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The Severity and Lack of Awareness of Dermatomyositis

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The Severity and Lack of Awareness of Dermatomyositis

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Requirements for the Degree in
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This research paper is dedicated to all of the UCSF and St. Francis healthcare professionals who genuinely cared about my father's condition and helped him win back his life. I would also like to thank my family and friends for their continuous support throughout the entire journey.

Finally, this entire senior project is dedicated to all those who live with dermatomyositis.

I aim to create awareness about this autoimmune disease so more research and resources could go toward improved treatment.

Abstract

Dermatomyositis is a rare autoimmune disease that affects a very small percentage of the population, close to 10 cases per million, according to the National Organization of Rare Disorders (NORD). The amount of men that are diagnosed with this disease are even smaller. However, hardly anyone knows what Dermatomyositis is, let alone what its side effects are. The purpose of this research paper is to exploit the severity of Dermatomyositis for those who are unaware of its existence, characteristics and significance within the health community. In doing so, I hope to create awareness throughout society by also telling my father's story through a narrative documentary, as he is currently living with Dermatomyositis.

Through better communication and further research on Dermatomyositis, awareness will increase, more studies can be conducted, and improvements can be made toward the rehabilitation process for the affected individuals. This is why I will be creating a narrative documentary to further exemplify the details in my paper. I will go into more detail regarding my father's story, connecting all dots to my research. Those who doubt the validity of the information provided will question my degree of membership and credibility. However, by maintaining professionalism and informative research to back up my personal connections and experiences, I will establish my reliability and validity.

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The Severity and Lack of Awareness of Dermatomyositis (DM)

A Review of the Literature & Proposed Research

Normally, the immune system protects the human body from becoming ill. Occasionally, the immune system fails to recognize healthy tissue and attacks it for being a ‘foreign object’ in the body. This development is commonly known as an autoimmune disease, a chronic condition where the body attacks itself. According to the National Organization of Rare Disorders (NORD) (2016), 30 million people, the majority of whom are children, are living with a rare disease in the United States. Dermatomyositis (DM) is one of the rare and unfortunate autoimmune diseases that strike a very small amount of people. Specifically, incidences of DM occur every “9.63 cases per million population,” and an estimated 3 per million children are diagnosed with the disease (2016). DM causes muscle inflammation and weakness, as well as skin irritability and sensitivity throughout the body. Women and children are most commonly diagnosed with DM and in some rare cases, men suffer from the disease, too. Unfortunately, my father was one of those rare cases and was diagnosed with DM in 2013. After a hard fought battle, my father was able to find an effective method of treatment and found the strength to recover and live a happy, close-to-normal life. Given the rarity of the disease, there is little to no substantial research in the field of health communication that conveys the severity and characteristics of DM. Using available research, I will create a documentary film about DM and my family’s experience dealing with the disease. Bill Nichols’ *Introduction to Documentary*, will provide a framework for me as I start to develop a storyboard for my film in order to effectively convey my message and inform my audience about the disease. (Nichols, 2010). The film will describe DM’s

characteristics, illustrate its severe impact, and argue why it is so important the general public know more about it.

Research on Dermatomyositis

There is a very wide range of different disorders and diseases that are affecting human lives every single day. Whether manageable, treatable or fatal, these rare disorders have a severe impact on the diagnosed individuals, as well as their families and caregivers. Specifically, Dermatomyositis is one of many rare muscle and skin abnormality autoimmune diseases. When specialists, also known as rheumatologists, classify DM as an autoimmune disease, they are implying that there is chronic muscle inflammation and weakness within the body, or inflammatory myopathies. As Dinieli, Gelard and Guerra (2016) point out in their discussion of polymyositis and dermatomyositis, there is a correlation between cardiac involvement between these two diseases. They note, “Cardiac involvement in patients with myositis varies between 6% and 75%, (depending) on patient’s selection modalities, definition of heart involvement, and methods used to detect cardiac abnormalities,” (p. 5).

