Lung Cancer and Stigma

FROM THE LAY CAREGIVER PERSPECTIVE

By MICHELLE LOBCHUK, RN, PhD

Most studies on lung cancer stigma have tended to focus on public and patient views without examining the impact on lay caregivers as vicarious and/or direct recipients of expressions of stigma. Furthermore, family and friends can also harbour negative attitudes toward patients with lung cancer that impact their helping behaviours.1,2

Lung cancer stigma is a complex social phenomenon that is associated with labeling the suffering individual as tainted or less desirable.3 Of all cancers, lung cancer is viewed the most as a “matter of personal responsibility”.4, p.1799 Besides the well-known linkage of the disease with cigarette smoking (80 to 90 per cent of patients smoked), other characteristics prime us to mark the individual with lung cancer as deviant. Nicotine stained skin, fingers and teeth, the stained and bad smelling clothing, the bad breath, the smoker’s cough, and the look of premature aging all tend to motivate repulsion towards the guilty individual. Smokers are often individuals who live in low socioeconomic circumstances and may not be highly educated. These characteristics can reinforce stigma.

Smokers are sensitized to feel they are part of a special deviant class who must re-pay society for their bad choices through heavy government tax on cigarette purchases and enforced observance of public smoking bans. Boldly labeled cigarette packages show stark visuals of their diseased lungs and physically wasted individuals in death beds. These images perpetuate public beliefs that all lung cancers are linked to cigarette smoking. The reality is that 10 to 20 per cent of lung cancer patients never smoked. Street5 noted that “care of self” is now placed as a responsibility to the public and engagement in smoking signals p.235 a weakness in self-control, a disease itself.

Regardless of current or past smoking behaviours, patients with lung cancer continue to bear ongoing moral responsibility when asked to confess their smoking history to health care providers. Despite advances in curative treatment for early stage lung cancers, the disease remains the number one cancer killer in Canada.6 Lung cancer carries a negative connotation of imminent death with subsequent fatalistic attitudes by, for example, practitioners in general practice.3,7

Caregiving family and friends are not immune to strong societal responses to tobacco use and smoking-related disease. Not all family caregivers are compassionate, especially when patients continue to smoke. Studies show that 13 to 22 per cent of lung cancer patients continue to smoke after diagnosis.2,8 As a case in point, a wife recalled her “livid” reaction to her husband’s lung cancer and continued smoking:

“I remember going to the store one time and buying him a carton of cigarettes and saying, ‘Here. Fill your boots. Kill yourself if you want. That’s what you’re doing.’”9

In our study with 304 pairs of lung cancer patients and family caregivers, we discovered that when patients continued to smoke, caregivers attributed more judgment and anger toward the patient thus leading to less engagement in empathic helping behaviour.2 Caregivers who blame, feel anger and have less empathy are at risk for providing less than optimal supportive, sensitive care that preserves the patient’s sense of dignity and quality of life. When caregivers blame patients, they experience greater levels of depression and even avoidance of the patient.10 Due to powerful societal messages about smoking, any one of us is at risk for responding with judgment and anger. Such negative responses can add to the suffering of patients who are made to feel guilty for having brought the disease upon themselves.

As a nurse I am concerned about the absence of practice guidelines that focus on supportive care for patients and families who must deal with complex psychosocial issues like lung cancer stigma. Best practice guidelines are built on evidence derived from research that is not well supported in lung cancer. In 2011 Charity Intelligence Canada (Ci) reported that, although lung cancer causes 27 per cent of cancer-related deaths, it gets only seven per cent of cancer-specific research funding, and 0.1 per cent of cancer donations.11 On the other hand, despite representing fewer than 10 per cent of cancer deaths, breast cancer is the most funded cancer (45 breast cancer charities) and it receives 28 per cent of all Canadian cancer research funding.11 The high survival rate for breast cancer is clearly related to well-funded research. Ci11 pointed out that lung cancer has a very high opportunity for donor impact in the area of “care”: that is, donor dollars can assist caregivers who care for the 84 per cent of lung cancer patients who do not survive. Speculation remains that blame associated with the disease curtails investments by donors toward much needed lung cancer research.
A lay caregiver had emailed me in support of my study on lung cancer stigma. She spoke of the lack of compassion and unwarranted stigma associated with her mother’s lung cancer.

“I just wanted to express my appreciation for the research you will be conducting with respect to the effects of stigma, including blame and anger, on the care that lung cancer patients receive from informal caregivers. My mother died last year of lung cancer as a result of a lifetime of smoking and I often wonder what role the feeling of having imposed this illness on herself played throughout her illness. It pained me to have to watch her go through the agony of being diagnosed with the illness, receiving chemotherapy and radiation while also having to bear the weight of this uncompassionate/unwarranted stigma. This research is incredibly important and will undoubtedly help families and caregivers understand how better to deal with lung cancer patients. Thank you for recognizing this issue as a critical component of cancer research."

Hopefully Canadians will be sensitized to the unique suffering of individuals and families dealing with lung cancer stigma that is fueled by society’s “just world mentality”: people deserve what they get. Although exciting advances are being made in curative treatments for early stage lung cancer, more research is needed for caregivers (e.g., how to offer non-judgmental care that counteracts the negative effects of stigmatized disease). Widespread societal messages tend to favour judgment, even by health care providers toward individuals with smoking-related disease. Guided by attributional theory, research efforts continue to advance our understanding of how to alter the harmful impact of blaming on empathy and helping behaviour toward patients with lung cancer who still smoke. Tobacco cessation literature indicates that social support is vital to offset any feelings of guilt for failure in attempts to quit smoking.

Ongoing intervention work in this area will likely continue to be challenged, as long as caregivers feel pressured—or feel free—to conform to society’s expectations to judge the individual with lung cancer as being socially irresponsible with one’s health. Also, as long as society and the government view lung cancer research as a low priority, the needs of patients and caregivers who must deal with this “uncompassionate/unwarranted stigma” will remain invisible. Caregivers will not know how to overcome judgmental attributions and emotional distress that adds to the suffering of patients.

One thing that we can do now to de-stigmatize the lung cancer experience is to ask yourself: Why do I need to know whether the patient with lung cancer smoked? If it comes from a desire to blame, you may be doing more harm than good.

Michelle Lobchuk, RN, PhD is Associate Professor and Manitoba Research Chair in Caregiver Communication, Faculty of Nursing, University of Manitoba.

© 2012 Michelle Lobchuk. Used with the kind permission of the author.

References