



# The Research Connection

The Psychosocial & Nursing Advisory Board to  
the New Jersey Commission on Cancer Research

Editor: Kathleen Neville, Ph.D., RN

Number 3

The Joint Psychosocial & Nursing Advisory Group to the NJCCR was appointed to advise the Commission of special research needs pertaining to nursing, psychology, sociology, and related disciplines for the purpose of addressing gaps in vital areas of cancer research and cancer care in New Jersey.

## 2006

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*Mildred Ortu Kowalski, RN, MPA (right), co-chair elect of the Nursing-Psychosocial Advisory Group, presents Dr. Wendy Budin (left) with a plaque honoring her 6 years of leadership as co-chair.*

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## Lung Cancer and Gender

By

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Lung cancer is the leading cause of cancer death in both men and women living in the United States (Fu, Kau, Severson & Kalemkerian, 2005). The high mortality rate of lung cancer is attributed to many factors. The most prevalent include the older age at diagnosis (most lung cancer patients are in their sixties), later stage of the disease at diagnosis, and existence of other comorbidities including asthma, cardiac disease and chronic obstructive pulmonary disease at the time of diagnosis (Birim, Kappetein, vanKlaveren & Bogers, 2006; Fu et al., 2005). In addition, it is estimated that 39% of patients have distant metastases at diagnosis (Mandrekar, Hillman, Allen, Marks, Maillard et al., 2006). The survival rate for patients with lung cancer is very low. Eighty percent of lung cancer patients survive less than two years after diagnosis (Ahuja, Weibel & Leone, 2003). What is even more distressing is that the majority of lung cancer deaths are preventable, as cigarette smoking has been attributed to be the causative factor for lung cancer in 87% of lung cancer patients (Ahuja et al., 2003).

Lung cancer is divided into two subgroups: small lung cancer and non-small lung cancer. Small cell lung cancer comprises approximately 10-15% of lung cancers diagnosed in the United States, is an aggressive cancer that frequently metastasizes, and less than 15% of patients survive two years or more (Chandra, Allen, Nichols, Deschamps, Cassivi, Pairolero, 2006). Non-small lung cancer is less aggressive and can be divided into different types. The three most common types include: squamous cell, adenocarcinoma and large cell carcinoma. Treatment for lung cancer includes surgery, radiation and chemotherapy. Most patients receive a combination of treatments based on tumor size, stage, location, and symptoms.

The role of gender in susceptibility to lung cancer and mortality has received attention in the literature, with conflicting findings (Gasperino &

Rom, 2004; Neugut & Jacobson, 2006; Twombly, 2004; Yoshino, Kawano, Oba, Yamazaki, Komentani & Machara, 2006). A prospective study of 50,000 rural men and women living in Norway demonstrated that smoking increases morbidity and mortality in women, usually due to cardiovascular disease and cancer. Mortality rates in women age 40-70 years was 9.4% for never smokers and 18.7% for continuing smokers. Women who never smoked lived on average 1.4 years longer than smokers. However, when examining gender and mortality rates, women smokers died less frequently than the male smokers (Vollset, Tverdal & Gjessing, 2006).

One of the largest longitudinal studies to detect lung cancer, The International Early Lung Cancer Awareness Project, used computed tomographic screening and smoking history to assess for gender differences. This large longitudinal study screened more than 16,000 current and former smokers. Rate of smoking was measured using PYI (pack year index). The PYI is determined by multiplying the number of packs per day by number of years smoking. All participants in this research project were asymptomatic with no history of cancer at the initial screening. In this study, women were diagnosed with lung cancer more frequently than men, even when smoking at a lower rate than men and had a lower mortality rate (Henschke, Yip & Miettinen, 2006). Other studies noted that women are diagnosed at a younger median age than men, even when smoking less cigarettes (Fu et al., 2005). These studies appear to indicate that women may be more susceptible to lung cancer.

