

Scoliosis Stigmatization and the Patient Experience

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On my honor as a University student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments.

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Introduction

Adolescent Idiopathic Scoliosis (AIS) affects up to 3% of children in the U.S., and approximately 5% of the global adolescent population. Detection and diagnosis of scoliosis is slow and is often missed, as the disease develops in late childhood with an abnormal curvature of the spine. Scoliosis is generally treated with one of two methods: a back brace or spinal fusion surgery. Even today, these methods do not cure scoliosis, but simply manage symptoms. Consequently, they are uncomfortably invasive and frustratingly restrictive. With both surgical fusions and braces, curves still slowly increase throughout time, and result in a significant reduction in spinal movement and rotation. In addition to extensive physical obstruction and pain, many scoliosis patients suffer from a repertoire of negative stigmas. The stigma of having a visibly deformed condition adds insult to the injury and can lower the patients' health-related quality of life. Specifically, patients suffering from scoliosis are largely at risk for developing certain mental disorders such as a distorted self-image or even attempts of suicide (Han, Xu, Yang, Yao, & Zhang, 2015). There is explicit need for a less burdensome treatment approach.

A physically handicapped person can be represented in an uncountable number of ways, though scoliosis and the disability and stigma that surrounds it is often overlooked. As previously stated, scoliosis is specifically characterized by an abnormal curvature in the spine that specifically causes uneven shoulders and/or hips, a bump in the lower back, and notable trouble walking and standing up straight. Having a physical deformity heightens the compel to adhere to social norms and to the societal categories' people construct. Patients suffering from scoliosis are largely at risk for developing certain mental disorders such as a distorted self-image or even attempts of suicide (Han, Xu, Yang, Yao, & Zhang, 2015).

Current research has demonstrated a few ways that patients cope with Scoliosis but there does not seem to be a concrete methodology. Patients have stated that they default to using blog posts as means to discuss their story in a therapeutic manner. Other patients have noted that picking up an old or new hobby has really helped them to integrate back into social scene and improve their mental health. However, there is the risk of being stigmatized within a new hobby that patients face. Generally, patients do not get into these activities until the wrath of their condition and treatment has mostly resolved, therefore, the physical deformation that elicits the stigma is hopefully no longer an issue.

The discovery of scoliosis and the mentioned treatment methods trace back to the Greeks of the classical era in 5th century. These outdated methods result in an undesirable appearance and overall quality of life. More advanced and evolved approaches remain undiscovered. However, when considering the cutting-edge technology present in our world today, we inquire why less invasive, less visible and less restrictive technologies have yet to be created. There is explicit need for a less onerous treatment method, but in the meantime, how do scoliosis patients manage the stigma that comes from these symptoms and treatment approaches?

[Thesis: Exploring the negative stigmatism in which scoliosis patients face from current treatment options and socialization]

Framework: Evolution and perception behind a spoiled identity.

Stigmatism affects the lives of a vast number of citizens. Stigma is not necessarily a fixed or inherent attribute of a person, but rather, can be viewed as a social experience and emblem of difference. Those who face stigmatism are disqualified from full social acceptance, before what is widely considered 'normal' (Goffman, 1968). The common response to a stigma is hiding. Hiding, however, can lead to further isolation, depression and anxiety when the stigmatized individual faces the public(Goffman, 1968). In turn, they can feel more self-conscious and afraid to display negative emotions. There are a few types of stigmas, though this focus will be on physical stigmas, which refer to the physical deformities of the body. Richardson, Hastorf, Goodman, and Dornbusch (1961) have shown that children have a

consistent psychological ordering of physical stigma in terms of how much they like or dislikes children with one physical handicap or another. They even show that “physical handicap is such a powerful cue in establishing preference that it largely masks preference based on skin color (Soble & Strickland, 1974, p. 467).

The stigma-derived secondary wounding within scoliosis patients will be examined through the framework of what Erving Goffman describes as a ‘spoiled identity.’ Spoiled identity refers to an identity that causes a person to experience a stigma, and grappling through life with such an attribute can be deeply discrediting and intrinsically harmful (Goffman, 1968). This attribute divides people into those who are normal, the ‘normals,’ and those who are not, the ‘non-normals,’ thereby making the non-normals less worthy. From a therapist, this negatively stigmatized attribute becomes internalized and an inherent part of who that person is. The silent messages repeated in their head can impact self-esteem, self-perception, mood and increase mental instabilities such as anxiety (Constantinides, 2015). I will explore the sociotechnical construction of a spoiled identity within society to wholly understand these unspoken effects patients bear and their origin of creation. I will also explore how attributes of the patients’ testimonies, such as self-esteem and anxiety, are portrayed; and how such might be reflected as discrediting within the framework.

