

# A Comparison of The Socialization of Children with Moebius Syndrome: The Effects of Access to Treatments

Greatness Adewumi\*

Baylor University, Waco, Texas

## Abstract

Moebius Syndrome is an uncommon neurological disease classified by the underdevelopment of the cranial nerves that control facial muscles. Symptoms of Moebius syndrome consist of paralysis of muscles in the face, difficulty in eating and speaking, and the incapability to express emotions through facial gestures. There is currently no cure for Moebius Syndrome, but several options are available for individuals with it to help better their lives. Facial Reanimation Surgery, tracheotomy, and occupational therapy are some effective treatments known to help those with this condition over the years. Unfortunately, not every child with this condition has the privilege of undergoing treatments that can support them because of their expenses. This disorder affects the socialization of children in various ways, especially when it comes to interacting with other children and people. In this study, we compared the social effects of surgical interventions that children with Moebius Syndrome underwent that treatment revealed that treatments can make a difference in the life of affected children.

## Introduction

Moebius Syndrome is a rare disease that affects the neurological system. It impacts an individual's ability to express their emotions by limiting their ability to control and move their facial muscles. This then influences a person with Moebius Syndrome through the inability to express their emotions such as smiling, laughing, and crying. This disease was first discovered in 1880 when it was found as a disease that is identified by the weakness of the cranial nerves (the nerves that control facial muscles) [1]. However, the cause of dysfunctional cranial nerves in Moebius Syndrome is unknown. Risk factors that could cause Moebius Syndrome include the usage of specific medications or unauthorized drugs during pregnancy. The disorder is developmental and varies for everyone who acquires it from birth. Some children with the condition may experience a cognitive hindrance such as walking, crawling, or even sitting later than anticipated [2]. Moreover, some children with Moebius Syndrome are more likely to have autism. There is no cure for people affected by Moebius Syndrome, but luckily, there are options to support them socially. The inability to control facial muscles makes it difficult for an individual with Moebius Syndrome to communicate with other people through facial emotions [3]. This also affects their social interactions with others because of the judgement faced by individuals who do not understand their disorder. These options include get-togethers or support meetings for those with the disorder. These communities can help by allowing those with Moebius Syndrome to socialize with others with whom they are comfortable and help reduce the stigma of the lack of socializing. For instance, in 2016, the effects of support meetings were compared between individuals with Moebius Syndrome who attended and those that did not for the people who participated in these meetings, there were drastic increases in their level of perceived awareness and social comfort. Treatments have noticeably changed the social lives of children with Moebius Syndrome because they support social functioning, which is essential for social situations [4]. Treatments such as occupational therapy and surgery have been found to often increase happier behavior and social connections in children with Moebius Syndrome because they help them feel better about themselves since they are able to improve their social abilities. Occupational therapy has assisted children with Moebius Syndrome by helping them do activities in their daily life that might be difficult for them. Surgical interventions like Facial Reanimation Surgery cause children with Moebius Syndrome to gain

the ability of expressing a smile through reversing the inability of expressing emotions. This specific surgical intervention is an innovative procedure that takes a nerve from the thigh and transplants it into the face to the masseter muscle, which aids in chewing. However, not every child with this condition has access to medical treatments or can attend get-togethers or support meetings. This may be due to the lack of emphasis on Moebius Syndrome, given that it is a rare disorder that only affects 2 to 20 people per 1 million worldwide and 1 in every 50,000 to 500,000 newborns. It is challenging for individuals with Moebius Syndrome to find others who have the disease, and they often feel a huge lack of support from the medical system. Nonetheless, there has been investigation into the options available for people with Moebius Syndrome. Children with Moebius Syndrome can have a better social experience if they use the medical treatments available to them. If they do not use these treatments, their social life may continue to be difficult. The most effective options, such as Facial Reanimation Surgery, Achilles Tenotomy, and Temporalis Tendon Transfer are inaccessible for some children with this condition due to the expense. Insurance cannot cover every cost for treating a child with Moebius Syndrome. Not every family of a child with this condition can afford these options to improve their child's social functioning [5]. We hypothesize that children with Moebius Syndrome who have access to treatments usually demonstrate an improved social life compared to affected children who do not have access to treatments.

Study 1, Children with facial paralysis due to Moebius Syndrome exhibit reduced autonomic modulation during emotion processing, investigated how the body temperature of children with Moebius

\*Corresponding author: Greatness Adewumi, Baylor University, Waco, Texas, E-mail: greatness\_adewumi1@baylor.edu

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Syndrome reacted when they imitated facial gestures, revealing how they handled themselves in specific social settings.

