When I first entertained the idea of using the dragon as a symbol of cancer, I was researching it from the English historical perspective. In the years of early Christianity there was the need to slay the pagan beasts. The saints such as St. George, slayed the enemy—"a dragon", because it needed to be conquered before it overwhelmed the hero and destroyed the villages.

When I apply this to our oncology patients, I think of the extensive symbolism that we use around the "battle" with cancer. Patients see cancer as the enemy to overcome, and the foe like, the dragon in old English times, to be fought and to be slayed. My thoughts then turn to the patient with advanced cancer, for whom this mythical creature is typically depicted as gigantic and powerful, not unlike the diagnosis of cancer. Their cancer or their "dragon" will ultimately lead to their demise and to the end of their life journey.

So what if rather than slay the dragon, they learn to tame, to harness, to find another way to live with this beast that has entered their lives and creates chaos and fear.

In fact, as I learned more about dragon lore I found that dragons are believed to have major spiritual significance in many religions and cultures around the world. Not only are they depicted as gigantic and powerful serpents or reptiles, but they have magical and spiritual qualities as well. Certainly they have been portrayed as great foes of heroes, but also as great teachers of wisdom.

What can we do as oncology nurses to help patients reframe their relationship with their advanced disease to assist them in the taming of the dragon so that they do not live in fear or are incapacitated by their diagnosis? But instead, are able to feel empowered to make the most of their time left in their journey, to find a way to maximize their quality of life, their interactions, and their relationships.

Continued on page 3
PRESIDENT’S MESSAGE

It’s Not Always What You Know, It’s Who You Know

Renita Vance
PSONS President

Ah-h-h, summer! A wonderful time to enjoy a different pace, with outdoor activities and picnics, time with family and friends and hopefully some time away from work! I hope you are enjoying these last few weeks of summer—it’s been a glorious one in the Pacific Northwest this year!

This has been a challenging year so far with the decline in the economy and seeing some of our membership lose their jobs and others taking cuts in pay or hours. It increases the stress we all feel in these uncertain times! It just reinforces for me the importance of organizations like PSONS where we can meet with colleagues and friends on a regular basis. When I reflect on the job changes I’ve made in my career, they are all a direct result of someone recommending me for a position. The old saying “it’s not what you know but who you know” is partly true when it comes to job opportunities. Staying in touch with colleagues and friends through the chapter can open doors to opportunities we might not otherwise know about. I encourage all of you to stay involved and participate in the many activities that PSONS has to offer!

Summer is also a time when we take a month off from our regular educational meetings. Juanita Madison has done a fabulous job of scheduling great educational programs for us each month and arranged for continuing education credit for each meeting. We’ve averaged about 30 at each educational program—a small number when you consider the membership of our chapter but a great turnout, nonetheless. You can find the schedule for the rest of the year elsewhere in the Quarterly. I hope you will schedule these chapter educational meetings into your calendar! We have a short business meeting at the start of each educational program and there are always several members of the board there so it’s a great opportunity to network with colleagues from other institutions and share issues and concerns with the board. Our next educational meeting is on September 23 and it will be a little different format focused on chapter activities. I hope to see twice our usual number at the September meeting!

The board has been busy planning a total update and revision of the PSONS website. The goal is to bring us current with the technology we have available and have a visually interesting website with current information as well as functionality that makes it easy to navigate. Natasha Ng and Cherie Toft Hansen are working hard to get the website ready to roll out to the membership by the September meeting. Stay tuned for the website rollout!

These are just two examples of the activities the board has been working on this year. We have a wonderful board who are committed to the chapter and are all working hard on various projects. We have quite a few chapter members who have volunteered to help with service projects, at educational programs, etc.

EDITOR’S NOTES

Linda Cuaron RN, MN, AOCN

The newsletter has a new look and some exciting new plans for bringing your clinical ideas and experiences to our pages. We have switched form using an offset press to photocopy, which is faster at no additional cost, plus we have the option to have some color on our front and back page. Let us know if your like the new look.

At the last Board meeting we discussed an idea to make it easier for you to contribute to the Quarterly. We’d like to post a small bulletin board in your staff lounge and post some questions and ideas that we’d like you to comment on. You would fax the completed page to the editor and your input would be part of a new column in the newsletter. We will also be asking the nursing faculty in the area to encourage students to write for publication.

The next issue will mark the end of my tenure as editor. There will be an article on the “nitty-gritty” of how our newsletter gets from the computer to your mailbox. Ours has been an award-winning newsletter with a proud tradition of providing a first experience for new authors and means of communicating with all of our members. The role of editor (or co-editors) is a great experience and a wonderful way to serve our oncology nursing community. Let any member of the Board know if you are interested in taking on this role.
Continued from page 1

In summarizing parts of my lecture, I will write about sustaining hope in patients with advanced cancer. I will describe techniques I have found helpful, and those pearls of wisdom found in the literature for establishing and clarifying goals of care then, lastly, transitioning patients for their final journey.

For those we care for or care about, those who have been diagnosed with advanced disease, Stage IV, or with metastatic and/or recurrent disease it is not “If I will die of this disease….but WHEN.” Hoping for the best possible outcome, while preparing the patient for the worst outcome are not mutually exclusive strategies. It is reasonable for patients and families to prepare for a range of outcomes. There is no harm in dealing with advanced directives and preparing financial matters, even while hoping for a cure or for a miracle. Addressing or raising these questions early on in the disease process makes it easier when emotional states are less impacted by physical states. It does not make it however less difficult for us when dealing with our own discomfort about discussing difficult topics. Acknowledging that each situation is unique and each person has individual coping styles and cultural implications, will guide us in how best to approach these topics.

Lived Experience

The lived experience of the patient with advanced cancer finds any resemblance of normalcy gone. They often find themselves in a condition of crisis after the diagnosis. Normalcy can be replaced with uncertainty and fear. Instead of “what are you doing” the questions becomes “how are you doing?” They give away control of their well being to total strangers in hopes they will have the answers to questions they don’t even know how to ask. It is a vulnerable time filled with selective hearing, stress induced emotions in the middle of needing to make life-affecting decisions.