Data Collection, Methodology and Evidence

To achieve such, I will explore patients’ firsthand accounts of dealing with the stigma of scoliosis. In order to gather such evidence, I will examine patient testimonies in regards to their personal experience with scoliosis. I will obtain this data from personal interviews, in addition to online blog/dairy resources written by patients. This data is of relevance as it will explicitly depict the kind of mental and emotional effects that patients suffer from and how they deal with such, clearly and effectively drawing attention to the problem. This data will also facilitate in tracing the origin and development of such secondary wounding.

Upon data collection, I will analyze the testimonies with Erving Goffman's Spoiled Identity framework in order to sufficiently identify present themes and thus organize similar connections and relationships. Specifically, the information will be separated case by case into varying categories of related personal experiences such as, bullying and name-calling, exclusion and family-related agitation etc., although subject to change upon data analysis. Proceeding the bracketing of similar or varying personal experiences, I will group the data under different locations and sources of the secondary wounding in order to find commonalities amongst patient lives. Management tactics, including groups of therapy, support groups, meditation etc., and also a group for the unmanaged will also be examined. This will assist in the identification of overarching themes pertaining to where the stigmatization originates from and how/if scoliosis patients manage such. Categories will be continually built until no new themes or subcategories are identified. Assessment of the relative importance and subtle variations of different and even counter themes will follow.

The data analysis and compartmentalization will be then formatted in a way to highlight congruencies and incongruencies among patient stigma management. However, it is important to address that patient experiences are subject to limitations such as available resources, including healthcare, economic mobility and time period. For example, a scoliosis patient from ten years ago may not have had access to the same kind of care that a current scoliosis patient has, altering the rationality of their testimony within the context of this approach. The conducted research will facilitate the classification of scoliosis patients' personal experience with negative stigmatism and how they manage such effects, in order to portray the need for a modified approach.

Five scoliosis patients' testimonies were examined from the Scoliosis Research Society 'Patient Stories' database. These patients' names are Sean, Cassie, Martha, Eliana, and Lindsay. All examined patients were diagnosed with scoliosis in their adolescent years. All patients underwent treatment for the condition whether it was back-bracing, spinal fusion surgery or both. It is interesting to note that all patients were not originally tested for the diagnosing of scoliosis, but rather, sought medical assistance after a visible and painful deformity arose.

Results

Negative stigmatism strongly affects patients' quality of life in both physical and mental aspects. Some patients experienced a degree of physical occupational disadvantages. For example, Martha, who was a popular model, started to lose clients as her scoliosis condition worsened. Cassie was continually disqualified during swim meets as the condition hindered her ability to compete competitively within the rules of the sport. Lindsay, who was a competitive gymnast, became severely injured from the abnormality of her spine (Scoliosis Research Society, 2020). Other patients experienced verbal discrimination and physical bullying from the visibility of the deformity. Sean was called a "freak" and a "cripple" and was sometimes hit in the face and pushed around (NAMI, 2020). Eliana was also ridiculed in school and mentioned that classmates would call her "camel humps," (Thecurvyspine, 2017).

Despite the type of discrimination, all patients faced mental suffering and insecurities that stemmed from this kind of treatment. All of the patients expressed feelings of insecurity, exclusion, and "just wanting to blend in." The examined patients mentioned the emotion of shame and wanting to "hide," whether it was staying home from school or wearing excessively baggy clothes in hot temperatures (Scoliosis Research Society, 2020). Three out of the five patients explicitly mentioned mental illness such as depression, anxiety and even an attempt at suicide. All patients discussed how the visibility of the deformation was the major cause of the stigmatization. Four out of the five patients stated that most of the stigmatization stemmed from the ignorance of the surrounding family and friends. For example, Eliana stated: "But, it wasn't like I was stigmatized by everyone, it was mostly people who didn't know about my situation, or wanted to know." (Thecurvyspine, 2017). Martha's parents initially refused to take her in to see a doctor because they thought she was just going through an awkward phase" (Scoliosis Research Society, 2020). Additionally, not one patient testimony opened with a statement

saying when they were diagnosed with scoliosis. All patients' stories opened with a freak accident that forced them into receiving tests for scoliosis. Perhaps further public education of Scoliosis could help in earlier identification, diminishing the visibility of the deformity and lessening the intensity of ridicule.

