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Living Life Laser-Focused: A Young Man Forced To Be Both Doctor and Patient

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Introduction

The authors wish to offer an explanation as to why they chose to present David's story in a less than traditional manner. Alessia Minicozzi is a medical sociologist specializing in ethnographic methodology. She has a deep understanding of the physician training process holding a Master of Bioethics. David Fajgenbaum is a trained physician who has dedicated his career to research for orphan diseases. David's passion for orphan diseases stems from his role as a patient with Castleman disease and he continues to fight to find a cure to save his life. Since the authors want to share David's story in a thoughtful and sensitive manner, they chose to mimic the format of a section in the Journal of the American Medical Association (JAMA) called "A Piece of My Mind." One of David's favorite articles from this section is entitled "Lack of Data," written by Julie Maher [1]. David was drawn to the honest way the ailing physician shared her frustration with the lack of data available to treat her illness. The authors hope that in forgoing the conventional methods of research used in most articles, they will not diminish the importance of David's journey. While Alessia did not take several months to conduct ethnographic interviews, she is one of the many volunteers that had the privilege to work with David for nine months. She gathered informal observations of David's work, experienced informal conversations and conducted two lengthy formal interviews. As a way to combat his illness, David became a leading expert of Castleman disease which leant well to explaining the intricacy of the disease. David and Alessia used literature resources to support the conclusions of his life story. They ask readers to view this article as a commentary and testament to the strong will of a patient with Castleman disease who happens to be a physician.

Discussion

5:35 pm not 5:30 pm, This was the start time David established to conduct our first interview for this article. Every minute of David's day is scheduled and planned. He has no time to waste in his laser-focused life as he battles idiopathic Multicentric Castleman Disease as a physician-scientist, advocate and patient. David is a 30-year-old male from Raleigh, North Carolina with parents that were born in the Republic of Trinidad and Tobago in the Caribbean. He earned a medical degree from the University of Pennsylvania, a Master of Public Health from Oxford University, and a Master of Business Administration from the Wharton School of Business at the University of Pennsylvania. He has co-founded two non-profit organizations: a national support network for grieving college students and an international research network dedicated to curing Castleman Disease (CD.) Volunteers, including many from the University of Pennsylvania community, and several of his family members run his nonprofits. He is an avid football fan/player, a struggling Catholic, a grateful husband, and a patient living with a deadly autoimmune disease.

Due to the complex nature of David's story, he does not easily fit into the current literature on physicians becoming patients. There is a good deal of available information addressing the effects of seasoned clinicians acquiring an ailment after years of practicing medicine [2]. These physicians are able to reflect on the switch in roles from physician to patient. There is a limited amount of literature, however, addressing medical students falling ill with severe diagnoses while still in school. These students often leave school and are not able to continue in the medical field [3]. David does not fall into either of these categories. He was able to both complete his medical degree and continue in the medical profession as a researcher. In order to tell David's story in a proper and thoughtful manner, it was vital for him to participate in the writing process of this article. By sharing David's story, we hope to enlighten and inspire the bioethics community to see the complementary roles of doctor and patient being performed by one brave and powerful individual.

When David was a third year medical student on an OB/GYN rotation, he began to experience night sweats, swollen lymph nodes, eruption of blood moles, severe abdominal pain and high fevers. As many medical students and professionals do, he diagnosed his symptoms as likely related to a virus. David never suspected his life was about to drastically change forever. Within a week from the onset of his symptoms, he went to an emergency department and was told he was experiencing multiple organ failure of his liver, kidneys, and bone marrow. Soon, David was placed in an intensive care unit. He spent seven weeks there without a diagnosis and with little hope of recovery. When David's family witnessed a lack of organization between specialists, they began to demand family meetings. During these meetings, David's loved ones ensured the specialists involved in his care were acting in a cohesive manner. In response, the medical professionals encouraged David and his loved ones to "let the medical experts handle things and to be the patient." David and his family continued to push for collaboration among specialists and a strategy to treat David.

Though his doctors did not know what they were treating, they decided to try high-dose corticosteroids and he started to improve slowly. He survived and eventually walked out of the hospital. Without a diagnosis and like any budding physician, he was starved for answers. He was frustrated with the manner in which his medical care was handled, so he decided to take charge and locate solutions. He requested a copy of all his medical records in an effort to identify what had nearly killed him.