Through years of research and searching for cures in diseases, or even trying to understand what certain symptoms mean, correctly diagnosing a patient is extremely difficult. In attempts to not only understand but also create awareness of these rare diseases and disorders, researchers, doctors and organizations have worked tirelessly. However, there is still much more to be done to understand dermatomyositis and to create awareness of these diseases.

Living with dermatomyositis, as with most other diseases or disorders, takes a tremendous toll on one’s mind and body. In my father’s situation, no doctor or specialist knew what had caused the disease. The degenerative changes or symptoms slowly started to affect my

father, he experienced muscle weakness in his upper extremities (arms and shoulders) and inflammation all over his body. Given our concern with these symptoms, we took my father to many doctors and specialists, including dermatologists, allergists and gastroenterologists until finally, he was admitted to our local hospital in hopes of understanding his unusual symptoms. While he was there, many doctors said he had hives and allergies, conducting a variety of tests with no definitive answer. They did, however, have an inkling that it could have been Rhabdomyolysis, which can be caused by autoimmune muscle damage such as Dermatomyositis. We came away feeling discouraged that my father's primary doctor had dismissed his situation and did not care enough to figure out what was wrong, saying he was just 'getting old' and 'too overweight.' Instead, his symptoms worsened over a couple weeks, and we ended up taking my father to UCSF's emergency room where he was finally diagnosed two days after being admitted. Although DM is a rare disease and my father's situation is rare in itself, all doctors should have a basic understanding of certain characteristics that may lead to an autoimmune disorder or disease. The fact that we had to wait 4-5 months to figure out what was wrong demonstrates a lack of awareness in the health community.

In addition to this awareness issue, when researching DM through a health communications database, only one article came up, and it analyzes the speech issues of women with DM; not even about DM itself (Peterson, G. 1958). Even though DM is rare, it is severe enough that we need to close the gap between the doctor's knowledge and societal awareness. To further understand DM and improve its rehabilitation process, there needs to be more research and communication about it.

Organizations like NORD and health articles like *Adult Health Advisor* (Developed, b. R., 2013) are detailed, yet comprehensive sources that appeal to lay, or general audiences. They are important resources because if a source is too hard to understand, people will not bother reading it, let alone take the time to understand it. Publishing comprehensive articles for the general public will create interest and awareness of conditions, such as DM.

Symptoms and Characteristics of Dermatomyositis

Detecting and diagnosing a disease is extremely difficult. For example, symptoms of DM can either be insidious or acute, gradual or sudden, respectively. My father's symptoms were more insidious as he developed the inflammatory myopathy part of DM; his muscles became inflamed and weak. In many cases, skin abnormalities and heliotropes (rashes) precede muscle weakness in the proximal muscles. However, the muscle weakness is the main issue with the disease in my father's case.

When muscle weakness occurs, the proximal muscles - the hips, thighs, shoulders, upper arms, and neck - are the most affected. Due to the insidious development of the symptoms, my father had problems performing various tasks, including dressing himself, lifting his arms and carrying heavy objects. By the time my father was admitted into UCSF, his symptoms got to the point where he developed swelling in the neck and tongue and had trouble swallowing (dysphagia) liquids and solids. My father's case of DM put him in a bed, unable to move, almost to the point where if you were unaware of what he had, you may have thought he was a quadriplegic. Thankfully, the doctors at UCSF were able to create a plan for his treatment, preparing him for his rehabilitation at SFMH.

Diagnosis of Dermatomyositis

As mentioned before, diagnosing a rare autoimmune disease for someone who statistically has a very low chance of developing the disease, is very difficult. When the doctors evaluated my father at UCSF, the symptoms pointed straight to DM. However, my dad was neither a female nor a child, therefore the doctors questioned whether DM was still the right diagnosis. There are a few different ways to diagnosis DM when symptoms are present: a physical examination and patient history. When the diagnosis is harder to confirm, certain blood tests and muscle biopsies can be performed to narrow results. My father had to have every test performed to have a definite diagnosis. The doctors did a thorough physical examination, including blood tests to detect elevated creatine kinase (CK) levels - muscle enzymes in the serum (liquid portion of the blood) that suggest muscle inflammation - and a muscle biopsy (thorough examination of a small piece of muscle tissue from affected area), that was later deemed unnecessary. In addition to all of these tests, my father took an electromyography (EMG) test, which measured and observed muscle and electrical activity through nerve stimulation on the affected muscles. During this test, a few needles are placed in certain areas of the body deep enough to detect whether or not there are neuromuscular abnormalities. While hospitalized, he had this test performed a few times. According to NORD, experts say that before performing a muscle biopsy, refrain from extracting muscle tissue that was previously put through an EMG test, given that the electric activity could cause inflammation, leading to false

