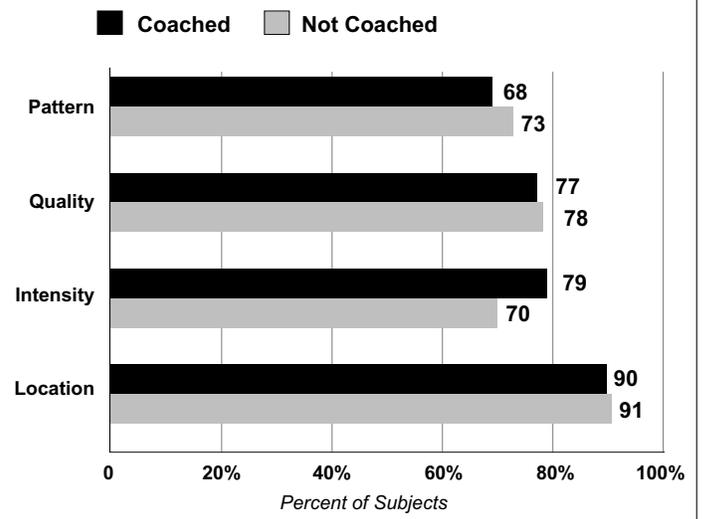


Figure 4a

the patient and the clinician know they're being tape recorded for a pain study. There were no differences between our groups at baseline, and that's good news from a research perspective.

At the end of four weeks, the not-coached group tended to decrease telling about all four pain parameters (Figure 4b). We found a statistically significant difference between the groups in telling about pain intensity and quality; the coached group tended to

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Results of Coaching Effect on Combined Patient-Provider Communication at 4 Weeks

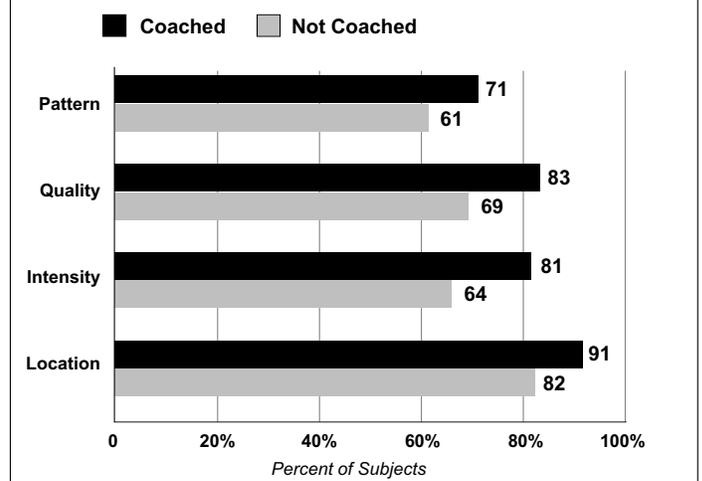


Figure 4b

Tough Talk: Discussing the End of Life

Sandi Johnson, MSW

Alexandra Hepburn, Grief Counselor; Pam Ketzner, Hospice ARN; Sandi Johnson, Oncology Social Worker and Dave Wendleton, Director of Spiritual Care, joined together as a panel to share their thoughts and work around having difficult conversations with patients who live with advanced cancer. The following synopsis reflects key thoughts.

Conversations around life, living, dying and death, rise out of a deep commitment toward allowing patients to express themselves and to set goals that reflect their hopes, desires, and wishes. As professionals we can assist in creating the space for conversations that allow the patient to step out and speak openly. It comes through seizing those moments when the patient reaches out to us, sometimes at unusual times and in unsuspecting ways (giving a bath, middle of the night blood pressure check). These are opportunities for us to guide them through a process that ultimately allows patients to live their lives as fully as possible in a way that gives them hope and a sense of control.

Creating space begins by providing care that is relationship-centered. Relationship-centered care has a component of privacy and respect for the choices the patient makes. Such space and care honors the family as an integral part of the patient's care team. It requires us as professionals to be genuine, real, and grounded in our life as it relates to living and dying.

Understanding the barriers healthcare professionals face will aid us in breaking through them. Sometimes the largest barrier is oneself and not being grounded in the meaning of life, its purpose, and where we stand in living and dying in relation to the patient. Another barrier we face in communication is creating the space for communication to occur. It is all about timing, about seizing the moment. Being short staffed, short on

resources, and tired, are all barriers to having these conversations.

Then, of course, there are the barriers the patient/family brings, such as cultural dynamics, energy level, and physiological and psychological impairments.

As a professional caregiver we have many roles in the task of having these conversations.

Role 1: Incorporate in our patient reports / care planning time patient goals that include the all aspects of the patient's mind, body, and spirit.

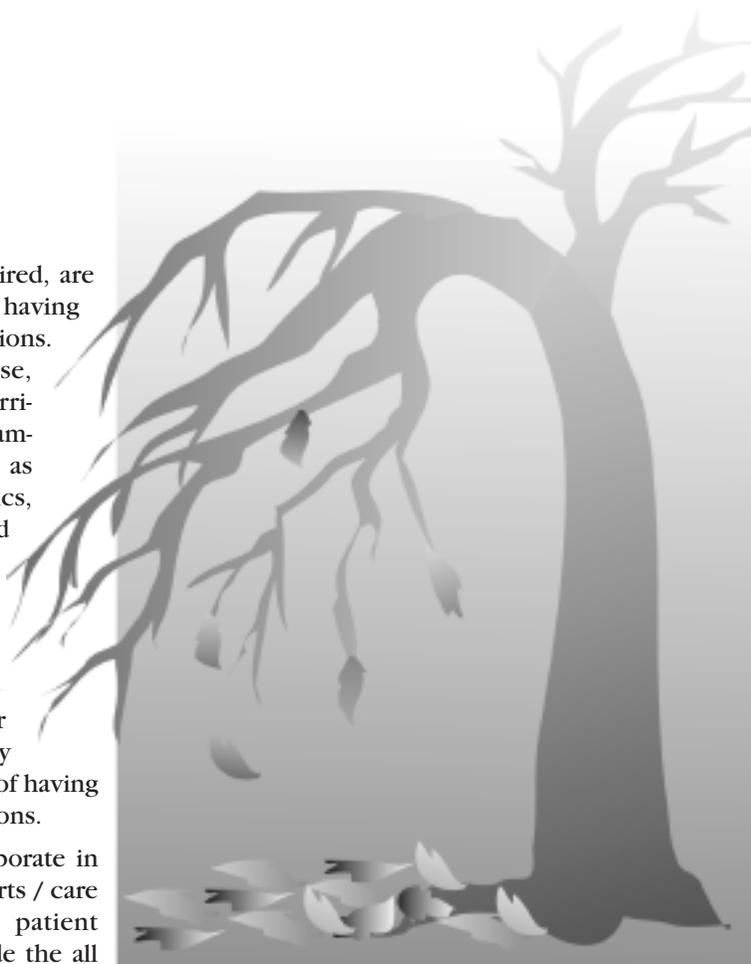
Role 2: Practice communication around the goals expressed by the patient and their family.

Role 3: Practice "opening the door." A great article to aid you in this process is found one by Lo, Quill, and Tulskey (1999) in the *Annals of Internal Medicine*. It provides cues such as: "What gives you greatest pleasure?", "What are your hopes, expectations for the future?", "What matters most to you?", and, "What do you want to accomplish?"

Role 4: Explore Spiritual issues with patients, families, and yourself: "What gives you meaning in life?" "Tell me about your most recent spiritual experience;" "What do you want to be remembered by most."