Three weeks later, David was back in the hospital with a relapse of symptoms and a biopsy was performed of his lymph node, which

identified a rare immune disorder called idiopathic Multicentric Castleman Disease, or iMCD [4]. David went on to publish the seminal paper in the journal, Blood that re-classified Castleman Disease and first described his subtype as "idiopathic Multicentric Castleman Disease." iMCD is a deadly subtype of CD, which is estimated to have an incidence of approximately 6,000 new cases per year [5]. Approximately 35% of patients die within five years of diagnosis [6]. This second episode proved to be extremely severe, and his physicians encouraged his family to call in their priest to administer last rites to David. Again, David survived and was able to leave the hospital.

This time, David went to PubMed to identify the most published and well-known Castleman Disease physician and located the top disease expert, Dr. Frits van Rhee of the University of Arkansas for Medical Sciences in Little Rock, Arkansas. Although David had a name for what ailed him, he soon discovered there were few answers available to patients with Castleman Disease. He experienced a third life-threatening episode when he was in Little Rock for an evaluation. This time, 7-agent combination chemotherapy put David's disease into a complete remission-for 15 months. During this remission, he returned to medical school and focused his attention on orphan disease research. He also published a case report on himself in JAMA Dermatology describing each episode of the eruption of blood moles or "cherry hemangiomatosis" as a harbinger of his disease. David's observation of these blood moles during his hospitalizations had been previously dismissed as insignificant and unrelated.

After David experienced his fourth episode and nearly died again, he began to look into the state of knowledge for the disease and the global efforts taking place to advance research. He quickly uncovered how little was known about the disease and how many hurdles were in the way of progress. Specifically, few researchers were collaborating, there was no strategy for how to advance understanding of the diseases, and there was inefficient use of limited funding and research samples. David responded by refocusing his purpose in life. He was determined to find a cure to this rare illness. He refused to waste time mourning what he cannot change, but rather devoted himself to looking for solutions and helping others. David turned to Dr. Frits van Rhee, together cofounding the castleman disease collaborative network, (CDCN). CDCN is a global network dedicated to supporting CD patients and accelerating CD research and drug development through facilitating global collaboration, investing in consensus-driven and patient-focused research, and the sharing of samples and clinical information.

Through the CDCN, David became further aware of the "systemic hurdles" in the way of life-saving progress for patients and decided to refocus from clinical medicine to research medicine. Between relapses, he returned to medical school to complete his degree, though opting out of obtaining a residency and being licensed to treat patients. In order to legally prescribe medication and provide medical treatment, a medical school graduate must complete a residency. When asked, David confided that if medical research were better managed to overcome systemic hurdles, effective treatments and even a cure would already be available for Castleman Disease. Needless to say, completing a residency is not a priority for David. His time is so valuable to him that he wants every minute to count toward locating a cure.

This decision to forego a residency is not often supported by medical educators and professionals [7]. The idea of not being able to practice medicine after going through a long and demanding training process is sometimes perceived as "giving up." The process of making it through a residency is considered a rite of passage within the medical profession. During this time, budding physicians learn how to manage various aspects of patient care. They are forced into unimaginable situations that can often impress upon the manner in which they treat patients in the future [7]. Residency can last anywhere from three to seven years, depending on the specialty.

Some senior physicians believe that residency is a sort of "boot camp," where junior physicians gain the skills and resilience to navigate the ruthless field of medicine [7]. With the idea of spending years gaining knowledge that is not necessarily required for conducting research, David went against over a century of tradition and made a major, and some may argue, ill-advised decision. Rather than spend his last year of medical school applying to residency programs, he decided to apply to business school at the University of Pennsylvania, focus his time on Castleman Disease research and his other waking moments with his wife, Caitlin.

His research paid off. He found that the previous model for thinking about iMCD pathogenesis was flawed. Lymph nodes, "tumors," were not responsible for activating the immune system and causing the immune system to attack vital organs. His new model proposed that the immune system was the problem thereby causing the lymph nodes to enlarge. This finding has helped to identify key research projects that the CDCN is currently funding or seeking to fund and has also uncovered classes of drugs, such as immunosuppressants, that may be effective for iMCD patients.

David would not be satisfied if his work were only to cure Castleman Disease; he feels the pull to help others with rare diagnoses that are climbing similar hurdles. For example, between episodes three and four, he contacted the recently retired Dean of the University of Pennsylvania Medical School, Dr. Arthur Rubenstein, who was the Interim Director of the Orphan Disease Center to offer his services. David's persistence landed him a group meeting with various leading experts of countless orphan diseases. Dr. Rubenstein quickly noticed that he was not dealing with an average medical student or even a junior physician.

David graciously recounts the way Dr. Rubenstein introduced him as a fellow colleague. Dr. Rubenstein openly acknowledges that he cannot see David as anything other than his equal. According to Dr. Rubenstein, David is the "expert of Castleman Disease." They have such a mutual respect and admiration for one another that Dr. Rubenstein is now the Senior Medical Advisor of CDCN. David is currently Associate Director of Patient Impact of the Orphan Disease Center.

