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“People are all about appearances”: A focus group of teenagers with Moebius Syndrome

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### **Abstract**

This focus group study examined the social experiences of 10 adolescents ages 12-17 with Moebius Syndrome, a rare condition involving congenital facial paralysis. Content analysis revealed five themes: social engagement/disengagement; resilience/sensitivity; social support/stigma; being understood/misunderstood; and public awareness/lack of awareness of Moebius Syndrome. Compared to previous research on adults with Moebius Syndrome, adolescents were more likely to experience bullying and social strain. Like adults, teenagers displayed resilience and communication skills. Greater public awareness is key to reducing the stigma associated with this condition, and social skills programs should be developed to support those who struggle with social functioning.

### **Keywords**

Moebius Syndrome, facial paralysis, stigma, adolescence, rare diseases

**“People are all about appearances”: A focus group of teenagers with Moebius Syndrome**

In addition to the usual developmental tasks of adolescence, including becoming independent from one's parents, fitting in with peers, and dating, teenagers with Moebius Syndrome, a rare condition resulting in facial paresis or paralysis, face challenges due to their unusual appearance, rare disability, and communication impairments (Briegel, 2012). Recently, the first study to examine the experiences of people with Moebius Syndrome during social interaction, which focused on adults, found a constellation of themes, including social engagement/disengagement, resilience/sensitivity, social support/stigma, being understood/misunderstood, and public awareness/lack of awareness of Moebius Syndrome (Bogart et al., 2012b). Although the lack of public awareness about the condition, stigma involved, and speech and emotional expression difficulties presented challenges to adults with Moebius Syndrome, many had an impressive variety of strategies to improve social interaction. Adults with Moebius Syndrome identified the use of compensatory expressive behavior, that is, expressivity in the body and voice to compensate for the lack of facial expression (Bogart et al., 2012a). Notably, many adults remarked that the most challenging time in their lives for social interaction was adolescence, a time when many reported having been bullied. The present study aims to extend this research to examine the social experiences of adolescents with Moebius Syndrome, allowing for developmental comparisons to be made.

**Moebius Syndrome**

Moebius Syndrome is a rare neurological disorder that results from an underdevelopment of the sixth and seventh cranial nerves occurring in an estimated 2 to 20 per million births (Verzijl et al., 2003). Moebius Syndrome is extremely heterogeneous—although the hallmark symptoms are facial paresis or paralysis and inability to abduct the eyes, in some cases, other

associated symptoms are present such as chest wall or limb abnormalities, micrognathia, and strabismus (Briegel, 2006). Although there is a risk of misdiagnosis due to facial and eye movement restriction, intellectual disability, which is usually mild, has been reported to occur among 9-15% of people with Moebius Syndrome (Briegel et al., 2009; Kuklik, 2000), and autism may occur among 0-5% (Briegel et al., 2009; Briegel et al. 2010). All symptoms may vary widely in terms of severity and visibility. Moebius Syndrome is more correctly considered a sequence, indicating that it is a collection of symptoms with potentially multiple etiologies resulting in vascular disruption during early development (Briegel, 2006). Possible etiologies include spontaneous genetic mutation and teratogens such as hypothermia and misoprostol (Briegel, 2006).

### **Stigma**

Stigma was defined by Goffman (1963: 3) as a mark of spoiled identity. Kurzban and Leary (2001) suggested that the evolutionary function of stigma was to prevent people from forming relationships with others who may have genetic disorders, contagious disease, or may not be able to contribute to a social exchange relationship. There are several reasons why people with Moebius Syndrome are particularly subject to stigma (Bogart et al., 2012b). First, their faces, a salient symbol of identity, are visibly different (Goffman, 1963). Second, as the face is the most salient communication channel (Ekman 1986), others may have difficulty recognizing the emotions of people with facial palsy, leading people to make erroneous assumptions that they are not rewarding social interaction partners (Cole and Spalding, 2008). Third, although most people with Moebius Syndrome are able to develop relatively clear speech through speech therapy, some individuals are difficult to understand, further contributing to communication problems (Meyerson and Foushee, 1978). Fourth, rare conditions, including Moebius Syndrome,