Role 5: Be Present. We need only to listen and then listen some more. You do not need to respond or give advice.

Role 6: Align yourself with your patient's wishes without reinforcing unrealistic plans.



Role 7: Provide the space for the patient and their family to openly discuss their fears. Assist the patient in sorting through the variables, the possibilities that are available. Have them define what quality means to them.

Role 8: Assure the patient and their family that their healthcare team will not abandon them. Explain how the goals of care are palliative and what this means.

Role 9: Acknowledge that there are limitations and there are endings, while at the same time assuring the patient that their choices lie in how they want to live the rest of their life.

Role 10: Redefine a. how you can help and, b. the goals for care. Help the family unit focus on living fully in dying; encourage life review/story telling/legacy.

Role 11: Be aware of your own comfort level, do not push the patient/family to talk.

Our role in this process is a parallel, inner event that is present between our patient, their family, and ourselves. It is all

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Discussing End of Life: Widening Our Perspectives

Continued from page 5

about the spirit. The meaning assigned to this experience relates to how we think our life and the world ought to be. Movement through the patient's experience and how we might want to participate as individuals in this journey is the paradox not only for the patient, but also for us as healthcare professionals.

Our place is one where we value honesty, trust, and safety. As a professional we are a companion along the road. We are invited to be present for the patient, and we guard the patient's work, we empower the patient and family to realize the brevity of life. Then, we must let go of our own desire to see events happen our way. We ultimately respect the work of the patient and the way they choose to live their life.

While we may be afraid of making a mistake in these conversations, the only mistake we make is not opening the door to having them. The ultimate goal is that even as we provide acute med-

ical care, we begin the practice of integration and care of the heart, mind, and spirit. We affirm that there is living and life even in our dying.

Henri Nouwen writes: "Every time life asks us to give up a desire, to change our direction or redefine our goals, every time we lose a friend, break a relationship, or start a new plan, we are invited to widen our perspectives and to touch, under the superficial waves of our daily lives, the deeper current of hope."



Resources

Dunn, Rev. Hank. Hard choices for loving people, A&A Publishers, Inc. PO Box 1098; Herndon, VA 22070

Durham, E., Weiss, L., (1997). How patients die. American Journal of Nursing, (12):41-6.

Hope vs. Truth: A Delicate Balance, (1999). In CA news and views. A Cancer Journal for Clinicians,

March/April, 49(2).

Kendall, ML, (1999). A holistic nursing model for spiritual care of the terminally ill. American Journal of Hospice & Palliative Care, Mar-Apr;16(2):473-6.

Lo, B., Quill, T., Tulskey, J., (1999). Discussing palliative care with patients. Annals of Internal Medicine., May 4;130(9):744-9

Reimer, JC, Davies, B., Martens, N., (1991). Palliative care: The nurse's role in helping families through the transition of "fading away." Cancer Nursing, 14(6): 321-327.

Remen, Rachel Naomi. Kitchen table wisdom.

Singer, PA, Martin, DK, Kelner, M. (1999). Quality end of life care: Patients' perspectives. JAMA, Jan 13;281(2):163-8

WEB Sites

www.agingwithdignity.org The site

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Patient-Centered Pain Management

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increase their telling. Clinicians need to know about pain intensity in order to titrate pain medications. Pain quality is important to help clinicians know whether or not the pain is neuropathic (nerve damage), which requires different analgesic agents than pain related to tissue damage (nociceptive pain).

We were pleased to see these increases after our coaching. We were discouraged, though, that coaching did not improve telling about pain pattern or pain location over the four-week study. Overall, however, the number of pain parameters (0-4) that were communicated during the clinic visit was significantly improved in the coached group (Figure 4c).

Even though we increased the telling about pain intensity, we didn't see any difference in either the visual analog scale of pain intensity or pain relief (Figure 4d). Again, this finding is good news for clinical practice but bad news for our research. I think it was really exciting to find that the average pain intensity for this group of lung cancer patients was 19, which is really low in

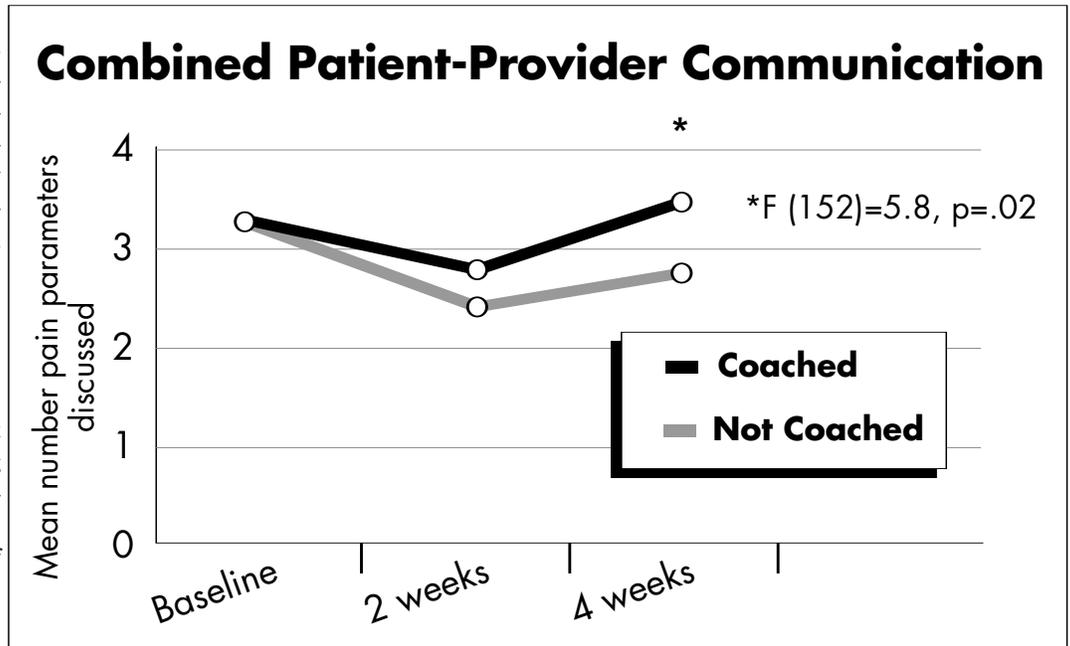


Figure 4c

comparison to other studies. This finding indicates that Puget Sound area clinicians are controlling pain better now than they did 15 years ago (Greenwald, Bonica & Bergner, 1987). Unfortunately coaching did not reduce the pain intensity further, perhaps because there was no change in the prescribed pain medications.

Patient-Provider Communication about Pain. Dr. Berry analyzed some of

the audiotapes, and found that often when patients tried to talk about their pain or other symptoms, the provider interrupted. This finding would help us to understand why the pain medications were not changed. As we look at these data, we found that coaching improved the sensory pain data reported, but it was very time intensive. It didn't give an adequate return on the amount of time we invested with these patients. We knew from the audiotapes, the providers cared about their patients, so it was a puzzle - Why would they interrupt the patient? Our hypothesis was that the patient mentioned pain at the end of the visit, when the provider needed to see the next patient. Those of us who do pain work know the end of the visit is the wrong time to talk about pain, because once a patient starts talking about pain, it can take 15 to 20 minutes to complete a pain assessment using an interview format. It is possible that these skilled oncology providers knew they didn't have that much time. So the easiest thing to do was to interrupt.

