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1st Place Contest Entry: Psychogenic Non-epileptic Seizures Disorder: Treatment after the Diagnostic Odyssey

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Essay: Use of Library Resources

The first day of university is daunting for most people. For us, it was exceptionally intimidating because our First-Year Foundation Course (FFC 100) professor tasked us to solve a grand challenge in science with no research experience. As a group of women pursuing healthcare careers, we decided to investigate rare brain disorders. Now, we are entering our final year of college and have gained an extensive repertoire of research skills and experiences that we owe to this project. During these past three years, we practiced finding and evaluating information, authored a formal Institutional Review Board (IRB) application for human-subjects research that was supported by peer-reviewed literature, presented our results at a national conference, and are currently finalizing a case report on psychogenic non-epileptic seizures (PNES) disorder.

This project presented an opportunity for us, as undergraduate students, to learn strategies for conducting efficient and accurate research, supported by the many resources available through Chapman's Leatherby Libraries. For example, in FFC 100, we attended a library instruction session. Dr. Dechow, the science librarian, introduced us to various techniques for addressing key research questions and identifying appropriate sources. This especially applied to narrowing our topic from "rare brain disorders" to "PNES," as well as building a foundational understanding of key terms used in neuropsychiatry (e.g., "epilepsy"). Using library tools such as the "Research and Guides" and "Zotero Quick Start Guide," we formed a systematic approach to tackling the current body of literature on PNES and established a method of tracking the relevant literature, which we still use today.

At the end of our first semester, we found a patient participant, designed a study, and began authoring a human-subjects research application. Our goal was to construct a case report

that provides a new story from the patient's perspective. To start, we needed a solid foundation of the current literature on PNES before delivering a formal IRB project proposal, and with this new goal, it was imperative to find the best information in support of our study.

We sought to identify and critically analyze information by using the TRAAP method: timeliness, relevance, authority, accuracy, and purpose. For example, Leatherby Libraries' built-in filtering allowed us to refine our search to publications from 1990-present to obtain updated information on PNES. The Boolean search tool was exceptionally helpful in finding relevant articles because PNES has many different titles. Thus, we conducted searches with the parameters of "psychogenic non-epileptic seizures" AND "functional neurological disorder" AND "pseudoseizures." Additionally, we split our research into categories such as "diagnosis" and "treatment," which we used to filter the results for key topics. The following were two notable peer-reviewed PNES articles that we discovered and vetted using TRAAP criteria: "Closing the Major Gap in PNES Research: Finding a Home for a Borderland Disorder" and "Addressing Psychogenic Nonepileptic Seizures: Clinical Challenges." These articles were by neurologists Dr. Brien Smith from the OhioHealth Physician Group and Dr. Benjamin Tolchin from Yale University, respectively. To address authority, we used articles by medical, neurology, and psychology experts to ensure our information could be cross-referenced for accuracy. Finally, we used this information to successfully complete several literature reviews that reflected reliable information and sound evidence for our IRB proposal.

In our third semester, our IRB proposal was accepted and we set out on our next goal: collecting information from the participant and writing the case report. To accomplish this, we interviewed the participant and meticulously analyzed their medical documents, which continued into our fourth semester. After completing the Grand Challenge Initiatives program, we

continued our research and sought to incorporate an expert's knowledge to confirm our interpretation of the participant's medical information. We reached out to several PNES experts, some directly from the articles we had cited. Two of the experts we spoke with are still assisting us today, including Dr. Benjamin Tolchin and Dr. Juliana Lockman.

The resources provided by the Leatherby Libraries have been essential to our growth as researchers and significantly supported the progress of this case report. Participating in this research project has provided us a valuable learning experience and opportunity to engage in the technical and critical thinking skills required of conducting a successful project. Ultimately, we are hoping this case report reaches the PNES community and provides insight into a patient's perspective on the challenges of living with PNES and pursuing treatment. We will use this experience as a foundation for our future endeavours as we continue to pursue our own interests in medicine and scientific research. Furthermore, this project serves as one example of how undergraduate students may tackle an ambitious project and succeed through the efforts of careful planning and by leveraging the many resources available at Chapman University's Leatherby Libraries.

Research Summary: Psychogenic Non-epileptic Seizures Disorder

Our project follows the experiences of a single patient with psychogenic non-epileptic seizures (PNES) and documents her unusual story in the form of a case report. PNES are unusual occurrences with a physical manifestation generally caused by underlying psychological conditions (Perez and LaFrance 2016). Currently, PNES is present in the general population at an estimated 2 to 33 individuals per 100,000 (Benbadis and Allen Hauser 2000). PNES disorder is not well understood by the medical community and can be challenging to diagnose (Bodde *et al.* 2009; Smith 2014). Additionally, physical symptoms present in a range of unexpected movement, behaviors, and more (Reuber and Elger 2003). Therefore, effective treatment varies across individual cases, although the current standard treatment is cognitive behavioral therapy (CBT) (Smith 2014). However, PNES may also be associated with underlying psychological conditions, further complicating diagnosis and treatment (Baslet 2012). This project encompasses extensive research on the current understanding of PNES, boundaries to treatment, and presents the patient's perspective to raise awareness of this disorder.

In our case report, based on an extensive review of her medical records, we present the pathway to diagnosis and the subsequent treatment for a 44-year-old woman initially rushed to the emergency room after experiencing what would later be diagnosed as PNES. In the coming months, this patient experienced multiple PNES episodes a day that prevented her from working and performing routine tasks. Thus, she pursued conversation with five medical professionals, none of whom were experienced enough with PNES to provide effective guidance on treatment. Moreover, this patient simultaneously sought out a variety of treatment specialists who claimed to have adequate knowledge of PNES, but she ultimately ceased treatment. After five months of consulting specialists and exploring treatments such as CBT, biofeedback, hypnotherapy,

physical therapy, and more, the patient decided to continue PNES management techniques on her own.

To understand the patient's perspective of PNES, we pursued a structured interview. The patient was asked about her understanding of PNES as a diagnosis delivered by medical providers, her experiences with a diverse set of treatments, and her perspective on how to care for individuals with PNES. From the interview, we learned that a significant barrier to her treatment appeared to be a gap in communication from the provider about the justification for each treatment method. Furthermore, the patient adjusted her lifestyle to accommodate PNES episodes, which has contributed most to management of her condition. In addition, the patient believes widespread education on PNES within the general population and increased awareness among medical providers will better assist individuals who have the condition.

We present this case study in context with extensive research on current literature about PNES as a means of exploring the complexities of treating individuals with PNES. Ultimately, we suggest a path forward for explicit research into the patient's perspective on their experience with treatment that can be used to improve the prognosis for other PNES patients.

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