Patients end up managing the outside world of good intentions. I liken it to with what happens when a woman is pregnant: she is told all the worst stories and more advice and suggestions than she could possibly have needed, much less wanted. The internet has definitely magnified this by creating confusion, a lot of distrust, and many “what ifs?” Part of good oncology care involves trust in the relationship with the health care providers; there is actually a healing that can occur as a result of the relationship itself, a kind of ministry of presence.

Then also for the patient this lived experience with advanced cancer brings the loss of time. Time is everything for the patient, caregivers, and loved ones. So much time ends up spent on the illness and not living to the fullest, and so little time spent on joy unless the patient is intentional. The other factors that often play into the patient’s experience are lack of energy as well as the loss of control as the mighty dragon beast is confronted.

One of the things to recognize as oncology nurses is that we just get a mere snapshot of the 24/7 of our patient’s lives. Most patients really put their best face forward, as they often appear overly hopeful in their relationships with their health care providers. I have seen patients in my practice who haven’t dressed or been out of bed all week get “made” up for their clinic visit or treatment.

The picture on page one is of my Aunt Karen, and was taken a couple of weeks ago by a wonderful caring oncology nurse. She had been diagnosed with breast cancer three years ago and was on a blinded clinical trial for Arimidex vs. Tamoxifen and was having blood tests every 6 months and had increased LFTs. I am guessing they were very elevated as they scheduled an ultrasound right away. She was diagnosed with pancreatic cancer that had already metastasized to her liver…. no symptoms. She would say to me, “for a dying person I feel terrific.” Most of her symptoms these days are related to the treatment side effects. She has been a caregiver to my uncle with fairly advanced Parkinson’s disease for over 5 years (not what she had envisioned for her retirement about that time). It has been a very isolating and limiting experience for her to be a fulltime caregiver. She has a strong faith and a supportive faith community. I went with her to her first appointment; her oncologist laid it out for her very well in a compassionate framework, was very clear this was not curative, and framed it that in the best of all scenarios a good outcome, if all went well, would allow her a year.

But she had a very practical pressing need. Though she needs to hope for the best, now is the time to plan for if things don’t turn out for the worst. She really needed to get her affairs in order and start planning for my uncle’s care … now….not in crisis….avoidance and denial were a luxury. So unless we explore what is important or pressing in our patient’s lives beyond the cancer experience we miss opportunities to support them in meaningful ways.

Finding ways to stay positive and hopeful but still attend to the practical is a challenging balance. I think oncology nurses have great opportunities and unique inroads with their patients to be able to help patients and families find their own journey and to instill and sustain hope despite the inevitable.

Continued on page 4
**Taming the Dragon:** Hope Becomes an Essential Ingredient

**Continued from page 3**

**Hope and Hopelessness**

What is hope? It is an essential ingredient of the human existence. Hope maintains strength and gives substance to courage and is about believing what is still possible. It is anything that contributes to a sense of meaning and purpose. It is a trust in oneself and the future. It is a belief and an attitude that something I desire or believe in can and/or will happen. It may be grounded in our spiritual beliefs, a belief that something eternal exists, or that something sacred is around us and in us. Hope remains open to the mystery that is around us. It remains open to all possibilities, including that things may turn out other than imagined and it can still be okay. Hope becomes the anchor as we wait out the storm. Having cancer can feel like a storm, a very significant storm.

Several studies have looked at characteristics of skilled clinicians who instilled hope through their interactions with patients and they found that they included: honesty, forthrightness, confidence, good listening skills, calm demeanor, good eye contact, compassion, and the ability to allay fears and anxiety. These are characteristics that I see in many of my fellow oncology nurses and are attainable with practice for those new into the field as well.

The well-known phrase, “while there is life there is hope” has far deeper meaning for our patients and it is power in the reverse “while there is hope there is life… hope comes first and life follows”. Hope gives power to life. Hope encourages life to continue, to grow, to reach out, to go on… despite living with a serious illness.

I once had a patient who was told they had six months to live; he was one of those patients who continued to choose treatment to fourth and fifth line drugs at great cost and significant side effects.

As a former navy seal, he had endured much, and he was one of those who had chemo within days of his death. His wife said later that though she had long since made peace with what was coming, he was so proud he had lived 18 months. I remember the nurses having to find him on his lawn mower in his back acre to change his epidural pain pump. Hope can be of making it to certain events or achieving goals of making it to daughters getting married, grandchildren being born, and upcoming graduations. It can be as simple as every day living, finding meaning in their own life. It can be hope of healing relationships or having special times with family and friends. Hope of good pain and symptom control, being will cared for and supported, and hopes of a peaceful death.

What influence do we have over another’s hope? Hope increases when honest information is provided and is reduced when information is withheld. Old and Swagerty identified these factors that increase hope: feeling valued; symptoms controlled; having meaningful relationships; honesty, humor and realistic goals. While factors that destroy hope are: abandonment; isolation; lack of directives or goals; unrelied pain or discomfort, dishonesty, and feeling devalued or worthless. The oncology nurse through their own relationship, addressing symptoms, and assisting with goals can increase hope for their patients.

And obviously, the opposite of hope is hopelessness, and it is a common reaction to cancer. In most of the literature the common fears were: fear of a painful death, poor symptom management, and the fear of abandonment. To be able to allay fears and anxieties we need to have the courage to explore what they might be... it is hard to address these if we don’t ask about them. The other areas that impact or add to hopelessness are the symptoms of depression and anxiety. In Mystakidou literature review, they found that 5-26% of cases had major depression associated with shorter survival times, prolonged hospitalizations, and lower quality of life. There were 25-48% that experienced anxiety with 2-14% meeting the criteria of an anxiety disorder. Thus, when patients complain of insomnia, I often will use that as an opportunity to ask about anxiety and what you are experiencing.

**President’s Message:** Chapter Volunteer Opportunities Abound

**Continued from page 2**

It’s exciting to see people who haven’t previously been very involved in the chapter take on some of the work of the chapter. There truly are opportunities for people with very little time and for those who have a bit more time. If you’re interested in hearing what the opportunities are and about the experiences of those who have volunteered, please ask a board member or come to the next educational meeting in September where we’ll be highlighting some of these activities.