may lead others to feel uncertainty and ambivalence during interactions (Bogart et al., 2012b; Joachim and Acorn, 2003). As a result of these factors, people with Moebius Syndrome are sometimes mistaken for having intellectual disability (Bogart et al., 2012b; Briegel et al., 2009). The tendency to stigmatize people like those with Moebius Syndrome is considered an overgeneralization of adaptive behavior, because in modern times this behavior serves no adaptive purpose (Kurzban and Leary, 2001). Certainly, Moebius Syndrome is not contagious and in most cases does not have familial inheritance (Briegel, 2006). Indeed, in modern society, stigmatizing such groups discourages tolerance of diversity.

### **Adolescence and Facial Difference**

Pubertal changes lead to greater focus on appearance in adolescence (Masten et al., 1995). The importance of appearance and fitting in may place teens with Moebius Syndrome at greater risk of social challenges, bullying, and body image issues. Toward middle and late adolescence, dating becomes important, and appearance plays a large role in attraction. Body image is based on the person's perception of how closely his or her appearance matches cultural standards of attractiveness. Adolescents with facial differences recognize the importance of appearance to others and often feel their appearance does not meet expectations (Egan, Harcourt and Rumsey, 2011; Robert et al., 1999).

Adolescents seek independence from their families, and their peers typically become their primary reference group (Smetana, 2006). Although young children with disabilities benefit from socially supportive families (Anderson et al., 1990), unwanted parental social support may threaten a teenager's autonomy and cause social strain, i.e. psychological distress resulting from criticism, unmet expectations, conflict, unwanted help and compromised privacy (Rook, 1990). Strong peer relationships during adolescence serve to bolster competence and self-esteem.

Having even one “best friend” makes teenagers less vulnerable to bullying (Hodges et al., 1999).

Despite all of the challenges of adolescence, teenagers with facial differences often adapt very well. Affected individuals often report similar or better body image, self-esteem, and psychological adjustment, compared to teenagers without facial differences (Berger et al., 2009; Briegel, 2012; Masnari, 2013; Robert et al., 1999). These findings highlight that facial difference is not a uniformly negative experience; it may be an opportunity for individuals to develop coping skills, compensations, and personal growth (Egan et al., 2011). However, research has also identified challenging areas, in particular, stigmatization and bullying. Masnari and colleagues (2013) found that bullying and staring predicted psychological distress and poor health quality of life in children and teenagers with facial differences. The researchers called for in-depth examination of stigmatizing experiences in order to develop interventions to support stigmatized individuals.

Research on adolescents with facial differences has generally focused on burns and clefts, and there has been little quantitative and no qualitative work on Moebius Syndrome. In the qualitative study of adults with Moebius Syndrome, participants emphasized the significance of having a very rare form of visible difference combined with difficulty communicating (via facial expression and speech; Bogart et al., 2012b). This finding suggests that teenagers with Moebius Syndrome may have experiences unique from others with facial differences that merit exploration. Briegel (2012) studied children and teenagers with Moebius Syndrome, 9 to 15 years of age, and found that participants rated themselves as having less anxiety and depression, and normal self-esteem compared to an age matched normative population, but their parents rated them as having more social problems. The purpose of this study was to develop a better understanding of the social experiences of adolescents with Moebius Syndrome.

## **Method**

A qualitative focus group method was utilized. The format was similar to the previous adult focus group study (Bogart et al., 2012b), extending the examination to a different developmental stage.

### *Participants*

Participants were recruited through Moebius Syndrome websites and email lists, the Moebius Syndrome Foundation newsletter, and the Moebius Syndrome Foundation Conference brochure. There were a total of ten participants (7 females and 3 males). Ages ranged from 12-17 ( $M = 14.30$ ,  $SD = 2.06$ ). All self-reported a diagnosis of Moebius Syndrome and were observed to have moderate to severe facial paralysis. Two were observed to have hand anomalies. None were observed to have intellectual disability. Most participants had readily understandable speech; one had moderate speech impairment and one had moderate-to-severe impairment. All participants spoke English as their native language.

