

EDITOR'S CHOICE

This study addresses quality of life issues—specifically, anxiety, depression, social competence, and satisfaction with life—in subjects with Moebius syndrome. Data regarding such issues in Moebius syndrome are extremely limited in the current literature, and this paper represents an important contribution to that body of knowledge. Relative to previous studies, the sample size is large and statistical power greater. Robust and valid measures were used to generate data. Comparison was made to both normative data as well as age and gender-matched controls. The Discussion clearly outlines limitations of the study, and the stated conclusions are appropriate without over-generalization. Furthermore, the Discussion is particularly valuable, as it presents important implications for understanding adjustment and satisfaction with life for patients with Moebius syndrome and facial differences in general.

Living With Moebius Syndrome: Adjustment, Social Competence, and Satisfaction With Life

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Context: Moebius syndrome is a rare congenital condition that results in bilateral facial paralysis. Several studies have reported social interaction and adjustment problems in people with Moebius syndrome and other facial movement disorders, presumably resulting from lack of facial expression.

Objective: To determine whether adults with Moebius syndrome experience increased anxiety and depression and/or decreased social competence and satisfaction with life compared with people without facial movement disorders.

Design: Internet-based quasi-experimental study with comparison group.

Participants: Thirty-seven adults with Moebius syndrome recruited through the United States-based Moebius Syndrome Foundation newsletter and Web site and 37 age- and gender-matched control participants recruited through a university participant database.

Measures: Anxiety and depression, social competence, satisfaction with life, ability to express emotion facially, and questions about Moebius syndrome symptoms.

Results: People with Moebius syndrome reported significantly lower social competence than the matched control group and normative data but did not differ significantly from the control group or norms in anxiety, depression, or satisfaction with life. In people with Moebius syndrome, degree of facial expression impairment was not significantly related to the adjustment variables.

Conclusions: Many people with Moebius syndrome are better adjusted than previous research suggests, despite their difficulties with social interaction. To enhance interaction, people with Moebius syndrome could compensate for the lack of facial expression with alternative expressive channels.

KEY WORDS: *anxiety, depression, facial movement disorders, facial paralysis, Internet study, life satisfaction, Möbius or Moebius syndrome or sequence, psychological adjustment, social competence (skills)*

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Most people with Moebius syndrome are born without the ability to smile, frown, raise an eyebrow, or form any other facial expression, and this absence of facial expression may result in significant challenges during social interaction. There is much evidence to suggest that certain facial expressions are universally recognized and displayed across cultures (Ekman et al., 1969; Ekman and Friesen, 1971, 1986; Elfenbein and Ambady, 2002; Matsumoto and Willingham, 2009), which means that people with Moebius syndrome are unable to participate in one of the only universal languages.

In addition to the challenges presented by the inability to communicate through facial expression, people with Moebius syndrome must adapt to other physical conditions that may occur with the syndrome, such as impaired lateral eye movement and limb abnormalities as well as the social stigma associated with a visible difference (Macgregor, 1979). This study quantitatively examines social competence, adjustment, and satisfaction with life in people with Moebius syndrome compared with people without the syndrome.

Moebius Syndrome

Moebius syndrome affects more than just a person's face. It is important to consider what may occur in the entire body of a person with Moebius syndrome in order to understand how the condition may affect adjustment and social outcomes. The etiology of Moebius syndrome is unknown, and this is perhaps related to the wide range of severity and variability of symptoms. One well-accepted etiological theory is that Moebius syndrome is caused by a vascular disruption during embryonic development (Briegel, 2006). Although there is documentation of genetic inheritance in a few families (MacDermot et al., 1991; Slee et al., 1991; Kremer et al., 1996; Verzijl et al., 1999), Moebius syndrome usually is considered to occur spontaneously in families (Briegel, 2006). Thus, Moebius syndrome tends to occur in isolation, and families are usually unfamiliar with the condition.

