

Social Interaction Experiences of Adults with Moebius Syndrome: A Focus Group

The Faculty of Oregon State University has made this article openly available.
Please share how this access benefits you. Your story matters.

Citation	Bogart, K. R., Tickle-Degnen, L., & Joffe, M. (2012). Social interaction experiences of adults with Moebius syndrome: A focus group. <i>Journal of Health Psychology</i> , 17 (8), 1212-1222. doi:10.1177/1359105311432491
DOI	10.1177/1359105311432491
Publisher	SAGE Publications
Version	Accepted Manuscript
Terms of Use	http://cdss.library.oregonstate.edu/sa-termsfuse

Social Interaction Experiences of Adults with Moebius Syndrome: A Focus Group

Kathleen Rives Bogart and Linda Tickle-Degnen

Tufts University

Matthew S. Joffe

LaGuardia Community College/City College of New York

Published in: 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. doi: 10.1177/1359105311432491

Acknowledgements

This work was partially supported by a US Moebius Syndrome Foundation research travel grant. We thank: the US Moebius Syndrome Foundation for allowing us to conduct the focus group at their conference and for providing research travel funding; Sarah Porter for assistance with data collection; Kathryn Chaimov, Susan Hernandez, Shayna KokEnnen, and Emily Krull for assistance with data analysis; Gary Bedell for comments on earlier drafts of this article.

Abstract

This focus group study explored the social interaction experiences and strategies of 12 adults with Moebius syndrome, a rare congenital condition characterized by facial paralysis. Content analysis revealed five themes of social functioning: social engagement/disengagement, resilience/sensitivity, social support/stigma, being understood/misunderstood, and public awareness/lack of awareness of Moebius Syndrome. Participants used compensatory expressive strategies such as vocal tone, gestures, and humor. The combination of being unable to express oneself with the face, having a facial difference, and having a rare disease is particularly stigmatizing. Increasing public awareness and developing social skills programs for people with facial paralysis could facilitate social functioning.

Keywords

Moebius Syndrome; facial paralysis; emotional communication; stigma; resiliency

Social Interaction Experiences of Adults with Moebius Syndrome: A Focus Group

People with Moebius Syndrome (MoS), a rare condition characterized by facial paralysis, report difficulty with social functioning, likely due to their difficulty communicating with the face (Bogart and Matsumoto, 2010; Briegel, 2007). Facial expression is crucial for emotional communication, social connectedness, and rapport (Ekman, 1986; Tickle-Degnen, 2006). However, people with MoS can use their bodies and voices to compensate somewhat for their lack of facial expression. Little research has addressed the actual experience of people with MoS during interaction and ways they compensate to improve it. This paper reports qualitative results from a focus group of people with MoS about their social interactions.

MoS is a congenital, nonprogressive condition characterized by bilateral facial paralysis and an inability to move the eyes side to side (Briegel, 2006). It is very rare, occurring in 2 births per 100,000 (Verzijl et al. 2003). There are a range of associated symptoms that may occur, such as limb malformations and muscle weakness. Speech difficulty and drooling resulting from paralyzed lips and weakness of the tongue is common (Briegel, 2006). After speech therapy, most are able to produce understandable speech (Meyerson and Foushee, 1978). MoS is formally considered a sequence, indicating that it can occur with a wide variety of symptoms (Briegel, 2006) and different challenges that may affect appearance, communication, and physical function.

The face of a person with MoS is visibly different¹ in motion and at rest due to lack of muscle tone, wrinkling, and facial expression. The eyes and lip corners may droop, resulting in the appearance of a frown, when ironically, no expression can be formed. MoS has commonalities with other visible differences in which there is distortion of facial features, skin,

¹ 'Facial difference' or 'visible difference' is the term preferred over 'disfigurement' because it is less negative.

or muscles may impair the ability to produce recognizable facial expressions (such as hemifacial microsomia or facial burns).

