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MY JOURNEY WITH LUNG CANCER: Antonella Gilmore



I was diagnosed with non-small cell lung cancer (NSCLC) at the age of 46. It came as a shock because I never smoked and considered myself a very healthy woman. After chemotherapy and concurrent radiation, I was fortunate to have a lobectomy, followed by more chemo and radiation.

Not knowing where to turn, I called Lung Cancer Canada. They put me in touch with Roz Brodsky who had just gone through the same thing. She was willing to share and support me as much as she could with her experience and wisdom. Without her encouragement and knowledge of lung cancer, I don't think I would have come this far.

There is a stigma attached to lung cancer. I felt judged and defensive. I was constantly proclaiming that I had never smoked and feeling that people did not really believe me. Going through this while I was going through treatment was very discouraging.

After a year of being closely monitored by regular MRIs and CT scans, a new lesion was found on my spine and then six new lesions on my brain. Fortunately, I was informed about lung cancer and the newest treatments available. Tests to see if my tumour had the EGFR (epidermal growth factor receptor) mutation were positive, and I was eligible for a targeted therapy for NSCLC.

My journey through diagnosis and treatment of cancer has been stressful on my whole family: My sons were teenagers when I was first diagnosed; I had to give up my job and we went from two incomes to just one; and my parents worried about losing another child (one of my brothers died of an aneurysm).

I credit my survival to my doctors and the new advancements that have been made. Lung cancer needs to be seen as a disease that benefits from individualized treatment and as much tailoring to the patient as possible.

My goal is to inform women about lung cancer and the benefits of early detection. I would like to help make lung cancer screening part of a yearly physical.

I am happy to be approaching five years since my diagnosis. I have learned to deal with uncertainty. I am stable and have been for over two years. I am doing well thanks to molecular testing and targeted therapy.

Antonella's symptoms, diagnosis and treatment:

- started with dry cough, shortness-of-breath, loss of appetite and feeling drained despite being on antibiotics
- lung biopsy showed NSCLC, adenocarcinoma subtype
- surgery planned but cancelled when tests showed the cancer had spread to the mediastinum.
- aggressive chemo and radiation meant travel to two hospitals, often on the same day
- eventual surgery removed the tumour in the upper right lobe of the lung but required more chemo and radiation
- back pain led to the discovery of a lesion on the lumbar (lower) spine — stereotactic radiotherapy (a very intense dose of radiation to a small tumour) was used
- MRI of the brain showed 6 small lesions requiring 10 more radiation treatments to the whole brain
- after 8 months, tests showed three tumours still in the brain and one starting to regrow—stereotactic radiosurgery, also known as Gamma Knife, was used
- tests for the EGFR mutation were positive
- May 2010, started taking IRESSA, a targeted therapy for NSCLC, non-squamous subtypes



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Patient Resources

A Patient's Guide to Lung Cancer is a Lung Cancer Canada publication designed to meet the educational needs of lung cancer patients and their families. Available in English and French.



Lung Cancer Canada Info Sheets

Available in English and French.

- Questions to Ask Your Oncologist When You've Been Diagnosed with Lung Cancer
- Lung Cancer and the Use of Oxygen Therapy
- How to Prepare for Lung Cancer Surgery When You Smoke
- Nutrition and Lung Cancer
- For Patients and Caregivers: Coping and Emotional Support
- Thoracic Surgery for Symptom Control
- Managing Daily Activities: Energy Conservation and Work Efficiency



Managing Shortness of Breath

Produced by Lorraine Martelli-Reid, MN, RN(EC), nurse practitioner Lung DST, Juravinski Cancer Program

The CD consists of a five part series:

1. Introduction/Learning Abdominal Breathing
2. Managing an Acute Episode of Shortness of Breath
3. Sitting to Standing
4. Climbing Stairs
5. Respiratory Muscle Exercises



Call or email Lung Cancer Canada to order material.

Material and resources are free for individual patients and caregivers.

