In Memory of Ellen DeBondt

Ellen DeBondt loved her life and lived each day to its fullest. Born Ellen Joan Wilson on July 27, 1966, in Jacksonville, North Carolina. After graduating from high school in Kahua, Hawaii, Ellen traveled with her sister, Shirley, to Virginia, where both attended George Mason University.

Ellen became a registered nurse, first working at Sibley Hospital in the District of Columbia, then as a traveling nurse and later as a hospice nurse in Northern Virginia. Ellen and her sister moved to Seattle in 1994. In Seattle she worked as a hospice nurse, and later she became an oncology nurse at the University of Washington Medical Center and then moved to the Seattle Cancer Care Alliance Pain Clinic.

Settled in Seattle, Ellen became involved with the Washington Kayak Club. In this time period, Ellen and Ken fell in love, and in August 1999, they wed on the beach at LaPush in a ceremony that included the couple entering through an archway of kayak paddles held by their friends.

Ellen and Ken had a special place in their hearts for the Olympic Peninsula, especially the Crescent Bay area. They spent many weekends surfing their kayaks on the Crescent Bay breaks. They moved to the peninsula in early 2008 and Ellen began working for Olympic Medical Home Health.

Ellen was killed instantly on Sunday, March 6, 2011, as she was beginning her day of work, when her pickup truck was hit by an oncoming vehicle that veered into her lane.

Ellen was always optimistic, positive, patient and extremely generous. She gave to those around her, but saw herself as the receiver, blessed with a life that she loved. She is survived by her husband, Ken, and Rio, her faithful dog and many family members and friends who miss her.

To read memories of Ellen from her oncology nursing friends please visit www.psons.org

Adolescents and Young Adults: Adrift in the Sea of Cancer Survival

Linda Cuaron, RN, MN, AOCN

Can cancer treatment for children and adults today be viewed as a “sea of success” with greater awareness, earlier detection, and discoveries in genomics and personalized medicine leading to the potential for cancer to become a chronic illness. Significant progress is being made in the area of clinical cancer research, surveillance and prevention, resulting in cancer incidence and cancer death rates that have declined in the United States.

The CDC defines a cancer survivor as anyone who has ever had cancer, from the time of diagnosis through the rest of their life. There are 12 million cancer survivors in the United States today, according to new statistics from the Centers for Disease Control and Prevention (CDC) and over 28 million worldwide. That is an improvement from the official US figure in 2007 of 11.7 million survivors, 9.8 million in 2001 and just 3 million in 1971. With about half of the nation’s cancer survivors having had either breast, prostate, or colorectal cancer and slightly more than half are women. About 7 million survivors are 65 or older, and about 4.7 million were diagnosed 10 or more years earlier. Earlier detection, improvements in diagnosing cancer, and more effective treatment and follow-up are some of the reasons for the increase in the number of cancer survivors over the years.

Adrift in the Sea of Cancer Survival

However, the story is not as bright for the adolescents and young adult (AYAs) cancer patients and survivors of childhood cancer. Survival improvement trends show a worse prognosis for AYAs diagnosed today than 25 years ago. Survival figures for children who have had cancer have improved by 1.5% per year for children younger than 15 and adults older than 50 years, but cancer survival has improved by less than 0.5% per year in 15 to 24-year-olds. This is in contrast to statistics seen at the beginning of the last quarter century when the diagnosis of cancer in 15-29 year olds carried a more favorable prognosis relative to cancer at other ages. That is no longer the case, and moreover, cancer survival has not improved at all in 25 to 34 year-olds. This deficit is increasing with longer follow-up of survivors. These deficits appear to be global and not just seen in the US. Figure 1 depicts the stark differences in 5-year relative survival for invasive cancer based on US Seer data from 1975-1997. Continued on page 3
**President's Message**

**A New Cycle of PSONS Activity Begins**

*Juanita Madison, RN, MN, AOCN  
PSONS President*

It's with a great deal of excitement and pride that I greet you as the new president of PSONS. Each Spring, the conclusion of the PSONS Business Meeting held during the Chapter’s annual Oncology Nursing Symposium actually marks the beginning of a new year or “cycle” for our organization. Newly elected board members and appointed committee chair persons begin their terms of service.

As I start my term as PSONS President, I’m joined by six newly elected or appointed Board members also beginning their terms in office. Please join me in welcoming to new Board positions:
- Lois Williams, President-Elect
- Jennifer Wulff, Secretary
- Heather Freeborne, Treasurer
- Reiko Torgeson, Membership Committee Chair
- Deb Forman, Nominating Committee Chair
- Robin Haaf, Research Committee Chair

With a great deal of gratitude, I’d also like to thank and acknowledge members continuing in roles on the board:
- Ryan Iwamoto, Education Chair
- Ellen Nason, Government Relations Chair
- Lenisc Taylor, PSONEC “Fundamentals” Committee Chair
- Judy Petersen, PSONS Quarterly Newsletter editor
- Nancy Thompson, Community Service Projects Coordinator
- Mary Jo Sarver and Terri Pointer, Vendor Relations
- Cherie Toftthagen, PSONS Webmaster
- Mona Stage, Scholarships Coordinator

Beginning my term as PSONS President, I’m filled with optimism about the Chapter’s future, as well as reverence for the work accomplished by past PSONS leadership and members. I had the pleasure of attending the annual Oncology Nursing Society (ONS) Congress in Boston, April 27th – May 1st. Attending Congress provided me with a wonderful opportunity to network with ONS Chapter leaders and members across the country. Lois Williams, PSONS President-Elect, and I attended a session titled “Best Practices in ONS Chapter Management”. The session was designed to provide chapter leaders with the opportunity to share successes various chapters have experienced over the last year and to take home new ideas for managing chapters. Lois and I listened as many ONS chapter leaders shared the challenges and frustrations they face, mainly due to lack of resources and volunteers.

Many chapters have difficulty meeting the ONS requirement to hold a minimum of four meetings per year. Few chapters have the resources to provide oncology nursing education programs offering continuing education (CE) credit. Most chapters struggle to get a newsletter published or maintain an up-to-date website. Lois and I shared some of the best practices from our chapter, including the work of our education, newsletter, website, and other committees. Listening to the challenges experienced by many chapter leaders across the country really highlighted for us the accomplishments of PSONS.

*Continued on page 4*

**Editor’s Notes**

**Yet Another Successful Symposium, Our 33rd Annual!**

*Judy Petersen, RN, MN, AOCN*

This issue is our traditional annual symposium dedicated issue. The 33rd annual PSONS Symposium “Preparing for the Future, Nurturing Our Presence” was held April 1st & 2nd at the Lynnwood Convention Center. The conference was well attended; there were 130 participants on Friday and 145 attended on Saturday. The symposium is always a great opportunity to network, catch up with old friends, and meet new oncology colleagues and this year was no exception. Many thanks to the symposium committee for this very successful event. It takes many hours and dedication to make it all happen. Thank you.

