P-034 - QUALITY OF LIFE IN CAREGIVERS OF CHILDREN WITH MUCOPOLYSACCHARIDOSIS

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INTRODUCTION: Mucopolysaccharidoses (MPS) are a group of rare genetic disease, characterized by deficiency of glycosaminoglycan degradations that causes progressive and generalized symptoms. Caregivers of individuals with disabilities may have reduction in Quality of Life (QoL) due dedication to the patient. OBJECTIVE: The present study aims to assess QoL in mother caregivers of children with MPS type I, IV and VI. METHOD: Cross-sectional study using a convenience sampling strategy. The World Health Organization Quality of Life Assessment (WHOQOL-BREF) was used to assess QoL. This study was approved by the Ethical committee of Pequeno Príncipe Hospital (CAAE 71602817.7.0000.0097). RESULTS: Seven caregivers of 7 patients with MPS (MPS I=1; MPS IV=3; MPS VI=3) were included. The average WHOQOL-BREF score was 72.7, with highest score in Social Relationships score (83.3) and lowest score in environment domain (55.0). No difference was identified between caregivers of patients with MPS I (60.0), IV (76.5) and VI (55.8). DISCUSSION: Caregivers median score of physical, psychological and social relationships domains was almost identified in healthy population but score of environment domain was lower. Assessment of the socioeconomic status revealed that most mothers were living in low-income or middle-income setting, fact that could impact in perception in environment domain. Although previous study of caregivers of patients with MPS presents with poorest quality of life, in this study caregivers had better perception of their own quality of life, with better results in all studied domains.