Genetic, metabolic and hormonal factors influence how one reacts to carcinogens. The influence of gender on susceptibility and mortality to lung cancer is attributed to many factors. Genetic predisposition, female hormones, smoking patterns, stage at diagnosis and vitamin D levels have all been hypothesized as possible factors to explain the differences in susceptibility and prognosis (Gasperino & Rom, 2004; Ganti et al., 2006; Neugut & Jacobson, 2006; Yoshino et al., 2006). In a study of approximately 500 women with lung cancer, women receiving hormone replacement therapy were more likely to die from the disease than women who never used hormone replacement

therapy (Ganti et al., 2006). In that same study, a history of both smoking and hormone replacement therapy increased risk for lung cancer even more. Earlier age at initiation of smoking is thought to damage lung DNA (Wiencke, Thurston, Kelsey et al., 1999). Season of diagnosis and survival rates were analyzed in over a million cancer patients in the UK. Researchers noted that the season a cancer was diagnosed and sun exposure was related to cancer survival. Vitamin D metabolites are theorized to play a role in tumor growth suppression. Findings were noted to be statistically significant for individuals with lung cancer and even more significant for women than men (Lim, Roychowdhuri, Peto, Schwartz, Baade & Meller, 2006)

Although women appear to be more susceptible to lung cancer, getting diagnosed at a younger median age and with lower smoking rates, survival time is higher. Women with non-small cell lung cancer survived an average of 55 months and males an average of 37.2 months after diagnosis (Moore, Doherty, Chamberlain & Khuri, 2004). Lung cancer patients receiving surgical treatment without chemotherapy and radiation had the most favorable outcome (Moore et al., 2004). Survival time after diagnosis with lung cancer varies with type of tumor. In a study of stage II non-small cell lung cancer at time of diagnosis, female gender was a positive prognostic factor, regardless of type of surgery and/or radiation (Wisnivesky, Hensche, McGinn & Ianuzzi, 2005). Survival time after diagnosis with lung cancer was greater for women than men regardless of stage at diagnosis (Birim et al., 2005; Fu et al., 2005). Another study noted that stage at diagnosis and not gender was a prognostic factor in non-small cell cancer (Yoshino et al., 2006).

Smoking cessation and survival was studied in 543 early non-small cell lung cancer patients. Smoking cessation positively impacted on overall survival and recurrence free survival. The longer the patient had stopped smoking, the greater the overall survival. The five year overall survival rate was 50%, 54%, 59% and 76%, respectively for current smokers, smokers who quit 1-8 years prior to diagnosis, smokers who quit greater than 18 years prior to diagnosis, and never smokers. In

examining the interaction effects for gender and smoking cessation, smoking cessation was significant for women only (Zhou, Heist, Liu, Park, 2006).

The PYI index was used to identify survival rates in a large sample of Japanese patients treated for lung cancer. Smoking habit was a significant prognostic factor for patients with stage 1 adenocarcinoma, regardless of gender, with patients with a PYI of less than 20, experiencing a more favorable outcome (Yoshino et al., 2006). Smoking cessation prior to lung cancer surgery increased survival rates (Sardari, Weyler, Colpaert, Vermeulen et al, 2005). Smoking status at diagnosis was a significant predictor for survival regardless of stage at diagnosis (Tannenmagi, Meslund-Dudas, Simoff & Kvale, 2004). In addition, patients who had quit smoking prior to the diagnosis of lung cancer experienced a better quality of life (Garces, Yang, Parkinson et al., 2004).

Although gender differences in survival are not clear cut, the need to implement smoking cessation for all smokers cannot be refuted. Although it appears that many factors impact on susceptibility and survival in lung cancer, smoking status is one that is modifiable. According to the National Health Interview Study (2004), greater than 20% of American adults still smoke. As healthcare providers, we have the opportunity to discuss the dangers of smoking at every patient encounter and we should take this opportunity to promote wellness. The positive effects of smoking cessation are especially noted in women. Individuals diagnosed with early stage disease, should undergo intensive smoking cessation to improve survival and quality of life (Tsao, Liu, Lee, Spitz & Hong, 2006). Since brief smoking interventions have been proven effective, it is important to assess smoking status and provide appropriate counseling at every healthcare visit (Giarelli, 2006).

#### References:

Ahuja, R., Weibel, S., & Leone, F. (2003). Lung cancer: The oncologist's role in smoking cessation. *Seminars In Oncology*, 30(1), 94-103.