Enjoy the remaining weeks of summer! We have lots of activities coming up in the fall—Fundamentals of Oncology, IOL, monthly educational programs, service projects, website revision, etc. It will be a busy time for all of us both personally and professionally and I look forward to participating in those activities and networking with you!
Taming the Dragon: Spiritual and Religious Components May Be Beneficial

Continued from page 4

they may be worrying about. Patients will say that the quiet of the night brings many of these fears to the surface.

In a study by Chochinov et al., it was reported that the single question “Are you depressed?” outperformed longer assessment tools in identifying depression in 197 cancer patients. This is an easy practice to adopt in our assessment of our patients.

Finding Inner Resources

Spiritual and religious concerns may be awakened and intensified at this time. The spiritual/transcendent dimension is a central component of hope. Patients and families can use encouragement or permission to bring this into their awareness as an essential part of their cancer care. We, as a western medical culture, too often focus on the physical, the cancer, and not as much on the coping and spiritual components. Oncology nurses can assist in ways to explore or find meaning in the current situation. Simple questions such as “Is faith or religion important to you in this illness? Do you have spiritual or religious practices or persons that help you?” “When bad things happened before… how did you cope?” Remember, we are in a key position to make referrals to appropriate persons or encourage them to mobilize their own resources.

How do we help patients tap into their innate knowledge and healing? We can encourage them to implement mind-body intervention into their treatment plan. Gordon reminds us that mind-body approaches to healing are based on the understanding our thoughts and feelings, our beliefs and attitude, can affect and shape every biologic functioning. How someone feels physically and emotionally, how well he or she functions in the world, and the level of distress from cancer and its treatment is an important factor not only on quality of life but, we are learning, on quantity of life as well. We are coming to some understanding of these processes. Research is examining the dysregulation of the immune system and stress hormones. The finding of stress induced higher levels of cortisol and adrenaline have been found to depress the immune function and even suggested to promote tumor vascularization.

It is important to recognize mind-body approaches are based on the understanding that the mind and body are inseparable and that the central and peripheral nervous system, endocrine, immune system, and all emotional responses share a common chemical language and are constantly communicating with each other. This area of scientific study is called psychoneuroimmunology and holds much promise. Encouraging our patients to enlist these techniques can be of benefit. They look to us to provide other ways that they can help with their well being and dealing with their cancer.

Mind body approaches and techniques have been shown to have physiologic benefits of decreased stress hormones, improvements of sleep, mood, pain and enhanced immunity. The psychological benefits have shown an increase in the sense of control in addressing the feelings of helplessness and hopelessness. Stress is a very subjective experience. If patients see themselves as helpless victims and cancer an overwhelming enemy, they experience far more stress that if they believe they can do something to help themselves. Mind-body approaches are a form of self care and a way of nurturing. It is much easier to advise or suggest techniques if we ourselves have experienced them. They can be come a very important part of our own self care and wellness as well. We can help our patients overcome fears or biases; they may be curious or be looking for input about integrative therapies. I encourage patients to explore ways to add to their “tool box”- besides their chemotherapy and/or radiation that they can use for their healing and wellness.

Palliative Treatment

The Chinese zodiac dragon represents strength, health, and harmony. Finding balance around the issues of truth-telling and prognosis for the health care team has many challenges. Patients face difficult decisions, especially in advanced disease, and as their disease progresses and they are on second and third line regimens. Assumptions cannot be made either way in what they may or may not want. Patients choices vary widely in weighing of trade-offs in decisions about goals for themselves. Patients may find it hard to get or accept truthful information about the benefits and harms of palliative chemotherapy.

When Khatcheressain looked at 95 consecutive patients receiving palliative chemotherapy prognosis was discussed only by 39% if their oncologists. Values used in decision making around treatments depend on personal experiences and cultural and spiritual meaning. One study they reviewed showed that patients with cancer were willing to undergo aggressive treatment with major adverse effects for a very small chance of benefit. This was different from what their physicians or nurses would choose.

One Medicare study showed that 20% of patients who had metastatic cancer started on a new chemotherapy treatment regimen 2 weeks before their death.

Chemotherapy for metastatic solid tumors such as lung, breast, colon or prostate cancer rarely, if ever, cures patients. Its indication is to improve symptoms and provide a period of disease free or overall survival. Palliative chemotherapy can relieve symptoms and improve quality of life and in some cancers bring months and sometimes years into the realm of possibilities. What we do know is patients are unlikely to benefit from chemotherapy when they have already...
ELECTIONS & SUBMISSION OF POSSIBLE CANDIDATES

Elector your leadership is one of the most important ways to exercise your right as a member and your commitment to both the society supporting you and to the oncology nursing field as a whole. We urge you to make a powerful impact by promoting excellence in oncology nursing and cancer care through a strong and vital leadership. This was a message recently sent out by Kate Shaughnessy, Member Relations Manager, Oncology Nursing Society (ONS) in regards to the national board elections. Many of you participate in elections by reviewing candidates and submitting your vote to ensure ONS remains strong and adequately supports your needs and that of the patients and families you care for.

Currently your Puget Sound Oncology Nursing Society (PSONS) board does not have a candidate for the president elect position for March 2008 – March 2009. The president elect position includes a great opportunity to be mentored by the current president for a year and advisor from the year before. No prior experience is needed, just a passion for oncology nursing, willingness to be part of a team, active membership for at least a year and a little extra time to spend helping promote the profession and enhance patient care. Over three quarters of our membership have the necessary qualifications.

Submission of potential candidate’s names and voting for your chapter PSONS board members are your responsibility and opportunity to elect and promote candidates who will lead our chapter in the direction you envision for members, patients and the community in alliance with ONS.

I have listed the duties of the president-elect and president from the bylaws for anyone who may be interested.

