



CAP Lung Cancer Medical Writers' Circle

Stacked Stigma in the Lung Cancer Experience

Annemarie Conlon, MBA, LCSW

If you have browsed the American Cancer Society or National Cancer Institute's web sites, or read some of the other articles written by the CAP Medical Writers, you will note the high incidence rate for lung cancer. Roughly 219,440 people were expected to be diagnosed in 2009 alone ^[1, 2]. This number exceeds that of breast (192,370), prostate (192,280) and colon & rectum cancers (146,970). An even larger gap exists in the survival and mortality rates between lung cancer and these other top cancers. The first question that comes to anyone with a modicum of critical thought is, "Why does such a disparity exist?" Why are the survival rates so much lower for lung cancer than these other cancers? One might consider that the low level of funding allocated to this disease dissuades researchers from pursuing lung cancer research, thus inhibiting the path to a cure or an agent that slows the tumors' growth. However, we can ask again, "Why does such a disparity exist . . . in funding?" Some speculate that the small funding dollars are the result of stigma due to cigarette smoking ^[3].

Frankly, I never put that together. I could not imagine that government decision makers would withhold funding from a cancer that had as high an incidence rate as lung cancer, and had such devastating effects on those with the disease as well as their family members. I decided to explore stigma more fully by interviewing oncology social workers employed at cancer centers across the nation who provided care to people diagnosed with lung cancer and their families ^[4]. All together these social workers had provided care to over 25,000 people diagnosed with lung cancer in the three years prior to my research. I wanted to know if stigma did exist in the lung cancer experience. I asked the social workers to describe to me any differences that they had observed between their patients who had lung cancer and those diagnosed with other cancers. Fourteen of the 18 social workers named stigma due to cigarette smoking as a primary difference in the lung cancer experience. The remaining four social workers confirmed stigma when asked if cigarette stigma existed. Social workers described patients who felt regret about their smoking behavior and other patients who were angry that they were diagnosed with a "smoker's disease" even though they had never smoked, not once. Then there were those who experienced guilt even though they had "done the right thing" by giving up smoking many years prior. Notably, whether a patient had smoked or not, being asked, "Did you smoke?" by others, created a feeling of being blamed for the disease.

In addition to the smoking stigma, two thirds of the social workers mentioned the high mortality rate as a core difference between lung cancer and the others cancers. Moreover, several social



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workers described the advocacy efforts for other cancer types as stigmatizing. These efforts appeared to demoralize people with lung cancer and increase the stigma due to cigarette smoking. Thus, there appeared to be a “stacked stigma” effect.

We defined stacked stigma as the presence of other stigmas or stigmatizing events that strengthen the primary stigma source ^[4]. In the case of lung cancer, the primary stigma source is cigarette smoking. Lack of advocacy efforts could create a stacked stigma effect for people diagnosed with lung cancer. For example, some of the social workers reported that when people diagnosed with lung cancer were confronted with advocacy efforts for cancer types other than lung cancer, they would conclude that these same efforts did not exist for lung cancer because of cigarette smoking stigma. Whereas, hypothetically, people with cancers other than lung cancer would see advocacy efforts for cancer types other than their own and not conclude that the lack of advocacy efforts for their cancer type was due to cigarette smoking stigma.

This example represents “overt” stacked stigma; it is easily identifiable and measurable. Covert stacked stigma may exist as well. However, it might be more difficult to identify. Lung cancer’s high mortality rate lends itself to this theory. Lehto & Stein ^[5] completed an extensive review of the death anxiety literature in health sciences. This resulted in their defining death anxiety as a “multidimensional construct related to fear of and anxiety related to the anticipation and awareness of the reality of dying and death that includes emotional, cognitive, and motivational components that vary by developmental stage and sociocultural life occurrences” ^[5]. They further noted that death anxiety could occur on an unconscious level. In a study comparing students reactions to different cancers, Mosher & Danoff-Burg ^[6] found that students with high death anxiety required greater social distance from those diagnosed with a poor prognosis cancer than those diagnosed with a generally non-terminal cancer. Thus, people with high death anxiety might pull away from those diagnosed with lung cancer due to the poor prognosis associated with this disease. This pulling away might be attributed incorrectly to stigma due to cigarette smoking, thus strengthening the smoking stigma and creating a covert stacked stigma effect. However, we need further research to test this theory

Overall, my research suggests that smoking stigma is prevalent in the lung cancer experience and that a stacked stigma effect exists. The next step is to translate this knowledge into increased funding for lung cancer. Perhaps the solution is to shift the blame away from the victim and put it where it belongs; on the tobacco industry that pushes its product and the media outlets that continue to glamorize smoking behavior ^[7]. Moreover, there needs to be an understanding that cigarette smoking is not the sole contributor to lung cancer.



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Annemarie Conlon, MBA, LCSW

Annemarie Conlon is a doctoral student at the University of Texas at Austin School of Social Work. She is the recipient of the American Cancer Society Doctoral Training Grant in Oncology Social Work DSW-06-222-01 awarded specifically for research in stigma and lung cancer. Prior to returning to school, Annemarie was the inpatient thoracic oncology social work counselor at MD Anderson Cancer Center in Houston, TX where she was awarded an internal grant to support a bi-weekly Lung Cancer Support Group and a weekly Caregiver's Afternoon Tea. Annemarie is currently a member of Dr. Jimmie Holland's Geriatric Research Group at Memorial Sloan-Kettering Cancer Center and continues to work on her doctoral research in lung cancer stigma. Annemarie's personal connection with lung cancer includes a mother, uncle and grandfather who were diagnosed with this disease.