results. The *Journal of Autoimmunity* also indicates that muscle biopsies are an effective way to assess DM, depending on the situation. My father had to have a muscle biopsy performed on his quadriceps. However, after-the-fact, the doctors realized they could have diagnosed him without it. Ultimately, all of these tests are to help the doctors create a concrete diagnosis of his condition. This process is a matter of determining which test is a better fit for the patient, depending on the status of his or her condition at the time of test.

Therapeutic Approaches for Dermatomyositis

Therapeutic strategies are dependent on the individual and his or her conditions. While my father was at UCSF and SFMH, he had a daily routine of occupational therapy, physical therapy and/or speech therapy. His conditions at the time required intense therapy from each type. In a sense, the rehabilitation process was like a child learning how to walk and eat again. This is what DM can do to someone; it is that severe.

Writing in the *Journal of Autoimmunity*, Iaccarino, L., Ghirardello, A. et. al.,(2014) note that immunosuppressive drugs are a common form of rehab and “help reduce the inflammation and skin irritation” all throughout the body (Iaccarino and Ghirardello, (p. 2). This form of treatment is considered mainstream medicine, otherwise known as the allopathic method, which is used or practiced by most doctors and practitioners. In short, allopaths try to fight the body’s natural response system by taking painkillers, anti inflammatories or decongestants. In the beginning of my father’s rehabilitation, these immunosuppressive drugs saved his life. Drugs like prednisone are needed for individuals with DM to reduce the internal and external inflammation.

However, after my father was released from SFMH, he decided to gradually remove himself from drugs and take a different route to a healthier lifestyle.

The overall mental and physical strength it takes for someone to recover from such autoimmune disease takes an overwhelming amount of resilience and faith. This life experience was a wake up call for my father. After re-learning all the basic abilities like eating and walking, my father decided to progressively reduce all immunosuppressive drugs and develop the homeopathic lifestyle. It all started with a Google search for healthy eating and what came up not only changed my father's life but also our entire family dynamic.

My father found Stephanie Austin, a Holistic Health Practitioner, in his Google search. Austin is the creator of Wellness by Mother Nature (WbMN), an online service aimed to assist individuals who seek positive lifestyle changes (Austin, S. 2013). A Holistic Health Practitioner is someone who notices an imbalance in a person's life in regards to their physical, mental, emotional and environmental components. Practitioners recognize the issue, teach their client on how to achieve and sustain good health through natural modalities and how to understand that good health requires balance; then empower the client to achieve his or her goals. Clients learn to evaluate themselves while making changes toward fixing their ill health. WbMN also uses natural medicine approaches to healing, which in many cases can be more beneficial than an allopathic approach.

Austin provides her clients with resources, inspiration, and services to enhance and guide them along their holistic journey. Since 2014, Austin has been able to help many people, of all sorts of backgrounds, rediscover themselves and find their way to a healthier lifestyle. WbMN uses the five avenues of health and happiness in all of its services and programs: mental,

spiritual, physical, emotional and environmental. Through these avenues, people have found the inspiration that Austin originally envisioned. In the long run, this service will allow people to gain knowledge and trust from Austin through her personal attention and immediate change in their lifestyles. WbMN is a very important resource because it provides an abundance of knowledge no matter what service one decides to engage in, where positive lifestyle changes are guaranteed.

