“Rare place where I feel normal”: Perceptions of a social support conference among parents of and people with Moebius syndrome

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**Abstract**

*Background*: Moebius syndrome is a rare congenital disorder resulting in impaired facial and eye movement. People with rare diseases like Moebius syndrome experience stigma and a lack of specialized information. Support conferences may provide important forms of social support for people with rare disorders. *Aims*: To examine reasons for attending, benefits, and limitations of support conferences. *Methods and procedures*: 50 adults with Moebius syndrome and 57 parents of people with Moebius syndrome completed open-ended items in an online study. *Outcomes and results*: Mixed-methods content analysis revealed that companionship and informational support were most frequently mentioned as reasons for and benefits of attending. Finances were the most frequently mentioned reason for not attending. Parents were more likely than people with Moebius to describe instrumental support as a conference benefit. When describing conference limitations, parents were significantly more concerned by lack of information relevance, while people with Moebius noted more often that conference attributes were not relevant to their age. *Conclusions and implications*: Being surrounded by others who share one’s condition offers a unique opportunity for destigmatizing companionship support, which normalizes, reduces isolation, and promotes solidarity. Ways to increase facilitators and decrease barriers to accessing support for rare disorders should be investigated.

*Keywords*: Moebius syndrome; rare disease; stigma; social support; companionship support: facial paralysis

**What This Paper Adds**

Although people with rare disorders are in greater need of social support than those with common disorders, there is a dearth of research on benefits, limitations, barriers, and facilitators of support delivery. Support conferences are a practical approach because it is not feasible to hold local support groups for rare diseases because affected individuals are geographically isolated. The only previous study on support conferences found measureable benefit six weeks after attending. The current study expands this work by examining open-ended responses about reasons for attending or not attending, and conference benefits and limitations using a mixed-methods approach. The methods of this study provide greater depth of knowledge of the benefits identified previously, including that companionship support reduces stigma, normalizes, reduces isolation, and promotes solidarity. Giving support, and for a minority of participants, being role models and volunteering emerged as novel benefits and reasons for attending. Conference limitations included perceived lack of information and age relevance. Parents were more concerned by the former, while people with Moebius were more concerned with the latter. Facilitators and barriers to attending support conferences were identified for the first time, including finances and location. Further research should examine ways to provide more accessible support avenues for people with rare diseases, such as online support groups with video conferencing.

**Highlights**

* Rare disorders like Moebius syndrome involve stigma and lack social support
* Reasons for attending, benefits, and limitations of support conferences were studied
* Companionship was the most important benefit and reason for attending conferences
* Finances were the most common reason for not attending
* Ways to improve access to support for rare disorders should be investigated

**1. Introduction**

Moebius syndrome is a rare congenital disorder characterized by facial paralysis, which is typically bilateral and complete, and impaired lateral eye movement (Verzijl, van der Zwaag, Cruysberg, & Padberg, 2003). It can be traced to underdevelopment of the 6th and 7th cranial nerves, and occurs in 2 to 20 people per million (Verzijl et al., 2003). In most cases, it does not run in families (Verzijl et al., 2003), meaning that upon diagnosis, parents usually have no knowledge about Moebius syndrome. A variety of other symptoms are sometimes present in those with Moebius, such as limb or chest wall abnormalities, speech clarity problems, and difficulty eating. Intellectual disability, which is usually mild, has been reported to occur among 9–15 percent of people with Moebius Syndrome (Briegel, Schimek, Knapp, et al., 2009; Kuklik, 2000), and autism may occur among 0–5 percent (Briegel, Schimek, & Kamp-Becker, 2010; Briegel, Schimek, Kamp-Becker, Hofmann, & Schwab, 2009). However, it should be noted that there may be a risk of misdiagnosis because the physical symptoms of Moebius syndrome may confound with diagnostic criteria of intellectual disability and autism (Bogart, Cole, & Briegel, 2014).

In a series of focus group studies, adolescents and adults with Moebius reported that the condition was highly stigmatizing due to the combination of having a rare disorder, having a facial difference, and being unable to express oneself with the face (Bogart, 2015; Bogart, Tickle-Degnen, & Joffe, 2012). Further, people with Moebius struggled to be understood on many levels, due to others’ misinterpretation of their lack of facial expression, speech difficulty, and others’ lack of awareness of Moebius syndrome. Moebius syndrome is a visible but unrecognizable condition. Others notice the unusual appearance of someone with Moebius, but misunderstand the cause, nature, and accommodations needed due to a lack of awareness about the rare disability (Bogart & Tickle-Degnen, 2015). Because of their lack of facial expression, people with Moebius are frequently mistaken for being unfriendly, sad, and intellectually disabled (Bogart, Tickle-Degnen, & Ambady, 2014; Bogart, Tickle-Degnen, & Joffe, 2012).

