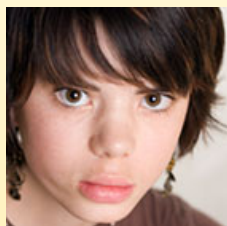


The Social Side of Moebius: A Focus Group of Teenagers with Moebius Syndrome

Andreea Barbu, Thanh Nguyen, Shivangi Agrawal, & Kathleen Rives Bogart, PhD
Oregon State University

Introduction



Moebius syndrome is a rare neurological condition that is characterized by facial paralysis, which causes difficulty with social interaction (Bogart & Matsumoto, 2010)

MoS can be stigmatizing for a number of reasons: the inability to express through facial expression, and the need to explain the disorder to strangers that do not know how to behave around the individual with MoS (Elliot et al., 1982)

A previous focus group with adults with MoS found that they use compensatory skills such as body movements and vocal inflection to reduce miscommunication caused by a lack of facial expression, and they displayed resilience by showing confidence, persistence, competence, and choosing to be unaffected by negativity (Bogart, Tickle-Degnen, Joffe, 2012)

The previous focus group found that adults have difficulty discussing their MoS with others, possibly due to social stigma of MoS or even the denial of their condition. However, they hope through media and social institutions that awareness of MoS would reduce the stigma (Bogart et al., 2012)

Methods

Participants:

10 teenagers between ages 12-17 (mean = 14 years). 9 were Caucasian and 1 self identified, 3 males and 7 females. All were students, 5 being in high school and the other 5 were in middle school, and all were observed to have moderate to severe facial paralysis.

Procedure:

A focus group was conducted at the biannual Moebius Syndrome Foundation Conference where these individuals were interviewed about their social interactions with people without MoS. Seven open-ended questions guided the discussion, which were chosen based on literature review and the researchers' expertise with MoS.

Analysis:

Transcripts were analyzed using conventional qualitative content analysis. 2 independent coders analyzed the transcript based on the coding system used in a previous study with adults with MoS (Bogart, Tickle-Degnen, Joffe, 2012)

Results

The social functioning experiences of the teenagers were categorized by the five following themes, each including the positive and negative aspects:

1. Social Engagement/Disengagement

Engagement included five codes: assertiveness, compensatory expressive strategies, managing others' reactions, outgoing and engaging, and show the person behind the Moebius

Um, well my teacher... [and]
Her assistant... they said that when they look at me they don't see that I can't smile because I can show my[...]emotions very well. And my mom and dad said I'm very expressive even though I have Moebius and I can't move my face. Yeah, they can tell when I'm upset, or angry, or happy.

Disengagement included two codes: passiveness and avoidance

I just ignore it [talking about bullying]

Results Continued

2. Resilience/Sensitivity

Resilience contained five codes: confidence, competence/skill, not letting others negative reactions affect me, persistence, positive outlook

I don't really think [Moebius limits us]. I mean like, we have it, but it's like nothing's really wrong with us... Like, most people, we can pretty much do anything

Sensitivity contained two codes: low confidence and others negative reactions affect me

In my activities all my friends joke around and, you know, I laugh... when I'm like, going to cry

3. Social Support/Social Strain and Stigma

Social support contained two codes: family/friend support and medical/institutional support

In elementary school, like, I had a lot of friends like I wasn't like a lonely person. I had a lot of friends but like I had a lot of support let's say, so like whoever like tried to know me down, all my friends would support me and be like 'hey, that's not cool.' So I just like, learned to accept that. Like I know like we're different and people stare but they just don't really know

Social Strain and Stigma had four codes: bullying, discrimination, facial difference, and prejudice

I have been called a freak. I have been talked about behind my back... There's enough of it. Because this is how I am. Because of the way I talk

4. Being Understood/Misunderstood

Being understood had two codes: understood and others seeing the person behind the Moebius

Once they got to know you, I think their personal impression will change

Misunderstood had three codes: misunderstood, speech difficulty, and emotional communication difficulty

I don't talk as much in other clubs 'cause they won't be able to understand what I have to say, so I keep to myself

Results Continued

5. Public Awareness/Lack of Awareness of Moebius

Public awareness consisted of one code: disclose and educate about Moebius

Usually I tell them like, what's wrong with me and they usually understand after that. If that doesn't work then I've got like my friends helping me

Lack of awareness contained four codes: lack of public awareness of Moebius, not acknowledging Moebius, other's don't know how to behave, and perceived as having an intellectual disability

Um, it was like 4th grade, 5th grade and then um, well there was this new kid and he thought he was so cool and then he was like 'you're retarded' and I was like 'not really' and I like defended myself and then, it's ironic because we started talking and he's like 'oh, I'm sorry' and we started hanging out and we became really good friends. And he's like 'oh, I'm sorry I called you that' and I was like 'yeah, I'm not retarded. Obviously.'

Conclusions

Teenagers with MoS identified their social interaction along five different themes: resilience/sensitivity; social engagement/disengagement; social support/stigma; public awareness/lack of awareness; and being understood/misunderstood

MoS can result in social interaction challenges for teenagers

Participants with MoS used compensatory expressions to adapt to their social interactions by using their body movements and vocal qualities

There were similarities between the findings from the previous study of adults is MoS and the teens in the current study.

Both reported resiliency, confidence, being persistent, being competent and choosing not to be affected by negativity

Some adults and teenagers are uncomfortable discussing their MoS with close family and friends, however both agree that creating awareness of MoS through media and social institutions may reduce stigmatization

A new finding among the teenagers was reports of social strain from family members, such as unwanted help and attention.