

Sarah Shores

Lang Prize

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Lang Prize Reflective Essay

I wrote “Androgen Insensitivity Syndrome: Differences of Sex Development” in the Fall Quarter of 2022 as a term paper for HDE 117 – Longevity. The term paper was assigned in the beginning of the quarter to provide students the opportunity to practice skills related to researching and writing scientific research papers. The topic could be of the student’s choosing so as long it was related to longevity and/or health. Immediately I knew that I wanted to write about an intersex condition since as a congenital disorder it can encompass both health and life span. I had learned about several intersex conditions from PSC 159 – Gender/Human Reproduction, where we covered information regarding the biological and psycho-social development of intersex individuals. After deciding that rather than covering intersex conditions broadly, I would focus on XY disorders of sex development (DSD), specifically androgen insensitivity syndrome (AIS). I felt motivated going into my rough draft as I had my notes from PSC 159 to loosely reference in terms of what background information might be beneficial as well as consulting Professor Carey about the relevance of my topic regarding the class as well as the general structure that I should present the information in.

To start off my research I wanted a general overview of my topic, so I searched "Androgen Insensitivity Syndrome" into Google Scholar as well as into the UC Davis Library Website. I fully read a handful of papers that covered the topic broadly as I wanted to ensure my foundational information was solid. After gathering information about the causes, symptoms, and general health outcomes I began to research using specific phrases such as “androgen insensitivity syndrome bone health.” I also experimented with using the acronym “AIS” following a keyword, as opposed to the full

name as I found that I would sometimes get relevant articles that would not show up had I used the full name of the condition. At this point in my essay, I began reading only the abstracts to determine whether the paper was relevant. Additionally, if I did not understand a portion of the abstract, but thought the topic of the paper was relevant, I would read further into the paper to complete my understanding.

The deeper I researched the subject the more outdated and undefined terms I came across. As a result, I had to learn through exposure to many papers what the old terms for AIS were and the ethics related to what people with the condition preferred to be called versus what doctors found more useful in a medical or diagnostic sense. This eventually ended up influencing my title “differences of sex development” as opposed to “disorders of sex development,” as this seems to be the term preferred by the AIS community. The phrase “disorders of sex development” seems to be preferred in a clinical setting by healthcare professionals. Discerning what papers were relevant and credible proved to be a little tricky when researching the psychosocial outcomes of certain AIS treatments as there were often two or more sides to each topic. This led me to research the pros and cons of certain surgeries and to ultimately value and be able to recognize articles that presented both schools of thought in an unbiased manner. So, while I did not use most papers that erred on the side of social advocacy or complete medical pragmatics, I wanted to have the context of to broaden my understanding of the subject, so I chose to read them despite it not being the topic of my paper. For this reason, I was surprised when several articles worth researching ended up accounting for one or two sentences of content in my essay.

Moving forward, I ran into some issues regarding the scope of XY DSD. At this point in development, I was unsure if the topic of AIS would have enough information to

stand alone. Halfway through the quarter I researched other XY DSD, specifically gonadal dysgenesis, which at one point accounted for half of my essay. It was disheartening to delete weeks' worth of research and sources, but after I found that I could develop AIS more thoroughly, I decided it would be better to narrow my research scope rather than inadequately summarizing two different conditions within a limited word count.

After reading a substantial number of articles and abstracts I found that there were some gaps in my understanding of the specificities of how AIS occurs on a hormonal level. Utilizing the UC Davis Library as well as Annual Reviews (recommended by Professor Carey) I was able to fill in the gaps in the information I presented regarding the specificities of fetal development that was left out by most AIS research articles that I encountered. This included refining my searches to “fetal endocrinology,” “fetal sex differentiation,” as well as definitions for certain undifferentiated fetal structures/hormones that appeared on several in several papers, but not state what the purpose of the structures/hormones were. This was particularly important for my comprehension in order to understand what occurs when fetal development is atypical, I first had to have a reasonably basic understanding of what occurs in typical fetal development, meaning I had to read/skim a few articles that did not mention AIS at all. Additionally, while conducting my search, I began to find a lot of outdated information. For example, it was difficult to find specific information about AIS that was written in the last five years, so I had to rely on older articles at times. Due to this topic not being on the forefront of research I quickly began picking up on inconsistencies with some statistics regarding the rates of germ cell tumors in individuals with AIS as well as basic protocol regarding how the diagnosis should be

approached. The issue of varying protocol was especially true when reading academic articles from different non-western countries. For these reasons I made sure that the statistics that I did note were from articles that were within a reasonable range of time and consistent with similar sources that were more up to date. Additionally, I attempted to prioritize articles that were written with a western audience in mind when I felt it was appropriate, for example when reading about diagnosis, process, and treatment protocol.