We found the patient's voice was being muffled by interruptions, even for those patients who were coached to tell others about their pain. One patient said, "You know, I had to go and grab the

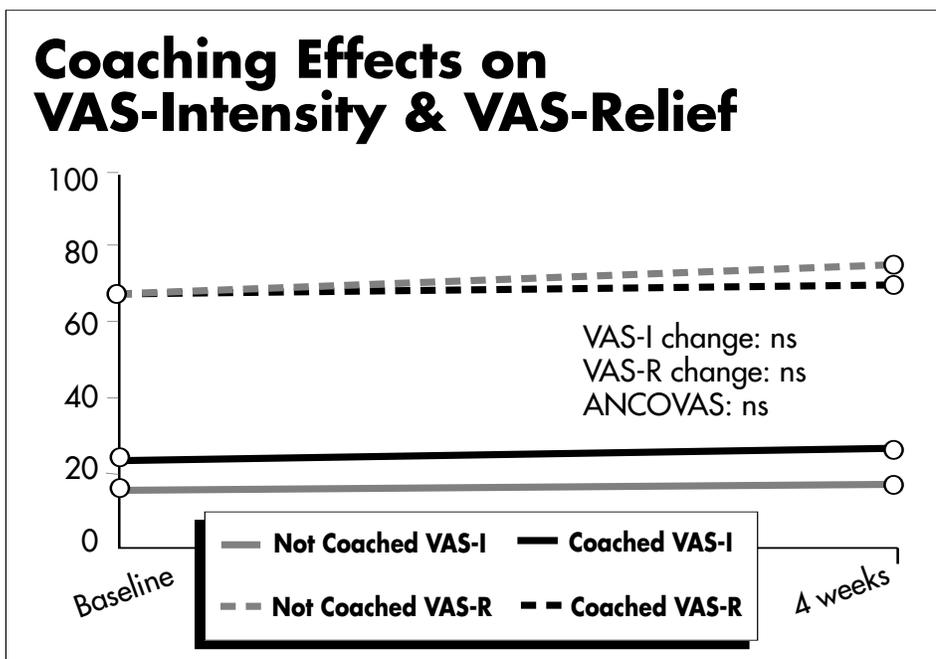


Figure 4d

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Curing and Caring, together.

The Seattle Cancer Care Alliance (SCCA) is a dynamic collaboration among three organizations known nationally and internationally for their patient care and research: Fred Hutchinson Cancer Research Center, University of Washington, and Children's Hospital and Regional Medical Center. The SCCA offers nurses the opportunity to work in a state-of-the-art environment, provide the most advanced care and use up-to-date technology and equipment.

University of Washington Medical Center, twice named a Magnet Hospital by the American Nursing Credentialing Center, is seeking nurses to join our oncology nursing team. Our oncology services include two hematopoietic stem cell transplant units, one of which has four ICU beds, and a hem/onc, gyn/onc unit.

Along with competitive salaries and excellent insurance and retirement options, we offer relocation assistance, generous amounts of paid time off, and six free credits per quarter at UW, home of the #1 school of nursing in the country. If you're ready to create best practice in a supportive environment, you won't find a better place to work.

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EO/AAE

Patient-Centered Pain Management

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doctor's arm and say, Doctor, let me tell you about my pain!" This example shows the extent to which this patient tried to communicate. We don't think many patients are going to be that persistent, to insist upon reporting their pain. Based on these observations, we knew that we needed to think of another way to communicate pain information to clinicians. We thought of using computer technology to collect the sensory pain data and then to summarize it for the clinician as an extension of the coaching intervention.

Computerized PAINReportIt. To that end, we developed the first, computerized McGill Pain Questionnaire and tested it in several studies here in the Puget Sound area. We wanted to find out how long it took patients to complete the questionnaire, because we know how important time is in clinical care today. We can let the computer calculate the time. We also used an acceptability scale with 13 items, for patients to tell us their opinion about completing the computer pain assessment tool. We also wanted to know, if they completed all the parts of the questionnaire or if they would leave questions blank.

When we started these studies, we recruited people from the general public to test our program because we could not bear to let sick cancer patients test a program that might crash as they tried to use it. We put two computers in our Comfort Coach, a 27 foot mobile home used to conduct behavioral observation research. We parked in the parking lots of Fred Meyer's, Sam's Club, senior centers, or other high foot-traffic areas to recruit people who had chronic pain without cancer. We also recruited patients at a privately owned radiation oncology clinic in Tacoma, and at the University of Washington in oncology inpatient units.

We asked these people and patients to use our program (Figure 5). PAINReportIt runs on Windows 95 or 98 and patients used a 19" touch screen monitor, like banking at the ATM. They completed the McGill Pain Questionnaire, demographic questions and computer usability questions. These data are automatically stored in an Access7 database as soon as the patient pushes the button to go to the next

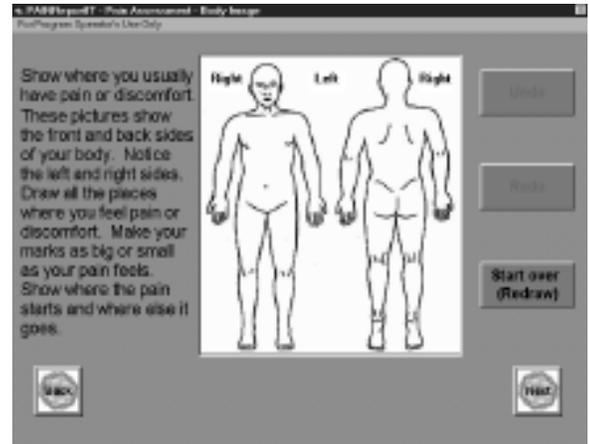


Figure 5

page, so there's no data entry for the researchers. The patient is able to draw on the body outline by touching the location of the pain. They then indicate the intensity of their pain by touching numbers, pick from 78 words to show the quality of their pain and from nine words to show the pattern of their pain.

Once they give us the information, we're able to generate a one-page summary report for patients and a two-page PAINConsultNt for clinicians based on the patient's data. For example, the PAINConsultNt gives recommendations

for analgesics based upon the patient's age and weight and the pain intensity level and pain quality derived from the verbal descriptors. If the patient describes neuropathic pain, PAINConsultNt gives suggestions including use of amitriptyline or Doxipen or Gabapentin for pain control. Based upon the information that the patient shares, PAINConsultNt also shows the data from the patient's pain location, summarizes all the intensity data and categorizes the verbal descrip-

tors as indicative of nociceptive pain, neuropathic pain, emotional response, the patient's coping response, and the temporal pattern of the pain. PAINConsultNt also includes information about things that aggravate the pain and things that alleviate it. If the patient gives data about pain medications, PAINConsultNt includes equal analgesic doses of other opioid drugs and lists drugs the patient reported that worked or didn't work

for his or her pain. With the one-page pain summary or the two-page PAINConsultNt we give voice to the patient's pain, because the patient has given the computer the information. In less than two minutes, this information is made available to the provider by the computer, giving voice to the patient's pain.

Patients in our initial studies of PAINReportIt were aged 50 to 65 years on average, many of them with no computer experience (Figure 6). We found the following:

■ In the outpatient sample, all of the

sections were completed by every patient and at least one pain site was validated with evidence of disease for all of the patients. These patients had bone metastasises so a bone scan showed indication of tumor in the area where the patients had reported their pain. Overall, 87 percent of the sites were validated usually by bone or CT scans.

■ The hospitalized patients completed all sections of the computer questionnaire. One patient who was vomiting profusely insisted on completing it.

