



Early detection, and overcoming ignorance and prejudice are central to improving the futures of lung cancer patients.

Fighting the Invisible Cancer

SHADOW BOXING

I have a friend, whom I shall call Sarah, who for the past 30 years has chain-smoked, stopping only when she simply can't smoke, in an airplane, a smoke-free zone, an office. The other day she came down with bronchitis again, and I could see fear flutter in her eyes. "Have you ever been tested for lung cancer?" I asked, and she said, "What's the point. If it have it, I'll die anyway."

This hopelessness imbues lung cancer from study to diagnosis to treatment to death. More people die of lung cancer than from any other kind of cancer, but you don't see bright celebrity ads asking for money for research; there is no Elizabeth Taylor headlining benefits. Famous people have died from lung cancer—King George VI, John Wayne, Nat King Cole—but the disease itself is shrouded in secrecy. "It's invisible," says Dr. Frances Shepherd, a leading lung cancer specialist at Princess Margaret Hospital in Toronto. "This is the disease people don't want to see. There are no strong lobby groups or support groups for lung cancer patients [in Canada]. There's a certain feeling that lung cancer victims brought it on themselves by smoking, but smoking causes heart disease too without the same associated stigma. Somehow, lung cancer can't seem to rise above this."

Dr. Shepherd finds this frustrating, to say the least. "We are actively trying to pursue both clinical and basic science research in lung cancer. However, we face great difficulties getting the necessary funding to do the research. We need a

BY GINA MALLET

Lung cancer kills more people than any other cancer, but the stigma attached to it—namely the perception that people bring it on themselves—makes it the bad boy when it comes to treatment, affecting specialist referrals, drug disbursement, early detection initiatives and clinical trials.

lung cancer research initiative similar to the one the government funded for breast cancer. The dollars spent per death on lung cancer pale in comparison to amounts spent on other disorders such as breast cancer or AIDS.” And not only in Canada: *The Toronto Star*, quoting from a *New York Times* article, recently reported that in the U.S. in 1999, \$900 was spent for research for each lung cancer death compared to \$9,000 for breast cancer and \$34,000 for each AIDS death.

Ignorance and prejudice have conspired to keep lung cancer down, according to Dr. Bill Evans of Cancer Care Ontario. Amazingly, it starts with the medical profession. Dr. Evans echoes scores of similar stories when he says, “I used to be told not many years ago that it was a waste of time to treat lung cancer.” Dr. Glenn Jones of the Hamilton Regional Cancer Centre says that the overwhelming role of smoking as a “behaviour of choice” has skewed doctors’ thinking. “That kind of stigma influences outcomes, with prevention as the main approach to lung cancer, not screening and not treatment. There’s more emphasis on changing behaviour in society.” Sometimes, to no avail: a recent B.C. study showed that all the efforts to reduce tobacco consumption in the schools failed.

Which brings us to an important consideration: smoking is an addiction, not just a dirty little habit. Moreover, the majority of people being diagnosed with lung cancer are former smokers or have never been smokers.

But the widely held perception that lung cancer is an intractable, self-induced disease that mostly affects older people makes for a triple whammy. As a result, Dr. Evans says, “Lots of patients are not referred to specialists.” And doctors’ failure to do so is not challenged by the patient who is both stunned and usually ignorant of developments. “If the doctor says you’ve got advanced

cancer and that’s not something we can cure, but it’s worth going to the local cancer centre, well, the patient Fred doesn’t want to, and his family doesn’t know that you can double the survival rate at five years of those with a locally advanced disease like Fred’s with chemotherapy and radiation.”

Ignorance starts with the words lung cancer. There are two kinds: the fast-moving small-cell variety is deadlier but recently showed promising response to treatment during phase III clinical trials in Japan. Then there’s the slower, non-small-cell lung cancer, for which there is a growing number of treatment options. Today, says Dr. Evans, 30 per cent of patients are operated on; the rest are treated with radiation and chemotherapy cocktails.

Chemotherapy has made significant advances in the last few years. In the United States, where chemotherapy trials are ongoing, the National Cancer Institute reports that the five-year survival rate has risen to 50 per cent for patients whose cancer was detected early, and to 15 per cent for advanced lung cancer patients. More recent clinical trials in the U.S. are designed to treat metastatic lung cancer.

Canadian patients, however, face handicaps in getting treatment. First, a patient may not be referred to a specialist. For example, in Ottawa, 70 per cent of lung cancer patients are referred but only 50 per cent of rural patients are. There are now treatment guidelines in place, says Dr. Evans, and the figures are improving. What remains is a discrepancy in actual treatment. It used to be that surgery was considered the best option, but there are now an increasing number of drug and radiation approaches. Expense is the problem. “The way things are funded in Ontario directs doctors to use the less expensive drug,” says Dr. Evans, “and what Ontario

Lung cancer is the most lethal—and the most stigmatized—of all cancers. Changes in the attitudes of both medical professionals and patients will result in fairer treatment, more equitable referral patterns, and more clinical trials and screening to improve future outcomes.

does influence other provinces quite a bit.” Vinorelbine tartate (Navelbine®) and cisplatin (Platinol®) are commonly used because they are inexpensive compared to gemcitabine (Gemzar®), paclitaxel (Taxol®), docetaxel (Taxotere®), and carboplatin (Paraplatin®). This applies to the regional cancer centres, it must be noted; other hospitals offer wider choices.