- Birim, O., Kappetein, A., van Klaveren, R., & Bogers, A. (2006). Prognostic factors in non-small cell lung cancer surgery. *European Journal of Surgical Oncology: The Journal of the European Society of Surgical Oncology and the British Association of Surgical Oncology*, 32(1), 12-23.
- Fu, J., Kau, T., Severson, R., & Kalemkerian, G. (2005). Lung cancer in women: analysis of the national Surveillance, Epidemiology, and End Results database. *Chest*, 127(3), 768-777.
- Chandra, V., Allen, M., Nichols, F., Deschamps, C., Cassivi, S., & Pairolero, P. (2006). The role of pulmonary resection in small cell lung cancer. *Mayo Clinic Proceedings. Mayo Clinic*, 81(5), 619-624.
- Ganti, A., Sahmoun, A., Panwalkar, A., Tendulkar, K. & Potti, A. (2006). Hormone replacement therapy is associated with decreased survival in women with lung cancer. *Journal of Clinical Oncology: Official Journal of the American Society of Clinical Oncology*, 24, 59-63.
- Garces, Y., Yang, P., Parkinson, J. et al. (2004). The relationship between cigarette smoking and quality of life after lung cancer diagnosis. *Chest*, 126(6):1733-1741.
- Gasperino, J., & Rom, W. (2004). Gender and lung cancer. *Clinical Lung Cancer*, 5(6), 353-359.
- Giarelli, E. (2006). Smoking cessation for women: evidence of the effectiveness of nursing interventions. *Clinical Journal of Oncology Nursing*, 10(5), 667-671.
- Henschke, C., Yip, R., & Miettinen, O. (2006). Women's susceptibility to tobacco carcinogens and survival after diagnosis of lung cancer. *JAMA: The Journal of the American Medical Association*, 296(2), 180-184.
- Lim, H., Roychoudhuri, R., Peto, J., Schwartz, G., Baade, P., & Møller, H. (2006). Cancer survival is dependent on season of diagnosis and sunlight exposure. *International Journal of Cancer: Journal International Du Cancer*, 119(7), 1530-1536.
- Mandrekar, S., Hillman, S., Allen, K., Marks, R., Maillard, J. et al. (2006). A prognostic model for advanced stage nonsmall cell lung cancer: Pooled analysis of North Central Cancer Treatment Group trials. *Cancer*, 107(4), 781-792.
- Moore, R., Doherty, D., Chamberlain, R., & Khuri, F. (2004). Sex differences in survival in non-small cell lung cancer patients 1974-1998. *Acta Oncologica*, 43(1), 57-64.
- Neugut, A., & Jacobson, J. (2006). Women and lung cancer: Gender equality at a crossroad? *JAMA: The Journal of the American Medical Association*, 296(2), 218-219.
- Sardari N., Weyler, J., Colpaert, C., Vermeulen, P., Van Marck, E., & Van Schil, P. (2005). Prognostic value of smoking status in operated non-small cell lung cancer. *Lung Cancer*, 47(3), 351-359.
- Tammemagi, C., Neslund-Dudas, C., Simoff, M., & Kvale, P. (2004). Smoking and lung cancer survival: the role of comorbidity and treatment. *Chest*, 125(1), 27-37.
- Tsao, A., Liu, D., Lee, J., Spitz, M., & Hong, W. (2006). Smoking affects treatment outcome in patients with advanced nonsmall cell lung cancer. *Cancer*, 106(11), 2428-2436.
- Twombly, R. (2004). New studies fan controversy over gender risk in lung cancer. *Journal of the National Cancer Institute*, 96(12), 898-900.
- U.S. Department of Health and Human Services, National Health Interview Survey. (2004). U.S. Department of Health and Human Services National Center for Health Statistics. Ann Arbor, Michigan: Inter-university Consortium for Political and Social Research.

Vollset, S., Tverdal, A., & Gjessing, H. (2006). Smoking and deaths between 40 and 70 years of age in women and men. *Annals of Internal Medicine*, 144(6), 381-389.

Wiencke, Thurston, Kelsey, et al. (1999). Early age at smoking initiation and tobacco carcinogen DNA damage in the lung. *Journal of the National Cancer Institute*, 91(7), 614-619.

Wisnivesky, J., Henschke, C., McGinn, T., & Iannuzzi, M. (2005). Prognosis of Stage II non-small cell lung cancer according to tumor and nodal status at diagnosis. *Lung Cancer*, 49(2), 181-186.

