

Lung cancer is a global epidemic and requires a global effort

Bonnie J. Addario

Bonnie J. Addario Lung Cancer Foundation (ALCF), San Carlos, CA, USA

Correspondence to: Bonnie J. Addario. Bonnie J. Addario Lung Cancer Foundation, 1100 Industrial Road, Suite 1, San Carlos, CA 94070, USA.

Email: bonnie@lungcancerfoundation.org.

Submitted Jan 19, 2015. Accepted for publication Jan 20, 2015.

doi: 10.3978/j.issn.2305-5839.2015.01.20

View this article at: <http://dx.doi.org/10.3978/j.issn.2305-5839.2015.01.20>

Although the words “epidemic” and “pandemic” are most commonly used in reference to contagious diseases, at what point does a disease become so deadly, widespread and virulent, so adept at overcoming bodily defense mechanisms, that it qualifies as being of “epidemic proportions”?

This descriptor surely describes lung cancer, a disease of global geographic reach that is non-discriminatory in attacking all people, regardless of age, sex, ethnicity or socio-economic background. Lung cancer has become of worldwide epidemic proportions over the past 100 years. Tragically, it continues to be a “grim reaper” in the 21st century.

Only a global effort will succeed in significantly impacting survival and transforming lung cancer from a global epidemic to a chronically managed disease and ultimately to finding a cure. My personal experience tells the story of why lung cancer continues to be of epidemic proportions. Of greater importance it reveals a path for clinicians, researchers, industry and patients to take to eradicate “epidemic” from the lung cancer lexicon.

Diagnosed with stage 3b lung cancer in 2004, I was overwhelmed and under-educated about the disease. All I knew was that I wanted to live. I was committed to finding a treatment plan that offered hope for survival.

Prior to diagnosis I had experienced chest pain and found myself in a whirlwind of doctor visits to no avail. A neurologist, thinking my condition was due to radiating pain from a bulging neck disc, placed me on Vioxx. As an anti-inflammatory drug, it did reduce my chest pain. For awhile I thought I was cured, but when I stopped taking Vioxx the pain came raging back.

I finally resorted to paying for a full body scan that found a tumor on my aorta and subclavian artery. After a failed biopsy I was told that exploratory surgery was the only option. “Exploratory” sounded ominous. I needed to

do some research before anyone took a scalpel to my chest. What I found was a Pandora’s Box of information about the disease’s complexity, subsets and the ability of lung cancer to outwit drugs, treatments, doctors and patients through mutations. I also encountered the “stigma” and blame associated with lung cancer, as well as the public perception, still prevalent today, that lung cancer is only a smoker’s disease. This misperception has always and still continues to hinder funding, which negatively impacts patient survival.

Fortunately, my research also led me to an amazing thoracic surgeon at the University of CA, San Francisco who had a relationship with my community hospital that had an oncologist, pulmonologist, radiation oncologist and pathologist. They all agreed that my case was challenging and if we didn’t begin treatment soon, the tumor would crush my aorta and end my life. Although atypical a decade ago, my doctors all gathered for a tumor board at which they put together an aggressive chemo/radiation plan that hopefully would shrink the tumor enough to allow me to have surgery.

Today I am here, minus my left top lobe, with some work on my esophagus, surgery on both arteries and several post-surgery pulmonary edemas. The collaborative treatment I received from a dedicated, creative interdisciplinary team willing to “think outside-the-box” saved my life.

Survival made me one of the most grateful patients in the world. It also gave me a new life goal: to make sure that every lung cancer patient received the same kind of care I had. However, I soon discovered that the interdisciplinary team care approach that had saved me from being a lung cancer epidemic fatality and made me a survivor was not the standard of care (SOC) in the US or the world. This remains true today.

To address what I saw as an appalling deficiency in lung

cancer health care, resources and survival, in 2006 my family and I founded the Bonnie J. Addario Lung Cancer Foundation/ALCF (www.lungcancerfoundation.org) and in 2008 started another nonprofit, Addario Lung Cancer Medical Institute/ALCMI, (www.alcml.net), a global consortium dedicated to facilitate and drive research. We have worked with thousands of patients/families worldwide, providing free educational and support programs, connecting them with doctors and access to clinical trials, funding innovative research where the need is greatest, advocating for patients to have a seat at the “stakeholder table” where life-and-death decisions are made about their survival now and in the future.