Contact Information

Lung Cancer Canada
1896A Avenue Road
Toronto, ON M5M 3Z8

Tel: 416-785-3439 or 1-888-445-4403
Fax: 416-785-2905 (Fax)

Email: info@lungcancerCanada.ca

Connect with us    from our home page:

www.lungcancerCanada.ca

Charitable Registration Number: 872775119 RR0001

Lung Cancer Canada wishes to acknowledge our community partners:





Celebrating Advances in Lung Cancer

On November 7, 2011, approximately 200 guests joined Lung Cancer Canada to celebrate advances in lung cancer and to launch our new research fund. Speakers Dr. Frances Shepherd and Dr. Heidi Roberts provided us with informative updates on the advances in lung cancer treatments and lung cancer screening, while Peter McKendrick shared his personal journey with lung cancer. Join us at this year's event on Thursday, November 1, 2012.



SAVE THE DATE

Our Second Annual Gala Event will be held on
November 1, 2012



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FOR MORE INFORMATION



Lung Cancer Awareness Month

November 2011 was a busy month for lung cancer awareness, with displays and education sessions at more than 30 hospitals and cancer centres across the country.

We are especially grateful to a group of nursing students at Sault College in Sault Ste. Marie who organized a full month of activities in support of lung cancer and Lung Cancer Canada.

Remembering Gabriella Micallef



Gabriella was diagnosed with advanced non-small cell lung cancer in 2006. Upon hearing the doctor's poor prognosis, her words were "I accept your diagnosis, but I do not accept your prognosis." She was courageous and gracious as she learned to live with this disease, and she brought passion and determination to everything she touched.

Nothing gave Gabriella more joy than when she completed her first Toronto marathon. Her last race was a 5km walk in the Scotiabank Toronto Waterfront Marathon on October 16, 2011, only five weeks before her death. She will be missed.

We would like to thank Gabriella Micallef and her team for raising \$25,000 in support of Lung Cancer Canada.

We would also like to thank everyone who participated, whether as a donor or runner — **together we raised over \$50,000 for Lung Cancer Canada!**



**come join our team
October 14, 2012!**

Lung Cancer Canada has been chosen as one of three featured charities for this year's Scotiabank Toronto Waterfront Marathon.

**So come on down. Join the fun.
Raise money for a great cause!**

Enter as a team or individual.
www.torontowaterfrontmarathon.com

For more information on putting together a team and our fundraising goal, contact Lung Cancer Canada at egosbee@lungcancercanada.ca

We hope to hear from you soon!



LUNG CANCER CANADA
Awareness. Support. Education.





Shame, Guilt, and Stigma in Lung Cancer

Dale Dirkse, B.A., Janine Giese-Davis, Ph.D.

Reprinted with permission from Oncology Exchange (February 2012)

Introduction

Lung cancer patients report the highest burden of distress of all cancer groups¹⁻⁷. Despite evidence that interventions may improve quality and possibly quantity of life⁸⁻¹¹, they access healthcare professionals for help with these concerns less often than other cancer groups¹²⁻¹⁴. Experiencing distress at diagnosis may be normal since lung cancer patients have a poor prognosis⁷ and receive their diagnosis at an advanced stage¹⁵. However, newly diagnosed patients surprisingly report more psychosocial than physical concerns, and these concerns remain common throughout their cancer journey¹⁶. This pattern of distress combined with their lack of help-seeking, have led researchers to look for explanations for this cycle and for ways that they can improve quality of life for lung cancer survivors. This review summarizes a developing literature investigating whether patients' shame, guilt, and experience of social stigma perpetuates their ongoing distress. Due to the link between smoking and a later lung cancer diagnosis, past smokers may feel responsible for their cancer¹⁷ and hide from others due to their shame and guilt related to smoking^{15,18-20}. Social stigma, in which others blame lung cancer patients for their disease, may also increase their social withdrawal, perpetuating and increasing their distress.