DUTIES OF THE OFFICERS

President-elect
1) Learn the role of the President.
2) Assume the role of the President in the following situations
   a) Absence of the President,
   b) Inability of the President to act,
   c) Resignation of the President, and/or
   d) Expiration of the President’s term.
3) Attend meetings of the chapter Standing Committees as delegated by the President
4) Consult with the President throughout term of office to provide for continuity and smooth transition of chapter leadership.
5) Maintain chapter records associated with the office of President-elect or Vice-president according to procedures established by the national Oncology Nursing Society.
6) Perform other responsibilities designated by the Board of Directors or the national Oncology Nursing Society

President
1) Direct the activities of the chapter subject to the control of the Board of Directors
2) If not elected, appoint Committee chairs, with Board approval, for all Standing Committees.
3) Coordinate the development of chapter goals, objectives, and budget with the Board of Directors and Committee chairs of the chapter Standing Committees.
4) Monitor the implementation of the chapter goals, objectives, and budget
5) Advise the general membership and the Board of Directors of progress toward the chapter goals and objectives, healthcare issues and trends, and information from the national Oncology Nursing Society
6) Schedule, formulate the agenda, and preside at a minimum of four (4) meetings of the Board of Directors
7) Schedule, formulate the agenda, and preside at a minimum of four (4) meetings of the general membership. At least one must conduct the business of the Chapter.
8) Serve as an ex-officio member of all Chapter standing committees except the Nominating Committee
9) Coordinate the completion, review, and submission of the Annual Report according to procedures established by the national Oncology Nursing Society
10) Review and sign the completed quarterly and Annual Treasurer Reports.
11) Mentor and prepare President-elect.
12) Schedule and attend a transition meeting between the outgoing and incoming members of the Board of Directors and standing committee chairs
13) Assure that the records of the chapter are maintained according procedures established by the national Oncology Nursing Society.
14) Serve as a liaison between the general chapter membership, the Board of Directors, and the national Oncology Nursing Society.
15) Represent the chapter at meetings of the national Oncology Nursing Society and other healthcare groups as approved by the national Oncology Nursing Society.
16) Perform other responsibilities designated by the Board of Directors or the national Oncology Nursing Society.

Remember each member of our chapter, who has belonged for at least a year, is a potential candidate to help the board to determine the direction and future of our Puget Sound Chapter. If you yourself are interested or know of a potential candidate please contact the nomination committee chair Kerry Kirkby or a board member as soon as possible.
failed standard regimens, have poor performance status, and otherwise have a poor prognosis.

Why is it so difficult to talk about key factors such as prognosis or the limitations of what we have to offer? Patients may respond with denial or anger or sadness. These are very normal responses but they may be a difficult experience for the nurse. The problem is that avoidance of these discussions altogether can lead to mistrust of the health care system and their providers, inappropriate use of life-sustaining therapies, increased medical complications and sequelae, and long hospital stays.

Palliative Care as a Framework

Implementing a framework that works well when we are working with patients with advanced disease where the path is more ambiguous is important. I believe incorporating palliative care is key to being able to meet the patients and families needs in a holistic manner. Palliative care inquires about the patient’s experience of the illness.

The focus of palliative care is optimal functioning, and the relief of suffering for patients facing life-threatening or debilitating illness. It also involves support for the best quality of life for both patients and families.

The definition and model of palliative care is becoming more familiar in the oncology realm. I appreciate that it serves as a visual of how much that patient’s journey is a process. It is not “black or white” or “either/or” but it is about transitions and balancing and recognizing as we put hope back into the context that it is multidimensional, as the patient and family experience multiple losses in a changing reality. One of the things we have learned from the palliative care research is the need to establish and clarify goals. Goals can serve as touchstones, guideposts, and avenues to improved quality of life (see Table 1).

In establishing or defining goals of care, nurses have a unique and often difficult position. They may find themselves in a position of attempting to clarify goals without knowing the extent to which the information about prognosis has been honestly communicated to the family. It may also be that the patient and family did not understand the information or “jargon” that was used. When I reflect on some of the language that has led to misunderstandings with patients...
Taming the Dragon: Palliative Care as a Framework

Continued from page 7

I care for, examples would be “partial or complete response”, “remission”, “no evidence of disease” in the context of advanced cancer. I am also reminded that there can be a notable power imbalance and many things that can influence the quality of information received despite our best intentions.

Depending on the setting in which you work, you may not have the luxury for a relationship or the time that is required to complete the process of establishing goals of care. But for some of us, we have multiple encounters with the same patients and families. Yet there are still many opportunities in even single encounters to explore some of the gentle questions to lead the patient through their own process and build on the seeds that were sown before. I find this framework helpful as a guide. My experience has taught me if you address the “elephant” in the room at the start of your relationship, it becomes much easier for both you and the patient to revisit the issues later as disease progresses. I have seen that the discussions patients and families face regarding the impending reality of the dying experience is eased if it is a conversation and relationship you have already started.

Disease Progression

When the tide turns, how do we know? The single most predictor in cancer is performance or functional status, which is an assessment of how much a patient can do for themselves, their activity and energy level. Patients with solid tumors typically lose about 70% of their functional ability in the last three months of their lives. Other indicators are multiple symptoms especially dyspnea and other signs of increased tumor burden such as malignant pericardial effusion, multiple brain mets, malignant ascites, malignant pleural effusions or malignant bowel obstructions.

There are tools available that can be helpful when assisting clinicians in their decision making, establishing eligibility for care programs, and eligibility for clinical trials. One in particular is the Palliative Prognostic Score that scores for the chance of survival from less than 1 week to 17 weeks irrespective of cancer type. Accurate prognosis can be important and provide patients and their families with information so that they can set realistic goals, define priorities and develop insight into their dying.

Often when we think about how to talk about prognosis it is helpful to translate it into time frames, hours to days, days to weeks, weeks to months, 2-4 months etc. I work with a nurse who always tells families her nursing degree did not come with a crystal ball but proceeds to lead them through the changes they have been observing and experiencing since her last visit to ground them in the process.

Not everyone wants to know the truth about dying and that reluctance needs to be honored. Living as fully as possible until one dies depends on being aware of the extent and the seriousness of what is going on with their illness. The end of life is not simply a problem to be solved; it is also a mystery to be experienced. We learn from the dying themselves, who know best what their deaths mean to them and how to cope with them. Decisions made at the end of life are often ambiguous and complicated by powerful emotions. We are not the experts in another’s dying experience and we need to approach it with humility. Truth about one’s situation makes possible communities of affection and trust in which again we return to hope. If we understand hope only as a future reality, we miss the relational dimensions of hope. It is ironic that not telling the truth about a medical situation is more likely to isolate a patient and thereby undermine hopelessness. Each spiritual agenda is unique to the belief system of the person but there are some more common themes and practices, these have been identified by Anderson as: remembering, gratitude, grieving, and the waiting time.