This year the chapter was able to provide 5 scholarships to members that covered the cost of the symposium registration. Two of these scholarships were designated in memory of Rose Preston, a past PSONS member who died in 2009 after a stem cell transplant. Rose was for many years a very active member of the symposium committee. The scholarship recipient’s application essays are included in this issue. We also had 6 of our colleagues from the Mount Hood ONS Chapter attend the symposium this year. Their Chapter also granted a scholarship to one of their members to attend our symposium.

Also as is traditional, our lead article is by Linda Cuaron RN, MN, AOCN, PSONS 2011 McCorkle Lecture recipient. This lectureship started in 1987 as a special tribute to Ruth McCorkle a founding member of PSONS. This award is given in recognition of a member’s significant contribution to cancer nursing. The chapter member is nominated by other

*Continued on page 8*
Adrift: Two AYA Groups at Risk: Survivors and the Newly Diagnosed

Continued from page 1

The world of traditional cancer care is well-developed with multiple organizations, cooperative research groups, advocacy and supportive groups, and numerous sub-specialties. Similarly for pediatric cancer patients there are defined research organizations, hospitals, specialists, and palliation and survivorship programs. There is active work in genetics and genomics for adult and childhood cancers, but this is limited for the AYA group.

AYA Cancer Survivors and the Newly Diagnosed

There are two groups of AYA patients that warrant concern. There are those who are survivors and are at increased risk for medical complications and/or cancer recurrence, and those who will become newly diagnosed during the ages of 15 - 29. It was reported at last year's American Society of Clinical Oncology (ASCO) meeting that long-term risks for cardiac problems were found among children and adolescent cancer survivors who were treated with anthracyclines and/or chest radiation. They were 6 times more likely to develop congestive heart failure than their siblings who did not have cancer. Further, it has been shown that the late effects of childhood cancer substantially reduce life expectancy.

The incidence in cancer in the AYA age group increased steadily during the past quarter century. We don’t know why……behaviors - smoking, sun exposure; environment; obesity, tumor biology, decreased surveillance?

The AYA group represents about 6% of all new cancer diagnosis which means 1 in every 168 Americans between the age of 15 and 29 will develop cancer. This group is 8 times more likely to experience cancer than those under the age of 15. Seer data showed that males in the 15-29 year age group are at higher risk than same age females for developing cancer, with the risk directly proportional to age. Non-hispanic whites have had the highest incidence of cancer during this phase of life and Asians, American Indians and Alaskan Natives, the lowest. The prognosis for males was worse than for females, and African American/Blacks, American Indian/Alaska Natives had a worse prognosis than white non-Hispanics and Asians.

The incidence of cancer in AYAs is increasing exponentially as a function of age, with approximately half of the AYA group in the 25-29 year age range. With the exception of invasive skin cancer due to ultraviolet light exposure, the majority of cancer types occurring in AYAs aged 15 to 29 years are not readily explained by either carcinogenic environmental exposures or family cancer syndromes. The fact that the AYA group has an exponential risk of developing cancer as they age suggests a possible molecular basis resulting in a basic carcinogenic exposure that is age-dependent, such as telomerase shortening or a mutation-to-malignancy rate that increases constantly with age.

The majority of research has focused on clinical trials for pediatric patients with an age limit for participation of 18. Even when eligible for pediatric clinical trials, AYA patients are often treated by adult oncologists. What is the result? Significantly worse outcomes and an event-free survival of 38% versus 64% were seen when adolescents were treated on pediatric protocols at pediatric institutions. Pediatric cancer patients had a greater than 75% event-free survival on the same protocols.

When clinical trials are not an option, AYAs with “adult” types of cancer, such as melanoma, breast cancer, and colorectal carcinoma, may need the treatment expertise available at adult cancer centers.

“There is no other patient age group for which the time period to diagnosis is longer, clinical trial participation lower, and fewer tumor specimens are available for translational research” (Bleyer, 2006). The lack of clinical trial participation is particularly problematic with only 1-2% of all 20-29 year olds with cancer participating in a therapeutic clinical trial sometime during their cancer experience. A correlation exists between the level of clinical trial activity and improvement in survival prolongation and mortality reduction. These factors explain much of the deficit in translational research and the lack of tumor specimens available for studies assessing molecular and cellular mechanisms of cancer in AYAs.

Prevalence and Distribution of Cancer in AYAs

The top ten cancers affecting this age group are lymphoma, leukemia, melanoma, female genital cancer, cancers of the breast, thyroid, sarcoma, testis, colon, and brain. The distribution of cancer differs by age group with a higher...
Continued from page 2

Not just over the last year, but over our 26-year history as a chapter, PSONS has really developed into one of the premier chapters in ONS, providing a rich array of programs for membership. Evidence of this was provided in a presentation given by outgoing PSONS President Cherie Tofthagen at the annual symposium business meeting April 1st. Cherie provided a comprehensive review of the Chapter’s major activities and accomplishments over the last year. They included:

- Redesigning and launching the new PSONS Website (www.psons.org)
- Presenting an OCN Review Course free to membership, offering a total of 12 CE credit hours
- Holding routine, monthly oncology nursing education programs, most offering CE credit
- Presenting a Fall and Spring session of the 4-day Fundamentals of Oncology Course, offering over 26 CE hours for attendees
- Completing 3 successful community service projects
- Publishing four PSONS Quarterly newsletters
- Awarding 2 scholarships to cover registration costs for attending ONS Congress and 5 scholarships for PSONS Annual Symposium
- Completing the first online membership survey

Whew…an immense amount of work! It leaves me breathless just typing the list. How has it been possible for PSONS to accomplish so much in one year period? Especially given that PSONS has no paid employees. It has all been made possible through the volunteer efforts of our membership. Volunteer members provide the foundation for our Chapter. Without their time and dedication to oncology nursing, none of the programs listed above would have been possible. I’d like to thank the outgoing board members and committee chairs who donated so much of their time. They include Bonne Childs (outgoing Treasurer), Karen Brandstrom (outgoing Membership Committee Chair), and Martha Purrier (who stepped in at the last minute as an “ad hoc” Symposium Co-Chair). I’d also like to thank Cherie Tofthagen, outgoing President, who will be staying on the Board as Immediate Past-President and Webmaster, and Nancy Thompson moving from her position as Secretary but staying on as Community Service Project Coordinator. And last, but most importantly, a special thanks to the many, many members who set aside time to volunteer!

So, as we move into summer, the new “cycle” for PSONS gets underway. The PSONS board and PSONS committees begin planning activities for the upcoming year. At this time, we look to our members and appeal to all to becoming involved as an active member of the PSONS Community. Your participation will be both personally rewarding and will improve oncology nursing and patient care.

PSONS has a number of ways for you to get involved, large and small. Not every volunteer opportunity requires attendance at monthly meetings. Some volunteer activities take only a few minutes, while others require a larger commitment. Take a look at the work of PSONS Committees and find one that’s a good fit for you. Perhaps you’d like join a committee and attend routine meetings. Do you have ideas about what types of education programs you’d like to see at next year’s annual symposium? We desperately need volunteers for the Symposium Planning Committee. Are you interested in learning about nursing research? For the first time in more than a year we have a Research Committee chair. We need volunteers with ideas on activities this committee could develop over the next year.

