



A Discussion about the Social Psychology of Moebius Syndrome

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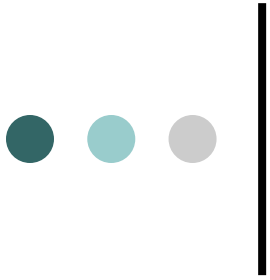




Overview

- Living with Moebius syndrome
- Others' impressions of people with Moebius
- Facilitating interaction





LIVING WITH MOEBIUS SYNDROME



Focus groups on Moebius syndrome

- 12 adults with Moebius
- 10 teenagers with Moebius
- Discussed social experiences



Bogart, K.R. (2014). "People are all about appearances": A Focus group of teenagers with Moebius syndrome. *Journal of Health Psychology*. Advance online publication.

Bogart, K. R., Tickle-Degnen, L., & Joffe, M. (2012). Social interaction experiences of adults with Moebius syndrome: A focus group. *Journal of Health Psychology*, 17(8), 1212-1222.



Social engagement

- “Moebius is the first thing that people notice.” —Adult with Moebius
- “You talk to someone for the first time, they might look at you kind of strange and wonder why you talk like that, why you look like that.” –Teen with Moebius



Social engagement

- “I figured out that once you’ve known people for a long time they just don’t notice your Moebius Syndrome anymore ... because your personality overshadows everything else physically ... When you first meet someone, all they have to go off of is appearance ... but once they find more things about you then, like, that’s not as significant cause they have other things to replace it.”--Teen



Social engagement

- Proactively manage others reactions:
 - “You’re trying to help them feel more comfortable with who you are. I just remind myself when I’m meeting someone new that maybe they haven’t seen Moebius before and maybe they’re not sure of your intelligence, so you want to stamp that out straight away ... You’re always telling jokes and that is so important to help people relax. I think the other thing is being confident in yourself.”--Adult
- “Don’t be extremely shy because I think it makes you more vulnerable to being teased.”
--Teen

Compensatory expression

- What helps you to express yourself?
 - Voice
 - Gestures
 - Touch
 - Humor
 - Clothing





Resilience

- “It’s good in some ways to have Moebius because it makes you a better person. And I like it because I get to go to the Moebius conference and I get to meet new people.”--
Teen
- One teen joked that “Moebius might be the next stage of evolution of people” because it made him a better poker player.



Prejudice/discrimination

- “Evidence shows that people with Moebius can get hired into jobs and so obviously it’s not a huge negative People can do well in their jobs and there are plenty of people at this conference who show that. I do think that it has happened to me that sometimes Moebius can affect how far you can go.”--
Adult



Being Misunderstood

- “This one joke I always use is that two of the hardest sounds for us to make is the M sound and the B sound. But what do they call the thing that we have?
Moebius, the hardest thing for us to say.”--Adult
- “All the time people say, ‘Are you joking? Are you serious?’”--Adult



Being Misunderstood

- In response to a boy asking what happened to him, the teen explained about Moebius.
- The boy said, “Oh, I thought it was serious like you were gonna die. Well, you’re really nice and people shouldn’t judge you for that.”



Public Awareness

- “It would be cool if there was a Moebius parade ... people holding banners saying “Moebius Syndrome rocks!” ... advertising it like on TV to make us more recognized. Cause then maybe people that don’t know if they have Moebius might figure out that they have it.” — Teen



Focus Group Conclusions

- Interactions generally positive
- Teenage years the hardest
- Struggle to be understood:
 - Speech difficulty
 - Lack of facial expression
 - Lack of public awareness
 - Prejudice



How does Moebius
affect social
interactions?



Do you explain
Moebius to others?



How does Moebius
affect getting a job?



Is Moebius a
disability?



Disability

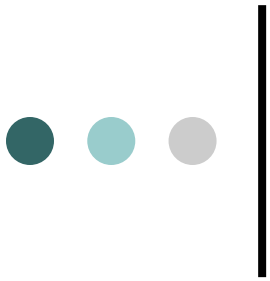
- Legal protections
- Why is disability a bad thing?
- Natural part of human diversity
- Disability community!
- Disability pride!



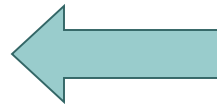
Abbreviated ADA definition

Disability is defined as:

- **a physical or mental impairment that substantially limits one or more major life activities.** Does not apply to impairments that are transitory, with an actual or expected duration of 6 months or less.
 - major life activities include, but are not limited to, caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, **speaking**, breathing, learning, reading, concentrating, thinking, **communicating**, and working.
- **OR being regarded as having such an impairment**



OTHERS' IMPRESSIONS OF PEOPLE WITH MOEBIUS



First impressions

- Universal communication



- Thin slice studies find that people can accurately recognize emotion and personality from video clips as short as 5 s.



First impressions of people with facial movement disorders

- Videos: people with facial paralysis or Parkinson's disease as short as 20 s.
- Perceivers: healthcare practitioners, students, older adults
- Design: perceivers view videos and rate impressions



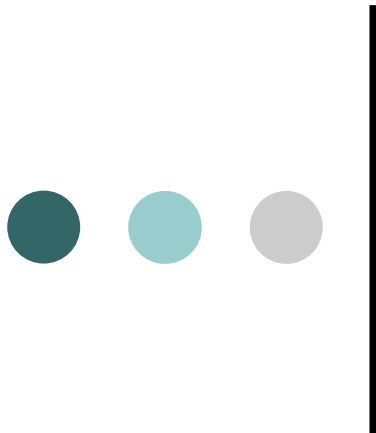
First impressions

- Findings: when rating people with low facial expressivity, perceivers:
 - have less desire to approach & form relationships
 - thought they were less happy and extraverted

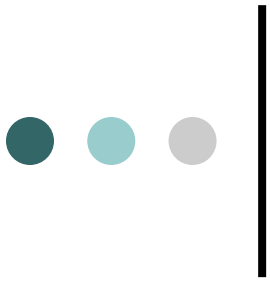


First impressions

- Healthcare practitioners experienced with facial movement disorders had same biases
 - Hard to override natural human tendency
- People who used compensatory expression were rated as happier



Have people formed
inaccurate
impressions about
you or your child?



FACILITATING INTERACTION



**For the person with
Moebius:** social skills
training



For the perceiver:
sensitivity training



Social Skills Workshop for People with Moebius

- Social skills study for teens at this conference
- Check website for updates



Training people to see beyond facial paralysis

- 67 undergrads assigned to:
 - Education
 - Control
- Thin slice extraversion rating study



Summary of education

- Symptoms of facial paralysis
- The perspective of a person with facial paralysis: “Try as I might, I can’t move my face to reflect my state of mind. I often appear unfriendly on the outside while actually smiling on the inside.”
- Override tendency to base impressions on face
- Focus on compensatory expression



Training people to see beyond facial paralysis

- Participants in the education condition rated people with facial paralysis as more extraverted
- Next steps: informational pamphlet for healthcare practitioners and educators



What do you think
can be done to
improve interactions?

Conclusions



- Social functioning is a challenge for people with Moebius
- People with Moebius are often resilient and have strategies for social success
- People interacting with them can learn to look beyond the face to improve their impressions

Acknowledgements

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● ● ● | Thanks to the Moebius Community!





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