■ When we first created this computer program and tested it in the general public, three subjects did not complete one section of the McGill Pain Questionnaire, perhaps because they were pushing the "next" button too quickly. We fixed the problem.

■ How long did they take to complete PAINReportIt? ■ hospitalized patients, really sick people, took on average 17.3+7 minutes.

■ outpatients from radiation oncology took 11.4+5 minutes.

■ general public sample took

14.5+6.1 minutes.

■ These results are important since the paper and pencil tool takes 10 to 15 minutes, but the data must be summarized, interpreted and entered in the computer for research or quality assurance purposes. There was no difference in the amount of time that it took people with computer experience and those who had never touched a computer, to complete this program.

■ We were very excited about the acceptability numbers. On a scale of 0-13, where 13 is maximal acceptability,

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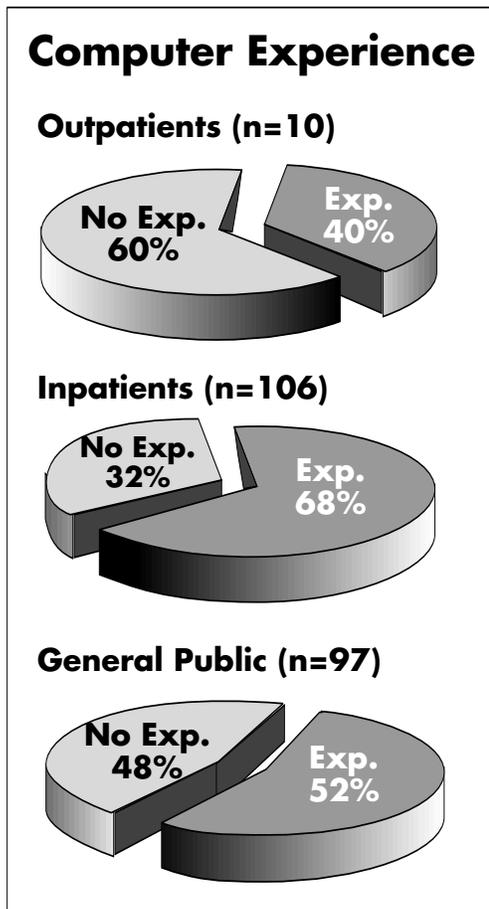


Figure 5

CALENDAR OF EVENTS

June

28 PSONS Board meeting

August

1 Quarterly deadline - Women's Health Issues. Guest editor: Cathy Goetsch

23 PSONS Board meeting

September

15-16 ONEC presents Fundamentals in oncology nursing (see also October). Swedish Hospital.

20 Government Relations Committee sponsors an educational meeting

October

17-18 ONEC presents Fundamentals in oncology nursing (see also September). Swedish Hospital

25 PSONS Board meeting

November

1 Quarterly deadline

15 Getting nurses interested in early detection and prevention

29 PSONS Board meeting

January

17 Fostering Hope, Mary Ersek RN, PhD

24 PSONS Board meeting

February

1 Quarterly deadline

21 Fatigue and its treatment, Lillian Nail RN, PhD

Goetsch website address

Cathy Goetsch wanted to let folks who attended her presentation at the symposium know the web address for questions about adoption & family history situations. Managed by a friend of hers for support and resources, it is: www.aiml.org.

Lymphoma: A Professional and Personal Viewpoint

Marilyn Patterson, RN, MSN, ACNP, OCN
Edited by Gloria Winters, RN, MN

I am so excited to see this room packed with dedicated, committed oncology nurses. I will refer to you as macrophages, because macrophages are the cells that go out and do all the work in the body to clean up messes and protect us from things. And that's exactly what we do for our patients. So from this day forth, you are a macrophage.

Let's talk about a case study of a young woman with non-Hodgkin's lymphoma. This young woman was a 35 year old white single female, divorced, with three children, receiving no child support. She was the financial and emotional support for those three kids. Interestingly, her profession was that of a bone marrow transplant nurse. She presented with a very large painless supraclavicular lymph node. She knew that it was there for about six months. Because it was not painful and because she was a busy mom, working every day, and because she was not sick, she did not follow through for a checkup. She

had no B symptoms. She was diagnosed with a stage IV follicular mixed cell lymphoma. She was told she was not curable.

So think about this young woman. You're oncology nurses. Think for a moment, if this was you, and you had to go home and to tell the three kids. Talk about stress, and we frequently talk about stress, this was an extremely stressful situation. But believe it or not, she's alive, and she's here today, because it is me. This is a picture of my three children, and that was 15 years ago. I'm approaching my sixteenth year of survivorship with lymphoma, and I am so proud.

But a cartoon by Gary Larson portrays more accurately how I felt.

Let me talk about toxicity and complications. Tumor lysis is critically important in lymphomas because when they have bulky disease, they can easily develop tumor lysis. In the old days we put patients into the hospital faster and hydrated them, hydrated them, hydrated them. And then we gave them their chemo and we kept them a few more days and hydrated them and hydrated

them. We don't do that anymore, so it's critical that patients understand tumor lysis and are told to drink. Paraneoplastic syndromes are common in your small cell lung cancer patients, but they're also very common in the lymphoma population. Neuropathy, from the drugs that you give the patients, is a problem. Depression - it's a very difficult disease with a black cloud hanging over the patient's life, whether they're in remission or not. Bone marrow suppression can occur, most certainly with the drugs, but also scarring can result. Organ toxicity we know, congestive heart failure from our adriamycin. Thyroid failure can happen with chemotherapy as well. Renal failure, because we didn't properly hydrate.

Ovarian and testicular failure. Let me tell you, folks, we think that our hormones are a pain in the neck, but trust me, having them is far better than not having them. We talk about our drugs putting patients into menopause. Ovarian failure has no similarity to menopause. Ovarian failure is exactly that, it is an abrupt drying up of the ovaries or the testicles. Menopause is a normal, gradual process that occurs with aging. Your body has some time to adjust and adapt. Yes, you have some symptomatology, but with complete ovarian failure, it is one day you have hormones, the next day you do not. And we do not really have good data and

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Patient-Centered Pain Management

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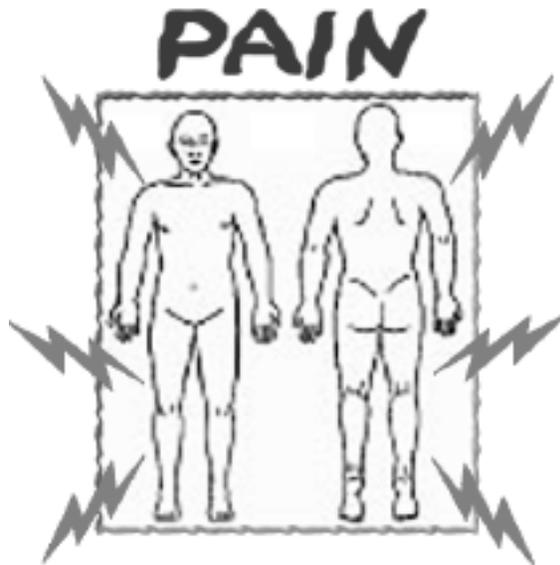
the average scores were between 11.1 + 1.7 and 11.8 + 1.4. Patients found PainReportIt© a very acceptable way to report their pain.