Perhaps you’d like to take advantage of an opportunity as a one-time volunteer. We have many one-time or short-term tasks and projects. Just a few examples include opportunities to staff the registration desk at a PSONS program, or work with the Education Committee to arrange and coordinate one monthly PSONS Education meeting at your institution. Do you want more information about what each committee does before you commit as a volunteer? There are several ways you can get this information. You can review the committee descriptions listed in the PSONS Membership Brochure or in the PSONS Bylaws. Both can be found on the PSONS website. Better yet, contact one of the PSONS Committee Chairs or elected Board Members via e-mail or in person at the monthly PSONS Education Meetings. Board member e-mail addresses are listed on the PSONS website.

I’d like to close my first message to membership as PSONS President by extending an invitation for all members to attend Board Meetings. They are scheduled every other month throughout the next year. The dates, times, and locations are posted on the PSONS Website (www.psons.org). Come, listen to the discussions planning Chapter activities, and be part of the planning process. Please feel free to e-mail me (psonspresident@gmail.com), with your ideas, input, questions, recommendations, or suggestions. I personally look forward to networking with you and working together to find ways your ideas and input can be put into action to make our organization even better over the next year.

JUNE PSONS EDUCATION MEETING

ONS Congress 2011 Highlights

SPEAKERS:
Marivic Mangila, Sharon Baker, Rick Taber and Judy Petersen

Wednesday, June 15, 2011
Highline Cancer Center

For the latest information on upcoming educational programs visit www.psons.org see the Committee tab for Education
Uncertainty can play a large role in the AYA cancer experience. Mishel’s “Uncertainty in Illness Theory” provides a framework for looking at the AYA experience. This theory states that uncertainty in illness situations can be experienced in four ways:

- ambiguity about illness and symptoms,
- complexity of systems of care,
- lack of information about diagnosis and seriousness of the illness, and
- the unpredictability of the disease.

The elements of this model ring true when reviewing of the literature about the AYA with cancer. Consider the issues impacting a “survivor” of childhood leukemia. An 11-year-old female diagnosed and treated in 2000. She may have received cytarabine, daunorubicin, etoposide, and prednisone. Today she is 21 years old, a college grad but unemployed and uninsured and cancer-free. She may delay or not seek health care for symptoms associated with prior chemotherapy because she does not associate current symptoms with prior damage from chemotherapy, or she may not have the funds. She may minimize or deny her symptoms. She might find the process of getting an appointment with a specialist too daunting to pursue or she might actually fear that her cancer has returned and that she will not survive further treatment. Because of her exposure to certain chemotherapy agents she is at risk for cardiac damage, nerve damage, secondary malignancy and infertility. Add to that the potential for insurance denial because of pre-existing condition and the challenges are overwhelming.

**Long-Term Concerns**

The Childhood Cancer Survivor Study was a cross-sectional survey of 655 consecutive survivors (approximately 5%) drawn from a group of 12,156 participants age 18 years or older, who at an age <21 years had survived 5 years from diagnosis of cancer. This study revealed that only 35% of AYA cancer survivors realized that they could have significant health problems after being treated for cancer. The survey asked about their knowledge of their cancer diagnosis and other associated therapies in a 3- to 5-minute telephone survey. Overall, only 72% accurately reported their diagnosis while 19% were accurate but not precise. Individuals with central nervous system (CNS) cancer and neuroblastoma were more likely not to know their cancer diagnosis. The accuracy rates for reporting their treatment history were 94% for chemotherapy, 89% for radiation, and 93% recalled that they had a splenectomy. Among those who received anthracyclines, only 30% recalled receiving daunorubicin therapy and only 52% remembered receiving doxorubicin therapy even after prompting with the drugs’ names. When prompted with choices of names of different diagnoses, 72% of the participants accurately reported their diagnosis with detail and 19% were accurate without detail. When asked the question of whether past therapies could cause a serious health problem with the passage of time, 35% of participants responded yes, 46% responded no, and 19% did not know. Only 15% responded that they ever received a written list of their dis-
Adrift: Caring for AYA Victims Poses Unique Challenges

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ease diagnoses and treatment, including names of chemotherapy agents, to keep as a reference in the future.

Developmental Issues

Caring for cancer patients of any age is never easy. But for the AYA there are unique challenges. Certainly there are biomedical and genomic issues which are not yet fully understood. Cancer in the AYA group has the greatest heterogeneity. But for any adolescent or young adult, regardless of health status, this is a time of rapid change related to development and emotional health, a time when they ask “who am I”. It is a time for examination and integration of values and beliefs with those of society as well as a time to develop independence. This is when they form meaningful relationships outside the family by establishing strong attachments to their peer group. Even as they strive to develop independence they vacillate between dependent and independent functioning.

Add cancer to the mix and you will find adolescents who are at risk for loss of control, loss of independent functioning, devastating impact of alterations in body image, isolation from their peer group, loss or change in goals for the future. Today there are many on-line forums, blogs, and websites to help the AYA and the health care provider. Some of the comments from an AYA blog, when asked to compare “real live” vs “cancer life” reveal their reality:

* “Doctors don’t trust me, I don’t trust them”
* “I had to deal on my own with things that no one may age knew anything about”
* “I met a grand total of 4 young adults in 18 months, all but one died”

There are key developmental milestones that are profoundly influenced by the cancer experience. During adolescence and into young adulthood, the focus is on committing oneself to concrete affiliations and partnerships. While in this developmental stage the young adult builds on the identity established in adolescence. A young adult learns to develop reciprocity in an intimate, interpersonal relationship in which it is possible to merge his or her identity with that of someone else without fear of losing the sense of self. This individual begins to strive toward financial, psychological, and physical independence and autonomous living. During cancer treatment, the young adult with cancer faces threats to achieving these key developmental steps that include altered body image, isolation from school/work/community, loss of ability to maintain or develop intimacy with significant others, change in a timeline for achieving goals, and a loss of independent functioning.

Clinical Trial Participation

Historically, 90% of children younger than 15 years with cancer are managed at institutions that participate in NCI-sponsored pediatric trials but only 21% of adolescents 15 to 19 years old participate in clinical trials with far lower estimates for 20- to 29-year-olds. This probably reflects the fact that the vast majority of AYAs with cancer are treated in community-based settings by oncologists who do not regularly enroll patients onto NCI-funded clinical trials. Experts argue that this deprives AYAs access to contemporary treatment approaches and clinical expertise that could improve outcomes and consequently see increasing enrollment of AYAs on clinical oncology trials as a critically important strategy for improving survival. The decreased number of AYAs participating in clinical trials also results in under-representation of their tumor tissue in the national tumor banks. Without blood and tissue from the cancers that affect AYAs, scientists are unable to advance our knowledge about these types of cancer.

Research is needed to understand how these cancers differ in AYAs in terms of tumor initiation, their biological features, and how they may vary in treatment response. Is there a difference in the AYA for susceptibility to cancer and tolerance of therapy?

Fertility

Certain types of chemotherapy and radiation can put females at risk of acute ovarian failure or premature menopause. These include total-body irradiation (TBI), and chemotherapy regimens containing high-dose alkylators. Males are at risk of temporary or permanent azoospermia resulting in infertility from a wide variety of chemotherapy regimens, TBI and radiation to the gonads (Levine et al., 2010).