Conclusion

Every person has his or her own story. Some get to write their own and some have theirs written for them. My father was born into a rough environment and grew up learning things the hard way, becoming the tough and determined individual that he is. He was born and raised in San Salvador, El Salvador during their civil war. Growing up, he was not only less fortunate than the kids his age in the United States, but he also had to witness violence and death at such a young age. He was exposed to government curfews, dead bodies on the streets, armed soldiers patrolling the streets and watching his every move. Saying that life in El Salvador during the war was rough, would be an understatement. At the age of sixteen, he his parents brought him to the United States where he was given the opportunity to change the course of his story and start a new chapter. He went to school, played soccer, found a job, worked his way to becoming a manager and met my mother; the rest is pretty much history.

Fast-forward to 2013 and a new chapter was created, however this time, it was written for him. Gradually, my father started developing all of these symptoms and not feeling like himself at all. Before you know it, he is lying in a hospital bed, motionless and weak. Of course this is

the last place he would want to be and if he had a choice, he would be on the soccer field. But this was an opportunity to take control and end this chapter of suffering and start a new one of health and happiness. That is exactly what he did. Regardless of how severe the DM was, he found a way to gain most of his strength back and is healthier than he was before his diagnosis.

Many rare disorders and diseases are hard to recover from, especially since they cannot be cured but rather maintained. There were two key ingredients to my father's recovery: his faith and perseverance throughout the entirety of his rehab and the decision to change his eating habits, which ultimately led to his lifestyle changes. Specifically, my father gave up eating gluten and red meats. More importantly, he added more things to his diet than he did giving up. And I would not call it a new diet, rather a new lifestyle. The reasons behind these changes were mainly because his immune system was weak and he suffered from a lack of energy. Eliminating certain things and adding others from his diet helped him repair the issue. If I were to have taken away anything from this experience, even though I do not have DM myself, I would say that living a homeopathic lifestyle will definitely lead to health and happiness, as I am also experiencing it first hand. The homeopathic method strengthens the body (immune system) and the mind. My entire family is living proof of what natural medicine can do for someone. With all due respect to mainstream medicine and all that it has achieved over the course of its existence, it cannot always do what nature can. For instance, Robert Kenner, director of the eye-opening, Oscar nominated documentary, *Food Inc.*, reveals the corruption of the relationship between the government and the food industry. The harmful effects the food industry has on human health and the environment is astonishing. The implementation of genetically modified organisms (GMO) and unsanitary intensive production of animals is negatively affecting the food that a

majority of the country consumes. Kenner's vision of a healthier lifestyle correlates with Austin's ultimate vision of health and happiness; it all starts with the knowledge of what you're putting into your body.

If DM was researched more and communicated better throughout all avenues, awareness would increase, studies would be conducted in hopes to figure out why and how DM happens, and finally, healthier methods of rehabilitation could be implemented, such as homeopathy, avoiding all sorts of negative side effects. All it takes is one person to spread the word and from then, the ball will get rolling. My father continues to write his own story. Now I am writing my own, hoping to spread the word of dermatomyositis and my father's story, influencing people from all over.

Proposed Methodology for Narrative Documentary

Throughout my father's recovery, my mother, my abuelo (grandfather) and I documented the entire process by keeping a detailed journal and filming his recovery. In the beginning stages of my father's struggles, I admittedly found myself in a world of denial. I could not bring myself to accept the fact that my father had to go through something so severe and rare. However, over the course of a couple months, my mother suggested that I start to film the rehabilitation process and make a documentary about his journey. This conversation happened three years ago. Now that I have the resources and the knowledge to create the documentary, this will be the second part of my capstone project.

Through a narrative documentary, which includes an individual who is never on camera and narrates the story being told, I will tell my father's story. I plan on interviewing professionals

who are familiar with autoimmune diseases, especially DM, immediate family members and friends, as well as my father's therapists from UCSF and SFMH. All of these subjects had a critical part in his journey and recovery. Their knowledge and participation in the documentary will help me further explain the severity and effects of DM. These individuals play a crucial role in the development of my film. I will be interviewing a few family friends – Sarah Blatner, Michael Maylan, Noe Garcia – to name a few. In addition to these subjects, I will ask some of my old teammates who have been through thick and thin with my family, such as Michael Linares and Victor Anguiano. Finally, I will interview my father's therapists while he was at St. Francis Memorial Hospital in San Francisco – Tim (Physical Therapist), Hannah (Occupational Therapist), Beverly (Day Nurse), Stephanie Austin (Holistic Health Practitioner) and Dr. Chi - who witnessed many of the struggles and successes of my father.

