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Biochemistry 4455G: Final Reflection

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Final Reflection

Jacklyn Krizsan

Introduction:

Over the course of this CEL experience, I learned more about teamwork, translational cancer research, and real-life applications of this knowledge than any other course I have taken to date. Working with community partners that have first-hand experience in the translational cancer research field provided a perspective like no other and being able to collaborate with an amazing team of three other students made for a lasting and memorable project.

Changes in Perspective:

Prior to taking this course, I had only considered translational cancer research through the lense of the researcher in a purely scientific manner. This course taught me the importance of the patient perspective and made me realize that the patients are the real reason we pursue cancer research. While knowledge for the sake of knowledge is important for understanding the world we live in, being able to make real changes to that world is far more relevant. For patients, this research and the translation of this knowledge into therapies can completely change their reality. As researchers, we have the power to prolong people's lives, prevent and treat disease, and overall improve the quality of life for millions of people.

Personal Change:

Understanding now that the real purpose of translational research is to better the human experience, I feel more personally connected to my studies. Having family members that have gone through or are going through cancer therapy, I understand the difference translational research can make in their quality of life. This personal connection has made learning about medical sciences, and cancer research specifically, feel more important to me and has inspired me to pursue cancer research in my graduate studies. I have a newfound drive to expand my

knowledge of this disease and hope to one day make a difference for those experiencing it first hand.

Most Important Lessons:

The most important lesson I learned in this course is how hard it really is to be a cancer patient and the rollercoaster of emotions and hardships one must go through during diagnosis, throughout treatment, and after treatment. Nobody is prepared for a cancer diagnosis and hearing that news can be devastating. After diagnosis, patients can feel lost and alone if they do not understand their disease. It is difficult for patients to fully understand their disease and treatment options because most literature is written for scientific audiences and good resources can be hard to find. The fact that cancer is often a life-long disease is not talked about enough and understanding that stress from the first diagnosis can follow a person for life is very important in understanding the patient perspective.

Challenges to Beliefs/Values/Ideas:

I used to believe that the most important aspect of patient care was development of new therapies. While this is still an extremely pressing issue, working with Richard and the LHSC has taught me that patient care is also extremely dependent on accessibility of information. Patients often have limited ability to make clinical decisions about treatment options due to eligibility and availability, leading to a sense of lost control and passivity about their care. However, giving patients resources to better understand their treatment and ask questions that ensure they are receiving the highest quality of care restores some power and promotes engagement with their clinician. This simple change allows patients to be part of their treatment, eliminates stress associated with uncertainty, and improves the overall quality of life for patients. I now understand that making a difference in patients' lives does not have to involve curing cancer and can be as simple as updating a website.

Message to Friends and Family:

I have already had several conversations about this course with both friends and family because of how unique it is and the real-world application of it. I have learned the importance of the patient experience and want to share this with my loved ones to hopefully enlighten them to the hardships that patients must endure. I think it is important for people to have a better understanding of diseases such as cancer that are expected to affect almost half of Canada's population. Public understanding of the disease and the hurdles patients, researchers, and clinicians must go through to develop and conduct treatment options is important when trying to implement change in a community. For example, a major hurdle our CEL group discovered was the unstandardized way lay summaries are written and the fact that they are not required. Policy changes to require companies to post lay summaries in a central database could have a real and lasting impact for patients but implementation requires the community support to drive these changes. It is also important for the community to understand the patient perspective to both promote empathy and prepare for the possibility that anyone could be diagnosed with cancer at any time. Furthermore, better community understanding of cancer can work as a preventative measure by teaching people to avoid potentially carcinogenic activities (smoking, tanning, etc.).

Effective vs Ineffective Engagements:

The opportunity to work as a team of four for this project provided many teachable moments on how to engage with teammates to produce the best outcomes possible. I learned that, as leader of the group, engaging people and encouraging others to complete a project is most effectively done when you lead by example. Before asking others to complete sections of a presentation or paper, a leader should complete their sections first and take care of their own duties before anything else. Building off of this, it is important to understand why members of a team might be taking longer to complete tasks because everyone has their own lives and work

at different speeds. Everyone in our group had difficulties working through the pandemic and balancing this group work with personal work and personal lives. Taking this into consideration and communicating these difficulties is essential for all members of a team to be successful. Lastly, working with a community partner involves other types of engagements. Trying to understand Richard's vision of the website without being able to talk in person meant proper communication was vital for fulfilling the LHSC's goals. I also found that presenting drafts of different deliverables was the best way to communicate what was specifically requested and allowed us to work together to refine and add to each deliverable.