Moebius syndrome is a congenital, nonprogressive condition, resulting in facial paralysis (usually complete and bilateral) and impaired abduction of the eyes (Moebius, 1888; Briegel, 2006). The syndrome is characterized by the maldevelopment or underdevelopment of the sixth and seventh cranial nerve, which occurs early in prenatal life (Briegel, 2006). The prevalence of the syndrome is estimated to be 0.0002% to 0.002% of births (Kuklik, 2000; Verzijl et al., 2003). Other congenital conditions are sometimes associated with the syndrome, including limb anomalies (such as club feet and missing or underdeveloped fingers or hands), Poland syndrome (underdevelopment of the pectoralis muscle combined with hand malformation), and hypoglossia (weakness or malformation of the tongue) (Richards, 1953; Verzijl et al., 2003). Despite the litany of comorbid conditions associated with Moebius syndrome, the syndrome and related symptoms generally cause only minor to moderate impairment in most people with the condition. Once feeding issues related to the inability to suck while nursing are resolved in infancy, people with Moebius syndrome are generally healthy and have a normal life expectancy (Briegel, 2006).

Not only do people with Moebius syndrome have difficulty communicating with facial expression, but speech communication difficulties also occur frequently due to paralysis of the lips and hypoglossia of the tongue. The inability to move the lips makes it difficult to form labial sounds such as *m*, *b*, *p*, *f*, and *v*. Although language delay occurs in 14% to 55% of children with Moebius syndrome, after speech therapy, most

people with the condition are able to speak with remarkable clarity (Meyerson and Foushee, 1978).

There have been inconsistent reports in the medical literature about the prevalence of mental retardation and autism in people with Moebius syndrome. Overall, the literature suggests a presence of mental retardation, which is usually mild, in 10% to 15% of people with Moebius syndrome (Kuklik, 2000; Johansson et al., 2001; Briegel, 2006). However, two recent studies found that all participants tested within the normal range on tests of intellectual function, memory, and attention, suggesting that previous studies with higher incidences of mental retardation may have been affected by selection biases and poor methodology (Ghabrial et al., 1998; Verzijl et al., 2005). Several studies suggest a strongly increased incidence of autistic spectrum disorders in people with Moebius syndrome, with varying reports of 5% to 29% incidence in people with the syndrome compared with 0.63% in the general population (Gillberg and Steffenburg, 1989; Johansson et al., 2001; Bandim et al., 2003; Verzijl et al., 2003). However, physical impairments caused by Moebius syndrome can account for most of the *Diagnostic and Statistical Manual of Mental Disorders IV-TR* (2000) diagnostic criteria for autism, including delayed speech and impaired social interaction. None of these studies controlled for all Moebius-related symptoms that could be attributed erroneously to autism. There is not enough evidence to conclude that people with Moebius syndrome have a high incidence of autistic spectrum disorders.

Adjustment in Moebius Syndrome

There is a dearth of research on people with Moebius syndrome, with only a handful of papers addressing the psychosocial aspects associated with living with the syndrome. Most of the psychological literature on the condition consists of case studies with fewer than 20 participants (Goldblatt and Williams, 1986; Calder et al., 2000; Meyerson, 2001). Briegel (2007) recently completed the only quantitative study on adjustment and personality in people with Moebius syndrome. In the study, 22 German adults with Moebius syndrome completed the Symptom Checklist 90-Revised (Derogatis, 1977) and the Freiburger Personality Inventory-Revised (Fahrenberg et al., 2001). Compared with normative data, participants with Moebius syndrome showed significantly higher traits of inhibition, introversion, and interpersonal sensitivity (feelings of inadequacy and inferiority) as well as lower satisfaction with life and achievement orientation. Differences in anxiety and depression scores in people with Moebius syndrome from normative data were nonsignificant ($p = .059$) but may indicate a tendency toward psychological distress. This possible tendency toward adjustment problems merits exploration with a larger sample and comparison against a matched control group.

Despite the challenges presented by Moebius syndrome, many people with the condition live professionally and

personally successful lives. It is valuable to study resilient people with Moebius syndrome in order to identify sources of strength and success. Meyerson (2001) conducted qualitative telephone interviews with 18 adults with Moebius syndrome who were known by the Moebius Syndrome Foundation to be professionally and personally successful. Some of the primary characteristics of successful people with Moebius syndrome were family support, faith, humor, sense of self, special skills, determination, and ability to network. Participants noted that social interaction can be difficult without facial expression, but they reported using eye contact to display confidence and prosody, body language, and verbal disclosure to express emotion.