### *Procedure*

This study was approved by the Oregon State University Institutional Review Board. Written assent and parent or guardian consent were obtained. The focus group was conducted during the biannual Moebius Syndrome Foundation Conference in Philadelphia, PA, USA. Two psychologists with expertise in Moebius Syndrome moderated the session. One of the moderators (the author) has Moebius Syndrome, which may have increased participants' comfort and trust level. This moderator limited her discussion of her personal experience with Moebius Syndrome during the focus group to avoid influencing participants. The focus group discussion was guided by eight open-ended questions drawn from previous research (Bogart et al., 2012b). Questions asked participants to describe: how Moebius Syndrome affected interactions, how it



affected participation in social activities and clubs, how it related to dating experiences, how it affected experiences with medical professionals, positive and negative experiences with Moebius Syndrome, how they chose to discuss it with others, and how they coped with it. Participants were told that there was no right or wrong answer to the questions, and that they were encouraged to share their opinion, even if it differed from others.

### *Analysis*

The discussion was audiotaped and later transcribed. As in the previous study, the transcripts were analyzed using conventional qualitative content analysis (Hsieh and Shannon, 2005). Codes and themes generated from the previous study were used as a starting point, from which codes were modified and added. Data were organized using the software program NVivo 9 (2010). Two researchers (the author, who was a moderator for the focus group, and a research assistant, who was not present at the focus group) analyzed the transcript by assigning codes to information units, finding themes that represented broader concepts, and categorizing each code under a theme. Researchers completed each step independently, then discussed and resolved discrepancies.

### **Results**

The codes and themes developed in the analysis of the adult focus group mapped onto the data from the present study well. Three additional codes emerged: positive outlook, social strain, and aggression. One code, discrimination, was used in the adult study, but was not used in the present study. See Table 1 for themes and codes.

INSERT TABLE 1 HERE

### *Social engagement/disengagement*

Social disengagement involved hesitancy and discomfort interacting socially. Participants

agreed that strangers noticed Moebius Syndrome right away. “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.” Several participants confided that they felt they were too shy. They feared being misunderstood and were insecure initiating conversation. One teenager cautioned against this: “Don’t be extremely shy because I think it makes you more vulnerable to being teased.”

Social engagement involved approaching and interacting with others. To avoid potentially negative first impressions, one teenager suggested: “Show the person behind the Moebius...Just have a conversation with them, just...talk about who you are,...they’ll know that you’re not that [different].” Another said:

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.

Outgoing and engaging behaviors were emphasized. “When you go up to someone, don’t be afraid to make eye contact and really socialize.” Participants compensated for facial paralysis by “expressing yourself, [using] tone of voice and your body language.” Extracurricular activities and club involvement brought peers with similar interests together. “It helps you meet new people and it’s really fun!”

#### *Social support/stigma*

Most participants reported prejudice and bullying including episodic and on-going name

calling, harassment, and social exclusion. One participant felt she was excluded by her classmates because “people [at my school] are all about appearances and stuff...I haven’t had a boyfriend yet, but I’ve been asked out, but it was a joke. They didn’t really want to go out with me.” Participants dealt with bullying differently. Some ignored or “brushed it off.”

[Bullies] kind of like the feeling of being insulting to somebody and to see them get angry...so if you don’t talk to them or even look at them, then they’ll lose that enjoyment of being rude to you and then stop it.

Explaining Moebius Syndrome was sometimes helpful. “I think when I was younger I would just ignore it but now that I’m older, I feel like I should explain [Moebius], and that’s what I do.” One teen considered responding aggressively, saying “Look buddy, back off” and, then, like, scare him,” but had not actually acted upon this idea.

Supportive friends defended against bullying. “I had a lot of friends and...I had a lot of support, so...whoever tried to knock me down, all my friends would support me and be like ‘Hey, that’s not cool.’” However, at least one participant lamented that she did not have friends to stick up for her.