Yes, since 2006 there has been success in the discovery of mutations (i.e., EGFR; ALK) aligned with targeted drugs (i.e., Tarceva/Erlotinib; Xalcori), many of which were only in clinical trials when I was diagnosed. The patient survival rate for the first five years after diagnosis has improved due to these discoveries and others. However, since President Nixon declared “war on cancer” in the US nearly 45 years ago, the patient survival rate after five years has only risen a couple of percentage points to 17% today, which means the death rate remains tragically high at 83% in one of the world’s wealthiest and most advanced nations.

Segue to 2015. The possibility now exists for patients to receive comprehensive genomic profiling, earlier diagnosis, multi-disciplinary team care, more surgical options (i.e., VATS) and intervention with gamma or cyber knife surgery for brain mets. This is the age of improved clinical trials/studies (i.e., LungMap; Genomics of Young Lung Cancer) that have a greater chance of success. It is also the emerging era of immunotherapy and other cutting-edge approaches of great promise in both early detection and screening.

This all sounds like a wonderful mix of medicine, research and treatment rapidly advancing us toward making lung cancer much less likely to be of “epidemic proportions”. Sadly, today’s reality of patient treatment and survival defies this promising picture. This disease remains the world’s number one cancer killer, taking more lives annually than breast, colon and prostate cancer combined.

What is the problem? Very few patients have access to care that actually saves lives. A decade since my diagnosis we have not moved the needle very far in delivering this potentially amazing care to patients. Although advancements are being made, we are unable to get these to patients in time to increase survival.

In the US alone 50% of clinical trials occur in just ten states. Only 4% of patients actually have access to clinical

trials. Multi-disciplinary tumor boards, comprehensive genomic profiling and targeted drugs are not standard in many community hospitals, where most patients are treated, and consequently patients are not always receiving the appropriate treatment to extend life. Unless we get the right drug and treatment to the patient at the right time and when it can make a difference in survival, lung cancer will remain of “epidemic proportions”.

Enough is enough! What are we to do to change this situation? Lung cancer starts and ends with the patient. Who knows better what it is like to live with this disease than patients, but how often are their voices heard when treatment/care decisions are made? Shouldn’t the patient’s expertise be shared, their voices heard by every stakeholder, professional and decision-maker fighting lung cancer?

The patient is the primary stakeholder (the “customer” in the business world) whose life is held in the balance by multiple stakeholders: physicians prescribing treatment, researchers looking through the microscope, pharma pursuing clinical trials, payers providing coverage, governments approving drugs and funding research. With technology, we now have the ability to aggregate data, share and make sense of it in real, life-saving time, but how often do stakeholders do this? Rarely, I’m afraid.

The answer to winning the war against lung cancer lies within the patient, in their specimens used for research, their willingness to participate in clinical trials and to share their “primary source” disease knowledge and personal experiences.

The solution lies in a collaborative global effort. Together we can advance change and save lives. All stakeholders, starting with patients, must be included in the conversation and we must now find a way to deliver to every lung cancer patient worldwide the kind of care that I received years ago.

As representatives of the patient voice, ALCF is not waiting for a “seat at the stakeholder table”. We are creating our own table for those who want to join us to make lung cancer a survivable disease. This column in *Annals of Translational Medicine* will help us to advance that goal.

Since my diagnosis I have constantly heard the term “translational research”, meaning from the bench to the patient. Transformational research is from the patient to the bench and back to the patient. We must add the patient to the process and understand that they are the beginning and the end of the process.

My goal with this column is global patient survival advanced through inviting stakeholders—clinicians,

physicians, researchers, patients, life science specialists—who believe that we can and will accomplish this goal to write articles and share what they are doing to make this a reality. We need to educate each other about processes that work. To accomplish this, we must open up our rich silos of information and share our knowledge across all disciplines and nations. This column is a venue for all of our voices and a way for you to have a seat at the stakeholder table.

I am alive today because I had an interdisciplinary team offering me an arsenal of options. The gauntlet is down

to create patient-centric, patient-accessible centers where individuals are guaranteed a SOC that gives them the very best opportunity for living with lung cancer. I ask you to be part of creating a SOC worldwide that will forever end lung cancer as an epidemic and turn it into yesterday's disease. Let the conversation begin!

Acknowledgements

Disclosure: The author declares no conflict of interest.

Cite this article as: Addario BJ. Lung cancer is a global epidemic and requires a global effort. *Ann Transl Med* 2015;3(2):26. doi: 10.3978/j.issn.2305-5839.2015.01.20