Shame and Guilt

Though only a few published studies examine shame and guilt in lung cancer patients, they each indicate that social stigma and feelings of guilt may lead lung cancer patients to blame and punish themselves. People who attribute their disease to internal causes, regardless of cancer type, report poorer self-esteem, higher anxiety, depression, and anger¹⁷. Several qualitative studies indicate that these feelings of shame and guilt negatively influenced patients' lives. For instance in one study, experiencing uncertainty, thoughts of death, and shame and guilt were the three themes endorsed as reducing quality of life²¹. Shame and guilt together led patients to feel a sense of social anguish²² because they often did not see a way to overcome these feelings.

Because feelings of shame lead people to hide from others, it also negatively influences lung cancer patients' relationships, with patients withdrawing from social activities and friendships, as well as failing to seek out support from friends or family^{18,21,22}. Patients may also avoid disclosing their diagnosis to friends, family, or others¹⁹, resulting in financial difficulties and less support¹⁸. Feelings of shame and guilt can affect medical treatment by delaying symptom reporting^{15,23} and increasing false reporting or non-disclosure to doctors

about smoking habits²⁴. These feelings of shame and guilt, in addition to poor prognosis and advanced state of disease, may in part account for a lack of success in creating lung cancer support groups and advocacy for the disease¹⁹. Overall, feelings of shame and guilt can cause emotional suffering that may increase the illness burden in these patients, lead to social isolation, and may be one of the reasons for their pervasive and ongoing distress.

Stigma

Healthcare professionals and the lay public recognize the stigma lung cancer patients experience. In an interview study, 18 oncology social workers reported that stigma related to cigarette smoking was a principal reason for patients' emotional burden¹⁹. Six focus groups made up of healthcare professionals and members of the public identified shame and blame as a main impediment to lung cancer patients' coping²³. This stigma is also present in the news. In a study of all cancer-related stories presented in Australian television news, only 2% related to lung cancer although it is the leading cause of cancer death. Furthermore, 62% of these reported on the disease present in non-smokers²⁶. Both this underrepresentation of the disease and portrayal of mainly non-smokers as deserving of sympathy may perpetuate the stigma and shame among patients with lung cancer, especially in those that have smoked.

Future Directions

So far, the majority of studies in this small literature on shame and guilt in lung cancer have used qualitative methodology and portrayed a vivid picture of the anguish these patients experience. These studies are a starting point for future rigorous research to understand how these emotions affect patients and most importantly, to test ways to combat these emotions so patient care can be improved²¹.

Past research has uncovered several areas that need attention. The first is equipping medical professionals to recognize and refer for psychosocial support when they see symptoms of shame in their patients, specifically targeting the social sources of the stigma. For instance, teaching lung cancer healthcare teams to recognize the signs of shame and guilt in their patients may empower them to reach out more empathically to their patients and refer them more often for psychosocial care. Healthcare professionals play a large role in alleviating distress, first in being aware of the high psychosocial needs of this population^{13,16}, enquiring about patients' emotional state¹⁶, helping patients to recognize and understand the stigma they face, and finally providing referral to counselling services¹⁹. There is room for improvement



when it comes to physician-patient communication. In a study of oncologists' response to patient concerns in consultations, they responded empathically to only 10 %²⁷. Empathy in physician-patient communication has been associated with patient satisfaction and improved adherence to treatment²⁸, and need not delay consultations²⁵. Lung cancer patients' unique distress levels serve as a compelling reason for greater empathetic communication by the medical team.

There is also a need for research to develop and evaluate specific interventions that target shame and guilt and interrupt the cycle of distress. It is important to understand the impact of shame, guilt, and stigma on lung cancer couples' communication²⁹ during their cancer journey, because patients may withdraw from marital as well as social communication. By understanding more clearly, and offering interventions more often to reduce the shame, guilt, and stigma that lung cancer patients experience, we might not only improve quality of life, but also improve our medical response. Many lung cancer patients receive their diagnosis at a stage too late for surgery¹⁵. If reducing the shame experienced by patients can decrease the delay in reporting symptoms, medical teams may catch the disease earlier when there are more effective treatment options available. In summary, this developing literature offers important clues to the cycle of distress lung cancer patients, and likely their families, experience. More research is crucial to understand these patterns, intervene more effectively, and improve quality of life for lung cancer patients.