Social strain was common. Unwanted help from parents diminished teenagers’ sense of control and self-efficacy. One participant’s mother had pressured her to visit a doctor for her hand abnormality, though the participant didn’t perceive the need. Reportedly, the doctor encouraged medical intervention during the consultation, but the teenager disagreed. Similarly, some teens resented that their parents required them to educate classmates about Moebius Syndrome. “[I had to] get up in front of the class and like do this whole PowerPoint...till 5th

grade. And then in 6th grade I had to go up in front of all the teachers and principal and explain it.”

Some had negative experiences with medical professionals. “I went for the smile surgery and...it didn’t work and it took like 16 hours. Then I was in the hospital for a month getting blood work every 6 hours. So...I really hate doctors.” He appreciated that his parents had let him make the decision to have the surgery, and he did not regret it.

Social support involved trusting and feeling valued by friends, family, and professionals. Several participants expressed trust and gratitude for doctors and speech therapists who had helped them. “I used to have trouble pronouncing words, so I got a speech therapist, and look at me, I can speak fine now!”

Although most participants had not yet begun to date, two described positive relationships. One told her boyfriend about her insecurities about her voice: “I’m so weird and...my voice is weird,” and he told her ““No, I like your voice!’ He treated me like anyone should treat anyone in a relationship so...it was just a regular experience for me.” Another participant asked his girlfriend what she liked about him, and she said ““well you’re attractive, but you have a good personality. You’re not shy, you’re really confident.’ And...every girl in my class and grade are like ‘Oh my god, your hair!’”

The Moebius Syndrome Conferences were a source of support. “I enjoy going to the conferences and meeting new people.” One participant commented that the focus group session itself was supportive. “This session has been really great cause...people got to share each others’ personal experiences and... then others got to connect with those experiences and share those.”

#### *Resilience/sensitivity*

Sensitivity involved internalizing stigma and having low confidence. One participant

shared that her friends often tease her, and she laughs along with them even though she feels like crying. On the other hand, resilience involved not taking others' negative reactions personally, and "staying positive." Several tried not to let bullying bother them. "I've been bullied and yes people say stuff but... I've kinda pushed it out of the way." Others emphasized that it is the other person's loss if they reject them. "I would just say, 'be yourself.' If they accept you, then they accept you, and if they don't, then they don't." Participants took strength from their skills: "I'm pretty confident about myself... I love music, it's like my passion. So I do marching band and band and all that...I don't really think [Moebius limits us]. I mean..., we have it, but it's like nothing's really wrong with us. Like most people, we can pretty much do anything."

Many used positive reappraisals to describe their experiences. "I've had, like a lot of us had, a lot of trauma and...a lot of experiences because of Moebius, but that made us stronger and made us who we are right now. So I'm actually lucky I have it." Another teen agreed. "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." One participant joked that "Moebius might be the next stage of evolution of people" because it made him a better poker player.

### *Being understood/misunderstood*

Being misunderstood distressed and limited some. "I don't talk much in clubs 'cause they won't be able to understand what I have to say, so I keep to myself." On the other hand, being understood meant having others understand their emotions and speech and "see beyond the Moebius." For example, one participant "won over" and befriended a bully.

[The bully said] 'You're retarded' and I was like, 'Not really,' and I defended myself,

and then it's ironic because we started talking and 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.'

Although people with Moebius Syndrome are at risk for having their emotions misunderstood, several teens felt that they could express themselves effectively with compensatory expression.

My teacher and her assistant said that when they look at me they don't see that I can't smile because I 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. They can tell when I'm upset, or angry, or happy or whatever.

#### *Public awareness/lack of awareness of Moebius*

Participants had mixed opinions about whether to tell others about Moebius Syndrome. Some did not discuss it even with their closest friends. "I have it but I didn't tell anyone about it for a long time." "Not a whole lot of my friends know I have it. They know I have something, but they don't straight up ask me. If they did I would gladly tell them I have it and what it is."

One participant was concerned that greater awareness would bring stereotyping and labeling. "Everyone knows about, like, Down's Syndrome and they know 'Oh, well he's this, so he's not normal.' They say might judge you like, 'Oh, he has Moebius so don't talk to him.'"