In conclusion, we demonstrated the feasibility of this idea, identified some program changes that we already made, and clarified ideas we are pursuing in current studies. PainReportIt© is an innovative method of amplifying the patient's voice related to the pain. If health care centers seek more time efficient, patient centered ways to monitor the health status, this method might be a very effective way of doing so. We believe this technology is an alternative way to elicit the essential information that patients need to share with clinicians about their pain in order to improve the efficiency for doctors and the nurses. We want the computerized tools to augment clinical practice rather than replace providers. We want to let the patient tell the computer the simple questions about the pain and leave it to the health professional, who has expert skill and knowledge, to do the more complex assessments. We found in our focus group work that patients are definite, they do not want the

computer replacing their doctor or nurse. They were concerned that because of managed care, we were developing PainReportIt© to take the doctor or nurse out of the pain assessment loop. We don't want to do so, but we want to improve the efficiency in health care so that doctors and nurses can deal with those issues that are very, very difficult to program a computer to do.

Currently we are conducting a couple of studies in the Puget Sound area and getting ready to start another study in Arizona. Look for results of these studies in the literature or at future PSONS meetings where we will share additional information about amplifying the patient's voice in pain and symptom management

using computer technology. Additionally, look for an innovative teaching tool that we are developing at the UW School of Nursing using some of the research data that we've collected over the past decade. This program, developed with funding from the Robert Wood Johnson Foundation, is called TNEEL (Toolkit for Nursing Excellence at the End of Life Transition). We will provide a CD-ROM free of charge to every school of nursing in the country and to about 1000 clinical agencies. TNEEL will be an innovative teaching/learning tool for nurse educators, both in schools of nursing, and nurse educators in clinical agencies to use multimedia teaching tools to improve care to dying patients and their



families. Agencies interested in obtaining a free CD-ROM should contact me at diwilkie@u.washington.edu. The CD-ROM will be available in September and we will teach people how to use it at a hands-on workshop held at the Space Needle on August 2, 2001. Contact the UW CNE department and ask about "Weaving End-of-Life Care into Nursing Education" if you or a colleague is interested in attending this inaugural workshop.

With our development of TNEEL we have come full circle. We are using what we learned in the very first study about pain behaviors to be able to teach about pain control behaviors in clinical care. These video clips help us to be

able to recognize that when we give voice to patients in a patient centered way, we interpret their behaviors cautiously based upon their intent. We can give voice to their sensory aspects of their pain by using standardized instruments as much as possible. As we move forward with the computer technologies available to us, we'll be able to use standardized instruments in a much more efficient way. We believe these innovations can be integrated into our clinical care. We hope that our research will help you integrate evidenced-based practice into the cancer care. In doing so you will amplify the patient's voice in the management of pain and other symptoms. Then the voices I hear will be silenced!



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PSONS PROFILE

Colette Chaney

By Gloria Winters and
Donna Carrera

When you spend time with Colette Chaney you get a sense that, with this remarkable woman, the best is yet to come. She is a woman of adventure, thoughtfulness, and curiosity. Her career is marked with work in psychology, pediatrics, research, and management - all in the context of oncology nursing.

Colette went to college with an interest in psychology - and a desire to work in a service capacity. She first earned her Associate of Arts in Psychology at Essex Community College in Maryland. During that time, she worked as a mental health counselor in an adolescent psychiatric facility along side of clinical psychologists. She knew that this work appealed to her, but also felt that going the distance for a PhD was more than she could manage on her own at the time. Nursing, however, was within reach, and would allow her to work professionally in this field.

Upon completing her AA degree, Colette kept up her work at Sheppard and Pratt, and entered Towson State University in the pursuit of a bachelors degree in nursing. Here she was introduced to the field of oncology nursing, and upon graduation she began working full-time on the pediatric oncology/BMT unit of Johns Hopkins Hospital. She had also been able to transition into a nursing position in her unit at Sheppard and Pratt, so for the first year out of school continued to work there part-time.

Then in 1989, Colette decided to try something new. Looking for adventure, she joined the traveling nurses, providing nursing care to people all around the country. She specialized in pediatric oncology and bone marrow transplantation, and had the opportunity to work at seven different major medical centers and pediatric hospitals. Approximately every thirteen weeks she moved to a new place and began

work, without the benefit of on-site orientation. For the next year and a half she went from Wisconsin to California, with stops in between at New Orleans, Chicago, Denver, and Phoenix.

Colette says that before she left on this venture she was a "classic Type A" personality - extroverted, self-confident, structured, and in control. The first two qualities were essential to embark on this venture, but flexibility was the essential take home lesson from the experience. Colette opened her eyes to the diversity in nursing practice, learning that there is more than one way to do things, and more than one way to do things correctly. Though frustrating at times, Colette stated that this opportunity taught her how to let go of some control and let fate help move her along a path. An already self reliant person, she feels that she grew both personally and professionally, learning to tolerate deviation and change.

In April of 1992 Colette returned to Chicago. She began working at Columbus Hospital as an assistant clinical nurse manager on their pediatric unit, but soon moved on to become a research nurse clinician in hematology/oncology at the Rush Cancer Institute. She describes this position as her favorite job so far, and for good reason. Working with the director of the program, she was afforded a great deal of autonomy and an expanded practice, developed wonderful relationships with patients, and experienced collegial practice in a large and diverse team. This fruitful time allowed her to



Colette Chaney

co-author many articles on issues related to leukemias, cell kinetics, and research therapies. One of the nurses she worked with was Patricia Jassak, and Colette ended up becoming the lead author with Patty on the leukemia chapter in *The Cancer Source Book for Nurses*, published by the American Cancer Society.

Colette's return to Chicago was spurred by a developing relationship with Robert Green. She had met him during her stay there with the travelling nurses, and they were married in 1996. We have him to thank for her presence here, as he decided to take a job with Microsoft in 1997, and they moved here. Colette left behind two courses toward her Master's degree, and a century old house under restoration.

Colette considered returning to pediatrics when she got here, and actually walked the halls of Children's Hospital trying to decide if it was time. It's obvious when you talk to her that she loves this area, and you get the feeling she may head in that direction again sometime. But it would have required renewing that specialty knowledge base, and Colette decided to start with a staff nursing job on the hematology-oncology unit at the University of Washington. She kept her eyes open

for something different and in the fall of 1998 an unusual position opened.

CTCA (the Cancer Treatment Centers of America) was planning to open a new program in disease management in Seattle. Colette had some reservations about the program, but considered their philosophy of cancer as a chronic disease, looked at the proposals, and reflected on her experiences as a patient advocate. It was clear to her that the numerous resources available to cancer patients didn't extend into the realm of the insurance industry. She decided to take the position of senior oncology case manager, striving to provide an advocate for patients from within the insurance industry. She serves as a consultant for CTCA at Premera Blue Cross in what can be a very difficult, challenging, and sometimes isolating role. Her goal is to build collegial relationships in the disease management program, and across the treatment team. The job has been a good fit, in that Colette always had an understanding of and sensitivity to the unique financial issues in oncology, especially after her work in research.

Despite her workload, Colette is quite active in PSONS and ONS. A member of ONS since 1993, she belonged to the Chicago Chapter when she lived there. She obtained her certification in 1994. PSONS was a logical starting point for becoming acquainted with oncology nursing in Seattle, and she has continued to expand her professional network. She regularly attends ONS and PSONS edu-

cational events, including the most recent communications workshop. She values opportunities to give something back to the organization, and has presented at ONS several times. This year was her first to serve on the planning committee for the PSONS symposium, working on publicity, speakers, and syllabus. She has eagerly re-upped, citing the pleasures of working under the leadership of Jormain Cady and Linda Hohengarten. She has also assisted on the PSONS education committee.