Adjustment Literature on Other Facial Movement Disorders and Facial Differences

It is likely that people who acquire facial movement disorders like Bell palsy or stroke later in life undergo a different adaptation process than people with congenital conditions like Moebius syndrome who have had facial paralysis for their entire lives. However, due to the rarity of facial movement disorders, most studies, including the ones described in this section, sample people with all types of facial movement disorders, both acquired and congenital, and do not distinguish between them. Congenital disorders resulting in facial movement problems are extremely rare; therefore, it is likely that the samples for these studies comprised mostly people with acquired conditions. We present these studies of various facial movement disorders with the caveat that caution should be used when attempting to generalize these findings to the Moebius syndrome population.

In a study of people with various types of facial neuromuscular disorders (out of 48 participants, only 2 had congenital conditions), participants had considerably high incidences of anxiety (VanSwearingen et al., 1998). Nearly 65% of participants had Beck Depression Inventory scores in the clinical depression range, which is three to five times higher than the rate found in the general population (Oliver and Simmons, 1984; Campbell and Cohn, 1991). In this study, psychological distress was a mediator of the relationship between impairment and social disability, suggesting that psychological distress has a primary role in social disability. Additionally, psychological distress moderated the relationship between physical impairment and disability, with people of equal impairment levels experiencing more physical disability if they had psychological distress. Thus, it appears that many people with facial movement disorders experience psychological distress, and this distress plays a key role in the quality of their social and physical functioning.

The specific impairment of smiling may be particularly interpersonally and intrapersonally challenging (VanSwearingen et al., 1999). Smiling is an important social cue that communicates an intention to initiate or continue an activity, elicits reciprocal positive interaction, and pro-

motes social cohesion and cooperation (VanSwearingen et al., 1999). According to facial feedback theory, smiling also may contribute to the experience of happiness through peripheral facial feedback (Tomkins, 1962; Laird, 1974). VanSwearingen et al. (1999) found that specific impairment of smiling ability in people with facial movement disorders predicted depression, even when controlling for overall impairment and disability.

Because people with Moebius syndrome often have an unusual facial appearance due to the absence of muscle tone, wrinkling, and appropriate facial expressions, it may be useful to consider the somewhat more extensive literature on adjustment in people with facial differences (disfigurements). A study of 650 outpatients with a range of acquired and congenital conditions resulting in facial differences found that 48% of these patients had borderline or higher levels of anxiety, and 27.5% of participants had borderline or higher levels of depression as measured by the Hospital Anxiety and Depression Scale (Rumsey et al., 2004). These percentages represent a much higher proportion of borderline or higher levels of depression and anxiety in people with facial differences compared with population norms.

Social Competence

Facial expression is central to social interaction. Darwin (1872/1998) theorized that facial expression of emotion evolved in animals and humans for adaptive value in fundamental life tasks. A large body of work now supports the existence of seven universal emotions (anger, contempt, disgust, fear, happiness, sadness, and surprise) that are produced and recognized across nearly all cultures (Ekman et al., 1969; Ekman and Friesen, 1971, 1986; Elfenbein and Ambady, 2002; Matsumoto and Willingham, 2009). In addition to communicating emotion, facial expression serves to initiate and regulate the dynamics of conversation and to supplement speech (Ekman, 1986). Facially expressive people are perceived as more confident and likeable and rated more positively overall (Shrout and Fiske, 1981; Riggio and Friedman, 1986). Thus, people who cannot produce facial expressions may be at a considerable disadvantage during social interaction (Ekman, 1986).

Social functioning has not been studied quantitatively in Moebius syndrome. However, a study of 24 patients with protracted Bell's palsy (onset was at least 1 year prior to the study) examined whether participants who were impaired in communicating emotions with their faces had impaired social functioning (Coulson et al., 2004). Participants who indicated they could not facially communicate one or more of six universal emotions showed lower social functioning relative to physical functioning, as measured by the Medical Outcomes 36-Item Short Form Health Survey (SF-36; Ware and Sherbourne, 1992), compared with those who could communicate all six emotions. Thus, it appears that impairment of even one facial expression of emotion is associated with reduced social functioning.