Others found telling others about Moebius Syndrome was useful. One participant told a story about a boy he had just met. "[The boy asked] 'what happened to your neck' because of the

[surgery] scars.” He explained about Moebius Syndrome, and 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.” This quote illustrates how others may not know what to make of Moebius Syndrome at first. In this case, the person was concerned, and once the condition was explained, he expressed relief.

I tell basically my friends ...and sometimes newer friends that I meet, because they ask me why my face doesn’t move...It’s good to explain because then more people will know that you have Moebius and they’ll spread on and on and on, and then sooner or later a lot of people will know you have Moebius.

For my biology class, we had to do a presentation, so I did one on Moebius, and I described it, and I think it was really good, because I haven’t really told people about it. They all said they really liked it. I feel like they were probably wondering but didn’t want to ask me, so it was really good for them.

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

## **Discussion**

The social experiences of teenagers with Moebius Syndrome replicated the themes found

in an adult sample: social engagement/disengagement, resilience/sensitivity, social support/stigma, being understood/misunderstood, and public awareness/lack of awareness of Moebius Syndrome (Bogart et al., 2012b). Several new concepts emerged from the teenagers' conversation: social strain, aggression, and positive outlook. Additionally, the topic of "discrimination," was present in the adult focus group, but did not appear in the current study. Each of these findings will be discussed in turn.

Participants in this study experienced social strain when parents and medical professionals offered unwanted help or treatment (Rook, 1990). As adolescence is a time in which people experience burgeoning independence, navigating a disability in this transitional period may be difficult (Anderson et al., 1990). Parents may be accustomed to helping their children manage symptoms and explain Moebius Syndrome to others and may resist transitioning responsibilities. There are surprisingly few studies of social strain among adolescents with disabilities. Future research should explore these potentially important and widespread concerns.

Aggression and positivity were discussed in the context of being bullied. Indeed, in the adult focus group, participants reported that bullying was at its worst during adolescence (Bogart et al., 2012b). Bullying was very much an active issue for the teens in this study, and they had a variety of responses to it. Some ignored it and tried not to take it personally. Others took a more active approach, explaining Moebius Syndrome to others. Several participants reported having friends that would stand up to bullies, a well-known protective factor (Hodges et al., 1999). Unfortunately, not all participants had friends like these. One teen considered responding aggressively to bullies but decided against it. Positivity may have been a coping strategy used in response to these challenges, and it is a source of resilience in individuals with facial differences



and the general population alike (Egan et al., 2011; Meyerson, 2001).

Finally, the topic of discrimination found in the adult sample, which was operationally defined as prejudicial treatment aside from bullying, was not present in the current study. Note that this does not mean that participants in the present study experienced less stigmatization; rather, the type of stigmatization reflected participants' life stage: teenagers experienced bullying, while adults experienced job-related discrimination.

Participants had a number of positive experiences and strategies. Many were outgoing and actively socially engaged, seeking out clubs of interest. They reported successfully using compensatory expressive behavior. A couple of participants had already been in healthy dating relationships. These individuals received reassurance about their attractiveness and value from partners. For one participant, an aspect of herself that she disliked, her voice, was something that her boyfriend admired. As many adults with Moebius were engaged in rewarding relationships (Bogart et al., 2012b), teenagers with Moebius can likely look forward to this as well.

#### *Methodological considerations*

The focus group was held at the Moebius Syndrome Foundation Conference because it was the only feasible way to assemble a group of individuals with this very rare condition. Thus, the sample is limited in that only teenagers with the interest and ability to attend the Moebius Syndrome Foundation Conference could participate. The goal of qualitative research is not to collect a representative sample, but rather to richly describe experiences. The fact that the focus group was held at the conference may have been a boon: participants' experiences with Moebius Syndrome may have been salient, and they may have felt particularly comfortable discussing them in the context of the gathering. A promising area for future research may be comparing the experience of people who do and do not attend the Moebius Syndrome Conferences. Another

limitation is that there were more female than male participants, so results are more likely to reflect the experience of adolescent girls than boys. Perhaps girls were more likely to feel comfortable discussing social issues in a focus group format.