A person with a background in psychology knows the importance of finding ways to manage stress. So it is not surprising that Colette makes it a priority to plan time away from nursing. She enjoys a variety of extracurricular activities. Some of her favorites include spending time with friends going to restaurants and tasting wines, listening to music, and taking in the symphony. To complement these quieter diversions, she takes on one new venture each year. This year she went on her first backpacking overnight trip, with her husband and two other couples. One day later, she was already planning the next trip. In past years she has taken on kayaking and downhill skiing, among others.

As of this moment, Colette does not know where her career will take her next. She remains open to new opportunities, and her love of adventure will surely take her down uncommon paths. ■

NEWS BITES

Welcome to SPU students

Welcome to Linda Kitzmiller, Donna Carrera, Makayla Blank, Corinne Schroeder, and Vladi Grib, students at Seattle Pacific University. As part of their coursework on professional development they will be serving as interns with PSONS for the next year and a half. They are assigned to specific committees and will be participating in a variety of assignments. Look for them at educational events, read their articles in the

newsletter, and look for their assistance with member development. Thanks to the great faculty at SPU for this wonderful way to bring us together.

New Advertising Editor

Welcome to Linda Eaton, the new advertising editor for the Quarterly.

New Arrival

Congratulations to Jormain Cady and her family, now blessed with the presence of Claire Amanda Jane Bramhall, born 4/7/01.



Puget Sound Chapter of the Oncology Nursing Society

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Letters, articles and announcements are requested from all PSONS members and other readers on topics of interest. Submissions and questions should be sent in electronic format to newsdesk@psons.org.

Neither the Puget Sound Chapter of the Oncology Nursing Society, the Oncology Nursing Society, the editorial board of the Quarterly, nor the American Cancer Society assume responsibility for the opinions expressed by authors. Acceptance of advertising does not indicate or imply endorsement by any of the above-stated parties. Published four times a year by the Puget Sound Chapter of the Oncology Nursing Society with the support of the American Cancer Society.

Call PSONS @ 206-283-9292
between 9 a.m. and 5 p.m.

WELCOME TO NEW MEMBERS

New members since February 1, 2000

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Multicare Allenmore

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PSHCS

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Overlake Radiation

Carol Mickley

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Cynthia Nelson

Stevens

Julia Phillips

Harrison Memorial

Elizabeth Poplawski

Moses Lake Clinic

Leah Raine

Swedish

Linda Raymer

Group Health

Karla Shultz

Overlake

Ruth Smith

Providence

Bonnie Stiff

Tacoma General

Kelli VanWagner

Swedish

Mistie Whittum

St. Peters

Dora Woodward

St. Francis

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Discussing End of Life

Continued from page 6

that introduces the reader to the 5 WISH-ES document. A fabulous tool that guides the patient in making end of life care decisions.

www.ama-assn.org Check out this site and review the EPEC information: (Education for Physicians on End of Life Care)

www.lastacts.org Committed to bring dying out in the open and to pursue better ways to care for those dying.

www.eperc.mcw.edu The End of

Life Physician Education Resource Center (EPERC) is a central repository for educational materials and information about end of life (EOL) issues.

www.partnershipforcaring.org Devoted to raising consumer expectations and increasing demand for excellent care at the end of life.

www.aacn.nche.edu/elnec/ National education program to improve end-of-life care by nurses from the American Association of Colleges of Nursing.

Year 2000
PSONS Quarterly
WRITING AWARDS

**The winners of the PSONS Writing awards
for the publication year 2000 are:**

Aurora Brandvold

PSONS member

for her article on the nursing role in clinical trials at FHCRC
in the February 2000 issue.

and

Saundra Akers

non-PSONS member

for her article on protective diet guidelines for the immunosuppressed
patient in the November 2000 issue.

Articles were judged for clarity of writing, timeliness of topic, usefulness to practice, and the ability to stimulate interest by the editorial board of the Quarterly. Recipients will have be invited to attend the "Communication Game" conference in the fall, and may attend a professional educational conference of their choice with a \$75 scholarship from PSONS.

Congratulations, Aurora and Saundra!

COMMUNITY CROSSINGS

Susan G. Komen Foundation

Linda Kitzmiller

PSONS has had a long-standing relationship with the Susan G. Komen Foundation. Many members of PSONS and other health care providers use the materials provided by the Komen Foundation to educate patients and their families. The Komen Foundation provides research grants and educational material pertaining to breast cancer. Komen was founded in 1982 by Nancy Brinker to honor a promise she had made to her sister Susan G. Komen, who ultimately died of breast cancer. The Foundation's mission is to eradicate breast cancer as a life threatening disease through research, education, screening, and treatment. There are 115 Komen affiliates in various cities across the United States.

Since its inception, the Foundation has awarded more than 500 research and project grants totaling over \$60 million. This year Fred Hutchinson and the University of Washington received grants from Komen. The Seattle affiliate awarded \$1.3 million in grants locally

for the year 2000. PSONS member Dr. Fran Lewis is among those who have benefited from these funds, as she described at her presentation at the symposium this spring. In addition to awarding grants, the local affiliate also supports nonprofit agencies providing screening, support, and treatment specific to breast cancer. Because the majority of the work performed at the Foundation is provided by volunteers, 90 cents of every dollar raised supports the Foundation's mission.

Komen provides booklets on breast health, early detection, support services, and information on recurrence to nonprofit agencies at no cost. A recent collaboration between PSONS and Komen resulted in a book titled Finding Your Way to Wellness. The book is meant to

be a guide for newly diagnosed breast cancer patients. This book provides information and resources on a broad range of topics related to breast cancer.

It is distributed to hospitals in the Puget Sound area at no cost.

Komen derives their funding through private donations, golf tournaments, and various other fundraisers. The largest fundraiser is The Komen Race for the Cure. It is the largest series of 5K runs/fitness walks in the world. Since its origination

in Dallas in 1983, The Komen Race for the Cure has grown from one local race to an international series. More than one million participants are expected in 2001. This year the race in Seattle will be held at Safeco Field.

Foundation Information

The location for the Puget Sound affiliate is:

The Susan G. Komen Breast Cancer Foundation

1900 No. Northlake Way #237
Seattle, WA 98103
206-633-0303

E-mail: www.komenseattle.org

To receive education material call Cheri Minear at 206-633-0303 or email her at: Cheri@PSKomen.org.

Information on grant proposals can be found at www.komen.org.

Proposals must be submitted no later than October 1, 2001.

SNAPSHOTS FROM THE SYMPOSIUM



Clockwise from left: Judi Updegraf is honored for her contributions to PSONS; Lecture participants enjoy themselves between speakers; A poster session; Symposium speakers Betty Gallucci and Diana Wilkie.

Lymphoma: A Professional and Personal Viewpoint

Continued from page 10

good ways to help these people through this very difficult time. It is not just infertility, and that is an issue as well.

Okay, the list goes on: lymphedema, cataracts, diabetes, secondary malignancies, chronic pain. Folks, you don't need to have a solid tumor to have pain. And some folks think people with leukemia and lymphomas don't have pain because they don't have a solid tumor pressing somewhere. That is not true. Nausea and vomiting. As good as we are, there are still people with breakthrough nausea and vomiting. And of course there are infections.