TABLE 1 Variable Descriptive Statistics, *t* Tests, and Effect Sizes

<i>Measure</i>	<i>Group</i>	<i>Mean</i>	<i>SD</i>	<i>t</i> (<i>df</i>)	<i>Significance (One-Tailed)</i>	<i>Effect Size (r)</i>
Age	Moebius	37.73	13.70	0.79 (72)	.43 (two-tailed)	.09
	Control	35.32	12.47			
Social competence	Moebius	36.35	10.37	-1.75 (72)	.04	.20
	Control	40.22	8.58			
	Norm data	40.65	9.32			
Anxiety	Moebius	7.89	3.85	0.67 (72)	.25	.07
	Control	7.32	3.49			
Depression	Moebius	3.95	3.60	-0.56 (72)	.29	.06
	Control	4.35	2.52			
Satisfaction with life	Moebius	21.62	7.20	-0.62 (72)	.27	.07
	Control	22.65	7.20			
	Norm data	23.5	6.43			
Facial Emotion Communication Questionnaire	Moebius	16.19	6.53	-8.19 (51)*	.00	.75
	Control	25.89	3.05			

* Equal variances not assumed.

Present Study

The only quantitative study on adjustment in people with Moebius syndrome reported low satisfaction with life and a nonsignificant tendency toward increased depression and anxiety (Briegel, 2007). Studies of people with various types of facial paralysis and facial differences found high incidences of depression and anxiety as well as problems with social functioning, but these studies did not report condition-specific results (VanSwearingen et al., 1998, 1999; Coulson et al., 2004; Rumsey et al., 2004). Previous studies on these populations are limited by small sample sizes, possible sampling biases, and the lack of comparison groups. The present study took a novel approach to achieve a larger sample by recruiting from the Moebius Syndrome Foundation, which is based in the United States, and conducting the study online so that people from across the country could participate. We strengthened our study by comparing results with normative data and an age- and gender-matched control group.

We hypothesized that people with Moebius syndrome, compared with published normative data and an age- and gender-matched control group, would have higher incidences of depression and anxiety (Hypothesis 1) and lower social competence (Hypothesis 2) and satisfaction with life (Hypothesis 3). Because Coulson et al. (2004) found that impairment in expressing emotions with the face was associated with reduced social functioning, we hypothesized that the degree of impairment of facial expression in people with Moebius syndrome would be positively related to depression and anxiety and negatively related to social competence and satisfaction with life (Hypothesis 4).

METHODS

Participants

Adults (18 and older) with Moebius syndrome were recruited by the first author—herself a person with

Moebius syndrome—through notices in the United States-based Moebius Syndrome Foundation newsletter, on the organization's Web site, and personal contacts obtained through the foundation and its conferences. The Moebius Syndrome Foundation does not have information on how many people with Moebius syndrome subscribe to the newsletter or how many view the Web site. Thus, the response rate is unknown and this was a sample of convenience. Participants received no financial incentives to participate in the study. A total of 31 participants indicated by self-report that they had been diagnosed with Moebius syndrome. Seven participants indicated that they had not been formally diagnosed with Moebius syndrome, but they believed they had the condition. Six of these self-diagnosed participants indicated some difficulty with facial movement and moving their eyes laterally. Because Moebius syndrome is very rare, it is likely that some people with the condition are never diagnosed properly by a physician. Facial weakness and impaired ocular abduction are the minimum inclusion criteria used for most studies on Moebius syndrome (Meyerson and Foushee, 1978; Stromland et al., 2002; Cronemberger et al., 2003; Briegel, 2007, 2006), so these six participants were included in the analyses in the Moebius syndrome group. One self-diagnosed participant indicated difficulty with facial movement and smiling, but he reported he was able to move his eyes laterally. This participant did not meet the inclusion criteria and was not included in further analyses. Thus, there were a total of 37 participants (23 women, 14 men) in the Moebius syndrome group. In this group, 33 participants (89.2%) were white, two (5.4%) were Native American, one (2.7%) was Hispanic/Latino, and one (2.7%) was categorized as "other."