Studies of facial paralysis and visible difference, which have been mostly comprised of participants with acquired conditions, show that these individuals have high incidences of depression and anxiety (e.g. Rumsey et al., 2004; VanSwearingen et al. 1998; 1999). Yet people with congenital conditions, who have been living with and adapting to their conditions all of their lives, may be better adjusted than people with acquired conditions, who had to relearn to function. Bogart and Matsumoto (2010) compared 37 Americans with MoS to 37 matched controls without facial paralysis and found no differences between the groups in depression or anxiety, but those with MoS scored lower on a social functioning scale. A study of 22 Germans with MoS found significantly higher levels of introversion and interpersonal sensitivity (feelings of inadequacy and inferiority) compared to normative data (Briegel, 2007). Levels of anxiety and depression were nonsignificantly higher than normative data. Although Briegel (2007) concluded that people with MoS have increased levels of anxiety and depression, their results are not necessarily incompatible with those of Bogart and Matsumoto (2010). Both studies found social functioning problems and no statistically significantly increased levels of anxiety and depression in MoS. Possible differences in results could be attributed to differences in sample size, measures, or cultural differences in disability stigma (Yang et al., 2007). Combined, these findings suggest that some people with MoS may have developed strategies to manage their lives and psychological distress more than individuals with acquired conditions. However, they may not be able to avoid some social ramifications, such as stigmatization. Thus, interaction may be one of their most significant challenges.

Goffman defined stigma as 'the process by which the reaction of others spoils normal identity' (1963: 3). People who are stigmatized are subject to negative reactions, prejudice, and discrimination (Elliott et al., 1982). Elliott and colleagues (1982) suggested that stigma leads people to judge others as illegitimate interaction participants because they lack the abilities to carry on an interaction, behave unpredictably, or are a threat to others or to the interaction. People with MoS may be stigmatized because their lack of facial expression make them incorrectly appear to lack interaction skills, be intellectually incapable of reciprocating interaction, unpredictable, or even contagious, due to the perceivers' lack of knowledge about causes of facial differences.

Joachim and Acorn (2003) suggested that the rarity of a condition contributes to stigma because it is associated with public misunderstanding, fear, and ignorance. In a focus group of people with scleroderma, a rare disorder of the connective tissue which sometimes results in visible difference, Joachim and Acorn (2003) found the combination of visible difference and disease rareness was particularly stigmatizing because individuals had the additional burden of having to explain themselves to others, and because others didn't know how to behave around them.

Rumsey and Harcourt (2005) suggested that visible difference should not be viewed as a solely negative experience—to do so is pathologizing—and encouraged researchers to identify sources of resiliency. Through focus groups and interviews with resilient individuals with visible difference, Egan et al. (2011) found themes of importance of appearance, personal growth, relationships with others, and coping. Similarly Meyerson (2001) examined resiliency and success in adults with MoS and identified factors leading to resiliency and success: humor,

determination to surpass others' lowered expectations of them, sense of self, special skills, family support, networking, and faith.

Study Overview and Purpose

Although people with MoS may have difficulty with social functioning (Bogart & Matsumoto, 2010; Briegel, 2007), the few existing studies have not provided insight into their specific social interaction challenges, experiences, and strategies. The purpose of this study was to explore, from the perspective of individuals with MoS, their experiences with and strategies for social interaction. Focus groups and qualitative research are a useful first step in building a new research area (Vaughn et al., 1996).. The interactional nature of a focus group has the potential to elicit information that could not be obtained from an individual interview (Vaughn et al., 1996). Participants can build upon others' statements, be socially supported, and learn from each other.