Unfortunately, the diagnosis of Castleman Disease was not the first time that David experienced devastating health news. While David was a sophomore at Georgetown University, his mother was given a terminal brain cancer diagnosis. Anne Marie Fajgenbaum was a devout Catholic and a loving wife and mother of two daughters and a son. Her faith was unwavering and she powered through her illness. She was the glue of his family. David was completely thrown off course when the anchor of his family needed care and support. As David put it, "she was a professional mother and the best one that anyone could be." He felt overwhelmed and isolated without a way to "fix" her ailment. Unlike his mother, David has struggled with relying on his faith and his Catholic upbringing. He relies on his strong belief in science and research to solve life's tragedies.

His mother taught him that if you want to do anything, you should do it correctly. As a way to honor this sentiment, David spent any free time caring for his mother and learning her disease path. He also

became directly involved with her treatment team. David recounts a conversation with his mother's surgeon when he asked about the life expectancy for patients with her specific diagnosis. The doctor responded by saying he had one patient that lived 5 years. David turned to his family and he announced that his mother would live 5 years and a day. She died within 15 months of her diagnosis.

During his time caring for his mother, David shifted his focus from initially attending medical school to becoming a sports medicine doctor to wanting to pursue clinical oncology. Although David decided not to pursue a residency in Oncology, his current faculty appointment is in the Hematology and Oncology Division at the University of Pennsylvania because of his current battle with Castleman Disease.

Despite the fact that his father is a retired orthopedic surgeon, David shared that he learned just as much about being a thoughtful physician from his mother. As an orthopedic surgeon, David's father often had a clear and direct intervention that could significantly improve patient outcomes [8]. Conversely, in the field of Oncology, the patient treatment plan is often complex and multifaceted [9]. This diverse specialty perspective is challenging to merge. Orthopedists are able to give quick and direct answers while oncologists are forced to accept that they may not offer direct solutions to all their patients. However, this difference in approach to medicine has not affected David's relationship with his father. They have a deep understanding and respect for their unique perspectives. In fact, David relies heavily on his family's support, especially that of his father's, when David is a patient undergoing treatment. David's father understands the complex healthcare system and often navigates the bureaucracy that David encounters as an inpatient. His physicians have, for the most part, come to welcome their input regarding his care [10].

When his mother was first diagnosed with cancer, the family pulled together and provided the best care for the woman they all loved. Although David had the support of his family, he still felt isolated being a college student with a terminally ill parent. As a way to honor his mother's memory and assist other persons in similar circumstances, David put together a non-profit organization called National Students AMF Support Network. AMF stands for both "Ailing Mothers & Fathers" as well as the initials of his mother, Anne Marie Fajgenbaum. He did not want others to experience the loneliness he felt when dealing with his mother's illness. David needed to do something.

As a standing Research Assistant Professor of Medicine in Hematology and Oncology at the University of Pennsylvania, David is a trailblazer. This accomplishment is unusual at such a young age and a testament to David's determination to achieve his life's goals. He works tirelessly to find a cure, or at the very least, to isolate an existing medication that can manage the effects of Castleman Disease. David has relapsed roughly every year and a half, which coincides with the time it takes for the immune system to reconstitute itself after combination chemotherapy. David didn't think it was possible to experience a longer remission and he knows that he will not be able to continue to survive these deadly relapses. However, he is now on his 21st month. Once he crossed the 18-month milestone, he began to dare to dream and plan for the future. The thought of having a family of his own is no longer impossible.

So would this progress, this stretching of three weeks to 18 months, to 21 months, have been possible were David simply a patient? What if he were simply the treating doctor? The answer is probably not. It was only with the unique perspective that his dual roles afforded him that allowed him to approach treating his illness with the sort of out-of-the-box thinking, the sheer determination of will to buck the prognosis of history and conventional research. As bioethicists, we can often see the patient and doctor on opposite sides of the operating table; we view doctors as educators and patients as receivers of this wisdom and care. But perhaps shifting this dichotomy to a more complementary view can help us approach rare cases with unclear outcomes in a more creative and productive way.

David is well aware that if he were to have another reoccurrence, all of the progress and momentum associated with his research may be interrupted. David, however, continues to look forward and hopes for the best. He just purchased a new house with his wife and gives lectures, conducts research, attends conferences and leads organizations. When asked what he would do once he finds a cure for Castleman Disease, he swiftly responded by saying he will find another rare disease to eliminate.

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