The questions I will be asking will vary depending on the interviewee. For the health professionals and therapists, I will ask more questions focused on dermatomyositis, methods of rehabilitation and the significance of my father's journey while he was in the hospital. For family members and friends, I will ask questions that correlate with their personal reactions to the situation and what their emotions were like. I will also include questions having to do with their relationship with my father and why it was important to them.

The interviews will be the informative part of the documentary. The true essence of the film will be the footage of my father's recovery, where the severity and effects of DM will be portrayed effectively. There will be a disclaimer because not all cases of DM are like my father's. There are three different types of DM: adult, child and sine myositis (solely skin abnormalities). My father had a rare case of DM as a male adult in his late forties. Furthermore,

the footage involved in the film will include everything from my father's physical and occupational therapy to many of the challenges he encountered while struggling and recovering from DM. I will strive to portray his ambition and perseverance through narration and strategic editing, in a semi-linear, yet chronological order.

As stated before, the purpose of this documentary will be to create awareness of DM through my father's story, providing an example of how serious and life changing such a rare disease can be. Throughout the entirety of this process, I will document my experiences and emotions felt during the production. The production of such a personal piece will resonate deeply with emotions I felt back when my father was in the hospital. A journal of my experiences and emotions during this process will also help me reflect on not only continuing to raise the awareness of DM but on the relationship between my father and me and how it has grown over the past few years. One lesson I have learned thus far is that, as humans, we do not realize how important something is in our lives until we hit a wall and we suffer or struggle. Daily routines that we are accustomed to are no longer familiar to our bodies. We take for granted the littlest things like putting on clothes, tying shoes and eating. These characteristics of a daily routine are just a few of the things that my father had to learn how to do all over again. The most unfortunate thing about life is that we cannot control certain things that happen to us. That is why we have to appreciate everything that we have and do on a daily basis, no matter how minuscule it is. Appreciate and cherish everyone and everything in your life for as long as you can.

Reflection of Narrative Documentary

I have been a filmmaker for eight years and the process of making a film has always been easy for me. When I started to plan this documentary a year ago, I was very excited to start producing the ideas that have been in the back of my mind since my father's diagnosis in 2013. However, there was one obstacle that slowed me down and hindered my ability to see clearly through the lense of a filmmaker - my personal connection and relationship to the subject, my father.

When my father was diagnosed with Dermatomyositis, this idea of documenting his rehabilitation process was solely intended for our family's purpose; there was no intention on having it become my senior thesis. However, when the time came to choose my final research topic I decided to take the health communications route and research Dermatomyositis and the severity of its effects. With the footage I filmed of his time in therapy, I figured it could be used in a narrative documentary to raise awareness of this rare autoimmune disease, while demonstrating the severity of his condition. In my Research Methods class, I was able to identify my approach and role in the documentary process. I would include both ethnography and autoethnography to my documentary process, given I am observing my father's point of view from the environment he lived in, as well as my personal experience and connection to a wider cultural and social understanding, respectively.

When creating a storyboard for my documentary, I knew that I would have to figure out the logistics of whom I need to interview, the content of the interview, the location of the interview, b-roll (footage that overlays the dialogue on screen), etc. I knew that the preparation for filming would dictate the outcome of my film. Questions had to be worded in a certain way in order to get the answers I wanted, which would ultimately help with the editing and

storyboarding process. Therefore, I chose certain family members, friends, and health professionals that had knowledge about Dermatomyositis and played an integral role in my father's journey.

An important lesson throughout this process was seeking help when I needed it. Before I was able to begin the production of the documentary, I needed the gear to do so; and to have the gear, I needed the money. As a college student, my budget was tight and I could not afford to pay for the gear with my own money. I decided to create a GoFundMe fundraiser in hopes of receiving the funds to move forward with my project. Without knowing how much I would raise, I had a low expectation of raising \$300-400. I shared the campaign on Facebook and within 24 hours, \$600 was donated toward the cause. I finished with \$900 by the end of the week. The outpouring of support was amazing and with that amount, I was able to successfully coordinate a professional multi-camera shoot, with great lighting camera quality.