Preventive measures should always be taken when possible. Shielding should be utilized when possible to reduce scatter radiation to the reproductive organs. Other methods must be accomplished prior to initiation of cancer treatment. These include for males, cryopreservation of sperm through banking, testicular tissue freezing, or testicular sperm extraction. Strategies for females include embryo freezing, egg freezing, and ovarian tissue freezing. Except for ovarian tissue freezing, the strategies for women involve multiple challenges. Embryo cryopreservation, for example, requires several weeks of hormone stimulation of the ovaries which may delay the initiation of treatment. Additionally, estrogen stimulation can introduce additional risks to the female patient newly diagnosed with cancer.

There are also practical and ethical considerations and barriers to address. Unfortunately, according to the NCI, fewer than 50% of oncologists follow national guidelines on fertility preservation published by ASCO in 2006. Oncologists may lack knowledge about fertility preservation techniques and guidelines and lack awareness of appropriate referral sites. There may be
Continued from previous page

underlying concerns about the potential delay in treatment posed by fertility preservation. It is the responsibility of the health care team to be a key stakeholder in the preservation of fertility for their patients. Education, support, and planning are critical to fertility preservation in the AYA at the time of diagnosis. It is recommended that cancer centers create linkages to specialized teams to provide guidance to the AYA of either gender. It is critical to plan ahead. If your facility does not have a plan in place today, research the ASCO guidelines and develop a plan.

Key Components to a Successful Program for Adolescents and Young Adults

In 2005-2006 the NCI and the Lance Armstrong Foundation sponsored the Adolescent and Young Adult Oncology Progress Review Group (PRG) who created the directive to develop standards of care for the AYA patient with cancer (Zebrack et al., 2010). Their position statement lays the foundation for creating nationally accepted criteria and standards of care for practice, which would lead to the development of formal, certified training programs for the AYA healthcare practitioners. They determined that “quality care for AYAs depends on four critical elements:

• Timely detection,
• Efficient processes for diagnosis, initiation of treatment, and promotion of adherence,
• Access to health care professionals who possess knowledge specific to the biomedical and psychosocial needs of this population, and
• Research that will ultimately derive objective criteria for the development of AYA oncology care.”

Timely Detection

At the helm of the lifeboat to improve clinical care for AYAs with cancer or survivors of cancer is the oncology health care team. The interval from onset of the first cancer-specific symptom to the first anti-cancer treatment is called “waiting time” and is longer in AYAs. The time to diagnosis is longer in AYAs than in children. The “waiting time” may be influenced by factors related to the individual, the health care system or the disease.

Make a commitment to increase awareness and education so that delays in diagnosis can be avoided. Maintain a high index of suspicion for late effects of anti-cancer therapy or recurrence in cancer survivors. Avoid failure to recognize cancer-related symptoms or recurrence of cancer. Be aware that AYAs often deny symptoms, are too embarrassed to report them or attribute them to psychosomatic manifestations.

Efficient Processes for Diagnosis, Initiation of Treatment, and Promotion of Adherence

Encourage and assist AYAs to seek care at a comprehensive healthcare center. Know that there are very few known causes of cancer during early adulthood and it “just happens” regardless of the health of the person. Realize that AYAs are least likely to have adequate health care insurance and that they should not allow themselves to “age out” of insurance.

Convey that what is done at the time of cancer diagnosis is important and that the best outcome is determined by the initial evaluation and therapy. Optimal cancer management means doing it right from the start! Provide social and emotional support, inquire about social needs at time of diagnosis. Refer to a social worker or mental health professional as indicated.

Access to health care professionals who possess knowledge specific to the biomedical and psychosocial needs of this population

Plan to provide adequate social support and prepare for fertility preservation. Help to reduce risk of medical complications following treatment by providing a summary of the diagnosis, types of treatments provided (including surgical procedures, names and doses of anti-cancer agents and amount of radiation delivered).

Be aware of the medical complications of cancer treatment in AYA cancer survivors. Provide risk-based survivorship care and symptomatic surveillance for late effects of cancer therapy. Don’t fail to educate regarding health promotion, wellness and cancer prevention (diet, physical activity, stress management, smoking cessation, sun protection). Have a plan for transition of care for survivors entering young adulthood.

Comprehensive Cancer Research

Once diagnosed, suggest clinical trials. Help the AYA find centers that participate in trials suitable for their age. Once enrolled in a clinical trial, the AYA needs understanding and support in order to best adhere to the trial’s requirements. Refer patients to a center with NCI funded clinical trials, or refer to oncology center that has an AYA focus and environment.

Ask the Patient!

A review of AYA responses to the question of what they would want to see in their cancer treatment program provided insights and suggestions that center around peer interaction and developmental tasks.

• “Break the rules on my visiting hours, if my friends can come at 8:30 p.m., let them in.”
• “Do not comment about my diet, I have cancer, I’m in the hospital. Heart disease is not my main concern. If I want McDonalds, let me have it.”
• “I want my oncologist to think of me in terms of my whole “person”, not just my cancer. I have a life, and I want to live it.”
• “I want you to talk to me about sex. I may be too embarrassed to bring it up, so I’m begging you to.”
• “Tell me the truth, even if it’s bad or scary. Let me know if it’s going to hurt.”

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Editor’s Notes

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chapter members and selected by the symposium committee. Titled “Adolescents and Young Adults: Adrift in the Sea of Cancer Survival”, Linda’s lecture brings to our attention the special needs and issues of the young adult cancer patient population and challenges us to respond.

The other symposium articles in this issue are authored by PSONS members who were presenters this year. (Joseph Tariman has moved to Chicago, but I know I’m not alone in still counting him as part of our chapter!) So if you didn’t make it to the symposium, this issue will give you a flavor for the high quality presentations.

This issue sadly commemorates another well-loved PSONS member, Ellen Debondt, who was suddenly taken from us when she was killed by a drunk driver as she was on her way to make a home visit to a patient. Many of us who knew Ellen will miss all things about her, but especially her smile, energy and optimism.

As usual we welcome any feedback and of course, future contributions! If you would like to join Sharon Rockwell and I in planning for and recruiting authors for our newsletter please contact us to discuss your ideas. You can contact us at psonscommunications@gmail.com or via my personal email judyp_73@msn.com. Please enjoy this issue and have a great summer!

Adrift: Adolescents with Cancer Have Specific, Unique Support Needs

Continued from page 7

• “Figure out a way to let me have Facebook! It’s my lifeline to the outside world.”

When asked, “Where did you want support but did not find it?” the AYAs identified childcare issues, financial issues, health insurance navigation, access to clinical trials, a place to study or work at the hospital and information about fertility and sex.

