

LOCUS Project

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New Project Report: The Idea

We wanted to organize events over a few days at the HSLC to raise awareness of Lung Cancer. We wanted to engage people in a discussion about how the stigma of this disease impacts funding, research, and individual patients. Ideally, we wanted to involve the wider community as well. We also brainstormed bringing someone in from the History of Medicine Department to talk about the role stigma plays in our social understanding of disease – from leprosy to HIV. It was important to us to involve individual patients and connect them with the HSLC community; this partially came from how moving other patient-student class interactions were. Patients seemed to really enjoy being able to instruct medical students and shape future clinicians. It's also a welcome and relevant change for pre-clinical students to learn from patients rather than from books.

Project Update: The Evolution

1) We had the opportunity to observe a lung cancer support group run through the Comprehensive Cancer Center. There we explained our project and goals, and recruited patients for our panel discussion with medical students.

2) Sarah pursued a speaker from the History of Medicine Department to discuss stigma and disease; she chose this job as she did her undergraduate work in the department here

at UW. She was woefully unsuccessful. Professors would have only been able to discuss the role of stigma in very specific diseases – none of which was lung cancer. An anthropologist/MD was suggested, but she was out of the country doing field work at the time.

3) We sought a medical oncologist to speak concerning the bio-medical side of lung cancer; we were impressed by Dr. Anne Traynor when she lectured us in our Neoplasms course. She was unavailable but suggested Dr. Tien Hoang who agreed to speak about current treatment, future directions, and how stigma affects research funding.

4) We organized a bake sale for the week by contacting various friends and classmates who enjoyed baking. We discussed where to donate the money raised – first thinking about the American Lung Association. However, upon further research, we learned that little of their funding goes to lung cancer awareness and research. We became aware of the National Lung Cancer Partnership, a local organization dedicated to lung cancer awareness, research and advocacy.

5) We contacted the National Lung Cancer Partnership concerning our project and they generously shared lung cancer pins, bracelets, and pamphlets to hand out over the course of the week.

6) We spoke to Dr. Remington at the Winter LOCUS retreat 2007 about finding funding for food at our meetings to attract better participation. He was willing to try to fund us

through the UW Comprehensive Cancer Center's Cancer Control Group and suggested we continue with our project and that he would take care of funding.

7) Once funding was secured, we planned for nourishment. During the first session of the week, we bought groceries for people to make sandwiches along with other healthy snacks. We worked with India Darbar Restaurant, owned by the family of a classmate, to get a good deal on Indian hors d'oeuvres to bring in for the patient panel. We thought the Indian food would be a draw to our classmates.

8) Logistically, finding a week was quite difficult. Spring semester is very busy and we did not want our project to be buried amidst other activities. We ended up choosing the week of April 23rd; unfortunately, this did coincide with Cover the Uninsured Month. We reserved rooms for our lunch events with Dr. Hoang and the panel of patients.

9) We had people sign a petition circulated by the Lung Cancer Alliance, another national organization dedicated to lung cancer research, advocacy, and awareness. The petition was addressed to Congress and urged the national government to earmark more money for lung cancer research, a cancer that is grossly underfunded given its mortality.

10) We advertised via e-mail, flyers, and classroom announcements.

Final Summary: The Reflection

Initially, we were intrigued by the topic of stigma and lung cancer because of Aimee's mom, who died from lung cancer 3.5 years ago. She told Aimee that after explaining to people that she had lung cancer, she felt the need to state that she had never smoked. Otherwise, she felt blamed for her disease. Even when lung cancer patients smoke or have smoked in the past, the fact that nicotine is a highly addictive substance is an obvious impediment to smoking cessation. It also bothers us that smoking rates are highly correlated to socioeconomic status, and the stigma and blame attached to lung cancer patients who are current or former smokers is partially another form of class bias. Furthermore, everyone has negative health behaviors, and not every disease that is associated with a negative health behavior is stigmatized this dramatically.

Overall, we thought the week was a success, particularly the patient panel. Our greatest student turnout was for the panel. Patients seemed to relish the opportunity to speak with medical students; and medical students engaged in the patients' stories. Family members of the patients were also involved – this actually gave the Cancer Center's Lung Cancer Group the idea to include family members in their panels. While the panel was our greatest success, the bake sale was also a success in that bakers were enthusiastic, and customers enjoyed the treats, gave generously, and shared their personal stories about family members with lung cancer. We raised approximately \$200 for lung cancer research and advocacy.

However, we did have several difficulties. One was that we wanted to target the wider community outside of medical students. However, we felt limited by our connections, our finances, and our inability to identify another group to include. Also,

our target population was our medical student classmates – and we were unsure how to have a wider event at a time when medical students could and would come. It is quite difficult to schedule events for medical students, since there are so many other organizations, events, and tests each week. Medical students are busy people, but life only becomes busier as responsibilities increase over the years; thus, we discovered that it is difficult to engage clinicians throughout their careers in discussions about the wider implications of disease and society. It was a disappointment to us that we were unable to find a speaker to specifically address the obvious role stigma plays in how people respond to patients with certain diseases. Throughout history, patients with stigmatized diseases have been treated with shame and contempt rather than with empathy. Unfortunately, we still hear our classmates stating that lung cancer patients who smoke or have smoked in the past bring their disease upon themselves.

In terms of continuing the project in the future, we can think of several possibilities. We have established connections with the two largest national organizations dedicated to the lung cancer cause, as well as the Comprehensive Cancer Center's Lung Cancer group. In fact, members of the Lung Cancer group contacted us a few months ago to see if medical students would be available to speak to patients and family members about the medical aspects of lung cancer at a public event at the hospital; one student attended. If medical students were interested in doing work on lung cancer, we have connections at UW that would be helpful. The "Free to Breathe" lung cancer walk will take place on September 27, 2008, and is a 5K designed to raise money for lung cancer research and advocacy. Students could field a team and have a booth with information for participants, as well as help organizers with publicity over the next few

years. Another legacy of this project is the encouragement of students in their pre-clinical years to contemplate wider aspects of disease and society, a worthy goal that LOCUS itself sets out to fulfill. This legacy could be carried out in many different forms; we particularly think that a “Stigmatized Diseases Week” would be fascinating and thought-provoking.

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