Poor social relationships and stigma have been found to contribute to psychiatric distress in a variety of disabilities (Breslau, 1985; Masnari et al., 2013). Briegel (2007) found that seven out of 22 German participants with Moebius syndrome could be characterized as experiencing clinical psychological distress. In contrast, a study on an American sample of 37 adults with Moebius syndrome found no significant differences in anxiety, depression, or satisfaction with life compared to matched control participants without facial paralysis and normative data (Bogart & Matsumoto, 2010). The only significant difference was that the Moebius group reported lower social functioning. In a study of 17 children and adolescents with Moebius syndrome, Briegel (2012) found little difference between the self-reports of participants with Moebius and normative data on psychosocial functioning. However, according to parents’ reports, the children experienced significantly more social and emotional problems than the general population. Similarly, in a study by Strobel and Renner (2016), adolescent self-reports and parental reports indicated specific reductions in social quality of life, but not in other domains. Both parents and children reported anticipating stigma from strangers.

In sum, qualitative and quantitative research shows that people with Moebius syndrome experience significant social challenges, including stigma and social functioning issues. Additionally, some people with Moebius syndrome have been found to experience elevated levels of psychological distress. The mixed psychological distress findings may be attributed to cultural or sample differences, or to individual differences in protective factors such as resilience (Meyerson, 2001), compensatory nonverbal or verbal expression (Bogart, Tickle-Degnen, & Ambady, 2012), or social support (Bogart & Hemmesch, 2016). Although there has been little research examining ways to ameliorate the psychosocial issues experienced by people with Moebius syndrome, social support conferences may be a promising avenue, as described below.

Moebius syndrome shares similarities with the nearly 7,000 other rare diseases affecting nearly 350 million people worldwide (Walker, 2014). Members of the rare disease community experience two universal themes. First, many people with rare diseases are unable to have the normalizing experience of meeting others like themselves (Limb, Nutt, & Sen, 2010). The resulting isolation and lack of public awareness is stigmatizing (Joachim & Acorn, 2003). Second, people with rare diseases struggle with obtaining information and medical care. Although primary care practitioners are the typical gatekeepers for these resources, people with rare diseases are more likely to obtain these resources through rare disease organizations (Aymé, Kole, & Groft, 2008). For these reasons, approximately two-thirds of people with rare disease feel they do not get sufficient support through the healthcare system (Limb et al., 2010; Shire, 2013).

 There are four types of social support generally described in psychology research (Bambina, 2007; Newsom, Rook, Nishishiba, Sorkin, & Mahan, 2005; Yao, Zheng, & Fan, 2015). Emotional support is expressed through caring and concern and signals that the person is cared for and valued. Informational support comes from advice and referrals and helps people understand the nature of their problem and generate solutions. Instrumental support involves practical assistance and resources. Companionship support is transmitted through group activities, interactions, and affiliations. It provides a way to cope with exclusion and stigma (Bambina, 2007).

Research on support groups for people with disabilities and health conditions has typically focused on common conditions like cancer (Telch & Telch, 1986) and rheumatoid arthritis (Bradley et al., 1987), and generally finds benefits to quality of life (Hogan, Linden, & Najarian, 2002). People with stigmatizing conditions (e.g. AIDS, substance use, breast and prostate cancer) are more likely to seek support groups than people with non-stigmatizing ones (e.g. heart disease; Davison, Pennebaker, & Dickerson, 2000). Research finds that people seek emotional and informational support from these groups (Rodgers & Chen, 2005). Companionship and instrumental support have received less examination in research on support groups. However, individuals in online support groups for a stigmatized condition reported increases in all four types of social support, and each of these predicted quality of life (Yao et al., 2015). Bambina (2007) found that companionship support was the most common type of support received in an online support group.

There has been little research on support for rare diseases and disabilities, even though these individuals are in greater need of support (Limb et al., 2010; Shire, 2013). A recent review of support needs of parents of children with rare disorders found that the most commonly reported needs were social (defined broadly as support from others such as in the form of support groups and companionship), followed by informational, emotional, and instrumental support (Pelentsov, Laws, & Esterman, 2015). Unfortunately, this has not been systematically examined among people living with rare disease themselves. People with rare diseases and their families want to meet others with their condition (Huyard, 2009), but the majority have never done so (Limb et al., 2010). In-person support groups may be an impractical resource to administer among a rare disease population because there are too few individuals or resources in any particular geographic area. A more practical avenue may be support conferences, which are regular, intensive meetings that draw participants from across the country or world to meet others who share the condition and experts who are familiar with their medical needs (Bogart & Hemmesch, 2016). The potential benefits and limitations of these conferences and facilitators and barriers to attendance and are under-researched.

The first study to examine support conferences for rare disease populations focused on the Moebius Syndrome Foundation (MSF) conference in the U.S (Bogart & Hemmesch, 2016). MSF has been holding biennial three-day conferences, which rotate around the country, since 1994. Recent conferences have offered three simultaneous presentation tracks: “Moebius research,” (e.g., genetics, diagnostic distinctions, facial reanimation), “Living with Moebius,” (e.g. social skills workshops, preparation for employment, anxiety and depression, adults’ panel discussion, “Just for Adults with Moebius” discussion group) and “Caring for someone with Moebius” (“Just for Moms” discussion group, feeding therapy, pediatric ophthalmology issues). The conference provides opportunities for informational support through formal presentations by expert healthcare professionals and researchers about topics such as feeding, genetics, surgical intervention, employment, ophthalmology, and occupational, physical, and speech therapy. Additionally, private consultations with geneticists, speech therapists, occupational therapists, psychologists, ophthalmologists, and plastic surgeons are available as a source of instrumental support. Discussion groups and social events such as communal meals, a talent show, and a dance, may provide informational, companionship, and emotional support.