Upon treatment, most patients noted that symptoms and social life improved. However, Eliana noted that, having now an 'invisible deformity' made it much more difficult for people to empathize with her. Cassie was able to pick up another hobby, Martha was able to model again through different agencies and Lindsay returned to dance practice despite a few restrictions (Scoliosis Research Society, 2020). Sean however, stated that hospital bills and childhood bullying trauma still kept him in a trance (*NAMI, 2020*). Patients mentioned no other support system besides their family, if they have any, and their one doctor. Additional counseling and therapy could help both the patient and the family in enduring scoliosis.

It is important to note that although these patients are victims to the demanding condition of scoliosis, they are still able to achieve life with joy. Cassie mentions that despite the gregarious surgery, she was able to successfully return back to her favorite hobby. She also offers words of encouragement: "Please know that Scoliosis does have an end and it is survivable. I can honestly say that going through the surgery was so worth it!" (Cassie, Scoliosis Research Society, 2020). Similarly, Martha indicated that after she overcame her fear of appearing different than other models, she put herself back out there and started working her dream job modeling for Victoria's Secret. Lindsay demonstrates her strong comeback by participating in 50-mile bike rides, yoga and dance classes. As an attack at Sean's former ridiculing bullying experience, Sean mentions he rejoiced in the fact that the surgery made him 3 inches taller. He stated he adapted a new confidence from this that he "never thought" he would obtain. Eliana mentioned that as a result from condition she got deeply into fitness and promoting a healthy lifestyle. She works out three times a week with a personal trainer that helps her open up her shoulders and increase her range of

motion. This lifestyle promotes her to feel “strong, confident and empowered” (Eliana, Scoliosis Research Society, 2020). It is paramount to recognize the kind of perseverance and strength these patients exhibit as a result of their struggle. Coming out on the other side of this psychological trauma proves resilience and power, which should be admired not only these examined patients, but all who suffer from Scoliosis. Many of them walk away from this with profoundly positive attitudes: “My goal is to let all of the children who are facing scoliosis treatment or surgery know that they are incredibly special and will go on to do amazing things” (Martha, Scoliosis Research Society, 2020).

Discussion

Stigma may be described as a label that associates a person to a set of unwanted characteristics that form a stereotype. When society categorizes individuals into certain groups the labeled person is subject to status loss and discrimination. The stigma affects the behavior of those who are stigmatized and can also shape their emotions. It is clear from this research that having a condition like Scoliosis can come with these unfortunate, and undesirable consequences. The patients that were examined in this study are witnesses and victims to the negative stigmatization that comes with Scoliosis. Examples of this negative stigmatization that have been discussed include: bullying, self-deprecation, body shaming and insecurities, as well as feelings of depression and anxiety. What Erving Goffman refers to as a spoiled identity, Scoliosis patients experience this by being socially discredited as a rejected stereotype. Using Sean’s experience as an example, this is specifically demonstrated by his encounters with being called a ‘freak.’

Individuals actively cope with stigma in ways that vary across stigmatized groups and within all kinds of individuals. Many of them develop a new hobby or get back into something they loved. Although

the experience of being stigmatized may take a toll on self-esteem, and other outcomes, many people with stigmatized attributes continue to perform at high levels, are happy, and appear to be quite resilient to their negative experiences. Sean, Eliana, Cassie, Martha and Lindsay demonstrated that what doesn't kill you truly does make you stronger. Many Scoliosis patients who have had the privilege of a relatively successful outcome, mention their gratefulness for their journey and the strength and perspective it has given them. Indirectly, this positive attitude towards their experience serves as a coping mechanism for their back-breaking peregrination. "Scoliosis is just like taking the green flag...work through the race and know that at the checkered flag it is so worth the journey." (Cassie, Scoliosis Research Society, 2020)

