Disability-Related Problems of Children and Adolescents with Moebius Sequence and their Mothers' Coping

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Moebius syndrome (Online Mendelian Inheritance in Man no. 157900) or Moebius sequence is a rare nonprogressive congenital condition of still not fully understood etiology and pathogenesis, which is usually defined as a combination of facial weakness (uni- or bilateral) with impairment of ocular abduction (uni- or bilateral).¹ Disturbances in psychomotor and speech development are very common, whereas intellectual disability occurs in only 10% of children and adolescents.¹ Therefore, parents of children with Moebius syndrome are confronted with a variety of medical, psychosocial, and economic issues. They are in need of adequate information about disability-related problems and how these might affect their daily life.

To investigate these important aspects previously not delineated, a cross-sectional pilot study, including 26 subjects with Moebius syndrome (12 males, 14 females, median age: 9.4 years, range: 2–14 years) and their mothers (median age: 38 years; range: 28–47 years), was performed. Mothers completed:

- The German version of the Handicap-Related Problems for Parents Inventory (HPPI),² which comprises three subscales and a total scale. Internal consistency (Cronbach's α) in this study was: "Total": 0.90, "Mother/Child Social": 0.86, "Mother's Life": 0.73, "Child's Health and Services": 0.65.
- The Social Orientation of Parents with Disabled Children (SOEBEK),³ a validated German questionnaire on parental stress and coping strategies.

Twenty-four of the subjects with Moebius syndrome lived in two-parent families, and none of them attended a school or institution for children with intellectual disabilities. A maximum of 7.7% of the mothers reported every day or more disability-related problems in different HPPI areas during the 2 months before the study (→ **Table 1**). HPPI scales did not differ significantly between boys and girls. Parental stress (SOEBEK; median: 20th percentile; range: < 3rd–85th percentile) was significantly positively correlated with all HPPI

scales (Rho: 0.605–0.713, $p \leq 0.001$). Mothers reached average levels (median: 45th–60th percentile) for the SOEBEK coping strategies "partnership intensification," "ability to meet own needs," and "use of social support" while "focusing on the child with a disability" was low (median: 25th percentile).

Table 1 Handicap-related problems and their frequencies during the past 2 months before the study ($n = 26$)

HPPI area	At least once every week (%)	Every day or more (%)
My child's healthcare and therapies	30.8	0.0
My personal aspirations	26.9	3.8
My relationship with my spouse	26.9	3.8
My child's leisure or fun time	23.1	7.7
My child's behavior and discipline	19.2	0.0
My child's relationship with other family members, excluding myself	15.4	7.7
My child's transportation	15.4	7.7
My child's feeding, dressing, and hygiene	15.4	3.8
My child's education	15.4	0.0
My child's health	11.5	3.8
My family finances	11.5	0.0
My relationship with my child	11.5	0.0
My child's relationship with other children, excluding siblings	11.5	0.0
My job, education, or housework	11.5	0.0
My spiritual or religious life	7.7	0.0
My relationship with other family members	7.7	0.0
My relationship with friends	7.7	0.0

Abbreviation: HPPI, handicap-related problems for parents inventory.

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This pilot study has some limitations, especially questionable representativeness and lack of a matched control group. Nevertheless, it presents initial data on disability-related problems in subjects with Moebius syndrome and their mothers' coping strategies. These findings, which need replication, should be helpful for counseling. Moreover, they are encouraging for families of a child with Moebius syndrome.

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