Now I can tell you as a person being treated, and I had multiple treatments and multiple relapses, but again I am so thankful to be here. I did develop neuropathy, I did develop some depression, I did develop some bone marrow suppression with scarring. I did develop hypothyroidism, I did develop complete ovarian failure. I have a cataract in my right eye, I did develop Type 2 diabetes. I did develop a secondary malignancy. I have a melanoma on my forehead and it's been excised. I think I'm on my ninth surgical procedure for cutaneous melanoma. I do have chronic pain because I have fibromyalgia that appears to be extremely common for some reason in the lymphoma population. And I no longer have nausea and vomiting, in fact I eat like a horse. I do have problems with infections. When I get sick, my husband will bring home a little bug, and he's better in two days, and I have it for five, seven weeks with multiple, multiple antibiotics.

I have to tell you a story about my life a little bit. I prayed and prayed as a single mom to be cured. During the time when my children were young and I didn't know what to do, a man came into my life. He was willing to be involved with me with these three monster children. They looked real cute in a picture, but they were monsters. And not only did he accept my children, he accepted the fact that I had cancer. He said I think you're a hero, and I want to marry you. We will be married now almost twelve years and he has helped

me and held my head through some horrible times, and he has helped raise my children. So here there was not a cure but there was a miracle. And that miracle healed me. I may never be cured, but I have most certainly been healed.

I must tell you I had a lot of problems with my treatments but fatigue was my number one and biggest one. It was so difficult for me because I was a high energy person and I had a lot to try to do in my life. And believe it or not, guys, it is the number one complaint voiced by cancer patients and it affects all aspects of quality of life. We talk about quality of life, we talk about it being a multi dimensional syndrome, symptom, domain. I can remember clearly, I was married to the husband who I adored, but I was so fatigued, I didn't want to have sex with my wonderful husband. But I was also so fatigued, I didn't want to have sex with Mel Gibson. We knew there was a serious problem.

Two critical points I want you to take home. Assessment and intervention is your job as macrophages. There is an example of Giorgio Armani with cancer related fatigue, and he no longer went to work and designed \$10,000 suits, he was at home acting like just the rest of us. So how about assessment, guys? We're going to make this short and sweet but it is very important. You need to use a patient self reported scale that has been shown, study after study after study, as being the most reliable. It's just like Margo McCaffrey says about pain - pain is what the patient says it is, fatigue is what the patient says it is. Obtain a baseline, then ongoing, and post treatment to follow that patient to see in fact if they do get better over time. Or perhaps they get better, but then they develop the fatigue again - that's a red flag that maybe something new is going on, like the hypothyroidism or type 2 diabetes. Assess for all four domains of quality of life, and that means cognitive, that means spiritual, that means physical, and that means psychosocial. Document your assessments on a nursing flow sheet consistently. If you can use some form of a number system, the next nurse coming behind you knows

exactly where that patient scored on that assessment. And find out from each and every one of your patients on each and every visit: what is it that that patient is no longer able to do that they were able to do last week or last month? Simple question.

We need to talk about cognitive fatigue, because it's true, it's real, I have it. I'm so glad I'm speaking in the morning because by afternoon, I would not know my name. This cartoon is an example of cognitive fatigue. Superman has had some chemotherapy and he says to his wife, dang, now where was I going? And I got to tell you, guys, I have a master's degree and people expect me to be smart. Yet when I moved to South Carolina it took me one full year to learn my phone number. I had to put it in my pocket and carry it with me because I just could not learn my new phone number. I forgot my son's birthday. Now I didn't forget to send a card and a gift, I forgot when this child was born. This child weighed 9 pounds, 8 ounces, 18 hours of labor, I had natural childbirth - this is not something a woman forgets! But I did.

Okay, how about interventions? We want to promote activity, yes, we do. But do we want to put somebody on a treadmill when they've got a hemoglobin of 9.2? I don't think so. Exercise as appropriate for that patient. Walking might be just fine. Please, please, please consider a cancer rehabilitation program for your patients. Make a referral, have them properly assessed, hopefully by a physiatrist - a physician who specializes in physical medicine. Please, please, please, aggressively treat anemia so you can get that patient through rehab, and get them into full activity again. Treatment can be erythropoietin. I'm sure you're all familiar with it. Some settings give it three times a week, some settings give it once a week. We are learning more and more about the value of erythropoietin, not just for building red blood cells, but there's actually erythropoietin receptors on the brain. Perhaps if we use it more aggressively, we can reduce some of the cognitive fatigue as well. There are actually stud-

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The Garden

Dan Shapiro, PhD
University of Arizona

My parents always kept a small plot of land in the backyard as a garden. It was roughly the size of an average bedroom. Pretty small. But they hovered around that garden all spring and summer. They plowed, fertilized, hoed, mulched, and sampled the soil. They watered. They pinched leaves. At night they pointed in hushed tones to pictures in books and seed magazines which eventually accumulated and took over the dining room.

And then a few months later there was a crop of something. Usually a crop of mutant something. One year it was zucchini. Thousands of zucchini crawled out of the garden as if they had been cast in a late night horror film. Neighbors came home to anonymous zucchini breads, pies, and cakes delicately balanced inside of screen doors or stuffed into mailboxes. Dad contemplated keeping a huge zucchini next to the bed in case there were intruders.

I was diagnosed during the planting month. Dr. Brodsky talked with his arms crossed in front of him, listing the chemotherapy agents I would be taking and the side effects. Prednisone. Procarbazine. Nitrogen Mustard. Vincristine. The latter two would cause nausea and vomiting. It sounded

unpleasant.

A few nights before I was schedule to start treatment I called a friend, the only person I knew who was my age and had had cancer. He muttered five gruff words into the phone.

“Chemo’s grim man, get weed.”

I trotted into the living room and nonchalantly announced to the family that I was going to buy marijuana to help with the nausea and vomiting.

There was an oppressive silence, punctuated only by the rapid tapping of my mother’s finger on an armchair.

Then she began, her voice carrying that staccato edge she generally reserved for my father. She told me in no uncertain terms there would be no drugs in the house. She berated me about the dangers of illicit substances, the horrors that visit lives filled with addiction, and swore to me that her roof would never shelter a drug user. She ended her diatribe with an outstretched finger.

