

ABSTRACT

Muscular dystrophy is a serious congenital disease that is currently incurable. There are many types of this disease, and one of its forms is Duchenne muscular dystrophy, which mainly affects boys and shortens their lives to a few decades. The absence of dystrophin in the muscles is manifested by the weakening of the muscles and their gradual loss. Boys soon lose the ability to walk and other momentum. At the same time, heart function, breathing, and bone quality are compromised. Such a life is not easy for a boy. Fatigue, lethargy, frustration come along with puberty. They have to get used to frequent medical examinations and checks, stretching exercises, various rehabilitations and stays in the spa. He needs to start asking for help and gradually asking for it more often and in many ways, eventually in almost all of them. Not only he needs psychological support, but also the caring family. The work seeks an answer to the question of what the quality of life with this disease can be, how it is experienced by the young person himself, and how it is seen by someone involved in the care. It describes this quality of life in different time periods gradually. Answers were also sought to the question of whether more could be done for the quality of life of these boys, e.g. through greater awareness of this issue, greater understanding. The investigation was conducted in the form of semi-structured in-depth interviews with young men with muscular dystrophy, several parents of the boys and with the educators who help care for these boys and young men. The result of the investigation is a research report beneficial for special pedagogy.

KEYWORDS

Duchenne muscular dystrophy, dystrophin, treatment and care, stages of life, quality of life.

