ABSTRACT

A qualitative study of the difficulties experienced by mothers of children with chromosomal disorder with multiple disabilities in school education

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22q11.2 deletion syndrome is a chromosomal disorder in which a variety of overlapping physical, intellectual, and mental disabilities are observed along different life stages, making it difficult to support these children under existing structures in educational systems. The purpose of this study is to clarify the difficulties in school education for mothers of children with diverse needs. Semi-structured interviews were conducted with six mothers to qualitatively analyze the difficulties and responses experienced throughout their schooling. As a result, it was found that children's needs are often overlooked in school, and that even when their needs are recognized, they are not supported. It was also found to be clear that mothers shoulder the burdens of many roles, such as providing and promoting education. It was suggested that there is a serious lack of support for the needs of children with multiple disabilities such as those with 22q11.2 deletion syndrome in Japanese school education. The role of psychological specialists, such as school counselors, in the current situation is discussed.

Key Words: 22q11.2 deletion syndrome, multiple disabilities, school education, role of psychological specialists, interviews with mothers