Study 2, A New Neuro rehabilitative Post surgery Intervention for Facial Palsy Based on Smile Observation and Hand-Mouth Motor Synergies, emphasized the importance of surgical treatments by comparing traditional treatment and FIT-SAT treatment (facial imitation treatment-synergistic activity therapy) in rehabilitation for Facial Reanimation Surgery.

Study 3, Living with Moebius Syndrome: Adjustment, Social Competence, and Satisfaction With Life, discussed the significance that surgical interventions have had on the social competence of people with Moebius Syndrome

## Materials and Methods

Information for this study came from three case studies comparing patients with Moebius Syndrome who have undergone surgical interventions and patients with Moebius Syndrome who have not undergone any treatments [6].

### Study 1

Study 1, Children with facial paralysis due to Moebius Syndrome exhibit reduced autonomic modulation during emotion processing, investigated 13 children with Moebius Syndrome identified by their facial paralysis [7]. The physiological behavior of these children was compared to a control group of 16 children who did not have Moebius Syndrome. The principal purpose of this study was to see how well children with Moebius Syndrome could imitate others' facial expressions and observe the effects of affected subjects not having the ability to mimic another individual's facial expressions.. All participants were left in a softly lit, sound-proofed, climate-controlled area to acclimate for 10–20 minutes. At random, five different emotional faces (surprise, anger, happiness, neutral, and disgust) were altered and shown to them. While these videos were presented to the participants, they were asked to evaluate the stimuli. Their temperature was recorded using a thermal camera positioned on top of the screen used for the video presentation. The thermal camera was one meter away from the participants' faces, and the camera was used to record the child's face from the front manually fixed and calibrated [8]. The second experiment in this case study tested whether autonomic nervous system responses during emotional processing were different in children with Moebius Syndrome than children without Moebius Syndrome (control group). When these participants were shown one-minute videos showing faces dynamically shifting from a neutral expression to one expressing disdain, surprise, rage, joy, or remaining neutral, their fluctuations in facial temperature and the amplitude of RSA (Respiratory Sinus Arrhythmia) were measured. Each facial expression was thoroughly examined for four seconds before the effects of the stimuli on autonomic nervous system reactivity were measured and assessed for identification.

### Study 2

A New Neurorehabilitation Post surgery Intervention for Facial Palsy Based on Smile Observation and Hand-Mouth Motor Synergies was based on four patients with Moebius Syndrome who received surgical treatment in 2016 and whose recovery was followed until September 2018. The study followed patients with Moebius Syndrome who underwent both traditional and FIT-SAT (facial imitation treatment-synergistic activity therapy) rehabilitative treatment following Facial Reanimation Surgery. FIT-SAT treatment was a new recovery treatment given to the patients after Facial Reanimation Surgery

which contains instructional videos of a person performing a smile to be imitated at home for up to six months post-operation. Traditional medicine was given to one side of their face to test the effectiveness and FIT-SAT to the other side. This research focused on seeing how effective the FIT-SAT treatment was compared to standard therapy after Facial Reanimation Surgery in patients with Moebius Syndrome. Requirements for participation in the study included congenital facial paralysis on both sides, activation of the right gracilis muscle following teeth-clenching treatment, activation of the left gracilis muscle after FIT-SAT treatment, and no congenital hand deformity anomalies. The patients first had Facial Reanimation Surgery performed on the right side of their faces and then used teeth clenching as the traditional therapy for recovery. After one year, these patients underwent Facial Reanimation Surgery on the left sides of their faces and then used FIT-SAT treatment for rehabilitation. The treatment for FIT-SAT started at their homes, and the initial kinematic acquisition was performed. At the end of the FIT-SAT treatment, the second kinematic acquisition was performed to measure patient progress after the insertion of the transplanted muscle. An optoelectronic device for motion analysis was used to collect kinematic data. The kinematic acquisition (identification of motion) had two blocks (homogeneous groups): first, an actor performed the smiles in an imitation block that the patient attempted to copy. The second block was a no-imitation block in which a performer did not grin but instead delivered a smiling rhythm. In this experiment, four responses were investigated through the movement of passive markers placed on both sides of their mouth and nose, including smile observation and hand contraction (HC), no smile observation and hand contraction (SO-HC), no smile observation, and no hand contraction (BC), no smile observation, and no hand contraction (SO).