Ferrari et al, (2010) describe key elements to consider when starting an AYA program. These include:

• Access to the newest Children’s Oncology Group protocols
• Collaboration with adult institutions
• Links to organizations involved in fertility preservation
• Close monitoring of patients to encourage treatment adherence and clinical trial participation
• Group adolescents on the inpatient unit in designated rooms together, when possible
• Group adolescent patients into designated clinic times
• Convert clinic playroom to teen room during this time
• Engage adolescents in monthly support groups held during clinic
• Engage parents in monthly support groups held during clinic

Remember that adolescents with cancer experience multiple distressing symptoms including pain, nausea, appetite changes, mood disturbances, sleep disturbances, and fatigue. Fatigue has been identified as the most prevalent and distressing symptom experienced by adolescents with cancer and places an extra burden on patients trying to participate in normal activities during treatment.

Research, Support & Advocacy

There is a lifeboat standing by, thanks to the support of The Lance Armstrong Young Adult Alliance, the Comprehensive Cancer Center Adolescent and Young Adult (AYA) Coalition - National Cancer Institute of the National Institutes for Health and many independent non-profit groups such as the “I’m too young for this” Foundation, Cancer Care “The Stupid Cancer Show” and Planet Cancer.

Is that a Lighthouse Ahead?

There has been significant increase in awareness of the AYA cancer survival gap since NCI, SEER and the Children’s Oncology Group published an epidemiological monograph in 2006. There has been research primarily conducted by oncologists, oncology nurses, pediatricians and psychologists. Research has been focused on identification and description of the issue but there is much more to do. Fortunately there are dedicated funding sources and the issue “fits” with ONS research objectives.

Call the Pilot!

Is it time for an AYA Navigator? Evaluate the way you provide care and services to the adolescent and young adult. Would an AYA Navigator provide the missing link necessary to help “bridge” the AYA survival gap? Consider creating or adopting pathways and standards of care for this age group. With an increased awareness of the issues surrounding the care and treatment of this unique group a dedicated navigator could make a significant difference in their cancer treatment outcome.

Take the Helm, Mate!

This is a call to action. The problem is significant and well-defined. Oncology nurses are well-suited to take the helm in the development of nursing care guidelines and programs. The Live Strong-NCI strategic plan included a call for core competency curricula and continuing education programs for the AYA group. Education on the issues related to appropriate care of AYAs with cancer is a need that has been identified.

Prepare for fertility preservation of AYAs who trust you with their cancer treatment. Utilize technology to educate, support, and promote adherence. Be aware of developmental issues that underlie the responses and behaviors of the AYA with cancer. Familiarize yourself with the many internet resources that AYAs are utilizing, and participate where you can. Embracing the technological tools of adolescents and young adults may provide health care providers with powerful instruments to reach and support the AYA survivors and those undergoing cancer treatment. Remember that for most oncology practitioners oncology care is a disease of the aging population and oncology culture is not geared to the culture or communication styles of the young…yet.

See article references, page 16
For many of these profiles, it is the first time interviewer and interviewee meet. Not so today. Ironically, Linda and I met when she was the editor of the PSONS Newsletter and I volunteered to write a profile. Little did she know at the time that years later she would be on the other end of the process!

Linda was raised in Albuquerque, NM with two sisters. One sister still in NM and one now in OR. An interesting fact about her family is that Linda’s mom’s side of the family predates New Mexico becoming a state. Linda attended college in state and majored in music which led to a unique degree in musical therapy. She traveled to Ann Arbor, MI for an internship and it was there that she got her first taste of sailing which would later become a wonderful hobby and passion.

After her internship in MI, Linda returned to NM eager to put her new skills to work. She landed a position at the children’s psych hospital. Culling everything she learned Linda developed their now famous Creative Arts Therapy Program. Here Linda wore two hats, one as musical therapist, and one as manager of the Artist in Residence Program overseeing other therapists from several disciplines such as art, dance and horticulture.

While Linda loved her job, she also yearned to experience other parts of the country. Remembering a visit to Seattle that she just loved, she decided to relocate here and found herself moving to Kingston, WA. As an outdoor enthusiast, Linda was sure she was in the right place personally but professionally she struggled to find a job that matched her unique skill set. It was at this time of professional exploration that Linda, who was also interested in considering nursing, would say that “nursing found me”. Linda knew she was interested in more physical science and she also liked the idea of research. So to figure out what her next move was, she literally went door-to-door to colleges inquiring about their programs. It was during this search that Linda met Faith Reyerson, RN, Dean of Nursing at Olympic College in Bremerton. Within two weeks, Linda was enrolled and completing her prerequisites for the RN program.

Once Linda had completed her AA at Olympic College, she was nominated for a Fulld Fellowship (of which only 100 across the US are nominated) to attend an international oncology nursing conference in London. After the conference, “I was hooked!” says Linda.

Moving to Seattle from Kingston cut her commute dramatically when Linda returned from London and decided to work at the University of WA in the Medical Oncology Unit. After taking the NCLEX to get her BSN equivalent, Linda spent five years doing full time nursing and part time school towards her masters.

Next on her career path was a stop at the Puget Sound Blood Center as a research nurse focusing on platelet studies. She worked under Cheryl Schlister, MD on the trigger trial to establish the minimum platelet level prior to transfusion (which for those of you who are curious was 10,000).

It was at this point that somehow Linda had found herself the target of a recruiter for Schering Plough. The job was Patient Care Consultant and it was the first field based role for nurses in industry (in 1996). Ultimately this job seemed the perfect blend of two careers. Among other things, her role involved 1) nursing education, 2) symptom management specialists, and 3) patient education and support groups. After four years, Linda was promoted to Project Manager where she spent more of her time on clinical trials management. One project she is especially proud of is the patient support trial for hepatitis patients. It was a 10 site, national, randomized trial that showed very positive outcomes.

As Linda’s career reflects, nurses are in high demand in industry. After Schering Plough, Linda worked as a Medical Science Liaison for Genentech for three years and then for Amgen as a Senior Clinical Nurse Liaison for two years. Presently, Linda is a Senior Scientific Liaison for Atellas (formerly OSI Pharmaceuticals).

I asked Linda who her most influential mentor was and she says, Betty Gallucci, PhD at the UW. “She was my thesis advisor and a wonderful support. She is the essence of nursing and nurse scientist because of her curiosity and creativity.” I also asked Linda what was unique to her nursing job and she says, “working with nurses all over the US”. “There are common threads” she says and she recalls a metaphor of nurses who came together to quilt during their free time but also to support and listen to each other. The challenging part of her job is, “the travel and being away from home so much”.

Linda has been a member of PSONS...
Management of Chemotherapy-Induced Peripheral Neuropathy

Joseph D. Tariman, PhD, APRN, BC

Overview

Peripheral neuropathy (PN) is simply defined as damage to the peripheral nervous system caused by injury, inflammation, or degeneration of peripheral nerve fibers. When PN is caused by chemotherapy, it is referred to as chemotherapy-induced PN or CIPN. CIPN is a challenging event that can affect quality of life and compromise optimal treatments for patients with cancer. The incidence of CIPN is increasing due to the advent of more neurotoxic drugs and improvement in overall survival, making patients with cancer live longer and receive more chemotherapeutic regimens.