METHOD

Participants

Participants were recruited with notices in the Moebius Syndrome Foundation Conference brochure and website. Inclusion criteria were as follows: 18 years or older, diagnosis of MoS, and ability to hold a comprehensible conversation in English. The ideal size of a focus group is approximately 12 or less to ensure that everyone can participate and reach sufficient depth of discussion (Vaughn et al., 1996). Thus, we limited participants to the first 12 individuals to qualify and agree to participate. Participants were 6 women and 6 men. Their age range was 18-60 (mean age = 41 years). Ten were Caucasian and 2 were Hispanic/Latino. Ten participants were from the US, one was from Canada, and one was from the UK. Participants reported a range of occupations including: teacher, accountant, clerk, homemaker, retired, and student. All

were observed to have moderate to severe facial paralysis. Two participants reported having facial reanimation surgery which gave them a limited ability to form a social smile, but no other facial expressions, although performance of this smile is usually effortful and not spontaneous (Zuker et al., 2000).

Procedure

This study was approved by the Tufts University Internal Review Board. By signing the informed consent form, they agreed to keep information shared in the focus group confidential. The focus group lasted 90 minutes and was held at the biannual Moebius Syndrome Foundation Conference in Broomfield, CO, US. There were two moderators, both of whom have MoS (the first and third authors). The moderators did not discuss their own experiences with MoS to avoid influencing participants. A research assistant, who did not have MoS, was also present to assist with administrative tasks. Participants completed a short demographic form before beginning the focus group discussion. There were 7 open-ended questions to guide the discussion, which were chosen based on literature review and the researchers' expertise with MoS. The discussion was audiotaped and subsequently transcribed to accurately record participants' responses. A researcher mailed a summary of findings to participants three weeks after the focus group and asked if there was anything they would like to add. Five participants responded, indicated their agreement with the summary and did not have additions.

Analysis

The transcripts were analyzed using conventional qualitative content analysis (Hsieh and Shannon, 2005). This method is ideal for use when there is little existing theory or research in an area. The software program NUD*IST Vivo 1.2 (1999) was used to assist with analysis. Five independent coders (the first author and four occupational therapy graduate students) analyzed

the transcript in an iterative process, which involved developing codes to represent key ideas in the transcript, finding themes that represented broader ideas, and finally, categorizing each code under a theme. Coders completed each step independently first, and then discussed their findings as a group until an agreement was made.

RESULTS

Analysis identified five themes describing the social functioning experiences of people with Moebius, each of which represented a continuum of positive and negative aspects: resilience/sensitivity, social engagement/disengagement, social support/stigma, being understood/misunderstood, and public awareness/lack of awareness of MoS. Table 1 shows themes and their corresponding codes.

INSERT TABLE 1 ABOUT HERE

Social Engagement/Disengagement

Participants felt that MoS played a salient role in social interaction when meeting someone new: ‘Moebius is the first thing that people notice.’ ‘I always think that there is a moment of hesitation when I start talking to people. They are listening but they are thinking, “Why is she talking like that?”.’

Sometimes others didn’t know how to interact with them and the interaction was uncomfortable for everyone involved. Depending on the situation, some participants responded with avoidance and passivity: ‘In this room I feel comfortable talking but if this was at school, I wouldn’t. I would sit here and I wouldn’t say anything. So it depends who you are talking to.’ However, participants felt their interactions were usually positive, particularly with people who were familiar with them, such as friends and family: ‘People notice it, but I have a normal

conversation afterwards.’ They listed a variety of expressive strategies to compensate for their lack of expression, which are shown in Table 2.

INSERT TABLE 2 ABOUT HERE

Many participants used their social skills to proactively manage other people’s impressions and reactions to them:

I have come to realize that you actually need to manage the reactions of the people that you’re talking to. 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... The more you do it, you kind of need to practice it and when you get a good response you think “ah, that worked. I’ll use that again.” Then you build up like a repertoire of different tools that you can use.

Participants felt it was important to ‘show the person behind the Moebius’: ‘You want to show them actually who you are and what your personality is and what you like, so you actually take them past the Moebius to help them see you as a person.’ Approximately half the group mentioned facilitating social interaction by being outgoing and engaging. For example, one man suggested starting conversations by talking about pop culture, a topic he found many people will readily discuss. One woman said:

For me it’s talking about something that I know about. So if you can be knowledgeable or interesting or funny, then that helps them see past the Moebius and actually see you as

having something to say that they might be interested in. I remember when I was younger, I was probably like quite a lot of you, quite shy. I started by asking people questions, because I worked out if you asked a question, you could get the other person to talk and you don't have to talk. Then, as the more confident I became, I found that I did have something to say.