A total of 249 participants for the control group were recruited through San Francisco State University's student participant database and completed the study for partial course credit. Thirty-seven participants (23 women, 14 men) were selected from this dataset to match the participants in the Moebius group with respect to age and

gender. The age difference between the two groups was not significant (see Table 1). The data from the remaining participants were not used for this study. In the control group, 28 (75.7%) identified themselves as white, four (10.8%) identified themselves as African American, four (10.8%) identified themselves as Asian, and one (2.7%) as Hispanic/Latino. Participants in the control group indicated they had never experienced facial movement problems.

Instruments

Hospital Anxiety and Depression Scale (HADS; Zigmond and Snaith, 1983). This 14-item scale was developed originally for use as a brief instrument for detecting depression and anxiety in outpatient nonpsychiatric hospitals. In a literature review of 747 studies using HADS, Bjelland et al. (2002) concluded that it is a reliable and valid measure for assessing the symptom severity and presence of clinical levels of depression and anxiety disorders in medical and psychiatric patients and in the general population. HADS was used in this study because it is unlikely to confound with physical symptoms, and it has been used to measure depression and anxiety among people with facial disfigurements (Rumsey et al., 2004). The scoring procedure involves reverse scoring negatively worded items and totaling the depression and anxiety scales separately. In the present study, the Cronbach alpha for the anxiety subscale was .77 for the Moebius group and .78 for the control group. The depression subscale showed a Cronbach alpha of .86 in the Moebius group and .55 in the control group. The low Cronbach alpha in the control group may be due to restriction of range in this group.

Satisfaction With Life Scale (SWLS; Diener et al., 1985). This five-item measure is one of the most widely used measures of life satisfaction or global well-being (Lucas et al., 2003). The SWLS is positively correlated with healthy psychological and social functioning and negatively correlated with measures of psychological distress (Arrindell et al., 2001). Scores are summed, with higher scores indicating more life satisfaction. Cronbach alphas for this study were high for both the Moebius group (.89) and the control group (.88).

Texas Social Behavior Inventory Short Form B (TSBI; Helmreich and Stapp, 1974). TSBI is a 16-item self-report measure of social competence and social self-esteem. The predictive validity of the TSBI is supported by improvements in TSBI scores after cognitive social behavior training therapy and the scale's effectiveness in predicting interpersonal attraction (Helmreich et al., 1970; Grant and Cash, 1995). Negatively worded questions are reverse scored, and scores are summed. Cronbach alphas were .85 for the Moebius group and .81 for the control group.

Many widely used social competence assessments include measures of nonverbal communication (Rosenthal et al., 1969; Riggio, 2005). Because people with Moebius syndrome are physically impaired in producing facial expres-

sion, such assessments would confound measurement. People with Moebius syndrome may compensate for their lack of facial expression with other behaviors to contribute to the overall success of an interaction. Thus, for the purposes of this study, *social competence* was defined operationally as self-perceptions of confidence, comfort, and competence during social interaction. TSBI was chosen for use in this study because it was designed to measure the constructs of social competence and social self-esteem rather than specific nonverbal behaviors. The TSBI Short Form A was not used because it includes the question "I feel confident of my appearance," which poses a potential confound given that people with Moebius syndrome may have unusual facial appearance. Thus, the TSBI Short Form B was chosen because it does not contain any questions related to appearance. Sample items from TSBI-B include "I would describe myself as socially unskilled" and "It is hard for me to start a conversation with strangers."

Facial Expression Communication Questionnaire (FECQ). This measure was created for this study to assess the self-reported ability to communicate the seven universal emotions with the face. One purpose of this measure was to confirm that participants with Moebius syndrome are impaired in facial expression of emotion as compared with the control group. A similar set of questions was used by Coulson et al. (2004) to determine whether participants with unilateral facial paralysis were able to form facial expressions. There are seven items in the FECQ, each measuring the ability to communicate one of seven emotions. An example is "I can communicate anger with my facial expression." Response choices were "strongly agree," "agree," "disagree," and "strongly disagree." Items were reverse coded, such that a higher score indicated more ability to communicate emotion. Cronbach alphas for this study were high for both the Moebius group ($\alpha = .94$) and the control group ($\alpha = .87$).

Demographics and Additional Questions. Participants also completed demographic questions about their age, gender, ethnicity, marital status, and whether they had been diagnosed with an autistic spectrum disorder, learning disability, mental retardation, or psychological disorder. Questions about the presence of symptoms noted in the literature to occur with Moebius syndrome, such as facial paralysis, limb abnormalities, and lateral gaze paralysis, were included in the demographic section for the Moebius group.