### Study 3

Study 3, Living with Moebius Syndrome: Adjustment, Social Competence, and Satisfaction With Life, included participants who were obtained through the Moebius Syndrome Foundation newsletter, website, and personal contacts made at conferences and through the foundation. There were two categories of people involved, including 37 individuals with Moebius Syndrome and 37 control participants. The main intent of this research was to examine if social competence, satisfaction of life, depression, and anxiety are higher among those with Moebius Syndrome compared to those who do not have Moebius Syndrome. The response rate for the study was unknown because there was no record of how many people visited the website or subscribed to the newsletter. The members of the San Francisco State University's student involvement database provided the control group. A 14-item measure called the Hospital Anxiety and Depression Scale (HADS) was used in this experiment to detect anxiety and depression symptoms and clinical levels in these subjects. The five-item Satisfaction with Life Scale (SWLS) assessed individuals' life satisfaction. The Short Form B of the Texas Social Behavior Inventory (TSBI), a 16-item self-report form, assessed the participants' social self-esteem and social competence. According to the self-report, the capacity to portray seven various emotions with the face was evaluated using the FECQ.

## Results

### Study 1

The trial held in Study 1 investigated the emotional effects of imitating facial expressions between children participants with Moebius syndrome and those without the disease. This experiment examined psychological responses to display the involuntary adaptation to communication skills (social cues). Stefani et al. used functional

infrared thermal imaging (fTI) and electrocardiography (ECG) to gather data from participants. fTI is a tool that documents the body's normal release of radiant heat. This technique is essential because it has been emphasized that there is an association between the temperature of the face and emotional condition. Stefani et al. used ECG to approximate the respiratory sinus arrhythmia (RSA) reactivity. RSA is a metric of pulse fluctuation related to unconstrained respiring that computes the parasympathetic area of the autonomic nervous system through cholinergic tenth cranial nerve prognosis to the heart. In other words, RSA is a method used by modern computers to decode and encode messages from the nervous system to the cardiovascular system (heart). The control group exhibited higher resting RSA (a higher sense of empathy or a desire to assist) as opposed to the Moebius group. For the Moebius Syndrome affected children, they had a lower resting RSA which demonstrates anxiety, depression, trait hostility, autism, and, more broadly, a physiological response to potentially dangerous settings.

This suggests that the reactions of children with Moebius Syndrome to emotional stimuli could explain their reduced social abilities. This finding also suggests that children with Moebius Syndrome have a less sensitive parasympathetic system than the control group. Response Accuracy Rates (RACC) in this study were noted as the correct responses of understanding the difference of facial expressions out of the total responses given to the children participants. Overall, the Moebius

syndrome group and the control group judging of the stimuli shown to them was highly accurate. The RACC (Response Accuracy Rates) values of the Moebius Syndrome group and control group is compared using the Kruskal-Wallis test. The control group's RACC scores were greater than the experimental Moebius Syndrome group's (p-value =.024) The p-value of the Moebius Syndrome group's was statistically significant. This result indicates that MBS participants performed worse than the control group in discriminating facial expressions (Figure 1,2).

### Study 2

The experiment that was conducted in Study 2 compared two different rehabilitation treatments for Moebius Syndrome patients. The first one was FIT-SAT treatment and the second one was traditional treatment which was used to determine which treatment was more effective.

FIT-SAT treatment incorporates clips that display instructions and facial exercises to be done at home for six month. FIT-SAT helps MBS patients rehabilitate motor function and the ability to smile every day. The authors compared FIT-SAT to traditional treatment, which is simply teeth clenching. Kinematic acquisition was utilized to collect data from the patients 2-3 months after the surgical intervention and 8-9 months after the surgical intervention to calculate the patients' progression. The data was acquired through an optoelectronic motion analysis system.