Preparing for the End of the Journey

In the process of remembering, the telling of stories helps to make sense of the illness. Story telling at the end of life validates the freedom for an individual to conclude his or her own story on their own terms.

One of my friends I work with recently had her very frail 90-year-old mother move in with her because she had “failed” assisted living. The mother is Catholic and has six very different daughters. She was never an easy woman in particular for my friend to be with; very demanding and self centered, and was no different in her behavior in her declining health. She kept asking as the different daughters came to visit, what were their happy memories of childhood, and as they told their stories (which did not include her) she did not like the answers. Finally, after observing this behavior after a few of the sisters, my friend figured out what she wanted to hear was that she had been a good mother. This was actually a point that they all agreed on: that it was not the first thing that came to mind as they were growing up but as they came up with edited versions they were able to reassure her of her place in their lives their mother became calmer. Telling stories contributes to the way people want to be remembered. Telling of stories requires the listener to hear them
Taming the Dragon: Grieving is an Unavoidable Dimension of Letting Go

Continued from page 8

and a bond of mutuality is created.

The practice of gratitude is a spiritual attitude formed by the recognition that life is a gift. No matter how long life might be prolonged, there can always be something more, patients and families often find death comes too soon. It is thought that being grateful and giving thanks are born out of acceptance of one’s own limitations in living and dying.

Grieving is an unavoidable dimension of letting go. “How could I not be among you? There are losses all the time for the dying person. In dying they are letting go of everything they have loved. It becomes a “litany of lasts” for patients and families... the last Christmas, the last dinner out, the last lovemaking. These can be very sad times but it also brings opportunities for celebration and connection to family and friends as one is intentional in things we take so much for granted. It is a great way to make memories and acknowledge the special relationship amongst friends and loved ones.

I had the honor of caring for an amazing woman with metastatic breast cancer who had multiple recurrences over many years. She retired from a career as a lawyer to devote her focus into being a mother and a wife in her remaining time. I met her five weeks before her death. She told me she expected she had less than a couple of months, her pain was significant, and her dyspnea great with her gnawing anxiety, she added mind body techniques might help her keep her benefits. We explored what was missing that intimate support of her mother and a wife in her remaining time.

She had picked out individually to hug and repaint and redecorated her room in preparation of her last time on the planet. She had definitely not come back for 9 months, she had treatment for another 4 months after that until it didn’t make sense to her and had her death at home on her terms. The opposite of fear is not courage but trust, as for our part, our patients are trusting that we will as a team hold and care for them in this intimate time. Those caring for the dying need to be comfortable with helplessness.

Extending the Support Team and Transitions

How can we best support quality of life in our patients and their families in this part of the challenging journey? What can you do? It is important to be the one advocating with your care team. Ask the questions that Singer et al., found to be most important to patients regarding end of life issues.

Are symptoms being adequately managed?
Are we inappropriately prolonging dying?
Are we helping them achieve a sense of control?
Are we relieving burden on their families, and helping to strengthen relationships with loved ones?

It is important to become familiar with your palliative and hospice referral sources. All healthcare professionals can develop effective palliative care knowledge, skills, and attitudes. Patients with advanced disease should be informed that palliative care is an integral part of their comprehensive cancer care.

Heyland et al., looked at 440 patients and 160 relations in the acute hospital setting. The purpose of the study was to describe what seriously ill patients in the hospital consider to be key elements of quality end of life care. The outcome at 6 months was that 60% had died. The responses of the cancer patients in the study are shown in Table 2.

If we help our patients with advanced cancer find peace and strength through

Table 2

<table>
<thead>
<tr>
<th>Key Elements Identified for Quality End of Life Care</th>
<th>N = 166</th>
</tr>
</thead>
<tbody>
<tr>
<td>To trust and have confidence the doctors looking after you</td>
<td>65%</td>
</tr>
<tr>
<td>Not to be kept alive on life support when there is little hope for a meaningful recovery</td>
<td>58%</td>
</tr>
<tr>
<td>That you doctor communicate information about your disease in an honest manner</td>
<td>55%</td>
</tr>
<tr>
<td>To complete things and prepare for life's end (life review, resolving conflict, saying goodbye)</td>
<td>53%</td>
</tr>
<tr>
<td>To not be a physical or emotions burden on your family</td>
<td>47%</td>
</tr>
<tr>
<td>Upon discharge from hospital have an adequate plan of care and health services available to look after you at home</td>
<td>44%</td>
</tr>
<tr>
<td>To know which doctor is the main doctor in charge of your care</td>
<td>42%</td>
</tr>
</tbody>
</table>

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Taming the Dragon: Grieving is an Unavoidable Dimension of Letting Go

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the lived experience, rather than live in fear of the inevitable, we may be tapping into inner wisdom and power as symbolized by myth of the dragon. We see this confirmed in our daily practice by those who do this journey well. I had a patient whom on her funeral program had the following shared by her family.

“In her own words, Kathy would prefer not to be remembered for any “heroic battle” with cancer (What’s heroic about undergoing treatment and trying to live?) but rather for her wonderful family, crazy menagerie, and terrific sauerbraten.”

What happens if we as oncology nurses do this well and empower our patients to reframe their experience and find their inner wisdom and access their inner power. Can we support them in defining meaningful priorities that add to quality of life, and assist them in finding ways to have a respectful death on their own terms? I believe we can, I believe we can support them in taming the dragon.

References
PSONS PROFILE

Rose Preston RN, BSN, OCN
1950-2009

Mentor…Teacher…Friend…Veteran…
Artist…Sister…Daughter…Oncology Nurse…

On April 16, 2009 Roseanna (Rose) Preston lost her long battle with MDS and died on the Bone Marrow Transplant Unit at the VA Medical Center in Seattle, WA. She will be missed by her family, her many friends, her co-workers, her PSONS colleagues, and the Seattle oncology nursing community.