Resilience/Sensitivity

Resilience/Sensitivity was a dimension of inner strength when faced with challenges in various life roles. Some exhibited low confidence in certain situations: 'I do have some kind of lack of confidence when I don't know people.' This was particularly marked in the realm of romantic relationships, perhaps due to the stigma associated with facial difference: 'I just assumed that no one would really be [romantically] interested in me.'

On the other hand, many participants were resilient; they displayed confidence, persistence, competence, and an attitude of not taking others' negative judgments personally and not letting MoS limit them: 'I think one important thing is being confident in yourself. Getting really hard [tough] so when you get these people who are, let's say, less than polite, that you realize that it's not your problem, it's their problem.' Having competence and skills took the focus away from MoS and gave participants something valuable to contribute to an interaction:

The only way to be successful at this job was to forget that I had Moebius, and once I was able to do that, I noticed that nobody else was worried that I had Moebius. Most people didn't care because we were serving each other and all we cared about was getting the job done. So in terms of being successful I guess I can say that I was successful in all the jobs I had.

I've liked doing different volunteer work but it always involves...establishing who you are with new groups of people. And in that case you're volunteering to do something, you're showing you can provide a service. So, it seems easier that way, you're all there to do the same thing and to help, a group effort.

Some people felt it was important not to let MoS limit them: 'I just go talk to people. I don't let Moebius limit me. I just go out and do stuff.' Another participant said: 'Now the only time I know I have Moebius is when I look in the mirror. So just forget about it, act like everybody else does.'

Social Support/Stigma

People reported experiencing social stigma in the form of prejudice, discrimination, and bullying. Many people experienced teasing when they were children, which led to low-self esteem when they were younger: 'When I was a kid people used to say, "oh you're retarded," or, "you look like a buck-toothed beaver."' Many felt that their interactions and confidence improved significantly in adulthood.

Several noticed children staring at them, which made them feel uncomfortable and reminded them that MoS was readily apparent. One participant suggested waving or saying 'hi' to the child to show him or her that he noticed the staring. Another suggested interacting with the child to educate him and show him that he was a normal person.

Several reported being avoided by others: 'I sat on a train recently and a lady looked at me a few times and then she moved away.' Participants encountered someone who would not directly address them, and instead addressed someone else they were with. During this situation,

one woman firmly addressed the person and said: 'You can talk to me, please.' Another woman said:

I was in a store at the mall and there was a lady passing out some kind of sample to everyone but me.... I walked by her several times and she never once looked at me. Normally stuff doesn't upset me but that just upset me so bad because I thought this woman is just acting like I'm nobody, I'm not here.

Many participants were professionally successful: 'We can succeed. It can be a huge obstacle in our way, so we just have to kick it aside.' However, many experienced subtle or overt discrimination from employers at some point. One man felt that subtle discrimination was at play when he didn't get a promotion for which he was qualified:

Evidence shows that people with MoS 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 MoS can affect how far you can go.

He pointed out that people with MoS can offer a diverse perspective to employers: 'I work a lot with employers and help them see that they lose out by not having us because we have a lot to give. We represent a diverse society and we should be there, everywhere, at all levels.'

On the other end of the continuum, social support took the form of support from family, friends, medical professionals, and organizations. One man who experienced hiring discrimination because he had MoS and was also an ethnic minority benefitted from an organization that helped people with disabilities find employment. Several were appreciative of the speech therapy they received as children: 'I had to go through speech therapy and it's

probably a good thing I did because if I had not gone, there might be a whole lot more people that wouldn't understand what I was saying.'