Now that I had the funds to rent the necessary gear, I asked my friend, Victor Anguiano, a broadcasting major at San Francisco State University, to help me with the interview process by formulating questions in a way that would help me effectively tell the story. With his professional experience and knowledge, I was able to conduct the interviews and film b-roll in a different, creative way. By asking for help, I was able to move forward with my project and have confidence that I would be prepared me for the fall semester of 2016, where I would start the editing process.

My personal connection to the subject and investment into this project hindered my ability to have a neutral opinion in approaching the creation of an effective storyboard. As I previously mentioned, I have never had trouble putting a film together. So when I struggled to

put the pieces together, I was stuck and could not create what I envisioned. Being a perfectionist and emotionally involved in this project, my expectations for the film's outcome were high. I found myself unhappy with everything that I wrote down. Even when people gave me positive feedback, I was still not happy with what I had created. Overcoming this obstacle of tunnel vision and the expectation of perfection was difficult and I knew that I would need to seek help from individuals with an unbiased perspective on my story. Their input would ultimately give me the push I needed to take a step back and put myself in the shoes of my audience.

When making a film, regardless of genre, appealing to your audience is one of the main goals, in addition to effectively communicating your message. As a filmmaker, I had to think of specific content that would engage my audience emotionally. Through personal experience of watching many different types of videos and movies, I find myself emotionally engaged within the first thirty to sixty seconds - if it is put together well. After that, if I am not engaged or interested in the content, I will stop watching. With my film, I hope to catch the attention of my entire audience right away so I have them committed to watching the entire documentary.

Aside from what I have learned throughout this process, some of the struggles I encountered were logging, transcribing, mixing audio, filming necessary b-roll and storyboarding. I knew that logging and transcribing would take a long time and become tedious, but it was hard doing it in an organized way that would help me with my storyboard. I had to organize all the footage by putting all interviewee subjects into subgroups of friends, family members and health professionals. Then, I added time codes to everything they said in their interview, making it easier to identify key quotes, which were used to guide my story in a semi-linear and chronological order.

Mixing audio has never been a strong suit of mine because I have always used a single song in any of my prior videos and adjusted levels accordingly. However, for my documentary I planned on using a few different songs, instrumental and lyrical. Therefore, I was introduced to Adobe Audition for the first time during the editing process and was able to mix the audio effectively, having smooth transition between segments of my film. I have used this experience to develop my skills in audio production and mixing because I know that I will come across this issue sometime in the near future when making videos.

Another obstacle that I came across was noticing I was short on footage and needed more b-roll that correlated with what was being said in the interviews. For example, I had to go back home a few times to film the field and performing arts center at my high school, Woodside High School, as well as UCSF hospital where my father was admitted and diagnosed in the beginning stages of his illness. Having to take time out of the editing process to go film more had its positives and negatives. I realize that it would have been best to film everything in advance, even if I did not end up using some of the footage. However, doing that would have taken time away from what really needed to be filmed. Because most of the footage was shot in 2013 during the time of my father's rehabilitation process, I thought that it would be enough. This learning experience has taught me to always film more than I think I would need because things can be added or subtracted from the storyboard, but it's safer to have more than not enough.

This entire process has taught me to manage my time better and allocate more time to certain parts like the logging and transcribing. Now that I have grown as a filmmaker, my videos will become more complex, therefore needing more time dedicated to them. Every obstacle that I encountered, I successfully overcame. I am looking forward to the impact that my narrative

documentary will have on the health community, people who are currently dealing with or have dealt with this disease in the past, and people affected by my father's story. May this provide insight as to how precious life is and encourage people to take care of themselves. If there is even the slightest doubt that something is wrong with you or a loved one, keep pushing for answers because there will be doctors that just simply do not know the answer, but there will be one that does. Throughout this entire process and everything that has happened in relation to this project, I have learned to have faith and be patient. Life is a miracle.

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