Maram Saada

Lang Prize

31 March 2022

Lang Prize Reflective Essay

Before deciding on a topic for my term paper, I first began by exploring the literature on longevity and finding niches within the scholarship that interested me. Through delving deeper into the topics discussed in the longevity class and papers highlighted by Professor Carey, I was able to find patterns in my interest. I found the concept of successful aging fascinating, and I was especially interested in the concept of lead-time bias. With adult-onset diseases, especially genetic conditions, patients are often diagnosed or warned that they may be carriers for the diseases well in advance of symptoms occurring. However, this does not necessarily mean improved survival, but customarily early detection and intervention. In previous psychology classes I have taken, we have discussed Huntington's Disease in the context of inherited genetic conditions, and I found that the concept of lead time bias was especially evident in people diagnosed with the disease. As a result, I elected to write my paper on the condition's etiology and treatment methods, keeping this idea in mind.

After settling on a topic, I first do a broad search on the subject using Google Scholar and the Directory of Open Access Journals (DOAJ) to familiarize myself with the topic and understand the terms and methodology usually used to explain the condition. In this stage, I do not read through all the articles I find; instead, I scan the abstract, and if I find a paper of interest, I read the discussion section as well. During this phase, I try to be quite broad in my search phrases and endeavor to use varied key terms. I try not to focus on apparent keywords, in my

case, 'Huntington's Disease,' but also use related words used in the literature, like 'chorea' and 'monogenic disease.' This approach expands the literature I am exposed to and subsequently aids in my compilation of the articles that could be of benefit. I keep a running list of authors and journals that I have repeatedly encountered that have written papers on my topic of interest throughout this process. I then use the advanced search tool on Google Scholar to assist in looking up specific researchers that authored papers on the topic, as it is likely they have more to say on the subject.

It is also essential to know how to search databases effectively. For instance, if I was looking for a specific phrase that I want to be included in the articles, I must put it in quotations, such as "Huntington's Disease." I can also use the "AND" or "OR" function to broaden or narrow the presented results. This tool is especially helpful during the starting stages of my paper when I am looking for an array of content on the subject and during the editing stages when I find I want to add more details to a specific claim I made. For instance, when writing the models section of my paper, I was looking for both large and small animal models, and in later stages of my paper, sheep models specifically. The "AND" function ensured I found articles that included the key terms "sheep" and "Huntington's Disease." Using these techniques ensures I am utilizing the databases' resources to their fullest extent and makes certain I find the content needed effectively.

After this initial and quite broad introduction to the topic, I began to compile the sources that are of most interest to me and formulate the structure and organization of my paper. In my case, I decided that for readers to interpret the scope of the diseases, they must understand where the disease comes from, which influenced my decision to start with the etiology. This section was straightforward to write as it primarily focuses on genomes and how chromosomal mutation begins. As a result, my search tools for this section were JSTOR and Sage Journals, as they had

an abundance of journal articles on biology and gene sequencing. While looking through the articles, if I find a particular journal beneficial, I also use BrowZine to look up other published papers. The most challenging part was filtering the sources during this phase, as some articles and journals were more advanced than I needed. As a result, when I choose an article, I first read the abstract to determine whether the paper is discussing a topic that will add value to my paper. Reading the abstract ensures I do not misuse time reading dozens of pages of the paper when it could be unrelated to my claim.

Throughout writing any piece of work, I always encounter journals and articles that are very insightful but do not align with my paper. They are either too focused on a specific aspect of the topic that I was not highlighting or too broad as not to add any substantive value. Knowing when literature will advance my paper or weaken my argument is vital in the research collection process. Some qualities I look for when evaluating a paper are confirming if the paper comes from a reputable source and is peer-reviewed. These features validate the integrity and quality of the paper I am about to read. I also consider whether a well-versed researcher in the field authors the paper and whether the article highlights new research methods that revolutionize the literature I have already read and understood. This type of research usually takes an existing experiment, tests a new theory, or uses the latest technology to look into a newly identified confounding variable. When papers use these techniques, it makes a reader aware that the writers are well versed in the literature and thus make good use of secondary data.

When finding sources for my paper's research models and treatment sections, it was difficult to find articles that highlighted the research I was looking to incorporate. For instance, finding research that utilized models to understand the progression and treatment of Huntington's Disease was quite hard. For this reason, I had to move away from focusing on research explicitly

done with Huntington's disease and broaden my search to include other degenerative and genetic diseases that have similar progression patterns. Therefore, I incorporated articles that discussed research models used to understand Batten's Disease's progression. I found that research on that subject was being reworked to fit into Huntington's Disease. Thus, understanding the general model in the context of another genetic disease will give readers insight into the available models that are not yet plentiful in the literature concerning Huntington's Disease specifically.

Another difficulty I faced was that most of the scholarly literature on the topic is focused on identifying the genes used to study the disease; however, at first, I found it difficult to find research on the people directly impacted. Data on survival rates and population mapping was easy to encounter, but I desired insight into the chronic years when people were going through the condition. I found this data hard to come by. Thus, I had to expand my search and look for Huntington's disease support group sites and hospice care websites which led me to the sources they cited for their patients. Going through this process connected the data with the lived experiences of the patients. This was an important aspect when understanding treatment options for the condition. In this case, research articles were not beneficial in my understanding, and so I re-routed my search towards books. In this case, I had to be vigilant of the sources I cited, as I had to ensure that the book was peer-reviewed. Ulrich's periodical was helpful during this process, as was the 'peer review' filtering option on ProQuest and Project MUSE. Ulrich's periodical is especially useful as it conserves time as it indicates whether the journal and so, by extension, the article I am interested in is peer-reviewed. These tools are especially useful as they help me evaluate the credibility of the sources I am considering. By identifying the publishers, identifying whether they are reputable, researching the authors, and seeing whether they are experts in their field, I can weigh the article's value. The database ProQuest was also helpful as it

suggests related items, which are articles and other sources that align with the paper I am currently looking at. This simplifies the process of finding other articles on the subject.

Another resource that was of great benefit to me during this paper is the resources available through the library. I frequently did not have access to articles on ProQuest or other databases; however, through the Shields Library, I can request to gain access either digitally or through print versions. This feature was very helpful, as it streamlined the research process, and thus if I felt the article could be of use to me, I can easily request to view the paper, usually instantaneously, as most recent articles have full-text availability and can be viewed online. If unavailable, I can also request the article through the interlibrary loan.

I sought to conduct a comprehensive review of the disease and holistically present the condition throughout the research process. My paper developed from the concept of lead time bias, and thus I employed the model's characteristics to guide my research. Lead-time bias encompasses more than hard science, namely that the person is diagnosed with the disease, but also incorporates the lived experience of the people facing the condition. As a result, sustaining this idea impacted the structure of my paper. Thus, I was looking at the physical attributes, genetic manifestations of the diseases, and psychological implications. As a result, the treatment section included both pharmaceutical and behavioral treatment options, and the progression metrics included biological and psychological deterioration. Through the concept in practice, readers of my paper are presented with both sides of the condition in order to better understand the disease. Thus, etiology is needed to understand research models, which is required to construct integrative treatment options.