Yoshino, I., Kawano, D., Oba, T., Yamazaki, K., Kometani, T., & Maehara, Y. (2006). Smoking status as a prognostic factor in patients with stage I pulmonary adenocarcinoma. *The Annals of Thoracic Surgery*, 81(4), 1189-1193.

Zhou, W., Heist, R., Liu, G., Park, S., Neuber, D., Asomaning, K. et al. (2006). Smoking cessation before diagnosis and survival in early stage non-small cell lung cancer patients. *Lung Cancer*, 53(3), 375-380.

## **A Diagnosis of Lung Cancer Challenges: Patient, Family and Caregivers**

by

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Lung cancer is one of the most common types of cancer in the USA. The American Cancer Society (ACS, 2006) estimates over 170,000 new cases of lung cancer will be diagnosed in 2006. For men, the 92,700 new cases is second only to prostate cancer in the number of new cases diagnosed in 2006. For women, the estimated 81,770 cases will be second only to breast cancer in the number of cases diagnosed (ACS, 2006). The incidence rates represent a slight decrease in

incidence for men in the US, between 1975 and 2002; but, an increase in lung cancer diagnosed in women (ACS, 2006).

While attention has been paid to the risk of smoking as it relates to lung cancer, tobacco use can be linked to only a portion of the diagnoses. Thousands of non-smokers each year develop lung cancer (ACS, 2006). The scientific community does not yet understand why some smokers never develop lung cancer, while some non-smokers do. Meanwhile, patients with lung cancer must sometimes face incorrect assumptions by others that they could have prevented their cancer, had they not smoked.

To help patients deal with the emotional impact, treatment decisions, and concerns that accompany any diagnosis of cancer, several large patient groups exist. These groups offer an array of services to patients with cancer, including but not limited to lung cancer. Additionally, there are patient advocacy groups which specialize in the needs of patients and families dealing with the challenges of lung cancer (see Insert). These groups hope to raise awareness of the disease, not only in the public eye, but also for legislators in Washington, DC, who control federal research funds. Research funds are of interest to cancer researchers, and others concerned with understanding and treating the disease.

One patient advocacy group, Lung Cancer Alliance (formerly called ALCASE), moved its headquarters from California to Washington, DC to actively interface with politicians. Closer to home, Joan's Legacy, located in NYC, was created to honor the memory of Joan Scarangelo, a newscast copywriter and non-smoker who developed lung cancer at the age of 47. Brian Williams has hosted an annual fundraiser held in NYC for this group. One of the group's main missions is to raise awareness of lung cancer, to support research, and to end any stigma that people diagnosed with lung cancer face.

Focusing on education, counseling and symptom management, Cancer Care is a large national group, with headquarters located in NYC, and several NJ offices. Offices in NJ include:

Ridgewood, Somerset, Millburn, Princeton and Trenton. This group provides education and free counseling to patients with cancer, including lung cancer. Dedicated to supporting patients who struggle to face an array of emotional battles, Cancer Care provides on-line, written and telephone education. Licensed social workers are available to assist patients and family members in need.

For those who are interested in support groups, educational workshops and mind/body programs, The Wellness Community offers a warm home-like atmosphere to support patients with cancer and their families. One of 21 communities throughout the USA, The Wellness Community in New Jersey is located in Bedminster. Free support and education are available both online and in person. A monthly Lung Cancer Networking Group meets there as well as weekly patients and caregiver groups.

Sometimes treatment schedules, office visits, or fatigue prevent patients from obtaining in-person support. Website and phone number information are provided (see below) to help readers explore the services offered by the advocacy groups. A number of resources are available through patient advocacy groups to help with these challenges. Each group offers one or more services to patients and families. Assistance with decision making, emotional support, financial assistance, education, counseling and side effect management may be obtained. Although each group has a different focus, the unifying theme is that the groups are available to help patients and family members cope with a diagnosis of lung cancer. If you or a loved one is facing a diagnosis of lung cancer, you may want to explore the support offered by patient advocacy groups.

## RESOURCES

**American Cancer Society** provides information and support for people with cancer and their families.

[www.cancer.org](http://www.cancer.org)  
1-800-ACS-2345

**American Lung Association** was founded in 1904 to fight tuberculosis, the ALA today fights lung

disease in all its forms, with special emphasis on asthma, tobacco control and environmental health. The website also includes the “Living With Lung Disease Wall of Lung Champions” which is dedicated to people who live each day with lung disease.