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Implementing Molecularly Targeted Treatments for Canadian Patients with Non Small Cell Lung Cancer

Peter Ellis, MBBS, MMed, PhD, FRACP, FRCPC

Adapted from Cancer Advocacy Coalition of Canada's Report Card on Cancer in Canada 2011–12

Historically, all subtypes of NSCLC were treated the same. Significant changes have occurred over the last five years in the management of non small cell lung cancer (NSCLC). More recently, the importance of accurate histological classification has been recognized. Data from several randomized trials demonstrate improved survival for patients with nonsquamous histologies. In addition, increased understanding of the molecular abnormalities associated with cell growth and proliferation of NSCLC has led to development of therapies targeting specific molecular pathways such as the epidermal growth factor receptor (EGFR) and anaplastic lymphoma kinase (ALK) gene. As a result of these changes, there has been a shift from a treatment algorithm applicable to the majority of patients, to a more complicated situation in which treatment decisions are influenced by a variety of factors including histologic subtype and molecular phenotype. It is not clear though, whether there is adequate infrastructure in place to facilitate rapid adoption of these changes.

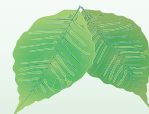
The diagnosis of NSCLC is often made on small biopsies or cytology specimens that make accurate histologic classification difficult. Also, there is often minimal diagnostic material available on which to perform additional molecular testing. This created a number of challenges. Firstly, this required additional diagnostic material in order to be able to do testing, which is not always available. More importantly though, it required accredited molecular testing laboratories in which to perform the EGFR testing. However, no mechanism for funding is in place for this to happen. There was not a reliable and valid system in place to perform EGFR mutation testing when an EGFR TKI therapy for EGFR mutation positive patients was approved by Health Canada. Five laboratories across the country undertook validation and quality control processes to establish a network for EGFR mutation testing using RT-PCR. They were: British Columbia Cancer Agency, Alberta Cancer Agency, University Health Network (ON), Centre de Lutte Contre le Cancer du CHUM (QC) and Jewish General Hospital (QC) through the support of a pharmaceutical company. The one year program for EGFR mutation testing commenced mid-March 2011, and there was rapid uptake from oncologists across the country. At the end of the 12-month period, government funding was still not in place to provide access to testing. Patients with private health insurance, or those willing to pay for the EGFR TKI therapy could still access testing. At this time though, testing rates dropped to between 50–100 tests per month. To date, only four provinces (Ontario, Quebec, British Columbia and Alberta) are funding EGFR TKI therapy for patients with EGFR mutation positive NSCLC. In at least two of these provinces,

this therapy was funded without incremental funding for EGFR testing. It is clear though, that a mechanism for molecular testing needs to be in place to allow appropriate patient selection and access to treatment.

We appear to have reached a therapeutic plateau with conventional chemotherapeutic drugs in the treatment of NSCLC. Molecularly targeted agents are now the major focus of clinical trials research in NSCLC. It is clear from emerging research that many molecular targets occur in only a small percentage of patients. As such, molecularly targeted agents are likely to be used in subsets of NSCLC patients who express a specific target. Such a situation is likely to exist in the near future for NSCLC patients with an EML4/ALK translocation. One of these medications is likely to be available to Canadian lung cancer patients in the near future, yet there is no mechanism in place within our healthcare system to provide testing to identify which patients might benefit from this treatment.

There is a need to develop a strategy across the country to provide access to molecular testing to identify appropriate sub populations of patients who are candidates for newer molecularly directed therapies. This situation exists not only for patients with NSCLC, but for patients with many different types of cancers. The strategy needs to be linked to drug approval processes. To approve a drug for public funding and not fund a mechanism to identify which patients might benefit from that drug is short sighted. The strategy also needs to be responsive to emerging data.

Lastly, the changing paradigm of treatment for NSCLC requires a change in the paradigm of diagnosis. This can only be achieved through collection of larger tumour samples during diagnostic procedures. These steps will require education and knowledge transfer strategies to implement effective change in practice.



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