More than a year ago, Dr. Eugene Humenick, an 82-year-old dentist in Gravenhurst, Ont., was diagnosed with lung cancer. Doctors told his wife he had between three and six months to live, and that it didn't matter when treatment began. He was referred to Toronto General Hospital, where he was treated with an infusion of talcum powder to fill in the lung cavities. That failed. It was due to his initiative that he was referred to a leading oncologist at Soldiers' Memorial Hospital in Orillia, Ont., Dr. Devon Bhatt. “He said to me, ‘I can't cure you but I can make your life better.’” Dr. Humenick was given Gemzar™, a promising drug that's not automatically prescribed because of its high cost. Now Dr. Humenick says, “I have very few side-effects and no nausea. I have a good quality of life ... considering I don't even think about it.”

There is now another emerging funding crisis. Thousands of lung cancer patients could have longer, better lives, and many people may actually be cured if there were an early detection protocol. In 1999, Claudia Henschke of New York's Cornell University published findings that she had successfully used a technique

called spiral CT to discover very small nodules much earlier than X-rays could. “That started the ball rolling,” says Nadine Jelsing of ALCASE, the only non-profit advocacy organization in the United States. Today, ALCASE gets 175 hits a day on its Web site (www.alcase.org), many of them asking where to find early detection CT clinics. The National Institute of Health has authorized 18 clinical trials for the CT scan across the U.S., and Jelsing says that ALCASE is urging people to enroll in them rather than going freelance. “If they're not enrolled in clinical trials, there's no data to be pooled, so public policy can't be influenced.”

As yet, there are no clinical trials of any early detection system in Canada. While another behaviour-related illness, HIV, gets huge research funding, lung cancer applications have been turned down. Two years ago, Dr. Stephen Lam of the B.C. Cancer Agency applied to the Canadian Institutes of Health Research (then the Medical Research Council) for money to study the cost effectiveness of low-dose spiral CT for lung cancer screening and was turned down. “Then we reapplied to the CIHR to be part of the European consortium to contribute 2,000 subjects to their 40,000-subject screening program, realizing that in Canada we would not have the money to do a 40,000 people trial.” The project was rejected, partly because of the high cost—close to \$500,000 per year—and partly because the panel did not think Dr. Lam could come up with 2,000 people.

If the CT scan is effective, it could potentially save thousands and thousands of lives. Says Dr. Frances Shepherd, “This is a radiologic test that could be done in a few seconds; it's easier than a mammogram; there can be between five or six of these done every hour on a CT machine—but is the government going to provide the equipment and doctors to do it?”

Once again, cost is an issue. CT machines are few in Canada and expensive. Considering the huge taxes reaped from the sale of tobacco, you'd think governments would feel obliged to give back some of that money for early detection initiatives. Without a vigorous public lobby, however, they won't. ♦

STEVEN EVANS



THE LUNG CANCER PROJECT

First Steps Towards a Lung Cancer Group in Canada

BY PAT KELLY

Lung cancer is the most lethal of all cancers: 21,200 new cases will be diagnosed in Canada this year, and 18,000 people will die, yet no support or advocacy groups exist for this under-treated cancer. PISCES (Partners In Self-help Community Education & Support) organized and facilitated a meeting in Montreal on April 19, 2001, bringing together patients, oncology professionals and industry representatives to find out how lung cancer patients could better be served by joining forces to fight the stigma and treatment shortcomings of this disease. The following is a brief summary of participants' comments, issues identified and possible actions.

THE PATIENT VIEW

"I am my wife's supporter, and thinking back on what was missing: there was no support, information or support people, and through the process we took it for granted that support was simply not available."

"Part of the change for patients will be to overcome guilt and passivity and begin to speak out publicly and openly."

THE HEALTH-CARE PROFESSIONAL VIEW

"I have been treating lung cancer for 25 years. It was a hard problem 25 years ago and it's even harder now—primarily because my professional colleagues are not offering treatment, and government attitudes state that it's not economical to treat lung cancer. This is just plain wrong!"

"I am struck by the commonness of lung cancer; it is far more common than AIDS and we stumble over it all the time. We are trying to advance the concept of cancer control—looking at prevention, screening, early diagnosis, treatment, research, support, palliation—and all of that is provided at less than \$40/person. Most poverty-stricken states in the U.S. would consider that to be a huge bargain."

BURNING ISSUES: BARRIERS TO CARE

- Lack of information and support for patients and family
- Variations in access to treatment
- Research advances not applied
- Human resource shortages

- Inconsistent education for providers
- Unmet needs for advocacy and increased public awareness

TO DO LIST

- Develop new messages targeted at changing public attitudes
- Hold a national forum (similar to Health Canada-sponsored forums held for breast, prostate, ovarian cancer)
- Explore linkages with ALCASE (Alliance for Lung Cancer Advocacy Support & Education)
- Change the outdated clinical stigma about giving treatment
- Survey and publish current knowledge of treatment among family doctors and specialists
- Promote information about clinical trials
- Balance quality versus length of life in decisions based on patients' preferences and values
- Develop and distribute decision aids (audio tapes, web support, etc.)
- Identify and train spokespersons to promote key messages and address public perception
- Develop a national centre of excellence for lung cancer research
- Redistribute funds tied to taxation level to address unmet needs of lung cancer patients

The next steps for the development of the PISCES Lung Cancer Project will be to research and develop a proposal aimed at addressing some of the priority areas, and to seek support from a broader stakeholder network of supporters and funders. If you want to be kept informed about the development of the PISCES/CACC Lung Cancer Project, or to receive a complete copy of the report, please send your contact information to www.pisces@netinc.ca. ♦

LUNG LINKS

LUNG CANCER CLINICAL TRIALS

information is available at www.centerwatch.com.

ALLIANCE FOR LUNG CANCER ADVOCACY, SUPPORT & EDUCATION (ALCASE):

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