[www.lungusa.org](http://www.lungusa.org)  
800-LUNG-USA (800-586-4872)

**CancerCare** is a national non-profit organization that provides free professional support services to anyone affected by cancer, including loved ones and the bereaved. CancerCare programs include counseling, education, financial assistance, and practical help are provided by trained oncology social workers and are completely free of charge.

[www.cancercare.org](http://www.cancercare.org)  
1-800-813-HOPE (4673)

**LungCancer.org** was founded by CancerCare as part of their ongoing programs for people with lung cancer. This informational website includes sections for Patients and Caregivers, Health Care Professionals, and a Media Center. You can find information on archived teleconferences as well as links to the services provided by CancerCare

[www.lungcancer.org](http://www.lungcancer.org)  
877-646-LUNG (877-646-5864)

**Lung Cancer Alliance:** A national non-profit organization dedicated to patient support and advocacy for people living with lung cancer and those at risk for the disease.

[www.lungcanceralliance.org](http://www.lungcanceralliance.org)  
1-800-298-2436

**Lungcanceronline.org** is an information resource for patients and families. Lungcanceronline.org provides an annotated directory to Internet information and resources for patients and families.

[www.lungcanceronline.org](http://www.lungcanceronline.org)

**Joan’s Legacy: The Joan Scarangelo Foundation to Conquer Lung Cancer:** Located in NYC, Joan’s Legacy is committed to fight lung cancer by funding innovative research and increasing awareness of the world’s leading cancer killer, with a special focus on non-smoking-related lung cancer.

[www.Joanslegacy.org](http://www.Joanslegacy.org)

**The Wellness Community:** The mission of The Wellness Community is to help people affected by cancer enhance their health and well-being through participation in a professional program of emotional support, education and hope.

[www.thewellnesscommunity.org](http://www.thewellnesscommunity.org)

The Wellness Community of Central New Jersey:  
908-658-5400

**Lung Cancer Circle of Hope:** The mission of LCCH is to educate the public and members of the medical community about lung cancer, advocate on behalf of lung cancer patients, their families and others at risk, influence public policy decisions relating to lung cancer and promote increased funding for lung cancer research.

[www.lungcancercircleofhope.org](http://www.lungcancercircleofhope.org)

732-363-4426

**Cancer Hope Network:** Provides free, confidential, one-on-one telephone support to recently diagnosed patients and their family members by matching them with trained survivors.

[www.cancerhopenet.org](http://www.cancerhopenet.org)

877-HOPE-NET

**National Lung Cancer Partnership (formerly Women Against Lung Cancer):** This organization's mission is to decrease deaths due to lung cancer and help patients live longer and better through research, awareness and advocacy. The National Lung Cancer Partnership is currently focusing its efforts on women and the gender disparities in lung cancer patients.

<http://www.nationallungcancerpartnership.org>

### **Local Lung Cancer Support Groups**

There are monthly lung cancer support groups held at four locations in New Jersey:

- Carol G. Simon Cancer Center at Morristown Memorial Hospital: 4<sup>th</sup> Wednesday, 2-3:30 PM. Call 973-971-5169
- Gilda's Club Northern New Jersey, Hackensack, NJ, 2<sup>nd</sup> Friday, 10:30 AM-12 PM. Call 201-457-1670

- Hackensack Medical Center's Cancer Center, 1<sup>st</sup> Thursday, 10:30 AM-12 PM. Call 201-996-5836
- The Wellness Community of Central New Jersey, Bedminster, 2<sup>nd</sup> Wednesday, 6:30-8 PM. Call 908-658-5400

## **What Makes a Lung Cancer Support Group?**

by

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There is a well-known body of research in psychosocial oncology which illustrates the value of emotional support and support groups in improving quality of life and extending life among some cancer patients.....but, just *what* attracts people to support groups?

What brings them to a Lung Cancer Support Group, in particular?