Being understood/misunderstood

Feeling misunderstood and seeking understanding was a central theme in the discussion.

The most common concern was others' difficulty understanding their speech:

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.

At a fast food place, I told [the cashier] what I wanted and she didn't understand so she asked again and I told her and she didn't understand. She turned around and walked off....She got someone else to help her and then they finally got it, but it was embarrassing.

Another aspect of being misunderstood was people misunderstanding their emotions, personality, or intent due to their lack of facial expression: 'People don't know if you're kidding, all the time people say, "Are you joking? Are you serious?"'

On the other end of the continuum, people felt understood when others were able to comprehend their speech and: 'see the real person behind the Moebius.' One man appreciated: 'people who see me for who I am and they can understand me clearly and they just see me, Mike², the person, instead of Mike, the person who has something wrong with him.' Several participants commented that they felt most comfortable and understood with family, friends, or other people with MoS.

² Pseudonym

Public awareness/lack of awareness

Related to a feeling of lack of understanding, the lack of public awareness about MoS was a significant concern. Most people have not heard of MoS and although they notice that a person with the condition looks and speaks differently, they do not know why: '[Strangers] don't know what they're seeing or they don't know how to behave.' Because the face is visibly different and not responsive, many mistake people with MoS as having an intellectual disability: 'People think I have mental retardation.'

Many participants were frustrated with the lack of public awareness about MoS:

They do a lot of run-a-thons for cancer and other common diseases. But not once have I heard on any radio stations or read in the newspaper or on the internet anything about Moebius. I think the news should get out to the public so people like us don't have to confront somebody that has to look at us for five minutes to try to figure out who the hell we are.

The fact that others are not likely to be familiar with MoS provoked a dichotomy amongst participants about whether or not to explain MoS. Several took a proactive strategy by educating new people, which made both parties more comfortable and got rid of the 'elephant in the room':

When I was a nurse and I was starting a new job at a nursing unit, we were used to having educational conferences about different things, so I decided to do one on Moebius. It was well-received. People were happy to get their questions answered. It seemed to break the ice.

When I'm teaching a new class, I spend about ten minutes talking about Moebius and what it is and why I look different and so on. I think what makes it successful is people respect the fact that you're not trying to hide or pretend, because they can see that I look different. I always say to them, "look, you're all too polite to say so, but you all can tell that I talk a little bit different, I look a little bit different. So here's what's going on." And I make some jokes...From that point on I don't say a word about it and it never comes up.

Others felt that people should just accept them as they are without requiring an explanation:

I don't explain it. I just let them think what they want. I mean even my [romantic partner of 30 years]...this is the first time we've ever talked about it. I know a lot of people probably won't agree with me, but I think it's rude when people you don't even know ask you about it.

Some felt conflicted, that they should explain themselves when meeting others, while at the same time feeling uncomfortable disclosing such personal information:

I feel that I have to explain myself. I usually don't, but that's the reaction that I get.

When I'm in a family situation, I feel more at ease than when I get in a group or a class or something I feel like I have to explain what is going on.

DISCUSSION

Participants in this focus group reported a variety of experiences with and strategies for social interaction. They felt that their interactions with family members and friends who could ‘see the real person behind the Moebius’ were positive but reported some negative experiences when meeting new people, a time when people are more focused on superficial information. Among their strategies to facilitate social interaction, the compensatory expressive strategies described in Table 2, such as using tone of voice, gestures, and speaking clearly, were particularly important for social functioning and reducing misunderstandings. Interaction with MoS involves a struggle to be understood on many levels. Barriers to being understood include: inability to form facial expressions, speech difficulty, others’ lack of understanding of MoS, and stigma. Further, there are several reasons why people with MoS are at risk for being stigmatized and judged as illegitimate interaction partners (Elliot et al., 1982): it is a disability, the face is visibly different, the public is ignorant about it, and the face is inexpressive, restricting the individuals’ ability to communicate, and giving the person the appearance of a lack of emotion or intelligence.