It is very important for all people living with scoliosis to be educated about their options. There is so much information available in regards to modern day treatment. New research and FDA approved devices are currently being explored. The FDA recently cleared The Tether™ which uses patented methods developed by the medical staff of Shriners Hospitals for Children in Philadelphia (Shriners Hospital, 2019). The product is commercially available for use for anterior vertebral body tethering(VBT), a surgical procedure for patients with Scoliosis who meet a specific criterion. It is an alternative to spinal fusion procedures. The Tether uses a strong flexible cord to gently pull on the outside of a Scoliosis curve and straighten the spine. The spine is straightened using the patient's growth process and it is anticipated that curve progression will be halted, and the spine remain straight (Shriners Hospital, 2019). Whether a child has common idiopathic adolescent Scoliosis or another type of complex spinal deformity, they deserve the most effective treatment. Individualized treatment plans using the most advanced and innovative techniques are now available and are being integrated into treatment approaches that were not explored in this research.

This study is limited by the logistics of the patient data. All of the patient data was told in a first-person narrative and therefore subject to their own social desirability bias. Most of the available patient

testimonies were from the perspective from females, and it is uncertain whether the discrimination could be more or less severe in regards to gender, however, it is more common for females to develop body image distortions than males. Patient data was also very variable, as they were not given a concrete set of questions to answer and as a result categorization and analysis was further simplified. The number of testimonies used is also an area of limitation, as additional testimonies could have identified different themes.

In the future, I would attempt to locate patients with scoliosis so that I am able to conduct first-hand interviews, face-to-face. I would like to make a list of questions and pre-plan my research in order to truly conduct this project independently without having to rely on third party data sources to draw conclusions from. In this case, I would be better able to articulate questions and construct overarching themes to make categorizing the data much clearer and more concise. It was difficult to group the data as the testimonies were told under very different narratives with scattered information. I was forced to identify themes as I was researching and this further contributed to the difficulty of this project.

I will use this research as a learning experience for my future engineering practice. I have deeply learned that research is best conducted when you create a concrete plan. Trying to find and conduct research along the way leads to a disorganized paper. Being able to organize your project and research in advance is what makes for the best, most fluid data finding process and results. I will also be more proactive in taking the initiative to conduct my own research. I was definitely timid and hesitant to go to the hospital and locate scoliosis patients on my own in order to conduct interviews. However, from tirelessly internet searching for data that meets my specific criteria proved to be quite inefficient and will definitely be something I take into consideration for my next research project.

Conclusion

Considering the advanced technology available for adolescent idiopathic scoliosis, it is unbelievable that stronger and more efficient methods for spinal curvature correction that are less cumbersome in multiple degrees, have not been adopted. Although this current lack of advanced practiced methods persists, the future in revolutionary approaches is promising. Companies like MIST are actively seeking out and conducting work to improve and elaborate treatment methods, with future hopes to treat scoliosis as whole condition rather than as a spinally deformed symptom. The visibly deformed spine gives scoliosis a negative stigmatism, inducing secondary wounding within patients, such as depression and self-esteem issues.

As current approaches are physically and emotionally burdensome, it is important to further understand how the stigmatism develops to thoroughly grasp how these patients are affected and to educate the public. If this research were to be taken further, I think it would be important to talk to patients face-to-face and specifically ask them if/how they have dealt with the negative stigmatization from Scoliosis. In future studies, potential solutions to combat this diminished quality of life experienced by scoliosis patients can hopefully be recognized. For starters, one solution could be better education for the public about the condition in order to harness improved diagnosis and therefore patient experience. In retrospect, it is of vital importance to the human wellbeing for everyone to attempt to understand one's visible, or invisible, suffering.

Despite sympathetic efforts, wholly understanding the depth of one's suffering may be difficult to the non-suffered. However, what is simple to commend and appreciate, is the fulfillment and propitious future Scoliosis patients have uncovered for themselves. Many Scoliosis patients come out of the woods with an evolved and admirable perspective to life. As they discover various methods of coping like adopting a hobby or exercising, they are able to construct a new life of noteworthy happiness and passion, with an eagerness to help and support others facing similar physical demands. "Though living with pain

can make you feel very isolated at times, don't let it prevent you from living your life to the fullest. Just remember, anything is possible.” (Martha, Scoliosis Research Society, 2020).

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