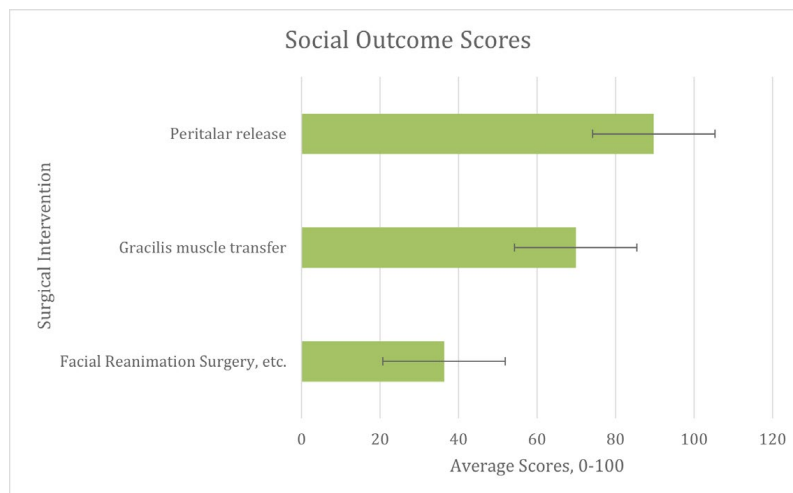


Figure 1

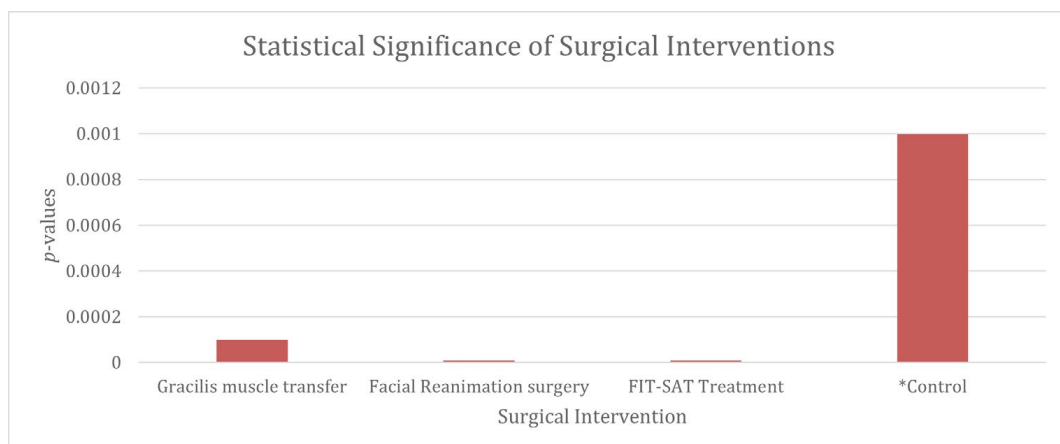


Figure 2

A Logic Learning Machine (LLM) is a method of machine learning focused on the development of accessible rules that is an efficient implementation of the Switching Neural Network (SNN). In this study LLM was used for the left and right sides individually to examine the effect of FIT-SAT therapy on activating the masseter muscle without clenching the teeth. After the data was analyzed, a comparison was done between the traditional treatment and the FIT-SAT treatment using the percentage of left side parameters and right-side parameters. The results demonstrated that there was no difference between the right side and the left side ( $p$ -value  $>.05$ ), and the result was not statistically significant. Overall, this result supported the conclusion that the FIT-SAT treatment and the traditional treatment are both successful for rehabilitation post-surgery. This finding demonstrates that Facial Reanimation Surgery can improve the social functioning of a patient with Moebius Syndrome since it has been reported that patients with Moebius Syndrome who have undergone Facial Reanimation Surgery have benefitted in social situations because they could use their communication skills to interact with another individual.

### Study 3

In Study 3, the anxiety, depression, social competence, and life satisfaction were compared between the two groups, which included two groups (a group of 74 (37 people with Moebius Syndrome and a group of people without Moebius Syndrome). When these participants were evaluated, it was shown that those with Moebius Syndrome exhibited worse self-perception of social competence and confidence in social circumstances. The findings also revealed that social interaction involving people with Moebius Syndrome could be labeled as limited if others misread their nonverbal signs. Especially since their failure to respond to another's feelings could cause the interactant to feel misunderstood or confused, leading to a perception of inappropriate behavior.

To measure social competence, several techniques were used. The FECQ (Facial Emotion Communication Questionnaire) was adopted in this study to compute the self-reported capacity to articulate the seven universal emotions through facial expressions. The HADS (Hospital Anxiety and Depression Scale) was used in this case study as a short test for diagnosing sadness and anxiety in outpatient nonpsychiatric hospitals. The SWLS (Satisfaction with Life Scale) was employed in this study to measure the indices of life satisfaction or overall well-being.

In this case, the Moebius syndrome group had a lower FECQ score ( $p$ -value  $<.05$ ) than the control group which indicated that the result was statistically significant. The levels of despair and anxiety were not significantly different between groups. In terms of social skills, the Moebius Syndrome group had a worse score than the control group, according to the TSBI's t-test. The Moebius Syndrome group had a HADS score below the cutoff of 8 which demonstrated that it was not likely that these individuals were suffering from severe depression or anxiety. Lastly, the control group and the Moebius Syndrome group had no significant differences in their SWLS score.