The lack of public awareness about MoS was particularly concerning to participants. As described in Joachim and Acorn’s (2003) focus group study of scleroderma, having a condition so rare that people do not understand one’s appearance or know how to interact is particularly stigmatizing. When people encounter someone with a well-known disability, such as mobility impairment or blindness, others are at least able to recognize the nature of the impairment and may have had experience interacting with others with the condition. They may respond with empathy and understanding (Joachim and Acorn, 2003). However, when people encounter someone with MoS, which is not generally understood by the public, they may react negatively because they are unsure how to interact.

Although all participants had symptoms of MoS that were readily apparent, some participants did not explain their condition to others, even close friends or intimate partners. This reticence may be due to shame from internalized stigma. Further, disability often results in a lack of privacy (Olkin, 1999); individuals are unfairly expected to provide personal information about their condition to strangers. On the other hand, people with MoS seek to be understood and wish for greater awareness of their condition. In line with this goal, several of the participants in our focus group educated people who might play important roles in their lives about MoS—when teaching a new class of students, or when beginning a new job, with close friends—and they reported that they felt more comfortable when they did. Indeed, participants in Egan et al.'s (2011) study on resiliency with visible difference felt they could reduce the stigma of their condition by talking about it openly. In Meyerson's (2001) study, all 18 participants encouraged being open and honest about MoS.

It is noteworthy that society places the responsibility of adaptation on the individual with MoS. It is up to the individual to put other people at ease, be outgoing and engaging, help them to understand their speech and emotions, and explain MoS. Participants in this study have developed an extensive set of compensations to improve interactions. Most participants felt that their social interactions were usually positive, several mentioned being in loving romantic relationships, and many were successful in their careers. However, the extra effort they must exert during social interaction can be exhausting (Cole and Spalding, 2008). Despite these challenges, people with MoS can have remarkable resilience (Meyerson, 2001). Indeed, they can have the same levels of satisfaction with life, anxiety, and depression as the typical population (Bogart and Matsumoto, 2010).

Advantages and Limitations

Due to the sampling limitations inherent in studying a rare condition such as MoS, only one focus group was held. In order to collect enough participants, the focus group was held at the MoS Conference. This raises the potential for sampling bias, since people with MoS who did not attend the conference for whatever reason (e.g. lack of awareness, lack of interest) could not participate. Further, the very nature of focus groups may attract people who are more socially adapted. The fact that the focus group was held within a conference can also be considered an advantage; the conference may have fostered social support, making people feel more comfortable discussing this sensitive topic, and leading to more in-depth and honest discussions. Acceptance of disability varies across cultures, so it is likely that individuals from other cultures have different experiences and strategies than our mostly American sample. Thus, our findings are not meant to be considered representative of all people with MoS, but rather to represent important dimensions of the MoS experience.

The fact that the moderators of the focus group had MoS themselves may have reduced the power differential issues common to focus groups (Fox et al., 2007), and increased participants' comfort level. Disability activism groups have called for an increase in research *by* people with disabilities *for* people with disabilities (Olkin, 1999). The credibility of the study is increased by the fact that two of the authors have personal experience with MoS.

Implications

According to participants' comments, the primary barriers to social participation for people with MoS are not within themselves, but rather, something that should be addressed by society at large: stigma, lack of public awareness, and others' difficulty understanding their expressions. Several participants called for public awareness campaigns about facial paralysis. Ideally, these campaigns could be directed at healthcare professionals, educators, employers, and

the general public to educate about facial paralysis and guide people to look beyond the facial paralysis and focus on the individual's body language and voice for cues to their emotions. In particular, this could improve healthcare practitioners' ability to recognize the person's emotions or pain and facilitate therapeutic rapport.

However, with a condition so rare, individuals with MoS will always encounter people who are not familiar with it. As such, we recommend that people with MoS take on the responsibility to educate others people who might play important roles in their lives. Educating others gives the person with MoS control over the situation, allows them to manage others' impressions, raise awareness, and can make both parties feel more comfortable (Egan et al., 2011; Meyerson, 2001).