Bogart and Hemmesch (2016) compared people who did and did not attend a Moebius syndrome conference on quantitative measures of social support and quality of life. Pre-post analyses of adults with Moebius syndrome found that people with Moebius syndrome who attended the conference showed a decrease in stigma and an improvement in social comfort and perceived knowledge compared to those who did not attend (Bogart & Hemmesch, 2016). Repeated conference attendance was also correlated with higher companionship, emotional, and informational support among adults with Moebius syndrome. Parents did not show pre-post change after attending a conference, but repeated conference attendance was associated with rare disease self-efficacy and perceived knowledge. Findings were consistent with the notion that parents typically seek the initial knowledge, informational, and instrumental support for their children upon diagnosis of a rare disorder present in childhood. Once people with a non-progressive condition like Moebius syndrome reach adulthood, they have likely become experts in self-management of medical aspects. Psychosocial issues like stigma, at that point, become most pressing. Indeed, Huyard (2009) found that parents of children with rare disorders sought cures for their children while adults with the conditions sought improvements in quality of life.

Given that there is evidence for the benefits of attending a support conference for parents of and people with Moebius, considering the barriers and facilitators to accessing these conferences is also important. The primary aim of the current study is to extend Bogart and Hemmesch’s (2016) work to explore, quantitatively and qualitatively, reasons for attending or not attending conferences and benefits and limitations related to attending. Further, we aimed to explore the responses of parents of and people with Moebius syndrome to identify similarities and differences in perceptions of the conferences. To accomplish these aims, we conducted a secondary analysis of Bogart and Hemmesch's (2016) survey, this time focusing on open-ended survey responses and using mixed methods rather than close-ended quantitative measures. This approach may generate factors that are not yet well-described in the literature or by existing measures. These findings may be applicable to other rare developmental disabilities involving facial paralysis or facial difference, such as Treacher Collins syndrome, Crouzon syndrome and Goldenhar syndrome, hereditary congenital facial paresis, and to the broader rare disease community.

**2. Method**

*2.1 Overview*

This project is a secondary analysis of data from Bogart and Hemmesch's (2016) quasi-experimental pre-post survey study comparing people who did and did not attend the 2014 MSF conference. The survey was administered four weeks before (Wave 1) and six weeks after the Moebius Syndrome Foundation conference (Wave 2). For the current study, only responses from Wave 1 were analyzed because the themes of participants’ comments were not expected to change systematically over time. An informal review of the responses from the Wave 2 confirmed this. Oversight of this study was provided by the first author’s Institutional Review Board and informed consent was obtained from participants.

*2.2 Participants*

Participants were recruited through notices posted by Moebius syndrome, facial paralysis, and rare disease support organizations and social media approximately four weeks before the 2014 MSF conference. These notices indicated that researchers were interested in hearing from adults with Moebius and parents of people with Moebius who do and do not attend the MSF conferences. A link to the online survey was included in the notices. Anyone with the link was allowed to access the survey.

Inclusion criteria were 18 years or older, ability to read and write in English, and self-report of having Moebius syndrome or being a parent of someone with Moebius syndrome. Parents of people with Moebius syndrome and adults with Moebius syndrome were sampled separately, rather than sampling parents and children from the same family. The rationale was that adults with Moebius syndrome and parents could answer parallel questions, and adults with Moebius syndrome would provide more accurate self-reports than children. One hundred and seven participants (50 people with Moebius syndrome and 57 parents of people with Moebius syndrome) provided complete responses at Wave 1 and were thus included in the study. Of adults with Moebius syndrome (*Mage* = 41.70, *SDage* = 15.72, 76% female), 54% (*n* = 27) had attended at least one conference at Wave 1 and 48% (*n* = 24) intended to attend the upcoming conference. Of parents of children with Moebius syndrome (*Mage* = 41.89, *SDage* = 10.00, 81% female), 58% (*n* = 33) had attended at least one conference at Wave 1 and 72% (*n* = 41) intended to attend the upcoming conference. Parents’ children with Moebius ranged in age from .33 years to 44 years (*m* = 10.56, *SD* = 9.17). See Bogart and Hemmesch (2016) for complete participant characteristics.

*2.3 Measures*

 The online survey, hosted on the survey administration website Qualtrics, assessed the following topics in order: demographic questions, number of conferences previously attended, open-ended questions described below, and close-ended quality of life measures (reported in Bogart and Hemmesch (2016)). For the purposes of the current study, five open-ended questions were examined. The following three questions measured reasons for attending or not attending the conferences: “Do you plan to attend the MSF conference this summer? If yes, why?”; “If no, why not?”; “In your own words, why have you attended the conference in the past?” (presented if participants indicated they attended in the past). One question measured conference benefits: “What do you feel were the benefits of attending the conference?” (presented if participants indicated they attended in the past). Finally, one question measured conference limitations: “What do you feel were the least helpful or beneficial things about the conference?” (presented if participants indicated they had attended in the past).