At the Carol G. Simon Cancer Center, the most commonly cited reasons are: the desire for information, the wish to speak with others who "really understand," and the need for a place to talk about thoughts and feelings which cannot be easily shared with family members. The unspoken message? Just being in the room with other people who are *living* with cancer is comforting. Being in the room with others who are living with *lung cancer* is even more comforting. This is, in part, because the information shared seems particularly relevant and members feel they have to "explain" less. There is a frequent exchange of facts about treatment options, management of side effects, and what to do "next." Sometimes there is expressed frustration and anxiety as one awaits test results or fear as a recurrence is discovered. But, it is more than that.

At times, there is discussion about the prevalence of lung cancer in women, the stigma and

guilt about smoking, the fact that so many group members never smoked or quit long ago, or their understanding that this disease “will eventually get me.” Every few months, the group talks about wills, advance directives, burial plots and cremation or distributing special belongings to loved ones. But, more often, it is about *hope*. It is about *listening*. It is about *humor*. The group loves to hear about a wedding, a birthday celebration, a great movie, a trip to see grandchildren, and details about how each has *lived* since the last meeting.

Whether an individual has had surgery for a stage I lung cancer, or whether they are making a decision regarding a newly discovered metastatic brain lesion, there is often anger, fear and disappointment. This supportive environment has allowed those with different stages of disease to continue to come together and express relief at a positive outcome or fear about sharing “bad news.” The group has been able to support each other and guide one another toward an amazing acceptance of where they are. The focus is on how to “tackle” this new situation, to appreciate even the smallest positive response, or how to carve out some time to enjoy a day, or just an hour. They teach one another how to embrace the reality without allowing negative thoughts to consume them and tarnish the time they have.

But, now the greatest question: How do they handle *loss*? Many members have died. Irene, one of the founders of the group, who lived with lung cancer for 6 years after receiving a prognosis of 4 to 6 months. Bob, who wrote a book to his teenage sons before his death and shared it with the group. Maureen, a 45 year old woman with an eight year old son who was always kind and gentle. Those in the group cope with these losses by remembering their friends out loud, smiling as they remember something special about them, and giving thanks for having known them. Often the group writes a note about what touched them the most or sends a card to the family. “Honoring” the life of the member who has died is critical, especially for those who are living. Perhaps the group has another important job to do: create a meaningful ritual for celebrating those who have died. After all, each wants to be remembered.

## Lung Cancer and Perception of Blame

by

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The diagnosis of cancer has long been associated with fear, shame and stigma. Susan Sontag (1978) noted that cancer is often “felt to be obscene—in the original meaning of that word: ill-omened, abominable and repugnant to the senses” (p. 9). The word cancer has been used as a metaphor for evil or undesirable elements in a person or society. Until fairly recently, cancer if discussed at all, was whispered about and referred to as “the Big C”. First Lady Betty Ford is often credited as being among the first high-profile people to publicly discuss her diagnosis of breast cancer. Her openness helped to promote a new attitude toward cancer in the United States.

While the stigma associated with cancer has in general diminished, people with lung cancer remain targets of guilt, blame and shame. The degree of stigma associated with a disease depends upon both the degree of responsibility conferred upon the patient; and the disability, disfigurement, loss of control, or disturbance of social interactions resulting from the disease (Albrecht, Walker, & Levy, 1982). A disease or condition may be perceived more negatively if it is associated with controllable rather than uncontrollable factors (Weiner, Perry & Magnusson, 1988).

While 85%-90% of lung cancer deaths in the United States result from cigarette smoking, 15,000 lifelong nonsmokers die each year of lung cancer (Thun, 2006). The perception that this disease is caused by controllable factors, and the accompanying perception that it is therefore “preventable” leads to the assignment of “blame”, and stigmatization among individuals diagnosed with lung cancer. According to Susan Mantel, Executive Director of Joan’s Legacy, a fund-raising group dedicated to promoting lung cancer awareness, prevention, and research, “When people develop breast cancer, people say ‘What can I do to help you?’ When people develop lung cancer,

people say ‘Did you smoke?’” (Marchione, 2005, p. 2).

In an effort to promote smoking prevention and cessation, smoking has been represented as “dirty”. Images of polluted lungs, dark, blurry smoke-filled rooms, and foul-smelling breath contribute to our view of smoking, and by association, smokers as “dirty”. This stigmatization of smokers may delay some people from seeking medical care or prevent others from accessing available psychosocial support.

