

Abstract

The bachelor thesis is focused on with the influence of current therapy on the quality of life of families of children with spinal muscular atrophy (SMA). The theoretical part of the thesis provides families a basic view of the issue of disease.

The aim of the bachelor thesis was to assess possible changes in the perception of quality of life of children with SMA before and after the application of the medicinal product Spinraza. Individual dimensions of quality of life and categories of common daily activities were assessed.

Methods: Quantitative research was carried out in the form of a questionnaire in three neuromuscular centers and the patient organizations SMÁci. Author's own questionnaire the design relies on a PedsQL touch screen (neuromuscular module). Research file consisted of 36 families of children with SMA (types I, II, III) treated with Spinraza.

Results: Spinraza has the effect of improving some dimensions of quality of life and on daily activities. Of gross motor skills in 77,78 % of children. The overall respiration condition was improved in 44,44 %. Swallowing improved in 34,29 % of children, especially in I. type. 16,64 % of families report their quality of life.

Conclusion: Spinraza affects quality of life of families of children. A positive, sometimes significant, effect led to improvement of the evaluation of daily life. The goal of healthcare multidisciplinary team is to permanently improve the quality of life of the SMA family.