*2.4 Data analysis*

First, a quantitative content analysis approach was used, following the recommendations by Lombard, Snyder-Duch, and Bracken (2002). An initial list of codes was developed by the first author and three research assistants after reviewing participants’ open-ended responses. This list included the four types of social support drawn from the literature as well as frequently mentioned ideas emergent from responses. These included age, finances, health/energy, identity, location, nonspecific support, and role model. A participant’s response to a question sometimes contained more than one idea, so following Lombard et al.'s (2002) recommendations, the first author divided responses into single idea units (e.g. sentences). Three coders (who were not the same research assistants involved in developing the initial codes) were trained by the first author to use this coding system. To prevent coders from being influenced by other participant characteristics (e.g. demographic characteristics or close-ended responses pertaining to social support), this information was removed from the coders’ dataset. An initial test of reliability was conducted by having coders independently code five participants (Lombard et al., 2002). A conservative interrater reliability statistic was chosen, and revealed “almost perfect agreement” (mean kappa = .86; Cohen, 1960). Coders met with the first author to discuss discrepancies in codes to improve future coding. Next, six more participants were coded. Following Lombard and colleagues’ guidelines, the pilot coding sample was greater than 10% of the sample (11 participants) and included more than 30 units. The interrater reliability was again “almost perfect” (kappa = .89). Once reliability was established, the remaining units were divided among coders, who independently coded separate units. Discrepancies between coders were resolved using majority rule. One code that was used infrequently (less than five times) were removed (i.e. identity). This process generated 11 final codes. See Table 1 for a list of codes, their descriptions, and frequencies.

To achieve the first aim of the study, the most commonly used codes are presented for descriptive purposes (see Tables 2 and 3). In concert with the quantitative findings, qualitative descriptions of codes are presented to contextualize and examine them more deeply. In order to examine the secondary aim exploring whether parents of and adults with Moebius syndrome described different ideas about the conference, *t* tests compared the mean use of each code across parents of and people with Moebius syndrome for each question type. A power analysis revealed that we would be able to detect a large effect (*d* = .80) with α= .05 and β = 80% with a sample size of 52. Our samples met these criteria except for parents of and people with Moebius who were not planning to attend the next conference (*n* = 42). Although that analysis was underpowered, we present it for descriptive purposes to guide future research. *T* tests were conducted on the mean code use for parents of and people with Moebius syndrome.

**3. Results**

*3.1 Reasons for attending or not attending*

Companionship support, followed by informational support, were mentioned most frequently by both parents of and adults with Moebius syndrome as reasons to attend the conference.

Qualitative responses indicated that parents of and people with Moebius syndrome attended to receive a variety of types of social support. Attendees sought to “[keep] up with all of the great friends that we’ve made” and “to meet new people” (companionship support). “[It’s the] rare place I feel normal.” Participants sought information from parents, adults with Moebius syndrome, and medical experts (informational support). “I look forward to the research and appreciate hearing updates on studies, surgeries.” Parents of older children noted a change in the type of support they sought over time, from informational to emotional support for their children. “I attended when she was young to learn more to help her. We took her when she became a teen to help with self-esteem issues.” “We feel that it is important for [our son] to meet other kids who know how he feels and understand him.” “For [my daughter] to feel like she is not the only person in the world with this rare condition.” Adults with Moebius also mentioned emotional support benefits, including support for anxiety, depression, self-esteem, social skills, “feeling understood,” and “gain[ing] confidence.” Participants also sought instrumental support in the form of speech and occupational therapy, or surgery consultations.

Although many participants initially attended to gain support, over time they also reported giving support to others. “At first I attended to find out information about helping my son, but as he is doing just fine, I now attend to meet up with old friends and to help out in any way I can.” “It's always touching when I can be of help to others.” “Growing up with Moebius syndrome is an experience very few people in the world can truly understand; giving and receiving support is incredibly important.” Relatedly, some participants noted that they attended to volunteer by “helping with the registration desk” and leading discussion groups and presentations, which was an empowering way to contribute to the community.

Practical concerns also influenced the decision to attend. The most common reason listed for not attending the upcoming conference was financial, with more than half of participants who did not plan to attend the upcoming conference citing this concern. This was especially likely to occur when it would be necessary to travel a long way or transport a large family. Relatedly, the financial impact of leaving work was also a common reason. Participants were more likely to attend a conference if it was near them or in a desirable location for a vacation. “It gives me an excuse to travel!” Participants noted that a conference scholarship offered by the MSF facilitated attendance by reducing the cost. Others engaged in personal fundraising. In addition, health and energy limitations were sometimes barriers to attending the conference. “[My son’s] anxieties and shyness (along with moderate motion sickness and digestive issues) prevent us from traveling that far.” “[My daughter’s] health is not good and I don't want to leave her.”

Parents mentioned age as a reason for not attending marginally more than adults with Moebius syndrome (adults did not mention this at all). This occurred when parents indicated their child was too young to travel or to benefit from the conference.