Chapple, Ziebland & McPherson (2004) at the University of Oxford confirmed that smokers perceive that others blame them for their cancer. In a qualitative study, investigators interviewed 45 lung cancer patients. Participants were interviewed in their homes between October 2002 and August 2003. They were asked to tell interviewers about their illness history, beginning with their first suspicion that they had a health problem. The audio-taped interviews lasted from one to three hours; transcripts were given to participants to assure that they had accurately expressed themselves in the interviews. Transcripts were reviewed for thematic content. Because the interviews were unstructured, inter-rater reliability scores were not established.

Participants felt that they were stigmatized because of the association between lung cancer with smoking. Some participants reported that people crossed the street to avoid contact with them; they suggested that the high death rate and the type of suffering and death associated with lung cancer contributed to the avoidant behavior.

Among lung cancer patients, even non-smokers may be blamed for their illness because they may be perceived as having “allowed” themselves to be victims of second hand smoke. Participants reported concern not only with the social stigmatization, but worry that treatment will be withheld or delayed because they were “to blame” for their illness. In Great Britain, some patients “perceive a disparity between the resources for lung cancer and those for conditions not considered to be self-inflicted” (Chappel et al., 2004).

In December 2000, the Cancer Research Campaign in Scotland named January Lung Cancer Awareness Month, citing that although 4,000 Scots die each year from the disease, compared with other cancers, it has a relatively low public profile. In a poll commissioned by this campaign, “62% of those questioned felt that smokers were to blame for their lung cancer”; 82% felt that smokers who “develop lung cancer had as much right to a hospital bed as those who develop other forms of cancer” (BBC News, 2000, p. 2). The article suggests that the perception exists that lung cancer is a “self-inflicted” disease, which contributes to the low public profile and the relative lack of resources being directed toward the disease (BBC News, 2000, p. 2).

Efforts to reduce or eliminate tobacco related illness are laudable. An outgrowth of these efforts though, may be a reinforcement of the human tendency to blame others for their misfortune, in an attempt to feel that one is fundamentally different from those who are suffering. Lung cancer patients struggle with not only disease, but with stigmatization, blame and shame that further complicate an already difficult disease.

#### References:

- Albrecht, G., Walker, V., Levy, J. (1982). Social Distance from the Stigmatized: a test of two theories. *Social Science & Medicine*, 16: 1319-27.
- BBC News. (2000). Lung Cancer Victims ‘to blame’. Retrieved on November 20, 2006 from <http://news.bbc.co.uk/1/hi/scotland/1089957.stm>.
- Chapple, A., Ziebland, S., McPherson, A. (2004). Stigma, shame and blame experienced by patients with lung cancer: A qualitative study. *BMJ*, 328,470.
- Marchione, M. (2005). Non-smokers fight lung-cancer stigma. *Mercury News* (AP).
- Sarna, L. Lung Cancer. (1998) *Psycho-oncology*. Holland, JC et al. (ed). NY: Oxford University Press.
- Sontag, S. (1978). *Illness as Metaphor*. New York: Farrar, Straus & Giroux, p. 9.

Thun, M. (2006). Lung cancer death rates in lifelong nonsmokers. *Journal of the National Cancer Institute*, 98, 691-699.

Weiner, B., Perry, R., & Magnusson, J. (1988). An attributional analysis of reactions to stigmas. *Journal of Perspectives in Sociology and Psychology*, 55, 738-48.

## ANNOUNCEMENT



***A Resource Book for Cancer Patients in New Jersey***  
*will be revised for 2007 by the Nursing & Psychosocial Advisory Group to the NJCCR.*

**To reserve your copies, please call  
 609-631-4747.**

## GETTING TO KNOW YOU

### A Series of Interviews with Members of the Psychosocial/Nursing Research Community in New Jersey

*This issue highlighting*  
**Mildred Ortu Kowalski, RN, BSN, MPA**

By  
 Denyse L. Adler, MA

Evolution is the word that comes to mind when meeting and talking with Milli Kowalski. Evolving from nursing student to PhD candidate; from floor nurse to VP of Nursing, to researcher; from manager of clinical trials to advocate for research and community liaison. Evolving from long-standing member of the NJCCR Psychosocial/Nursing Advisory group to newly installed co-chair. At the same time, evolving to a growing family with four children with all the demands and activities that family life imposes. Taken together, they represent a considerable challenge all the more impressive because each of these roles and positions were hard won and heartfelt and she gives them each the same intensity and dedication.