Rewards and Challenges:

The impact our group had on real-world patients at LHSC is the biggest reward in this course. Having an opportunity to ease any stress and help a cancer patient or their family in any way was the most important part of this course. The ability of this course to change my perspective on cancer research was also a very rewarding aspect that I had not anticipated. I greatly appreciate the insight provided from all of the guest lectures, Richard, Dr. Allan, and the other CEL groups. I feel more connected to my discipline now and have a greater appreciation for translational cancer research.

While the rewards far outweigh the challenges, there were some difficulties our group faced along the way. In a general sense, trying to complete our project in the middle of a pandemic while we were trying to balance other courses and personal life posed some issues. In particular, scheduling meetings around everyone's lives proved to be difficult at times but good communication and compromise helped us overcome this. More specifically, compiling trial results and lay summaries was more difficult than anticipated due to the unstandardized way in which companies post these. While creating a flowchart on how to use clinicaltrials.gov, we also realized there are several different patient consent form document layouts. This meant the trial number on consent forms differs between patients enrolled in trials with different companies.

Moreover, it can take years for companies to post results while they finish the trial, analyze data, and publish those results in a paper. Additionally, there is no requirement for companies to produce lay summaries of their trials and, if they are posted, there is no central database where all summaries are posted.

Impact on LHSC:

We sought to improve the LHSC patient experience by increasing the accessibility of four different areas: trial results, lay summaries, support groups, and other helpful resources. The previous Clinical Cancer Research Unit (CCRU) website was confusing, did not have the majority of these resources, and patients were requesting a change. Clinical trials are required to post their results on the clinicaltrials.gov website but this website is also difficult to navigate without a scientific background. We created a flowchart on how to find specific trials using the patient consent forms that patients are given. Next, we compiled lay summaries from all the companies working with LHSC and supplied hyperlinks to each so that patients could better understand their trial. Additionally, we made a brief glossary that explained certain terms that are often used in trial summaries to further make the summaries accessible. We then included a variety of support groups that patients and friends/family can freely use to help with any mental strain caused by the process. Lastly, we included lists of frequently asked questions and extra resources that can provide further information for patients, friends and family to improve the overall experience. This collection of deliverables directly addresses the concerns specifically outlined by patients to improve the patient perspective. These patient-centric website upgrades should ease some of the stresses of enrolling in a trial, lead to increased trial recruitment, retention of participants, and increased engagement in trials for the CCRU.

Personal Impact Story:

Over the course of this semester my aunt, who had been in remission for lung cancer for several years, announced that it had returned. Being in the biochemistry and cancer biology module, I understand that cancer often returns and being a cancer patient is really a life-long ordeal. I understand the biology and pathology of cancer cells and cancer progression. I understand how different treatments work, how they are developed, and their safety and efficacies. What I did not understand was the personal impacts cancer can have on a person and their family. I did not understand the devastation of finding out such a horrible disease has returned after enduring countless chemotherapy and radiation sessions, and I did not understand how hopeless it feels when you are told those therapies will not work this time. I still do not understand how that feels from the actual patient perspective but I do now from the close family perspective. Having this occur during this semester really helped put everything in perspective and enforced the importance of the translational aspect of translational research. If we are not researching cancer for the purpose of preventing and treating such a horrible disease so that nobody will have a similar experience, then why are we researching it at all?

'Big Picture' Thoughts:

This course mainly focused on translational cancer research but it is important to understand that the topics discussed can apply to almost every other realm of research and every other realm of research can apply to translational cancer research. Like myself, I am sure many researchers are focused in their own area of study and rarely get a chance to expand their research to a more holistic view. On a small scale, the most exciting cancer research discoveries are cross-discipline including immunology, anatomy, pathology, and any other medical science fields. However, it is also important to consider wider range interdisciplinary advancements, including psychology, sociology, history, and even politics. Incorporation of other disciplines can greatly improve the quality of patient care because we are considering all possible needs rather than only physical.