

Moebius Syndrome Awareness Day 2016 at Oregon State University

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Introduction

Moebius Syndrome (MoS) is a rare congenital neurological disorder that results in facial paralysis and difficulty or inability to form facial expression. The rarity of this condition causes low awareness and as a result, people may react negatively to a person with Moebius Syndrome because they are unsure of how to interact with them (Bogart, Tickle-Degnen & Joffe, 2012).

In focus groups of both adults and teenagers with Moebius Syndrome, one of the prevalent themes of discussion was the desire for education on the condition (Bogart, 2015; Bogart, Tickle-Degnen & Joffe, 2012).

Interventions focused on educating the public about the condition have resulted in more favorable ratings of pictures of people with Moebius Syndrome in terms of traits such as extraversion as well as increasing interpersonal sensitivity (Bogart & Tickle-Degnen, 2015).

Two methods of describing Moebius Syndrome are the Medical Model of Disability and the Social Model of Disability. The medical model is a description of Moebius Syndrome focusing on symptoms and treatment, whereas the social model is a description focusing on how Moebius affects patient's lives and social relationships.

The goal of this experiment was to spread awareness and gauge public opinions on Moebius Syndrome. It was hypothesized that participants in the social model group would have more positive ratings of people with Moebius Syndrome and place a higher importance on social understanding.

Methods

Participants:

Eighty-four English-speaking participants (76 Students, 5 Staff/Faculty Members and 3 Community Members) were included in the study.

Materials:

Information Cards for the Social and Medical Model of Moebius Syndrome

Survey with pictures of people with Moebius Syndrome and knowledge pre and post-test

Signmaking Materials (pens, paper)

Candy; offered for participation



Figure 1. Researchers Natalie Weber and Hanna Thompson tabling in the Memorial Union Quad on January 21, 2016

Procedure:

Participants were quasi-randomly assigned to two treatment conditions. Each condition described Moebius Syndrome, with one condition being the social model and the other the medical model.

- Medical Model: Described the symptoms and curative efforts of the condition
- Social Model: Described the stigma and social barriers associated with the condition

Participants were then asked to rate four pictures of people with Moebius Syndrome in terms of friendliness and capability; as well as existing opinions on Moebius Syndrome.

After the survey was completed; participants were invited to create a sign about what they believed others should know about Moebius Syndrome, which they were asked to post on social media using either “#MoebiusOregonState” for the social model or “#MoebiusOSU” for the medical model.

