Potential and Development of Children with Atypical Rett Syndrome (CDKL5 Gene Mutation) and Augmentative and Alternative Communication

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Abstract : Every child needs communication. If spoken language is not or not fully available due to congenital or acquired limitations, those affected need appropriate ways. These can be found in many possibilities of Augmentative and Alternative Communications (AAC). In the communication promotion of severely impaired children, who can use their own body communication forms only to a limited extent for the differentiated understanding, computers with eye control play an essential role. It takes some time to understand the individual forms of communication of the child. Children who depend on the AAC need competent support to learn to communicate in a motivated way in their everyday life. The aim of the present parents' survey (n = 4), which was evaluated descriptively, is to demonstrate the development of communicative abilities as well as the motivation to use complex communication aids with eye control by patients with atypical Rett Syndrome. An increase in communication skills, well-being, self-reliance, and self-esteem, an improvement in social participation, as well as a reduction in anger and screaming events, were noted. The complex visual communication tools were available daily for 3 out of 4 patients with atypical Rett Syndrome. It raises research questions regarding speech understanding and the ability to drive eye control technology in a larger group of atypical Rett Syndrome patients.

Keywords: augmentative and alternative communications, AAC, atypical Rett-syndrome, children, development

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