Building on her experience and expertise in delivering nursing services, Milli moved into direct research activity with the pharmaceutical industry giant Novartis, in 1988. Her career demonstrated rapid and impressive upward movement; from Clinical Research Associate to Clinical Research Manager. Now she has accepted the special challenge as Assistant Director of Patient Advocacy Relations. Each new step was a logical and appropriate consequence of the skills and sensitivity she gained in the previous position, married to her early and ongoing love of research and exploring new horizons.

Milli's work with the pharmaceutical industry began with entering data from clinical trials, to writing new protocols, to supervising and managing multi-site and then global clinical trials – a broad responsibility. *Her commitment to research is deeply seated in her belief that research is a critical element in health care that puts evidence*

*behind actions.* She believes that research outcomes should drive all behavior in healthcare for all of us as practitioners and as patients. It has been demonstrated frequently that intuitive thinking is not always correct thinking; i.e. if a little of a substance is good then more is better, or if a short course is good, longer will be better. Recent evidence has demonstrated that this approach is often wrong; more important, it has been demonstrated that protocols that were considered “conventional wisdom” may not be wise at all.

Throughout her demanding career both as a nurse and clinical researcher, Milli appreciated the importance of, and need for academic achievement as well. Moving from her initial nursing diploma she gained a BA in Health Education and School Nursing, a BSN in Nursing, an MPA in Public Administration and is now completing work toward a PhD in the Division of Nursing at New York University. Quite an accomplishment considering the demands of work, family and a full range of volunteer and association activities.

Milli’s current role as Associate Director of Patient Advocacy Relations is a very interesting and exciting opportunity for her to integrate her understanding of the importance of clinical research with the real-time needs of patients in the community. In this position, Milli is liaison to cancer advocacy groups with a focus on learning about comprehensive community needs and to create a synergy between those concerns and the contribution of Novartis Oncology in addressing them.

Her commitment to academic excellence is an inspiration to all of us who “just don’t have the time.” Although meeting the extensive demands of graduate work, especially the final dissertation, is a considerable challenge, she has continued to persevere. Her observations that patients from different ethnic groups responded to pain differently, lead her to explore patients with varied cultural traditions. She was motivated by the difficulty in measuring outcomes in diverse populations; a critical concern if outcomes are to be globally applicable. This led her to explore the relationship of ethnic differences, information, and adjustment and pain, and to explore specifically the

experience of Japanese American men, whose cancer incidence triples after they come to the US.

The focus on Japanese American men has presented unique challenges in completing the doctoral work: gaining acceptance among cultures that are not traditionally open to discussing pain and disability; finding willing participants for the clinical project; and, gaining acceptance as a woman in working with men. Intermediaries were often necessary to help recruit potential enrollees. Milli met all of these issues head on, and is close to completion of her research and writing.

When asked to offer some advice to aspiring researchers in the clinic or other settings, she drew from her own experience and offered these recommendations:

1. Get involved in some small way to start: help with a small study; respectfully question longstanding beliefs or “we have always done it that way;” and seek out like minded individuals.
2. Don’t be afraid to ask questions.
3. Approach management with your interests and try to provide a real plan for some initial data gathering.
4. Recruit others to create a team approach.
5. Be realistic in both your research and academic interests; be sure that the clinical population is available and establish achievable goals for your initial research and academic plans.
6. **Engage your passion.**

Milli’s work, from caring for patients in ICU, to research settings, to meetings with advocacy leaders has made a significant contribution to the health of residents of New Jersey and the broader healthcare community. She downplays her role, but her ability to cram so much caring and accomplishment into her life is an inspiration to the rest of us.

Milli can be reached at [Mortu@usa.net](mailto:Mortu@usa.net).

# ATTENTION

The NJCCR is planning to publish this newsletter via email only by the end of 2007.

Also, in order to offer our readers more, we plan to offer nursing, social work, and other professional CEU credits.

Therefore, please provide your name and contact information, most importantly your email, to Michael Toleno at ([njccr@doh.state.nj.us](mailto:njccr@doh.state.nj.us)).



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