### *Implications*

Participants emphasized that their challenges with Moebius were primarily due to others' perceptions of them. People with Moebius syndrome are usually able to manage functional limitations associated with the condition (e.g. dry eye, eating, speaking), so Moebius Syndrome is a prime example of how disability is primarily socially constructed. Thus, ideally, stigma reduction should happen at the societal level through awareness and positive exposure. Remarkably, adolescent and adult focus group participants alike spontaneously suggested having public awareness campaigns for Moebius Syndrome (Bogart et al., 2012b). Spreading awareness can serve to stamp out misconceptions about Moebius Syndrome and provide guidance to others on how to interact and attend to compensatory expressive behavior. Efforts such as the awareness parade suggested by one participant could be focused on Moebius syndrome specifically, but may be more practical as broader scale campaigns for people with facial difference or disability in general. Such efforts are an empowering way for individuals with disabilities to take control of public opinion and feel pride, rather than shame, for their identity and community. Indeed, the concept of disability pride has been espoused by disability studies scholars and activists as a way to reduce stigma (Zola, 1993), and several disability pride parades have been held worldwide.

Even with the most successful acceptance campaigns, practically speaking, individuals with Moebius Syndrome will always encounter people who are unfamiliar with it, and they will be tasked with managing their impressions. Moebius Syndrome is so rare that, although others

will notice it, they are unlikely to understand the nature of the condition, and they may mistake the person for being unfriendly, sad, or intellectually disabled. A remarkably common concern that arises among participants in qualitative studies of Moebius Syndrome is whether or not to discuss the condition with others. Some people with Moebius Syndrome reported not mentioning it to even close friends or partners of many years, while others discussed it with people they were close to (Bogart et al., 2012b; Meyerson, 2001). The shame felt by some individuals with Moebius Syndrome can inhibit related discourse. Certainly, people with Moebius Syndrome should not feel obligated to tell everyone they encounter—doing so would be a burden on one's privacy. However, explaining one's condition to significant people such as teachers, friends, and potential romantic partners can increase understanding and awareness (Egan et al., 2011).

Although some teens with Moebius Syndrome feel they are doing well socially, stigmatization has been linked to psychological distress among teenagers with facial differences (Masnari et al., 2013), so interventions should be developed for those who feel they need support. No intervention specifically designed for people with Moebius Syndrome or facial paralysis exists. The United Kingdom charity Changing Faces offers a widely-used social skills program for people with facial differences (Blakeney et al., 2005), which could be adapted specifically for persons with facial paralysis. Drawing from the issues raised by teens during the focus group, an intervention should offer practical help in dealing with bullying, support the use of compensatory expressive behavior, and help teens effectively negotiate speech communication problems. As social strain was a concern for some participants, some families may benefit from an intervention or counseling to help them transition management of Moebius Syndrome from the parents to the teenager.

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**Table 1.** Continuum of Themes and Codes Representing the Social Functioning Experiences of Teenagers with Moebius Syndrome

Theme	Positive Side of Continuum	Negative Side of Continuum
Social Engagement/Disengagement	Assertiveness Compensatory expressive strategies Managing others reactions Outgoing and engaging Show the person behind the Moebius	Passiveness Aggressiveness Avoidance
Resilience/Sensitivity	Confidence Competence/skill Not letting others' negative reactions affect me Persistence Moebius doesn't affect me Positive outlook	Low confidence Others' negative reactions affect me
Social Support/Stigma	Family or friend support Medical or institutional support	Bullying Facial Difference Prejudice Social strain
Being Understood/Misunderstood	Understood Others see the person behind the Moebius	Misunderstood Speech difficulty Emotional communication difficulty
Public Awareness/Lack of Awareness of Moebius	Disclose and educate about Moebius	Lack of public awareness of Moebius Not acknowledging Moebius Others don't know how to behave Perceived as having an intellectual disability