The common chemotherapeutic agents associated with CIPN include thalidomide, bortezomib (common novel agents used for myeloma), vinca alkaloids (vincristine and vinblastine), platinum-based drugs (cisplatin and oxaliplatin), and taxanes (paclitaxel and docetaxel). Platinum-based drugs cisplatin and oxaliplatin are common agents used in the treatment of breast, ovarian, and colorectal cancers. Although uncommon, radiation can cause PN when sacral (see figure 1) and brachial plexus are involved in the treatment field. The prevalence of CIPN is not clearly reported. Estimates are confounded by the use of different neurotoxic chemotherapies and varying doses and dosing schedules (e.g., use of bortezomib, thalidomide, and dexamethasone regimen). Additionally, the usual time course of the development of CIPN and resolution are not characterized in combination chemotherapies.

Pathobiology

The pathobiological changes associated with CIPN are not well described as of yet. Some factors described as contributors to CIPN include advanced age, chemotherapy dose and cumulative dose over time, therapy duration, co-administration of other neurotoxic agents, and pre-existing conditions (e.g., diabetes, alcoholism). CIPN can be associated with multiple and different agents used in various types of cancers. In patients with myeloma, the pathogenesis of CIPN associated with bortezomib or thalidomide is unknown. In breast cancer population, earlier reports showed paclitaxel causing mitochondrial dysfunction (swollen and vacuolated C and A sensory neurons) and damaging the largest sensory neuron with the longest axons in the thoracic ganglia and lumbar dorsal root ganglion. Though more work is still in progress, CIPN researchers have proposed the following mechanisms underlying CIPN:

- Damage to neuronal cell bodies in the DRG
- Axonal toxicity (demyelination, impaired transport)
- Axonal membrane ion channel dysfunction (Na+ channel)
- Mitochondrial damage and inflammation
- Vascular changes

More studies are needed to validate these findings in order to identify potential therapeutic targets for the prevention and treatment of CIPN.

The signs and symptoms of CIPN could be mild to moderate in intensity but in some cases could be very severe. CIPN signs and symptoms are outlined in Table 1. In general, moderate to severe CIPN symptoms could trigger dose delays, dose modifications, or treatment interruptions.

Assessment

There are many tools to assess CIPN. These tools include total neuropathy scale (TNS), EORTC’s quality of life questionnaire-CIPN subscale (QLQ-CIPN20), Functional Assessment of Cancer Therapy (FACT)’s gynecological oncology group neurotoxicity tool.

Table 1. Signs and Symptoms of CIPN

<table>
<thead>
<tr>
<th>Mild to moderate</th>
<th>Severe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Temporary numbness</td>
<td>Burning pain</td>
</tr>
<tr>
<td>Burning</td>
<td>Muscle wasting</td>
</tr>
<tr>
<td>Tingling</td>
<td>Paralysis</td>
</tr>
<tr>
<td>Electrical</td>
<td>Organ dysfunction or failure</td>
</tr>
<tr>
<td>Paresthesias or prickling sensation</td>
<td></td>
</tr>
<tr>
<td>Sensitivity to touch</td>
<td></td>
</tr>
<tr>
<td>Muscle weakness</td>
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PSONS Profile

Continued from page 9

and ONS for 18 years and has held numerous roles including: Editor (2 yrs), Research Chair (2 yrs), trained nurses in poster making class, and developed a writer’s workshop. Linda is the 2011 McCorkle Lecture recipient.

When she does have time for fun, Linda likes to travel with her partner and discover new places. She loves fishing in Alaska, novels, movies, gardening, and boating. She and her partner have two cats, Smokey and Samurai. And lastly, a surprise about Linda that you may not know, she sailed double handed (that’s sailor talk for two people) from Rhode Island to Bermuda and back. Bon Voyage!
neuropathic pain scale (NPS),\textsuperscript{13} and FACT-Taxane subscale.\textsuperscript{14} Some of these tools contain both objective and subjective measures of CIPN. There is still no standard tool for CIPN assessment. However, research studies are moving toward cancer specific or chemo-specific CIPN assessment.

In clinical practice, objective assessment for CIPN can include tests for touch, vibration, gait and balance, proprioception, reflexes, muscle strength, and perception of sharp/dull. These tests are recommended as adjuncts to the subjective symptom assessment. Cutaneous touch can be tested using Semmes-Weinstein monofilaments while proprioception can be tested using the Romberg’s test. The perception of sharp/dull can be easily performed using the pin prick test. It is also important to pay attention to signs and symptoms of motor involvement such as weakness, gait disturbance, balance disturbance, difficulty with fine motor skills such as buttoning clothing and writing.\textsuperscript{15,16}

Prevention and Treatment

Below are the summaries of prevention studies related to CIPN:\textsuperscript{17}

- Vitamin E - 4 clinical trials showed positive results in cisplatin and oxaliplatin containing regimens.
- Calcium/Magnesium - 1 trial showed positive results in oxaliplatin containing regimen
- Glutamine - 1 trial showed positive results in oxaliplatin containing regimen
- Glutathione - 1 out of 2 trials showed positive results in cisplatin based regimen, 1 positive trial in oxaliplatin-based regimen
- N-acetylcysteine - 1 trial showed positive result in oxaliplatin-based regimen
- Oxcarbazepine (Trileptal) - 1 trial showed positive result in oxaliplatin-based regimen

The summaries for treatment of CIPN are as follows:\textsuperscript{17}

- Nortriptyline (NTP, Pamelor, Norpress or Nortrilene) - No CIPN benefit
- Amitriptyline (Elavil) - No CIPN benefit
- Gabapentin (Neurontin) - No CIPN benefit
- Lamotrigine (Lamictal) - No CIPN benefit

Due to the lack of positive results in CIPN clinical therapeutic trials, emphasis on safety is being highlighted for patients. General safety recommendations include:
- Assessment of the water temperature at home
- Use of protective gloves while washing dishes
- Use of pot holders
- Use of cotton socks
- Establish well-lit rooms without glare
- Clearing walkways and avoiding the use of throw rugs
- Creating non-skid showers by installing tub mats

Summary

CIPN remains as a major clinical challenge and will continue to present more clinical problems if not addressed by oncology nurse clinicians. Patient and family education should include instructing the patient on how to notify clinician if signs and symptoms worsen, cautioning patient on operating machineries, and instructing family members to assess hot and cold temperatures if the patient is unable to do so.

There are no gold-standard, evidence-based recommendations for the assessment of CIPN. However, it is critical that oncology nurse clinicians must assess CIPN at the initiation of cancer therapy and identify individuals at risk for severe CIPN. Oncology nurse clinicians should utilize CIPN assessment tools consistently for early detection of worsening CIPN and intervene promptly.

References


Managing Dyspnea in Cancer Patients

Kathy A. Witmer, MN, ARNP

Dyspnea has been defined as an “uncomfortable awareness of breathing.” The word dyspnea comes from the Greek root dys, which means abnormal or disordered and pnoia, meaning breath.

Dyspnea is prevalent in cancer patients, particularly in patients with lung cancer, effecting up to 87% of patients diagnosed with the disease (Dudgeon, Kristjánsson, Sloan, Lertzman & Clement, 2001; Muers & Round, 1993). Additionally, dyspnea is present in 55% of the advanced cancer population at the time of referral to palliative care and in 79% of the same population in the last week of life (Ripamonti & Fusco, 2002).