*3.2 Conference benefits*

Again, companionship support and informational support were mentioned most frequently as conference benefits. Participants noted companionship support by valuing the relationships developed at the conference. Repeated attendance left participants feeling part of a family. “Most of my best friends are parents of or people with Moebius that I've met over the years.” Participants felt normalized by being surrounded by others like them. “At [the] conference [Moebius] is the norm.” Further, the companionship support obtained at the conference reduced feelings of isolation. “The greatest benefit was in Philly two years ago when [our son] got off the elevator, saw a kid about his age, and said, ‘that boy looks like me.’” “[I] feel that I'm not the only one struggling with the obstacles…I face.” “[We want our daughter] to feel like she is not the only person in the world with this rare condition.” “I found a place here [where] words were not necessary to establish acceptance and feel part of a community.” Participants recognized that, due to the rarity of Moebius syndrome, they wouldn’t meet others with the condition without the conference: “As a child, I never met anyone similar to me and it is amazing to me to connect with all these wonderful people.” Being around others with Moebius syndrome also provided insight into seeing how others see them, “their mirror image.” “[I] better understand myself through the eyes of another with Moebius.”

Attendees also recognized the value of informational support through up-to-date “expert advice.” “I have learned about some of the health, social, academic, and psychological aspects of Moebius that my son and family might face and learned from others how they deal with them.” “Gaining a realistic view of Moebius syndrome and how it will affect our daughters’ development and social interactions.” “Learning about treatment options.” In addition to learning from experts, respondents also appreciated “learning from [the experiences of others with Moebius] in dealing with it.”

People with Moebius were marginally more likely to describe emotional support than parents. The comments of people with Moebius syndrome revealed a unique feeling of “being understood.” “I found out that there are a ton of people out there who understand me.”

Parents mentioned instrumental support significantly more than people with Moebius (who did not mention it at all). Parents exclusively described the benefits of consultations with healthcare professionals. Parents also mentioned nonspecific support marginally more than adults with Moebius. The higher use of nonspecific support may be accounted for by the finding that parents described seeking support for both their children and themselves “I find out about ways to help [my daughter] navigate life.”

Additionally, people with Moebius syndrome were seen as role models. A parent noted that “meeting adults with Moebius who are healthy and happy” was comforting. “It was really encouraging to meet adults who have Moebius syndrome and to see the young adults and teens - knowing that our kid would be okay. That he'd grow up and be successful.” Indeed, the role models saw benefit as well. An adult with Moebius syndrome noted “I enjoy and embrace being a silent role model for parents and kids.”

*3.3 Conference limitations*

Lack of relevance of informational support or to a particular age were mentioned most frequently when participants described what they liked least about conferences. Parents were more likely to have concerns about lack of informational support relevance, while people with Moebius had more concerns about age appropriateness of conference activities.

Concerns related to information support included wanting different information or feeling that information presented was “not applicable to our situation.” “I was looking for more info [about] parenting kids with Moebius.” Others felt that certain medical talks were hard to understand. Another concern was that “presentations were duplicated from previous years—but I can understand why—not everyone can attend every conference.” As a solution to these issues, one parent suggested that “notes and PowerPoints should be made available to families.” A contrasting concern about informational support was that “sometimes there were multiple sessions occurring at the same time so I missed things I wanted to see.”

Some adults noted that certain sessions and activities were not useful for their particular age or life stage; information on feeding, surgeries, causes, and treatments did not apply to them because they either had already received the information or were not interested. Participants noted that some talks did not address their particular symptoms: “every bit of information given could be vital to different people because not everyone with Moebius has had the same symptoms nor the same experiences.” “For me, the least helpful thing was the seminar about eyes and clubbed feet.”

Parents mentioned nonspecific support marginally more often than people with Moebius. For the most part, this occurred when instead of listing a limitation, parents responded by listing benefits, like “everything was very beneficial for my family.” One negative nonspecific support example came up: “in the mom-to-mom sessions there is a lot of guilt and getting stuck on the ‘why’ rather than how can we help our child succeed to their best ability.”

**4. Discussion**

 This study used a mixed-methods content analysis approach to examine reasons for attending or not attending Moebius syndrome conferences and conference benefits and limitations according to parents of and people with Moebius syndrome. Companionship was the most frequently mentioned code when participants were describing reasons for attending and conference benefits, a novel finding because companionship support is less frequently studied in the social support literature, and many previous support group studies cite emotional support as the most important (Hogan et al., 2002; Rodgers & Chen, 2005; Yao et al., 2015). In our sample, companionship was mentioned more frequently than emotional support, perhaps because the unique isolation and stigma of having or caring for someone with a visible rare disorder may lead people to strongly desire and benefit from socializing and sharing activities with people who have the same experience (Pelentsov et al., 2015). Similar to our findings, in one of the few studies examining companionship support, it was found to be the most commonly given form of social support in an online support group for cancer (Bambina, 2007).