Additionally, a facial expression recognition task during which participants viewed photos of people forming various emotional expressions was presented as part of the Internet survey. The findings from this part of the study are not discussed here and are reported in Bogart and Matsumoto (in press).

Procedure

The present study received institutional review board approval from San Francisco State University. Participants

indicated implied consent at the beginning of the Internet-based study. Participants completed all measures listed above in one 30-minute Internet-based survey. There were eight counterbalanced versions of the survey for each condition, with the demographic questions always placed at the end. Participants were randomly assigned to a version of the survey.

RESULTS

Preliminary Analyses

Participants with Moebius syndrome had significantly less ability to produce facial expression than the control group, as measured by the FECQ (see Table 1). There were no significant differences between the 31 formally diagnosed participants with Moebius syndrome and the six self-diagnosed participants on FECQ, HADS, SWLS, and TSBI scores. Moreover, all hypothesis test results remained the same when the six self-diagnosed participants were removed from analyses. Thus, results are reported on all 37 Moebius participants.

Associated symptoms and information. Of the participants with Moebius syndrome, 18 (49%) reported limb abnormalities such as talipes and polydactyly. Twenty (54%) reported having at least one surgery on their faces to treat symptoms of the syndrome. Seven participants with Moebius syndrome (19%) had some type of facial reanimation surgery, and five (71%) of these participants considered these surgeries to be successful. Five participants in the Moebius syndrome group (14%) and three participants in the control group (8%) reported having been diagnosed with learning disabilities. Two participants in the Moebius group (5%) reported having been diagnosed with mental retardation, and none reported a diagnosis of mental retardation in the control group. There were no participants in either group who reported a diagnosis of an autistic spectrum disorder. Twenty participants with Moebius syndrome (54%) and 12 control participants (32%) reported having a diagnosis of a psychological disorder at some point in their lives. Fifteen participants in the Moebius group (41%) and 11 participants in the control group (30%) reported having been diagnosed with depression. Seven participants with Moebius syndrome (19%) and three control participants (8%) reported diagnoses of generalized anxiety disorder.

Hypothesis 1: People With Moebius Syndrome Will Have Increased Anxiety and Depression

There were no significant differences in depression or anxiety scores between the Moebius and control groups. Statistics for all hypothesis tests are in Table 1. Normative data are not published for HADS. Instead, scores for each subscale are interpreted as noncases of anxiety or depression (less than a score of 8), possible cases (scores of 8 to 10), and probable cases (more than a score of 10).

The Moebius group means for both the anxiety and depression subscales fell below the cutoff of 8, meaning that it is unlikely that these participants were experiencing high levels of depression or anxiety.

Hypothesis 2: People With Moebius Syndrome Will Have Reduced Social Competence

A *t* test revealed that people with Moebius syndrome had lower social competence, as measured by the TSBI, compared with the control group. The Moebius syndrome TSBI score was also significantly lower than the published normative data for the TSBI.

Hypothesis 3: People With Moebius Syndrome Will Have Decreased Satisfaction With Life

There were no significant differences in SWLS scores between the Moebius and control groups. Additionally, the Moebius syndrome group did not differ significantly from the published normative data for SWLS.

Hypothesis 4: In People With Moebius Syndrome, Impairment in Communicating Emotions With the Face Will Be Positively Related to Depression and Anxiety and Negatively Related to Social Competence and Satisfaction With Life

FECQ scores were not significantly correlated with depression ($r = .11$), anxiety ($r = .16$), social competence ($r = -.14$), or satisfaction with life ($r = .13$).

DISCUSSION

This Internet-based study examined anxiety, depression, social competence, and satisfaction with life in adults with Moebius syndrome. Of the factors examined, the only significant difference found between the Moebius group and the age- and gender-matched control group or normative data was in social competence. As hypothesized, people with Moebius syndrome had lower confidence and self-perceptions of social competence in social situations as measured by the TSBI compared with the matched-control group and normative data. Although people with Moebius syndrome scored significantly lower on our FECQ than the control group, severity of facial expression impairment in people with Moebius syndrome was not related to anxiety, depression, social competence, or satisfaction with life.