Born in Kenosha, Wisconsin, Rose graduated from the University of Wisconsin-Milwaukee in 1972 with her BSN in nursing. She spent the early years of her career as an Army nurse, serving in Tacoma, WA and Honolulu, Hawaii. Captain Preston was honorably discharged in 1975, and moved to Seattle, where she began her career as an oncology nurse at Fred Hutchinson Cancer Research Center. She then heeded the call to care for her fellow veteran’s and spent the last 25 years of her career as a nurse at the Seattle VA Medical Center, working on the Bone Marrow and Medical/Oncology unit “2West.”

Rose’s friends and family gathered to remember her at a memorial service at the VA. Words like “caring,” “smart,” “mentor,” and “educator” flowed with her colleague’s tears. “She had a brain like a carbon copy,” said Lydia _____, RN who worked with Rose for over 20 years. “She knew more about oncology than any one else on the unit,” remembered Abby Wade. Dr. Wu and Dr. Chauncy both spoke at the memorial, paying tribute to the wonderful oncology nurse who was so instrumental in their early education as oncologists.

PSONS was a big part of Rose’s professional life. She was a long-time member of PSONS, and served a half dozen years on the PSONS Symposium Committee. She encouraged other oncology nurses to be active in our organization, and was herself a role model of professionalism.

Rose was an active woman, with a full life outside work. She had a bevy of friends, a large family (5 siblings!), and varied interests. Rose was an avid reader, made the best jam, excelled in needlework, and was a talented artist. She was an accomplished watercolor media collage artist, showcasing pieces at numerous galleries and shows. Rose won many awards, including 2 awards from the National Collage Society. Her love of art was enhanced by membership in the Northwest Collage Society and the Mercer Island Visual Art League, where she served as president from 1991-1992.

Rose’s family will miss her, including her mom, 5 siblings, and numerous nieces and nephews who adore her. In Seattle, she will be missed by her many friends and admiring colleagues. Rose, thanks for all you gave to your patients, your community, and your profession. And from those who knew you through PSONS, thanks for all you gave to us.

The PSONS Research Survey Results

Joseph Tariman, PhC, MN, APRN, BC, OCN & Marilyn Hammer, PhD, RN, DC

The Oncology Nursing Society (ONS) is at the forefront of evaluating and disseminating information on evidence-based practice (EBP) for oncology nursing globally (Doorenbos, et al., 2008a). Part of ONS’s actions of helping oncology nurses to follow EBP includes a series of Putting Evidence into Practice (PEP) cards that provide information for nurses directly at points of care in addition to providing current information to educators (Doorenbos, et al., 2008b). In alignment with this mission and the goals of ONS’s research vision, “to support the mission of the Oncology Nursing Society to promote excellence in oncology nursing and quality cancer care through the integration of research and evidence-based practice” (Oncology Nursing Society, 2009), the Puget Sound Chapter of ONS (PSONS) conducted a research survey in 2008-2009 to determine the local research priorities, application of EBP and PEP cards, and educational needs of Puget Sound area oncology nurses.

This report describes the findings of the survey and implications for the future PSONS research agenda. Comparisons were also made to the 2008 ONS Research Priorities Survey (Doorenbos, et al., 2008a)

Methods

Members of PSONS (N = 284) were approached in 2008 through listing a link to an online version of the survey in the PSONS newsletter. A few area oncology nurses requested and were given paper versions of the survey. The

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Registration Open for Institutes of Learning and Advanced Practice Nursing Conference
Gain new skills you can immediately apply to your practice at the ONS 10th Annual Institutes of Learning and the Advanced Practice Nursing Conference this November in Tampa, FL. Don’t miss this chance to get hands-on, interactive education that will equip you to provide even better cancer care. You’ll also make professional connections that will serve you for years to come. Plus, if you register by September 7, you can take advantage of extra Summer Special savings!

ONS 10th Annual Institutes of Learning: http://www.ons.org/meetings/iol09/
Advanced Practice Nursing Conference: http://www.ons.org/meetings/apn09/

ONS Imprint Publishes General Health Books
Hygeia Media publishes health books for a general audience. Tell your friends, family, and patients about the first two books available through ONS’s new imprint, Woman Cancer Sex and Coping with Cancer: A Patient Pocket Book of Thoughts, Advice, and Inspiration for the Ill. http://www.ons.org/publications/hygeia/index.shtml

How Do Patients in Rural Areas Access Cancer Treatment?
In the July ONS Connect feature article, find out how rural oncology clinics are offering the same, high-quality treatment and care as larger cancer centers. How far from your facility is the nearest cancer center? Take our instant poll. http://www.ons.org/publications/journals/connect/index.shtml

Essential Evidence-based Nursing Resources for Your Practice
Evidence-based nursing involves incorporating valid, relevant, research-based information into decision making. In order to incorporate evidence and research into practice, it is important to identify credible resources. The ONS Web Site’s research area is your gateway to essential information evidence based practice, research and the PEP Resources. http://www.ons.org/research/

New Publication Answers Your Questions About Chemo/Bio Administration
ONS Clinical Top 20: Answers to Your Questions About Chemotherapy and Biotherapy provides quick, easy answers to the 20 most frequently asked questions ONS receives in its clinical questions mailbox related to these cancer treatments. Our nurses on staff provide you with practical, evidence-based answers that will help keep you and your patients safe.
Member Price: $7.00, Nonmember Price: $10.00 http://ecourse.ons.org/ProductDetails.aspx?sku=INPU0232

Come Talk with the Experts!
Next Hot Topic: Psychosocial Issues in Cancer Care
Do you have a burning question you can’t find the answer to? Do you want to know what your colleagues do about certain issues? Come chat and find out! The Hot Topic Chats are free, convenient, and a great way to talk to the expert on a multitude of topics! http://onsopcontent.ons.org/ Education/hot-topics/index.shtml

Do you know that question that you wonder about? You know, that one “burning question” that is controversial, or is about new information, or is just hard to find the answer to? Did you ever wish you could just sit down and talk to the expert, ask that question, and have a casual conversation that allowed you to fully explore your burning issue?
Then come chat in the ONS Hot Topic Chat Series! Meet experts in many different topics, ask those questions, and engage in a dialogue with peers on the most timely and relevant issues in oncology practice today!