Qualitative analysis of descriptions of companionship support revealed that participants perceived it to offer several destigmatizing functions, including normalization, reduced isolation, and solidarity. The experience of being nearly a majority group member for a weekend provides normalization. The conferences offer a place where one does not have to explain one’s condition to strangers and the condition is accommodated. Many participants noted they felt isolated by their disorder in their everyday lives. They would never have the opportunity to meet someone else with Moebius syndrome otherwise, so this aspect of the conference was highly valued. Many noted an instant connection that was attributed to shared experiences with Moebius syndrome that few others could understand.

Informational support was mentioned second most frequently when describing reasons for attending conferences and benefits. Parents are the initial seekers of information about a child’s developmental disability (Bogart & Hemmesch, 2016; Huyard, 2009; Pelentsov et al., 2015), and our results confirm that they value this sort of support. However, adults with Moebius syndrome also appreciated the opportunity to be educated by experts on Moebius syndrome. This is consistent with the frequent role reversal that occurs with a rare disorder in which the person with the condition or a caregiver must educate healthcare providers (Pelentsov et al., 2015).

Parents, but not adults with Moebius, described instrumental support as a conference benefit. This may be because parents seek the initial treatments for a child’s developmental disability, and once individuals with a stable disability reach adulthood, they require fewer new consultations and treatments.

Novel factors related to the rewards of giving support, and for a minority of participants, being role models and volunteering, also emerged. Giving support provides a sense of meaning and that one is valued (Taylor & Turner, 2001), and it is associated with better health and lower mortality risk (Brown, Nesse, Vinokur, & Smith, 2003). In a review, Hogan et al., (2002) noted the promise of support interventions that promote both giving and receiving support. Participants initially sought social support, and over time, shifted to giving support. This has interesting parallels to the literature on generativity, which is thought to increase with age, and is considered an important component to a meaningful and satisfying life (McAdams, de St. Aubin, & Logan, 1993).

*4.1 Strengths and limitations*

As with most research on rare disease samples, this study includes limitations that influence interpretation of these results. First, the study did not have sufficient power to detect small or medium effect sizes. Second, only parents of and people with Moebius syndrome who were somewhat engaged in Moebius syndrome and other support communities may have seen the notification of this study. Of those who did see the notification, participants self-selected into this study. As such, our sample may not be representative of the larger Moebius syndrome community, especially since motivation to participate in the study may be related to motivation to attend support conferences. Third, this project did not include comparisons with control groups (either from a common disorder or another rare disease), which may weaken generalization of these results to the larger rare disease community. However, rare disease do share common characteristics that may contribute to similar support needs. Fourth, although coders demonstrated high reliability for assigning codes to participant responses, we were unable to assess the reliability of the primary data. Finally, error may have been introduced into these analyses due to the differences in time elapsed since previous conference attendance, and participants’ interest in or familiarity with details of the specific 2014 MSF conference prior to attendance.

Despite the limitations noted above, the current study has several strengths. These are the largest samples of parents of and adults with Moebius syndrome collected in psychology research to date. Using both quantitative and qualitative content analyses allowed for triangulation of findings. The validity of our content analysis is supported by convergence with previous qualitative and quantitative findings (Bogart & Hemmesch, 2016; Briegel, 2012; Strobel & Renner, 2016), and the current analysis extends that knowledge by providing rich detail about perceptions of support conferences.

*4.2 Guidance for improving support for rare disabilities*

 Conference attendance reasons, benefits, and limitations identified in this research can be used as guidance when developing supportive interventions for people with a variety of rare disabilities. Finances, energy and health limitations, and location emerged as barriers to attending the support conference. Indeed, previous studies have noted that support groups tend to disproportionally attract people with higher socioeconomic status (Taylor, Falke, Shoptaw, & Lichtman, 1986), and parents of children with rare disorders report significant financial stress associated with healthcare costs and time away from work (Pelentsov et al., 2015). Participants acknowledged that the financial support offered by MSF in the form of a first-time conference attendee scholarship and personal fundraising helped to offset these costs. Additional financial support may be needed to allow for repeat attendance.

The limitations noted about the conference were issues about informational support and relevance to current symptoms or life stage. The challenges of covering representative topics in support groups have been previously noted (Taylor, Falke, Mazel, & Hilsberg, 1988). Many participants recognized that topics that were not relevant to them were relevant to other attendees. Although participants report that there is still more work to be done, the MSF conference does at least provide sessions tailored to specific groups of individuals (e.g., adults, teens, parents).

Support conferences may be ideal interventions for delivering all types of social support to people with rare disorders. Being able to see others with one’s rare condition in person, particularly if it is a visible condition such as Treacher Collins syndrome or Goldenhar syndrome, may be crucial for companionship support and destigmatization. However, the finding that limited resources and travel are barriers to attending support meetings points to the need to explore other practical avenues of support. Other formats that allow participants to see others like them, such as smaller, regional support meetings, or online support groups with video conferencing features may offer some of the same benefits. Informational support needs may be met through these avenues and many others, including websites, webinars, and brochures. More resources are needed to develop and study unique avenues for support delivery for people with a variety of types of rare disorders.

**References**

Aymé, S., Kole, A., & Groft, S. (2008). Empowerment of patients: lessons from the rare diseases community. *The Lancet*, *371*(9629), 2048–2051. https://doi.org/10.1016/S0140-6736(08)60875-2

Bambina, A. (2007). *Online social support: the interplay of social networks and computer-mediated communication*. Amherst, New York: Cambria press.