In contrast to Briegel's (2007) smaller study of Germans with Moebius syndrome and the previously described studies of mostly acquired facial movement disorders and facial differences, the present study, which is the largest psychological study on Moebius syndrome to our knowledge, did not find increased levels of depression or anxiety or decreased satisfaction with life in people with the syndrome. There are several explanations for the differences between our findings and past research. First, most

studies on facial movement disorders included both participants with congenital and acquired conditions and did not analyze them as separate groups. It is likely that people with congenital versus acquired conditions undergo very different adjustment patterns. Because many common types of acquired facial paralysis result from illness or injury, negative adjustment, particularly at onset, may be more likely than among adults who were born with a condition and have lived with it their whole lives. This does not explain why our results differ from the only other quantitative study of adjustment in Moebius syndrome (Briegel, 2007). One possible explanation for the differences between our findings and those in Briegel's (2007) study of Germans with Moebius syndrome is that our study had a larger sample and was presumably more powerful, which suggests that the nonsignificant tendency toward depression and anxiety they reported may have been spurious. Additionally, cultural differences in the stigma associated with a disability may affect adjustment patterns and may reflect differences in our American and their German samples.

Another possible explanation for our novel results stems from our recruitment method. Most studies of people with Moebius syndrome, facial movement disorders, and medical conditions in general are limited by selection biases because they tend to sample from hospitals, medical clinics, and institutions (Briegel, 2006). Thus, the severity of symptoms and distress reported may be inflated because these studies do not include people who do not spend time in these institutions. Recruiting from the Moebius Syndrome Foundation is likely to result in sampling individuals who would be less represented in other studies. However, it is possible that our study was limited by selection bias in the opposite direction: High-functioning participants with Moebius syndrome may have self-selected for the study, particularly because it required use of the Internet. However, even if this is the case, we argue that at the very least, the results of our study show there is a large group of people with Moebius syndrome who are well adjusted despite social interaction problems, and this offers a heartening new perspective. We suggest that the Internet can be a useful data collection tool to collect larger samples in future research on rare conditions.

In addition to comparing the Moebius group with normative data, which has been the standard for previous studies on facial movement disorders and facial differences, we attempted to strengthen the study by including a matched control group to ensure that the Moebius group was compared with a representative group that encountered the same procedure and history effects (VanSwearingen et al., 1998, 1999; Calder et al., 2000; Rumsey et al., 2004; Briegel, 2007). We were unable to match the control group on variables such as ethnicity, education level, and socioeconomic status due to a limited number of participants in the student participant database, and these unmatched variables could potentially affect adjustment, social skills, or satisfaction with life. However, because the

results were the same whether we used the control group or published norms, it is unlikely that the unmatched variables impacted the results.

The low social competence found in our sample of people with Moebius syndrome compared with matched controls and normative data is likely a result of the inability to produce facial expressions and the visible difference associated with Moebius syndrome. The quality of social interaction is reduced if people misunderstand the nonverbal cues of people with Moebius syndrome. Matthew Joffe, a psychotherapist with Moebius syndrome, described how social interaction can be a tiring, effortful exercise in impression management and minimizing misunderstandings. "Every time I meet someone I am managing how they perceive me, how I can try to help them, how I can help them if they don't know me, how they might be shown how to respond" (Cole, 2009, p. 200). During interactions with a person with Moebius syndrome, for example, an interactant may not notice when the person with the syndrome is joking or expressing sarcasm. Without facial cues, a simple greeting like "nice to see you" might be misinterpreted as insincere or sarcastic. Mirroring and nonverbal synchrony are important for developing rapport, empathy, and emotional convergence between interacting individuals (Hatfield et al., 1994; Tickle-Degnen, 2006). If a person with Moebius syndrome does not respond with similar facial expressions in response to an interactant's display, the interactant may feel confused or misunderstood and behave accordingly. Thus, in a sense, the problem lies in the person interacting with the person with Moebius syndrome because the interactant may not be attending to valid cues. These interactions could lead people with Moebius syndrome to experience discomfort and reduced confidence during social interactions, and they may affect the way they perceive their social abilities and approach future social situations. Clinicians should be aware of the potential effects of Moebius syndrome on social competence and emotional communication during interactions with patients.