Some of our participants felt a lack of confidence when meeting new people and were frustrated by others' inability to recognize their emotions. In order to support individuals with these concerns, we recommend a social skills training program such as the one provided by the UK charity Changing Faces, a group workshop for people with visible difference involving instruction, modeling, role play, feedback, and group discussion (Robinson et al., 1996). It provides practical solutions to specific issues, such as how to respond to strangers' questions about their condition. A preliminary study suggested that, after participating, individuals felt reduced distress and increased confidence when meeting new people (Robinson et al., 1996). In order to address participants' concerns about others' difficulty recognizing their expressions, teaching the compensatory expressive strategies identified in this research could be a novel addition to a social skills intervention. For example, participants could practice gesturing and verbalizing their emotions during role play. There is a paucity of evidence-based interventions for people with FP or visible difference (Bessell & Moss, 2007). We encourage developing and

testing such an intervention, which could be useful for people with many types of facial paralysis and facial difference, particularly those with acquired conditions who may have difficulty adapting.

FUNDING

This work was partially supported by a US Moebius Syndrome Foundation research travel grant.

REFERENCES

- Bessell A and Moss TP (2007) Evaluating the effectiveness of psychosocial interventions for individuals with visible differences: A systematic review of the empirical literature. *Body Image* 4(3): 227–238.
- Bogart KR and Matsumoto D (2010) Living with Moebius syndrome: Adjustment, social competence, and satisfaction with life. *Cleft Palate-Craniofacial Journal* 47(2): 134-142.
- Briegel W (2006) Neuropsychiatric findings of Möbius sequence: a review. *Clinical Genetics* 70: 91–97.
- Briegel W (2007) Psychopathology and personality aspects of adults with Möbius sequence. *Clinical Genetics* 71: 376-377.
- Cole J (2001) Empathy needs a face. *Journal of Consciousness Studies* 5(7): 51–68.
- Cole J and Spalding H (2008) *The Invisible Smile. Living Without Facial Expression*. New York: Oxford University Press.
- Egan K, Harcourt D, and Rumsey N (2011) A qualitative study of the experiences of people who identify themselves as having adjusted positively to a visible difference. *Journal of Health Psychology* 16(5): 739-749.
- Ekman P (1986) Psychosocial aspects of facial paralysis. In: May M (Ed) *The Facial Nerve*. New York: Thieme.
- Elliott GC, Ziegler HL, Altman BM, and Scott, DR (1982) Understanding stigma: Dimensions of deviance and coping. *Deviant Behavior* 3(3): 275–300.

- Fox FE, Morris M and Rumsey N (2007) Doing Synchronous Online Focus Groups With Young People. *Qualitative Health Research* 17(4): 539 -547.
- Goffman E (1963) *Stigma: Notes on the management of spoiled identity*. New Jersey: Prentice-Hall.
- Hsieh HF and Shannon SE (2005) Three approaches to qualitative content analysis. *Qualitative Health Research* 15(9): 1277-1288.
- Joachim G and Acorn S (2003) Life with a rare chronic disease: The scleroderma experience. *Journal of Advanced Nursing* 42(6): 598-606.
- Macgregor FC (1990) Facial disfigurement: problems and management of social interaction and implications for mental health. *Aesthetic Plastic Surgery* 14(1): 249–257.
- Meyerson M (2001) Resiliency and success in adults with Moebius syndrome. *Cleft Palate—Craniofacial Journal* 38(3): 231-235.
- Meyerson M and Foushee DR (1978) Speech, Language and Hearing in Moebius Syndrome: a Study of 22 Patients. *Developmental Medicine & Child Neurology* 20(3): 357-365.
- Noller P (1985) Video primacy—A further look. *Journal of Nonverbal Behavior* 9(1): 28-47.
- Olkin R (1999) *What Psychotherapists Should Know About Disability*. New York: The Guilford Press.
- QSR NUD*IST Vivo (1999) Software user guide. Victoria, Australia.
- Robinson E, Rumsey N, and Partridge J (1996) An evaluation of the impact of social interaction skills training for facially disfigured people. *British Journal of Plastic Surgery* 49(5): 281-289.