Bogart, K. R. (2014). The role of disability self-concept in adaptation to congenital or acquired disability. *Rehabilitation Psychology*, *59*(1), 107–115. https://doi.org/10.1037/a0035800

Bogart, K. R. (2015). “People are all about appearances”: A focus group of teenagers with Moebius Syndrome. *Journal of Health Psychology*, *20*, 1579–1588. https://doi.org/10.1177/1359105313517277

Bogart, K. R., Cole, J., & Briegel, W. (2014). On the Consequences of living without facial expression. In *Body--Language--Communication: An International Handbook on Multimodality in Human Interaction* (Vol. 2, pp. 1969–1982). Berlin, Germany: Walter de Gruyter.

Bogart, K. R., & Hemmesch, A. R. (2016). Benefits of support conferences for parents of and people with Moebius syndrome. *Stigma and Health*, *1*(2), 109–121. https://doi.org/doi: 10.1037/sah0000018

Bogart, K. R., & Matsumoto, D. (2010). Living with Moebius syndrome: Adjustment, social competence, and satisfaction with life. *The Cleft Palate-Craniofacial Journal*, *47*(2), 134–142. https://doi.org/10.1597/08-257.1

Bogart, K. R., & Tickle-Degnen, L. (2015). Looking beyond the face: A training to improve perceivers’ impressions of people with facial paralysis. *Patient Education and Counseling*, *98*(2), 251–256. https://doi.org/10.1016/j.pec.2014.09.010

Bogart, K. R., Tickle-Degnen, L., & Ambady, N. (2012). Compensatory expressive behavior for facial paralysis: Adaptation to congenital or acquired disability. *Rehabilitation Psychology*, *57*(1), 43–51. https://doi.org/10.1037/a0026904

Bogart, K. R., Tickle-Degnen, L., & Ambady, N. (2014). Communicating without the face: holistic perception of emotions of people with facial paralysis. *Basic and Applied Social Psychology*, *36*(4), 309–320. https://doi.org/10.1080/01973533.2014.917973

Bogart, K. R., Tickle-Degnen, L., & Joffe, M. S. (2012). Social interaction experiences of adults with Moebius Syndrome: A focus group. *Journal of Health Psychology*, *17*(8), 1212–1222. https://doi.org/10.1177/1359105311432491

Bradley, L. A., Young, L. D., Anderson, K. O., Turner, R. A., Agudelo, C. A., Mcdaniel, L. K., … Morgan, T. M. (1987). Effects of psychological therapy on pain behavior of rheumatoid arthritis patients. Treatment outcome and six-month followup. *Arthritis & Rheumatism*, *30*(10), 1105–1114. https://doi.org/10.1002/art.1780301004

Breslau, N. (1985). Psychiatric Disorder in Children with Physical Disabilities. *Journal of the American Academy of Child Psychiatry*, *24*(1), 87–94. https://doi.org/10.1016/S0002-7138(09)60415-5

Briegel, W. (2007). Psychopathology and personality aspects of adults with Möbius sequence. *Clinical Genetics*, *71*(4), 376–377. https://doi.org/10.1111/j.1399-0004.2007.00787.x

Briegel, W. (2012). Self-perception of children and adolescents with Möbius sequence. *Research in Developmental Disabilities*, *33*(1), 54–59. https://doi.org/10.1016/j.ridd.2011.08.013

Briegel, W., Schimek, M., & Kamp-Becker, I. (2010). Moebius sequence and autism spectrum disorders—Less frequently associated than formerly thought. *Research in Developmental Disabilities*, *31*(6), 1462–1466.

Briegel, W., Schimek, M., Kamp-Becker, I., Hofmann, C., & Schwab, K. (2009). Autism spectrum disorders in children and adolescents with Moebius sequence. *European Child & Adolescent Psychiatry*, *18*(8), 515–519. https://doi.org/10.1007/s00787-009-0003-1

Briegel, W., Schimek, M., Knapp, D., Holderbach, R., Wenzel, P., & Knapp, E.-M. (2009). Cognitive evaluation in children and adolescents with Möbius sequence. *Child: Care, Health and Development*, *35*(5), 650–655.

Brown, S. L., Nesse, R. M., Vinokur, A. D., & Smith, D. M. (2003). Providing social support may be more beneficial than receiving it results from a prospective study of mortality. *Psychological Science*, *14*(4), 320–327.

Cohen, J. (1960). A coefficient of agreement for nominal scales. *Educational and Psychological Measurement*, *20*(1), 37–46.

Davison, K. P., Pennebaker, J. W., & Dickerson, S. S. (2000). Who talks? The social psychology of illness support groups. *American Psychologist*, *55*(2), 205–217.

Hogan, B. E., Linden, W., & Najarian, B. (2002). Social support interventions: Do they work? *Clinical Psychology Review*, *22*(3), 381–440.