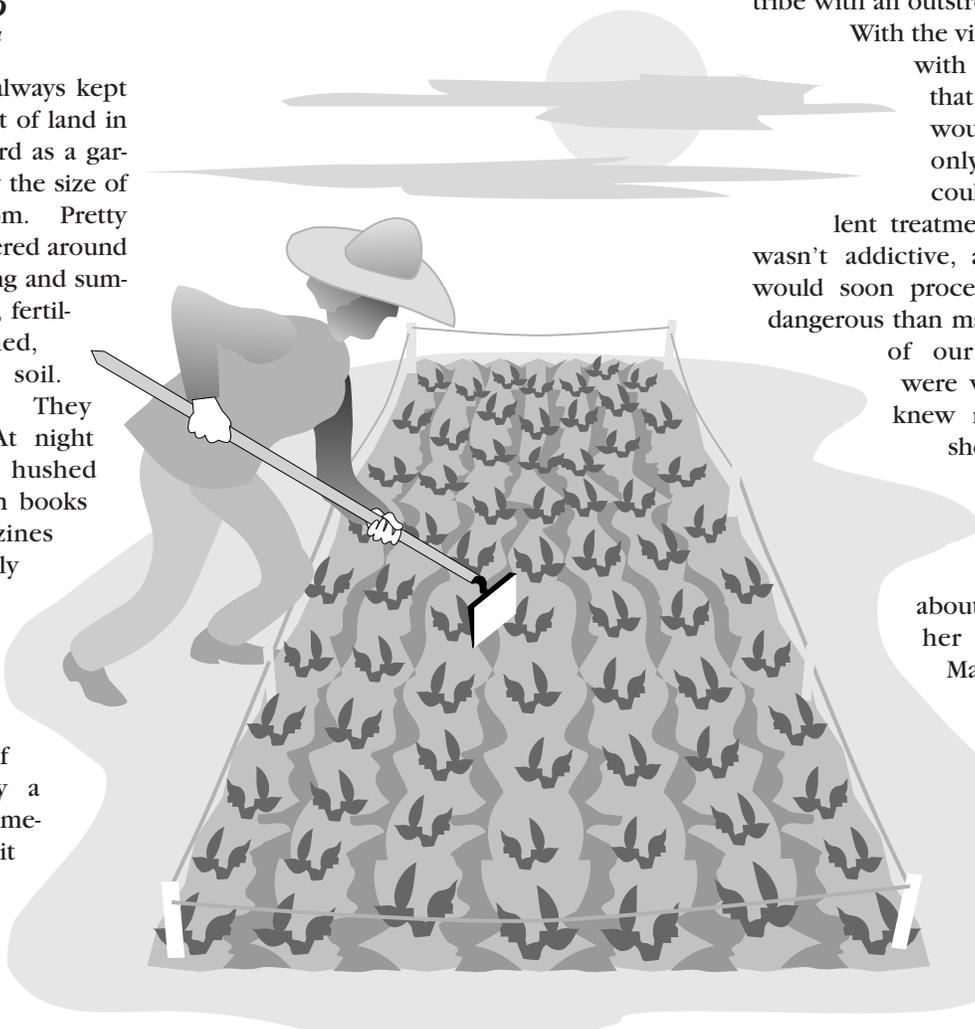
With the vigor of an adolescent with a cause, I argued that for me, marijuana would be medicine, the only medicine that could temper the violent treatment I faced. That it wasn’t addictive, and that my body would soon process toxins far more dangerous than marijuana. At the end of our conversation we were where we began. I knew my mother. Once she was entrenched in a position argument was futile. I retreated.

I still wonder about what happened to her during the night.

Maybe she studied the pamphlets the doctors provided, maybe she woke up in a sweat, the remnants of noxious dreams about her

son and chemotherapy still etched in her mind’s eye. I don’t know. But I do know this. The next morning my mother ran her finger down the “smoke shop” listings in the phone book. She called a number of establishments, asking detailed questions and jotting down words like “bong,” “carb,” and “waterpipe.” Then she gathered her keys and purse, and thirty minutes later was walking down the aisles of a head shop called “Stairway to Heaven,” taking notes and carefully checking the merchandise for shoddy workmanship.

I was sitting on the ground in the backyard when my mother’s car pulled



into the driveway. A few moments later she appeared on the back porch waving a three foot bong over her head. She proclaimed her find with the same robust voice she'd used for years to summon my brother and me to dinner from afar.

"Is this one okay? They didn't have blue..."

When I entered the house she delicately handed me the bong and some money. She brushed dust from my shoulder and softly told me to do whatever I needed to get the marijuana. After a quick phone call I left to get my purchase. When I returned with the small baggy my mother asked to see it. I felt a sharp adolescent fear, conditioned from years of living under my mother's vigilant eyes. I handed it over. She looked at the small bag. Incredulous.

"Where's the rest of it?" she asked.

"That's it ma," I said. She squinted at me. "I swear, ma. That's it."

She murmured quietly. "Honey, give me the seeds."

I thought of huge zucchinis.

When my father learned of my mother's plan he clipped two articles out of the part with the titles: "Police Raid Yields Results," and "Drug House Seized." He put them under a magnet on the refrigerator and underlined the worst parts. That night, as we prepared for dinner mom read them, nodded soberly, and said, "Bring them on."

Through that summer my parents plowed, fertilized, hoed, mulched, and sampled the soil. They watered. They pinched leaves. And that August the mutant crop arrived. Ten bushy plants grew over 11 feet tall in our backyard, eclipsing the sunflowers in front of them. Far more weed than I could have smoked in a lifetime.

Mom's garden became a metaphor for me, that in the face of illness we must take square look at what's truly important to us.

Reprinted from the book "Mom's marijuana: Insights into living," by permission of the author.



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ies that show that little micies that were given erythropoietin, and the other little micies weren't given it and then they were all thrown in a maze of water. The micies that did get the erythropoietin were able to learn the maze much, much quicker and were able to find the little beach area or wherever they were supposed to hang out. They got to spend more time on the beach than the other micies, okay? And you're going to hear more about that, that is definitely understudied, it is still in the animal studies.

Also critical, guys, is making sure you have all the building blocks to build red blood cells, and that includes folic acid. I developed through my treatment a severe folic acid deficiency where I had next to no folic acid in my body whatsoever. I also, believe it or not, developed scurvy. Yes. Not diagnosed by my oncologist, but by my dentist.

Iron deficiencies are common. So I believe, it is my opinion that a patient on baseline needs to have those three studies done before you even give them one drop of chemotherapy and/or radiation. We need to know how they're coming into this. We need to give them as much help to get through this very, very critical difficult time as possible. We need to provide education, and that means staff. Guys, we are getting more and more and more research about this fatigue and we're going to learn more about it and you need to be updated on it, and about the only way you're going to do that is to have conferences. Patients need to understand it, but so do their caregivers because they're even more confused by it than the patient is.

And thanks to the biotech industry, we have found new technology, we have growth factors. Now I'm sure there's some of these biotech scientists that learned it the hard way, like in the Gary Larson cartoons, but we are thankful for what they have done.

And what has almost 16 years of survivorship done for me? Well, it took those children and it raised to be these great big wonderful people. Well, some of them are big, like my son. My daughter was married a little over a year ago. And her name is Harmony and she lives in Connecticut. My son, Ben, and his

beautiful wife, Tracy, and I hope they did not sneak in here today, but they live here in Seattle. I have my blessed husband Chris. He happens to be a geriatrician, which means he treats the elderly, and he comes exhausted. He works 12 hours a day and he's absolutely beat, and his patients are all 80 years old and older, but you know what? When he comes home at the end of the day I look like a babe. So this is my wonderful family, and being allowed to live and raise these children was absolutely the greatest gift anybody can ever have. And you have the power to help this happen.

Who can say with certainty that one will live to see tomorrow? None of us know that. We're on the highway, Interstate 5, all kinds of things. You had an earthquake last week. I mean, you never know what's going to happen, right? So the quality of our life and the protection of each and every day is critical not just for our patients, but they're critical for us too. I hope today I got you ready to see the difference and the impact that you have as nurses on your patients' lives.



Editor's note:

This presentation by Betsy Patterson was transcribed for our use in the Quarterly. I deeply regret that the full presentation was not able to be included in this newsletter, as Ms. Patterson more than ably accomplished her goal of bringing those in attendance up to date on the world of lymphoma in a delightful, engaging, and knowledgeable presentation. She presented information on current issues and trends in diagnostic work-up, classification and staging, epidemiology, risk factors, prognostic factors, treatment, and investigational drugs. Because it was impossible to do justice to her update in these pages, I have chosen to present her concluding remarks, that capture the personal as well as the professional viewpoints she shared. For those wishing to read the full unedited presentation, please visit the website and use the following address: http://www.psons.org/psq_articles/vol24_no2/keynote.htm. Please note that this address must be typed in as it is not a direct link from our page, out of respect for member privileges. You may also obtain it from Gloria Winters at newsdesk@psons.org or 425-485-0105.

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