Although people with Moebius syndrome had lower social competence and less ability to express emotions with the face as measured by the FECQ, the two variables did not show the predicted correlation. The FECQ was a measure we created for this study; it is possible the measure was not sensitive enough to make fine-grained distinctions between levels of impairment and was effective only at detecting large differences between the Moebius and control groups. Our interpretation is that the mere presence of difficulty communicating with facial expression is enough to disrupt social competence. There may be other factors moderating the effect, such as asymmetry of the face or use of other channels to communicate, that merit future study.

Although VanSwearingen et al. (1999) suggested that impairment of facial movement may result in increased depression due to lack of facial feedback, our results, which do not show increased depression in our sample of people

with Moebius syndrome, do not support this. Ekman (1992) suggested that commands in the motor cortex, which are intact in people with Moebius syndrome and most types of facial paralysis, and not peripheral facial feedback, affect emotional experience. Ekman and Levenson (P. Ekman, personal communication, 2007) found that people with Moebius syndrome showed the appropriate discrete physiological responses to emotional stimuli, even if they were not able to produce facial expression. Thus, we caution researchers and clinicians against assuming that people with Moebius syndrome experience emotion differently from the general population.

It is interesting that although this study's participants with Moebius syndrome did not differ from the control group in measured anxiety and depression, they more often reported having been diagnosed with anxiety or depression at some time in their lives. There could be several explanations for this disparity. People with Moebius syndrome may have sought psychological treatment more frequently than the control group and had more opportunity to be diagnosed. Another possibility is that people with Moebius syndrome experienced anxiety and depression earlier in their lives but are now adjusted. Alternatively, clinicians might overdiagnose people with Moebius syndrome with anxiety and depression because they present with flat affect.

None of the participants with Moebius syndrome reported having been diagnosed with an autistic spectrum disorder; although, previous literature reports 5% to 29% incidence of autism in people with Moebius syndrome (Gillberg and Steffenburg, 1989; Johansson et al., 2001; Bandim et al., 2003; Verzijl et al., 2003). Additionally, only 5% of participants with Moebius syndrome reported having been diagnosed with mental retardation, which contrasts with the reported 10% to 15% incidence of mental retardation in other studies (Kuklik, 2000; Johansson et al., 2001; Briegel, 2006). Our results could be an indication that previous estimates of incidences are inflated. However, the low incidences also could be an indicator that high functioning people who were not on the autistic spectrum self-selected for the present study. Another possibility is that some participants have autistic spectrum disorders and either did not report them or were not diagnosed.

This condition-specific study shows a different pattern of results than studies with mixed samples of various types of congenital and acquired facial movement disorders or facial differences. It is important that researchers begin to differentiate between these conditions in order to produce a more nuanced understanding of the factors involved. Our results suggest that many people with Moebius syndrome, who have lived with the condition all of their lives, may develop resiliency and effective coping strategies to maintain optimal intrapersonal psychological adjustment, despite the difficulties they experience during interpersonal interaction. It would be useful to continue Meyerson's (2001) exploration of resiliency in people with Moebius syndrome and to consider applications to ease the

adjustment problems found in people with other facial movement disorders.

Future studies should explore other factors that may affect social skills in people with Moebius syndrome such as coping style and use of alternative communication strategies. Although facial expression is often the primary and most salient source of information during social interaction, prosody, body language, posture, proximity, touch, and verbal disclosure are other important channels for communicating emotion that people with Moebius syndrome can use. Social skills training programs have been shown to benefit people with facial differences who experience problems with social interaction (Robinson et al., 1996). Thus, a social skills training program that promotes the use of alternative channels such as prosody, gestures, and verbal disclosure to communicate emotion may benefit some people with Moebius syndrome.

CONCLUSIONS

Many people with Moebius syndrome are psychologically adjusted and lead satisfying lives. The lack of research on quality of life issues of Moebius syndrome, and facial paralysis in general, is disconcerting. Future studies on resiliency in people with Moebius syndrome may be useful for people with acquired facial movement disorders, who may have a higher incidence of adjustment problems. This area is ripe for research on facilitating social interaction, which, for some people with Moebius syndrome, is the last piece in the puzzle of living with the syndrome.

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