To compare the social outcomes of Moebius patients that underwent surgical interventions, we analyzed the results from these studies that tested their social ability. For Study 2, using the  $p$ -value given from the LLM specifically for the efficacy of the FIT-SAT treatment revealed that although it was just as effective as the traditional treatment done on Moebius patients, it was still a productive treatment because the result was statistically significant. This displayed the aftermath of the FIT-SAT treatment as supportive for Moebius patients that wanted more symmetry in their smile which affected their social interactions with other people.

For Study 1, using the  $p$ -value obtained from the facial regions of interest (ROIs) on patients with Moebius syndrome, it was shown as statistically significant. This displayed that Moebius patients that have not undergone surgical interventions are emotionally affected which may explain their impacted social life.

### Discussion

The findings from our study suggest that children with Moebius Syndrome who have undergone treatments show an improved social life. Because of their condition, children with Moebius Syndrome are usually expected to have a complex social experience. Although their backgrounds may influence their future interpersonal interactions, it is hardly seen in social situations when it comes to interacting with other individuals. As shown in Study 1, children with Moebius Syndrome are more prone to have a lack of ability in their social skills since they are at a higher risk for lower social skills. It is challenging for them to interact with other people without feeling like they are an outlier because of their disease. A child with Moebius Syndrome who does not receive treatment is more likely to experience poor social consequences. As demonstrated in Study 3, where the TSBI t-test measured a lower social competence for the Moebius group, without any treatments, it is common for these children to feel more anxious when around others, have a sense of low self-esteem, struggle with insecurity, and isolate themselves from other individuals. Conferences and support groups may provide social assistance, which helps those with this condition feel less stigmatized. Children who are a part of these groups are more likely to have more positive mindsets, feel more secure and safe, and interact with others. According to the data displayed in Study 2 & 3 there was a trend in the lives of individuals with Moebius Syndrome. Children with Moebius Syndrome who have had surgical procedures to help them smile experienced a social change since smiling was a social function they needed to engage in with other people. A patient's social life can improve due to the treatment because they could use their face to communicate with another person. Interacting with someone else with a smile can say many things. They could show how happy they are simply by showing their teeth. These findings support the notion that providing additional support to children with Moebius Syndrome will positively influence them. Surgical interventions that help people with Moebius live more comfortably may assist them through their daily lives. Surgical treatments and therapy, like conferences, have had incredible social effects on children with this disease. These options help because they not only allow them to socialize with other children who have the same illness as them, but they also allow them to socialize with people from the outside world. As a result, people with Moebius Syndrome who receive treatment or therapy are more likely to have positive experiences in various settings like their workplace, school, gatherings, and many other events. As described in Study 3, the participants with Moebius Syndrome were more likely to identify as having a lack of self-confidence and low social competence in social settings. One cause of this could be low awareness of rare neurological disorders and the need for facial equality in society. Many people are unaware of Moebius Syndrome which usually causes them to be perplexed when they witness someone with the disease. To make a difference, more awareness of rare disorders needs to be raised to the public. This may help people with the disorder to not feel as isolated from others since it is a part of them that they have no control over. Future research should focus on finding a cure to Moebius Syndrome to better the lives of those with the condition. Increased acceptance of people with disabilities will also help to reduce the social stigma surrounding individuals with Moebius Syndrome.



Due to Study 3 and Study 1, the findings in this study are limited due to the disease's lack of attention, which results in few case studies being available. Although statistical data was provided, there was no way of knowing whether it was completely accurate because the studies had not been repeated and small sample size that could cause the results of the data to appear worse due to its skewness. Essential data and details may have been left out because the data was self-reported, which would have added to the experience and analysis of the evaluated patients. There may have been an over-exaggeration of events after these patients completed the experiment and were monitored. Despite these potential errors, we believe that the implications of this study are important for the Moebius syndrome community because it will bring awareness to the rare neurological disorder and its effects on social life. It will inform individuals apart of the scientific community about the importance of making socialization comfortable for everyone regardless of a condition they have. It will also inform the medical community of the significance of surgical interventions because of how they can possibly improve the lives of children with this disease. Hopefully, in the future, more scientists can become involved into researching more about the Moebius syndrome community and discovering the cure for the disorder along with allowing individuals with Moebius syndrome

to have more access to healthcare and surgical interventions to possibly make life a better place for them.

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