Nurses in Washington Internship (NIWI) Available
Scholarship applications for the 2010 Nurse in Washington Internship (NIWI) program, being held March 14-16, 2010, are now being accepted! Applications are due October 9. Several scholarships are being offered this year including a full scholarship, a registration scholarship and new this year – a student registration scholarship.
http://www.nursing-alliance.org/content.cfm/id/niwi#scholarship

2009 Scholarship
This full scholarship is sponsored by Elsevier/Saunders publishers and the editors of Policy and Politics in Nursing and Health Care (5th Ed.) on behalf of the book’s many contributors.

2010 Scholarship
Scholarship applications for the 2010 NIWI are now being accepted by the Alliance. The deadline for submission of the completed applications is Friday, October 9. Nursing Contact Hours NIWI 2009 was approved for 2.75 contact hours by the Tennessee Nurses Association, an accredited approver by the American Nurses Credentialing Center’s Commission on Accreditation. The Alliance will seek approval for contact hours for the 2010 NIWI.
For More Information:
Please contact Alliance Headquarters Offices at 859-514-9157 or alliance@AMRms.com.

ONS Imprint Publishes General Health Books
Hygeia Media publishes health books for a general audience. Tell your friends, family, and patients about the first two books available through ONS’s new imprint, Woman Cancer Sex and Coping with Cancer: A Patient Pocket Book of Thoughts, Advice, and Inspiration for the Ill. http://www.ons.org/publications/hygeia/index.shtml

How Do Patients in Rural Areas Access Cancer Treatment?
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Evidence-based nursing involves incorporating valid, relevant, research-based information into decision making. In order to incorporate evidence and research into practice, it is important to identify credible resources. The ONS Web Site’s research area is your gateway to essential information evidence based practice, research and the PEP Resources. http://www.ons.org/research/
The PSONS Research Survey Results

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majority of surveys were distributed in paper form at the 2009 PSONS annual symposium (N = 115 attendees). The majority of symposium attendees are also members of PSONS. Although the survey was created to specifically target members of PSONS, it is unknown if any of the survey respondents who attended the Symposium were non-PSONS members.

The survey consisted of 25 questions, the first seven specific to the respondents’ educational level, practice focus, and practice setting. Subsequent questions pertained to following guidelines for EBP use and usefulness of PEP cards, areas respondents felt were priorities for their patient populations, and where they felt both research and educational needs should be directed in the future.

Statistical analysis was conducted using SPSS version 16.0 statistical software to determine general descriptive findings. The survey instrument was created by the PSONS Research Committee. The instrument was not tested nor revised for validity and reliability. A Cronbach’s alpha was determined for a generalized idea of the reliability (consistency) of the survey. In general a Cronbach’s alpha above .8 is considered a reliable instrument.

Results

The survey administered was found to have a Cronbach’s alpha of .682. A total of 82 oncology nurses (respondents) completed the survey. The majority of respondents (N = 46 / 56.1%) were bachelor’s prepared nurses. The distribution of respondents by education level is shown in Figure 1. The large majority of respondents were involved in direct patient care (82.9%). Most respondents also provided services to patients with a variety of malignancies (N = 41 / 50%) with the second most noted patient population being hematological malignancies (N = 14 / 17.1%). Most respondents also administered chemotherapy to patients (N = 48 / 58.5%) and a number of respondents also were involved in hematopoietic stem cell transplantation (HSCT) (N = 10 / 12.2%) or a combination of chemotherapy/biotherapy/HSCT (N = 10 / 12.2%). Most patients treated by the respondents were either adults (N = 34 / 41.5%) or within the category of adult/older adult/special populations with comorbidities (N = 40 / 48.8%). Most respondents worked in urban settings (N = 49 / 59.8%) with fewer in suburban areas (N = 19 / 23.2%) and a few in rural areas (N = 6 / 7.3%). Most respondents also worked in either outpatient clinical settings (N = 45 / 54.9%) or acute care/in-patient facilities (N = 25 / 30.5%).

Pertaining to respondents’ practice settings following guidelines for EBP, 38 (46.5%) indicated they did, 29 (35.4%) indicated they did not, and 13 (15.9%) were unsure. Seventy (85.4%) survey participants responded to both questions about PEP cards. Use of PEP cards and how helpful users felt they were are shown in Table 1. All symptom areas had the majority of respondents rank them as either “highest importance” or “very important”. Specific symptoms inquired about in the survey can be found by viewing the survey itself (PSONS Research Survey). The highest overall rated areas of concern were pain, nausea/vomiting/retching, patient education, ambulatory problems, and treatment decision-making.

Thirty five (42.7%) respondents reported that research was conducted in their practice settings. The remainder of respondents indicated research was not conducted where they work (N = 31 / 37.8%), six were unsure (7.3%), and 10 (12.2%) did not respond to the question. Seventy of the 82 respondents (85.4%) answered the question regarding their personal involvement in research. More than half (N = 39 / 55.7%) indicated they were either currently involved (N = 11 / 15.7%) or had been involved (N = 28 / 40%) in past research. An additional 15 (21.4%) indicated they would like to become involved in research and 16 (22.9%) chose the answer choice, “no, I hear the word research and run in the other direction”.

Survey respondents were then asked to rank the research areas identified by ONS as top priority in the order of importance to themselves. They identified research in cancer symptoms and side effects as the most important research area followed by (in descending order of importance) health promotion, late effects of treatment, public awareness, and management of the psychosocial needs of patients/caregivers.

The majority of respondents were involved in direct patient care (82.1%) and most respondents also provided services to patients with a variety of malignancies (50.1%). Most respondents were involved in urban settings (59.9%), with fewer in suburban areas (23.1%) and a few in rural areas (7.2%). Most respondents also worked in either outpatient clinical settings (55.0%) or acute care/in-patient facilities (50.1%).