There are clinical causes of dyspnea in cancer patients, some of which include: airway disease (endobronchial obstruction due to tumor or foreign body, or extrinsic compression), inflammation (ILD) or infection (bacterial, viral, or fungal), pleural disease (tumor spread, or malignant effusion), chest trauma (rib fractures, pneumothorax, or bone metastasis), pericardial effusion (restrictive cardiomyopathy, or tamponade), cancer spread (lymphangitic, or metastasis to the lungs or chest wall structures), and ongoing central respiratory motor activity. This mismatch produces the sensation of respiratory discomfort (ATS, 1999). Since 78% of all cancers are diagnosed in patients 55 years or older, many of those patients also have co-morbidities that may also contribute to the development of dyspnea.

The assessment of dyspnea in the cancer patient is a critical part of patient evaluation and should always start with a thorough history and physical. This assessment can be directed by the potential clinical causes as well as causes that may have resulted from their treatment. A review of systems should emphasize the search for corresponding pathophysiology and indirectly evaluate the respiratory structures (airways, parenchyma, pleura, diaphragm and vocal chords) cardiovascular health, neuromuscular function and functional capacity.

Diagnostic testing commonly follows to identify the specific causes of dyspnea. These may include imaging (chest xray or CT), pulmonary function tests, cardiovascular testing (EKG, echocardiogram, VQ, or CTA), and exercise testing. This approach can lead to the diagnosis in most, but not all cases. Correction and improvement in symptoms generally follow, decreasing the intensity of the dyspnea and increasing the comfort with which patients can perform activities of daily living.

The American Thoracic Society (ATS) published a position statement on dyspnea in 1999. According to the ATS, the treatment of dyspnea is rooted in the discussions of the mechanisms underlying shortness of breath. Treatments are also categorized and related to the pathophysiologic mechanisms leading to dyspnea versus the underlying disease. The ATS recommends that providers select the therapeutic interventions that address these different mechanisms in order to relieve the patient’s dyspnea.

Oncology providers are intimately involved in treating cancer patients and their dyspnea. A practical approach is both efficient and effective in a busy oncology practice, and often includes the following directed interventions:

1) Treat the cancer.
2) Provide supplemental oxygen to reduce the ventilatory demand, metabolic load and central drive.
3) Prescribe the following medications in the appropriate patients:
   a. Steroids for inflammation
   b. Bronchodilators to reduce resistive load
   c. Antibiotics for active pulmonary infections
   d. Opioids and or anxiolytics to alter central perception
4) Provide nutritional support to improve respiratory muscle function.
5) Blood transfusions or epoetin alpha to correct anemia and improve oxygen carrying capacity.
6) Drain effusions and or treat the pneumothorax.
7) Assess exercise tolerance and plan activities.
8) Assess anxiety & teach coping strategies. (Houlihan, Inzeo, Joyce, & Tyson, 2004).

Dyspnea is a complex symptom! It is

Continued on next page
not only subjective but it has multiple causes. Patients report variability in the intensity of their dyspnea symptoms, when they experience dyspnea, or with which activity. Their emotional response to dyspnea may vary as well. Goals for treating dyspnea in the cancer patient should aim at promoting patient comfort, increasing exercise tolerance and promoting physical and social well being (Carriere & Johnson-Bjerklie, 1986). Modest alterations in physiologic and psychological variables, as a result of a particular treatment, can produce a clinically meaningful reduction in symptoms (ATS, 1999). Effectively managing dyspnea in any patient is a clinical challenge and often requires a combined approach of various interventions. Please, consider quality of life in your cancer patients with dyspnea as you make your treatment decisions.

References


PSONS Community Service Project

Northwest Harvest: PSONS Meets the Challenge

Nancy Thompson, RN, MN
PSONS Community Service Coordinator

Once again PSONS has risen to the challenge in collecting food and cash for the Northwest Harvest Food bank at the 2011 annual symposium. When I dropped off this year’s donation, there was a long line of people waiting for food. There were so many people waiting for food they had a security officer managing crowd control! I didn’t ask them to weigh our donation since they were so busy but it filled the back of my car and I needed a cart to deliver all of it.

$335 was also collected in cash and checks. Northwest Harvest was participating in the “Alan Shawn Feinstein Foundation of Rhode Island Challenge”. All the hunger organizations who participate in the challenge get their funds matched by the Feinstein Foundation for all the cash they raise in March and April. This essentially doubled our donation!

In 2010, one in seven households in Washington struggled to provide enough food for their family. This year, the state’s budget crisis will result in the elimination or significant reductions of critical services that help struggling families meet their basic needs, like keeping food on the table.

Thank you for sharing your pantry and cash with those less fortunate!

The next PSONS community service project will be the fall school supply drive so watch for sales this summer on back packs and school supplies!

2011 PSONS Scholarship Awards

Mona Stage RN, BSN

Once again PSONS was able to provide education scholarships to its members. Applicants are nominated by other members or themselves. Each recipient submitted an essay describing their current role in cancer care, how attendance at the education conference would improve their practice and what plans they have to disseminate and use the information. Below are the essays submitted by the scholarship recipients.

To read each essay in its entirety, please visit www.psons.org

Rose Preston PSONS Scholarships

Mesha Park - UW

I am an Oncology nurse at UWMC working with Hematology Oncology/Bone Marrow Transplant patients. Oncology has been a passion of mine from the start due to positive experiences I had experienced as a nursing student 10 years ago. I enjoy every aspect of Oncology from educating new patients, families and new nurses, to comforting patients and their families who are headed in the direction of palliative or comfort care.

Patricia Koehler - Premera

I developed Breast Cancer in 2005 and was treated with lumpectomy, followed by mastectomy and then chemotherapy. Prior to being diagnosed I worked as a general case manager at Premera Blue Cross but felt after my experience with cancer that I could better serve in the Oncology Department so I transferred there and feel I am at home.

PSONS Symposium Scholarships

Stacie Birk - UW

I have been an RN at the University of Washington on the Blood & Marrow Transplant (BMT) unit for the past 4.5 years. My unit focuses on primary care nursing. This is my one and only nursing job and I have to love the constant learning required in the teaching hospital environment and the primary nursing care model. I am blessed with the opportunity to have cross-trained into our Oncology ICU over the last year and have thoroughly enjoyed the learning challenge. I am also chemo/biotherapy certified via ONS and serve as one of the charge nurses on the night shift.

Susan Aronson - VMMC

I have worked on the in patient Oncology unit at Virginia Mason Medical Center for a total of 14 years. I became interested in working in Oncology while as a senior nursing student from the University of Washington I chose the Peter Canlis Cancer Unit for my senior practicum rotation. Upon graduation I started working at VM on the Oncology unit. I took an extended leave of absence from the world of Oncology nursing as I raised my children for 15 years before coming back to VM and Oncology in 2004.

Robyn L. Haaf - FHCRC

Most of my career as a nurse has been spent in the field of oncology and although I don’t regret the experiences and skills developed while working in a rural hospital or as an EMT or as a traveling nurse/slave labor, the years as an oncology nurse have had the largest influence in shaping my time in the medical field. In the oncologic world, my career has spanned the gamut of inpatient chaos control, outpatient chemotherapy, bone marrow/stem cell transplant, general oncology and currently, a clinical research nurse at Fred Hutchinson Cancer Research Center in Seattle.