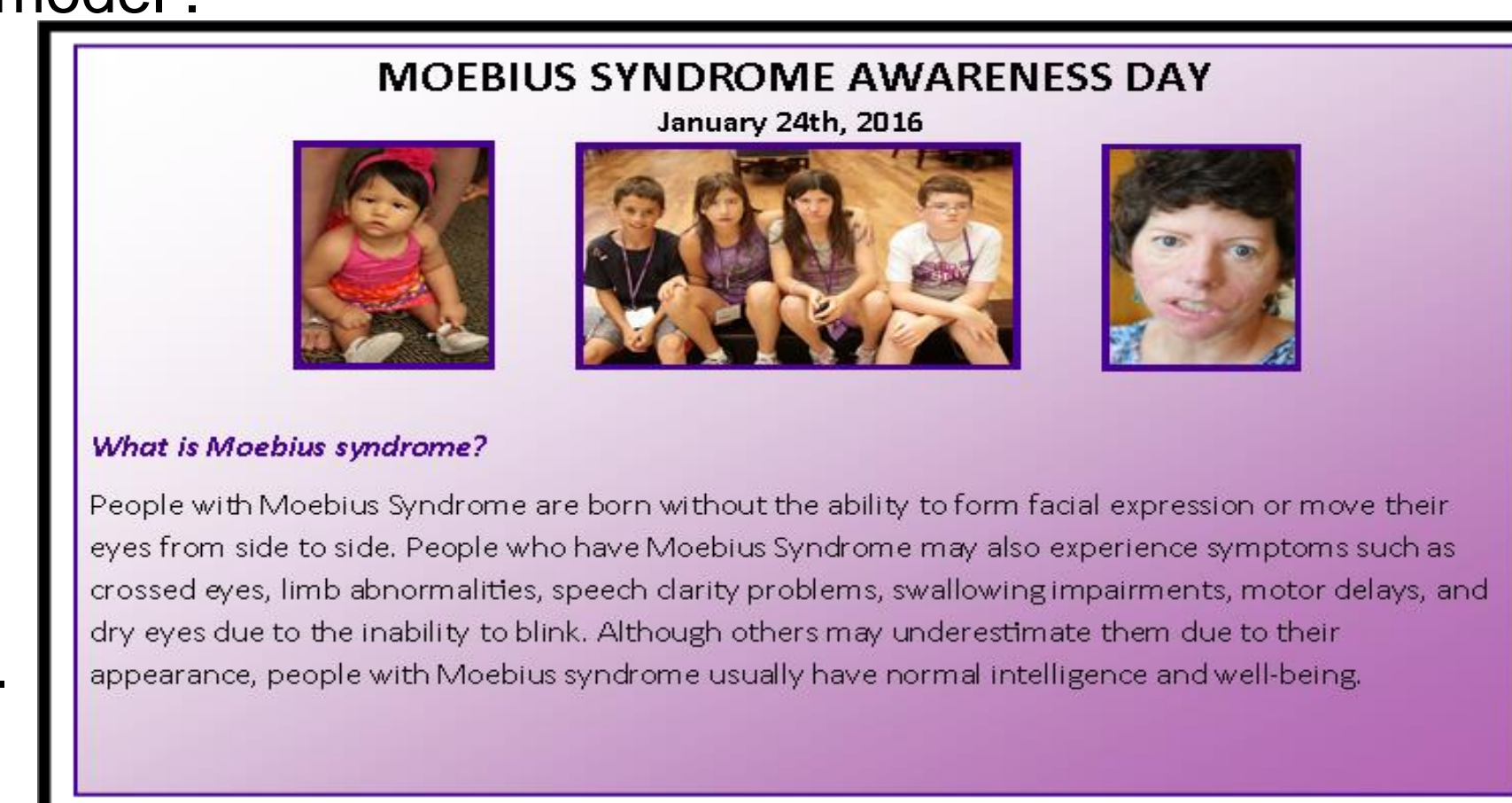


Figure 2. Social Model Information Card used in Intervention

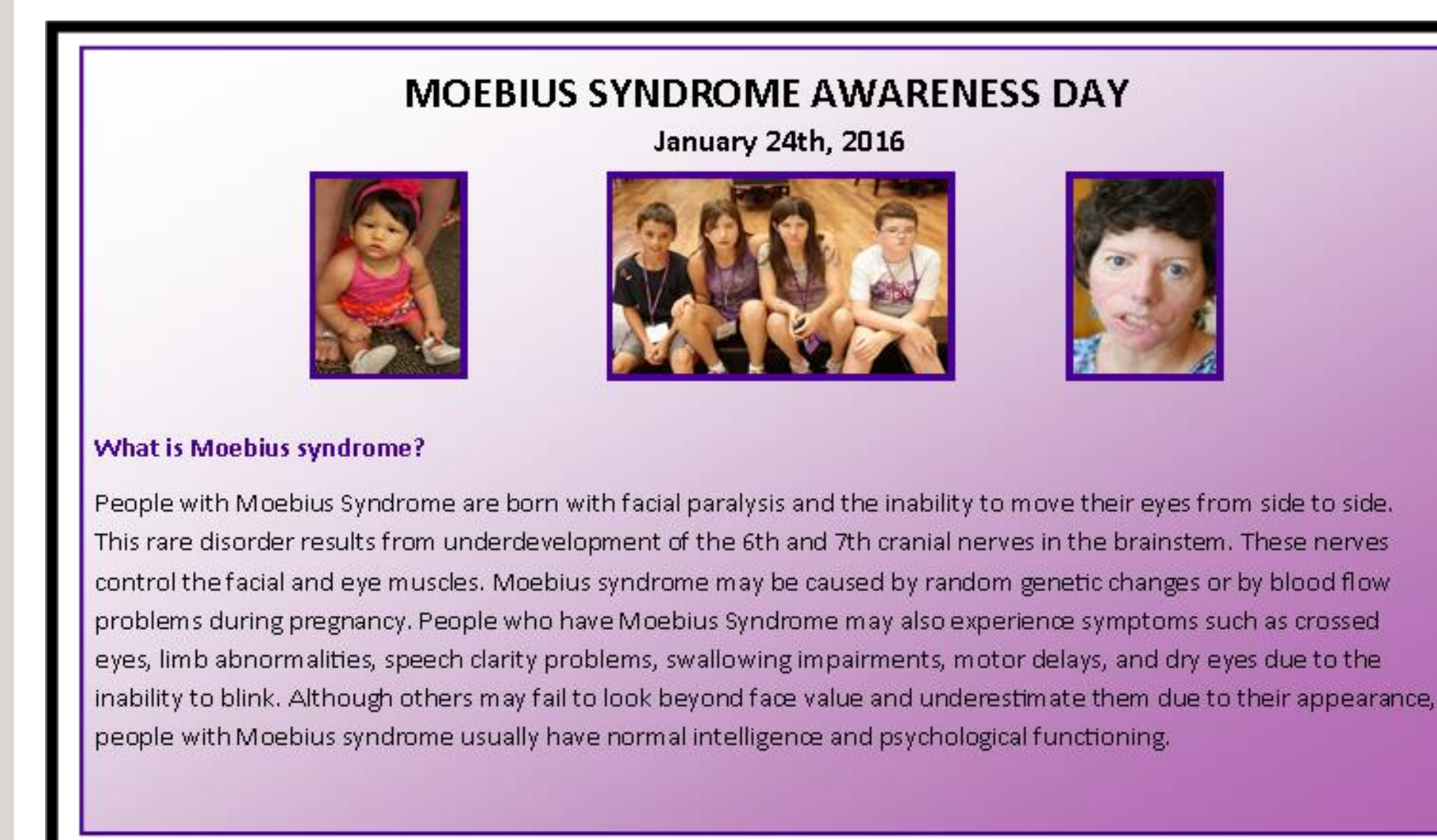


Figure 3. Medical Model Information Card used in Intervention

Results

A mixed ANOVA was conducted to examine the interaction between model and changes in perceived knowledge before and after receiving information about Moebius. There was no significant relationship between model and knowledge.

No significance in the relationship between model condition and perceived warmth and competence of individuals with Moebius Syndrome.

Results showed a significant increase in perceived knowledge about Moebius, regardless of model condition: $F(1, 82) = 351.81, p < 0.001$.

A paired samples t-test was performed to examine how participants ranked the importance of social inclusion/understanding compared to the importance of a medical cure. Regardless of model condition, participants ranked the importance of social understanding/inclusion as more important than a medical cure: $t(83)=5.15, p < 0.001$.