- Rumsey N, Clarke A, White P, Wyn-Williams M, and Garlick W (2004) Altered body image: appearance-related concerns of people with visible disfigurement. *Journal of Advanced Nursing* 48: 443–453.
- Rumsey N and Harcourt D (2005) *The psychology of appearance*. Buckingham, UK: Open University Press.
- Tickle-Degnen L (2006) Nonverbal behavior and its functions in the ecosystem of rapport. In Manusov V and Patterson M (eds) *The SAGE Handbook of Nonverbal Communication*. Thousand Oaks, CA: Sage.
- Vaughn S, Schumm JS, and Sinagub J (1996) *Focus Group Interviews in Education and Psychology*. Thousand Oaks, CA: Sage Publications.
- VanSwearingen JM, Cohn JF, and Bajaj-Luthra A (1999) Specific impairment of smiling increases the severity of depressive symptoms in patients with facial neuromuscular disorders. *Aesthetic Plastic Surgery* 23(6): 416–423.
- VanSwearingen, JM, Cohn JF, Turnbull J, Mrzai T, and Johnson P (1998) Psychological distress: linking impairment with disability in facial neuromotor disorders. *Otolaryngology-Head and Neck Surgery* 118(6): 790–796.
- Verzijl HT, van der Zwaag B, Cruysberg JR, and Padberg GW (2003) Möebius Syndrome redefined. *Neurology* 61(3): 327.
- Yang L, Kleinman A, Link BG, Phelan JC, Lee S, and Good B (2007) Culture and stigma: adding moral experience to stigma theory. *Social Science & Medicine* 64(7): 1524–1535.
- Zuker RM, Goldberg CS, and Manktelow RT (2000) Facial animation in children with Mobius syndrome after segmental gracilis muscle transplant. *Plastic and reconstructive surgery* 106(1): 1.

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

Theme	Positive Side of Continuum	Negative Side of Continuum
Social	Assertiveness	Passiveness
Engagement/Disengagement	Compensatory expressive strategies Managing others reactions Outgoing and engaging Show the person behind the Moebius	Avoidance
Resilience/Sensitivity	Confidence Competence/skill Not letting others' negative reactions affect me Persistence Moebius doesn't affect me	Low confidence Others' negative reactions affect me
Social Support/Stigma	Family or friend support Medical or institutional support	Bullying Discrimination Facial Difference Prejudice
Being	Understood	Misunderstood
Understood/Misunderstood	Others' see the person behind the Moebius	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

Table 2. Compensatory Expressive Strategies

Compensatory Expressive Strategy	Representative Quote or Description
Tone of voice	'I have this theory that my voice is my face. Obviously, we can't express all the emotion that we want to express with our faces, but I'm a really expressive woman. I have loads of emotion inside me and I want people to know if I'm happy or cross or down or whatever it might be. I have learned over the years that because I'm musical I've been able to train my voice to convey the emotion that I want to show.'
Gestures	
Touch	'If you touch them on the shoulder, put your arm around them, or take their hand, they respond better to you. It's that personal closeness I guess.'
Humor	To disarm the other person and show the person behind the Moebius
Props/clothing	One woman who could not smile found that wearing a smiley face pin to compensate led people to respond to her in a friendlier way.
Speak slowly, loudly and clearly	'It's also important to speak in a loud enough voice. When I was young, I was a little bit shy, and sometimes when you're shy, that leads you to sometimes stutter and speak softly. And if you have Moebius Syndrome, to number one, stutter at all and to number two, speak softly, is a killer.'
Verbal disclosure	'It helps to articulate how something makes me feel, to give them as many clues as possible about what I'm thinking.'