Huyard, C. (2009). What, if anything, is specific about having a rare disorder? Patients’ judgements on being ill and being rare. *Health Expectations*, *12*(4), 361–370. https://doi.org/10.1111/j.1369-7625.2009.00552.x

Joachim, G., & Acorn, S. (2003). Life with a rare chronic disease: the scleroderma experience. *Journal of Advanced Nursing*, *42*(6), 598–606. https://doi.org/10.1046/j.1365-2648.2003.02663.x

Kuklik, M. (2000). Poland-Möbius syndrome and disruption spectrum affecting the face and extremities: a review paper and presentation of five cases. *Acta Chirurgiae Plasticae*, *42*(3), 95.

Limb, L., Nutt, S., & Sen, A. (2010). Experiences of Rare Diseases: An Insight from Patients and Families. Rare Disease UK. Retrieved from http://www.raredisease.org.uk/documents/RDUK-Family-Report.pdf

Lombard, M., Snyder-Duch, J., & Bracken, C. C. (2002). Content analysis in mass communication: Assessment and reporting of intercoder reliability. *Human Communication Research*, *28*(4), 587–604.

Masnari, O., Schiestl, C., Rössler, J., Gütlein, S. K., Neuhaus, K., Weibel, L., … Landolt, M. A. (2013). Stigmatization predicts psychological adjustment and quality of life in children and adolescents with a facial difference. *Journal of Pediatric Psychology*, *38*(2), 162–172.

McAdams, D. P., de St. Aubin, E., & Logan, R. L. (1993). Generativity among young, midlife, and older adults. *Psychology and Aging*, *8*(2), 221–230. https://doi.org/10.1037/0882-7974.8.2.221

Meyerson, M. D. (2001). Resiliency and success in adults with Moebius syndrome. *The Cleft Palate-Craniofacial Journal*, *38*(3), 231–235.

Newsom, J. T., Rook, K. S., Nishishiba, M., Sorkin, D. H., & Mahan, T. L. (2005). Understanding the relative importance of positive and negative social exchanges: Examining specific domains and appraisals. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *60*(6), 304–312. https://doi.org/10.1093/geronb/60.6.P304

Pelentsov, L. J., Laws, T. A., & Esterman, A. J. (2015). The supportive care needs of parents caring for a child with a rare disease: A scoping review. *Disability and Health Journal*, *8*(4), 475–491.

Rodgers, S., & Chen, Q. (2005). Internet community group participation: Psychosocial benefits for women with breast cancer. *Journal of Computer-Mediated Communication*, *10*(4), 0–0. https://doi.org/10.1111/j.1083-6101.2005.tb00268.x

Shire. (2013). *Rare disease impact report: insights from patients and the medical community*. Retrieved from https://globalgenes.org/wp-content/uploads/2013/04/ShireReport-1.pdf

Strobel, L., & Renner, G. (2016). Quality of life and adjustment in children and adolescents with Moebius syndrome: Evidence for specific impairments in social functioning. *Research in Developmental Disabilities*, *53*, 178–188.

Taylor, J., & Turner, R. J. (2001). A longitudinal study of the role and significance of mattering to others for depressive symptoms. *Journal of Health and Social Behavior*, 310–325.

Taylor, S. E., Falke, R. L., Mazel, R. M., & Hilsberg, B. L. (1988). Sources of satisfaction and dissatisfaction among members of cancer support groups. In *Sources of satisfaction and dissatisfaction among members of cancer support groups* (pp. 187–208). Thousand Oaks, CA: Sage.

Taylor, S. E., Falke, R. L., Shoptaw, S. J., & Lichtman, R. R. (1986). Social support, support groups, and the cancer patient. *Journal of Consulting and Clinical Psychology*, *54*(5), 608–615. https://doi.org/10.1037/0022-006X.54.5.608

Telch, C. F., & Telch, M. J. (1986). Group coping skills instruction and supportive group therapy for cancer patients: a comparison of strategies. *Journal of Consulting and Clinical Psychology*, *54*(6), 802–808. https://doi.org/10.1037/0022-006X.54.6.802

Verzijl, H. T. F. ., van der Zwaag, B., Cruysberg, J. R. ., & Padberg, G. W. (2003). Möbius syndrome redefined. *Neurology*, *61*(3), 327–333. https://doi.org/10.​1212/​01.​WNL.​0000076484.​91275.​CD

Walker, K. K. (2014). Cognitive and affective uses of a thoracic outlet syndrome Facebook support group. *Health Communication*, *29*(8), 773–781. https://doi.org/10.1080/10410236.2013.800830

Yao, T., Zheng, Q., & Fan, X. (2015). The impact of online social support on patients’ quality of life and the moderating role of social exclusion. *Journal of Service Research*, *18*(3), 369–383. https://doi.org/10.1177/1094670515583271

**Table 1**

*Code descriptions and frequencies of use in participant responses*

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**Table 2**

*Mean code use describing reasons for attending or not attending an upcoming conference*

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*Note*. Unless otherwise noted, numbers represent mean use of codes for parents of and people with Moebius syndrome. † denotes p < .10

**Table 3**

*Mean code use describing perceptions of previous conferences*



*Note*. Unless otherwise noted, numbers represent mean use of codes for parents of and people with Moebius syndrome. † denotes p < .10; \* denotes *p* < .05