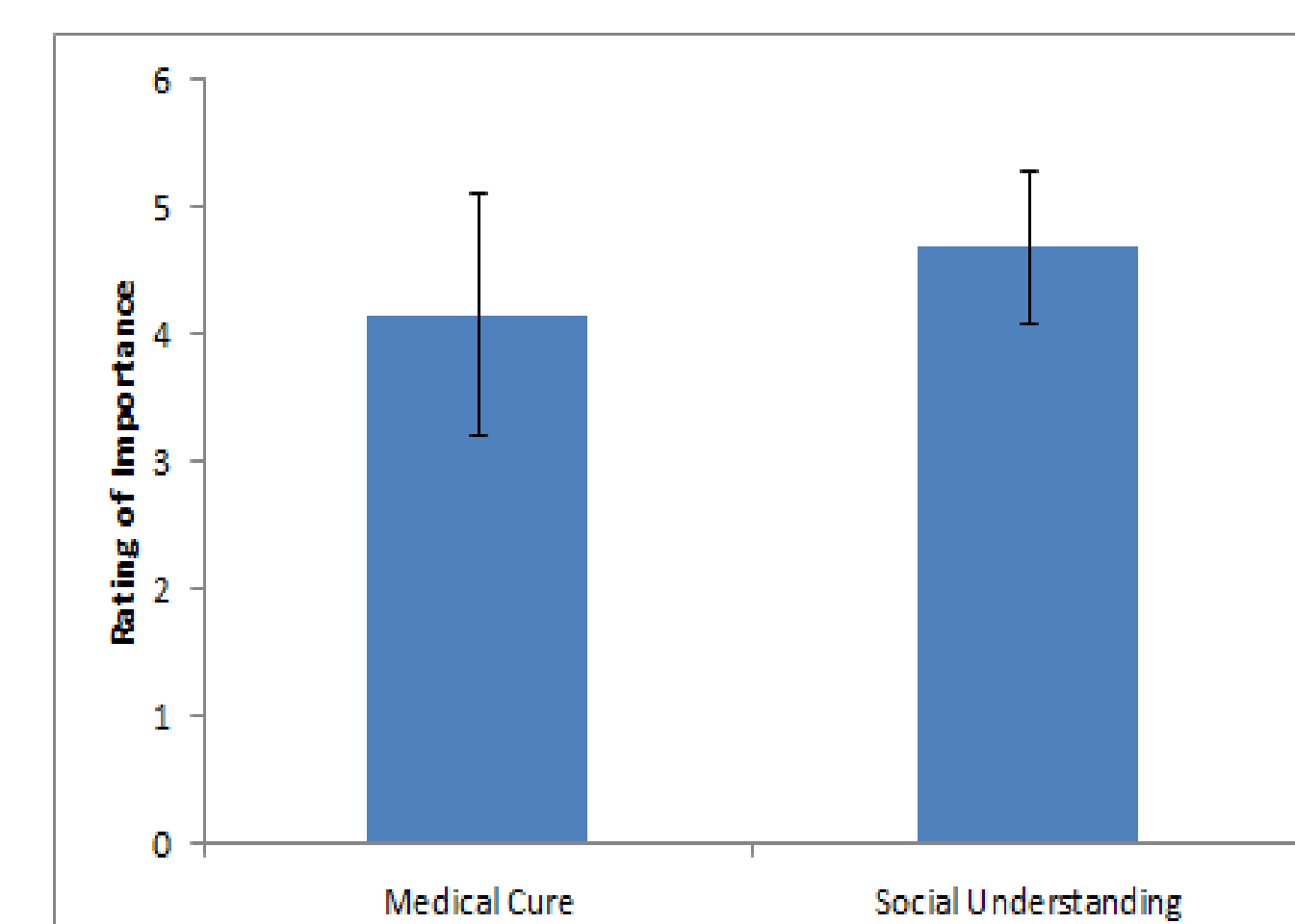


Figure 4. Error bars represent standard deviation

Discussion:

Regardless of medical or social model participation, perceived knowledge of Moebius Syndrome saw a significant increase throughout the course of the intervention.

Participants viewed social understanding as more important, regardless of model.

Social media component was not successful, as only three people posted pictures of themselves with their sign.

Conclusions

Knowledge intervention, regardless of model is effective at increasing a participant's perceived knowledge. Curative Efforts are believed to be less important than Social Understanding among participants in either model.

Limitations

Experiment facilitators were present and possibly influenced participants.

Voluntary Response Bias: Participants who already have an interest in awareness events were more likely to approach our event.

Facilitators background in social model research may have influenced their delivery of the medical model condition.

Participants were informed about Moebius Syndrome using either the Social or Medical model prior to rating their perceived knowledge.

Further Research:

An extension of this research will include an online version of the experiment's survey using the web app, "Qualtrics."

The use of Qualtrics will:

Eliminate the possible influence of facilitators.

Allow the collection of data from participants that would not usually voluntarily participate in these studies.

Allow participants to complete the survey without feeling rushed by other factors.

Further research will incorporate social media in a way that is straightforward and easier to participate in, thus yielding more data

Key Reference:

Bogart, K. R., & Tickle-Degnen, L. (2015). Looking beyond the face: A training to improve perceivers' impressions of people with facial paralysis. *Patient Education and Counseling*, 98, 251-256. doi: 10.1016/j.pec.2014.09.010