Pertaining to respondents’ practice settings following guidelines for EBP, 38 (47.4%) indicated they did, 29 (35.6%) indicated they did not, and 13 (15.9%) were unsure. Seventy (85.3%) survey participants responded to both questions about PEP cards. Use of PEP cards and how helpful users felt they were are shown in Table 1. All symptom areas had the majority of respondents rank them as either “highest importance” or “very important”. Specific symptoms inquired about in the survey can be found by viewing the survey itself (PSONS Research Survey). The highest overall rated areas of concern were pain, nausea/vomiting/retching, patient education, ambulatory problems, and treatment decision-making.

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Survey Results

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effects of cancer treatment and longterm survivorship issues for patients and their families, nursing-sensitive patient outcomes, translational research, and individual and family-focused psychosocial and behavioral research. ONS has identified these research areas as having equal importance (Berger et al., 2009). The recent survey of ONS members at large indicated a more finite breakdown of important research issues with the top five (in descending order of importance) being quality of life, pain, late effects of treatment, access to care, and palliative care (Doorenbos et al., 2008a). It is unknown how many of the PSONS survey respondents also had responded to the ONS survey. Four respondents indicated they had research interests and/or educational needs at their facilities and requested assistance from PSONS.

Discussion

The survey instrument used in this investigation was created to elicit information from Puget Sound area oncology nurses. Although validity and reliability were not tested prior to use, helpful information emerged from the results. The majorities of respondents were bachelor’s prepared, worked in urban settings, and were involved in the administration of chemotherapy for the treatment of a variety of cancers. A number of respondents were also involved in HSCT. Almost half of the respondents noted that their facilities adhere to EBP. Among the 37 respondents who indicated they use PEP cards, the large majority found them very helpful or somewhat helpful. Of note, 22 respondents indicated they did not use PEP cards, yet 31.8% of them reported on their helpfulness instead of indicating that they “did not use PEP cards”. One respondent who reported not using PEP cards also found them to be “very helpful”. Additionally, 36.4% (N = 4) of respondents who indicated they were unsure if they used PEP cards also reported on their usefulness. Such responses might be an indication of a flaw in the instrument in that respondents might not have clearly understood the question. This is congruent with the below desired Cronbach’s alpha score for instrument reliability.

In addition to not using an established reliable and valid survey instruments, a number of limitations should be noted. Not all surveys were distributed in the same format (paper and online versions were available, although the majority answered in the paper version) and it was uncertain if all respondents were members of PSONS (and by default, also members of ONS). Furthermore, by targeting members of PSONS/ONS who are exposed to the ONS research priorities, respondents may have had biases in answering questions about the needs of patients they specifically care for. Questions pertaining to ranking research priorities were also limited exclusively to the ONS research priority list.

Overall, important information emerged through this survey. It is now known that among respondents, the top priority for research in the Puget Sound area is in cancer symptoms and side effects. This will help establish the PSONS research agenda for the next several years.

Acknowledgements

The authors would like to express sincere gratitude to the PSONS Board of Directors who aided and supported this research endeavor and all those who responded to the survey.

References


Use of PEP Cards and Perceived Helpfulness

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Make Your Reservations Now! for the
Nurse in Washington Internship (NIWI)

2010 NIWI
March 14-16, 2010
Washington, DC
The Liaison Capitol Hill, an Affinia Hotel
415 New Jersey Avenue, N.W.
Washington D.C. 20001
Phone: 866-233-4642

Room Rate: $269/night, plus 14.5% tax
Reservations after Friday, February 19, 2010 will be based on
availability at the hotel’s prevailing rate.
Registration for the 2010 NIWI will be available on the PSONS

Comments from 2009 NIWI Participants:

“The material presented was relevant, practical and outstanding. I thought I knew quite a
bit about policy - but I learned a ton of practical tips and advice.”

“This conference was very inspiring. I feel like I know much better how to get started and
feel confident that I can do it.”

“Came in nervous - left confident!”

NIWI Attendance
NIWI is open to any RN or nursing student (all levels of education) that is interested in learning more about the
legislative process. There is not an application or acceptance process to attend NIWI. You just need to register
and pay the registration fee. For more information on our scholarship, see below.

2010 Meeting Schedule
NIWI 2010 will begin on Sunday at 1:00 p.m. and end Tuesday with a closing reception.

Internship Objectives
• Describe how nurses can be involved and influence policy at the local and national level.
• Discuss how to work effectively with legislative staff to advance policy agendas.
• Describe key steps to effect change in the legislative process.
• Identify techniques to advance legislative issues at the grassroots level.
• Identify legislative, political, and economic forces driving health care policy and delivery changes today.
• Learn to schedule Capitol Hill meetings.

The NIWI Experience
• Advocacy 101: Overview of Public Policy Process
• Advocacy Training
• Panel Session with Expert Nursing Advocates
• Congressional Staff Panel Session
• State Team Break Outs for Hill Preparation, including role playing
• Opportunity to meet with your Representative and Senator on Capitol Hill
• Networking with other nurses with similar clinical and political interests

“Because of NIWI, I now have a heightened understanding of the legislative process and
how it impacts nursing practice and patient care.”

~ Robert T. Carroll, PhD(c), RN, ACRN,
NW AIDS Education and Training

“Knowledge gained from the 2006 NIWI
conference has already proven valuable to my
career.”

~ Christina Foushee, RN, MS, PhD
Student, University of California, San Francisco

Puget Sound Quarterly Vol. 32, No. 2 15
Expanded Insurance Benefits Break Down Barriers to Hospice Care, According to New Study

Claire M. Spettell, Ph.D.

Patients with advanced illnesses more than doubled their use of hospice care when a major national health plan made hospice care more readily accessible, according to the results of a comparative study published in Journal of Palliative Medicine.

In contrast with many insurers that limit access to hospice care, national healthcare insurer Aetna (Hartford, CT) studied a trial of expanded insurance benefits for hospice care and added nurse case managers who provided information to patients and their families. The result was a dramatic increase in both overall hospice use and the mean number of days in hospice care.

“The scientific data has been clear for many years; hospice care for the last months of life is the best care during that period. It’s delightful that national health insurers are investigating how to translate that science into better care for those they insure,” says Charles F von Gunten, MD, PhD, Editor-in-Chief of Journal of Palliative Medicine, and Provost, Institute for Palliative Medicine at San Diego Hospice.