Congress Scholarships

Marivic Mangila - Highline

My oncology career began 4 years ago as a new graduate in a Medical Oncology inpatient unit. In those two years, I gained a good foundation in nursing. Currently, I work in a comprehensive cancer center primarily as an infusion nurse. In the past two years, I have had the opportunity to learn the chemotherapy protocols, side effects, and how to respond to patient’s emotional response to their cancer. During this time, I have also worked as the office nurse, where I see patients at their initial consultation with the oncologist in which I participate in the pre-treatment assessment/teaching appointment preparing patients and their support for their chemotherapy.

Sharon Baker - Swedish

I am currently working in a hospital based outpatient clinic. Our practice focus is medical oncology. I am looking to round out my knowledge around survivorship.
BOOK REVIEW

“The Immortal Life of Henrietta Lacks”
by Rebecca Skloot

Reviewed by Michaele Wetteland, RN, OCN

If you work in oncology, there are two recent books that should be on your must-read list. The first is “The Immortal Life of Henrietta Lacks,” the story of an African-American woman who died from ovarian cancer in 1951. The second is the Emperor of Maladies, by Siddhartha Mukherjee, which I intend to review in the next newsletter.

Henrietta Lacks’ cancer produced a remarkable strain of hardy cancer cells, still alive today, billions of cell divisions later, and widely used in cancer research. These ‘He-La’ cells are so aggressive they must be carefully monitored in the lab setting.

The book is not only a compelling look at those unique cells, –her legacy to all of us in oncology– but also the story of one black family’s struggle with the medical establishment of the post-war era.

The author, Rebecca Skloot, tracks down Henrietta’s poor, under-educated family who struggle with the medical establishment of the day. The author interviews Henrietta’s former husband, children: David (Sonny), Lawrence, Zakariya (Joe), Relatives Cootie (cousin), Cliff, Gladys (sister), Sadie (friend) give vivid accounts of what health care was like for African-Americans in the 1950’s. I found it hard to believe that this happened in my lifetime. This was not one of our finer eras in medicine. As I read this, I was embarrassed and appalled.

It takes the persistence of the author and a kindly PhD student and cancer researcher, Christoph Leagauer, to bring the family and the HeLa cells together. Christoph’s kind words set the stage. “It must be pretty hard for you to come into a lab at Hopkins after what you’ve been through. I’m really glad to see you here.”

One of my favorite parts of the book occurs when Sonny, one of Henrietta’s sons, drops off the author at one of Henrietta’s sons house to interview him. As she leaves the car, Sonny calls out “Gook Luck.” She writes “All I know about Sonny’s brothers was that they were angry and one of them had murdered someone. I wasn’t sure which one, or why.” As she walks inside the house, she sees Lawrence “his 275-pound, six foot frame spanning the width of the narrow kitchen.” He asks her “You wanna taste the meat I cooked?” “How could I resist?” she says, but telling her reader the fact that she had not eaten pork for a decade “suddenly seemed irrelevant.”

I highly recommend this book for its glimpse of medical history into our specialty, but most importantly to learn the power of patient education and compassion.


Adrift in the Sea of Cancer Survival
Continued from page 8

References


In Memory of Ellen DeBondt

Ellen DeBondt loved her life and lived each day to its fullest. Born Ellen Joan Wilson on July 27, 1966, in Jacksonville, North Carolina. After graduating from high school in Kahului, Hawaii, Ellen traveled with her sister, Shirley, to Virginia, where both attended George Mason University. Ellen became a registered nurse, first working at Sibley Hospital in the District of Columbia, then as a traveling nurse and later as a hospice nurse in Northern Virginia. Ellen and her sister moved to Seattle in 1994. In Seattle she worked as a hospice nurse, and later she became an oncology nurse at the University of Washington Medical Center and then moved to the Seattle Cancer Care Alliance Pain Clinic. Settled in Seattle, Ellen became involved with the Washington Kayak Club. In this time period, Ellen and Ken fell in love, and in August 1999, they wed on the beach at LaPush in a ceremony that included the couple entering through an archway of kayak paddles held by their friends.

Ellen and Ken had a special place in their hearts for the Olympic Peninsula, especially the Crescent Bay area. They spent many weekends surfing their kayaks on the Crescent Bay breaks. They moved to the peninsula in early 2008 and Ellen began working for Olympic Medical Home Health.

Ellen was killed instantly on Sunday, March 6, 2011, as she was beginning her day of work, when her pickup truck was hit by an oncoming vehicle that veered into her lane.

Ellen was always optimistic, positive, patient and extremely generous. She gave to those around her, but saw herself as the receiver, blessed with a life that she loved. She is survived by her husband, Ken, and Rio, her faithful dog and many family members and friends who miss her.

To read memories of Ellen from her oncology nursing friends please visit www.psons.org

Adolescents and Young Adults: Adrift in the Sea of Cancer Survival

Linda Cuaron, RN, MN, AOCN

Cancer treatment for children and adults today may be viewed as a “sea of success” with greater awareness, earlier detection, and discoveries in genomics and personalized medicine leading to the potential for cancer to become a chronic illness. Significant progress is being made in the area of clinical cancer research, surveillance and prevention, resulting in cancer incidence and cancer death rates that have declined in the United States.

The CDC defines a cancer survivor as anyone who has ever had cancer, from the time of diagnosis through the rest of their life. There are 12 million cancer survivors in the United States today. According to new statistics from the Centers for Disease Control and Prevention (CDC) and over 28 million worldwide. That is an improvement from the official US figure in 2007 of 11.7 million survivors, 9.8 million in 2001 and just 3 million in 1971. About half of the nation’s cancer survivors have had either breast, prostate, or colorectal cancer and slightly more than half are women. About 7 million survivors are 65 or older, and 4.7 million were diagnosed 10 or more years earlier. Earlier detection, improvements in diagnosing cancer, and more effective treatment and follow-up are some of the reasons for the increase in the number of cancer survivors over the years.

Adrift in the Sea of Cancer Survival

However, the story is not as bright for the adolescents and young adult (AYA) cancer patients and survivors of childhood cancer. Survival improvement trends show a worse prognosis for AYA’s diagnosed today than 25 years ago. Survival figures for children who have had cancer have improved by 1.5% per year for children younger than 15 and adults older than 50 years, but cancer survival has improved by less than 0.5% per year in 15-24 year-olds. This is in contrast to statistics seen at the beginning of the last quarter century when the diagnosis of cancer in 15-29 year olds carried a more favorable prognosis relative to cancer at other ages. That is no longer the case, and moreover, cancer survival has not improved at all in 25 to 34 year-olds. This deficit is increasing with longer follow-up of survivors. These deficits appear to be global and not just seen in the US.

Figure 1 depicts the stark differences in 5-year relative survival for invasive cancer based on US SEER data from 1975-1997. Continued on page 3

In Memory of Ellen DeBondt

July 27, 1966 - March 6, 2011

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