

Summary

Quality of life of parents raising children with chronic conditions relative to support received from non-governmental organisations

Introduction: A child's chronic condition leads to fundamental changes in the functioning of the entire family. Awareness of the disease and its incurable nature as well as a constant struggle for the child's better future adversely affect the quality of life of the parents and other family members. Cerebral palsy and autism are chronic conditions which pose enormous challenges related to specific needs of the affected child. The burden of 24-hour-a-day care, lack of support from family or public institutions, as well as difficulties in coping with the child's condition significantly affect parental quality of life.

Purpose: The study was designed to examine the importance of support from non-governmental organisations, as reflected by self-perceived parental quality of life, and to investigate selected psychosocial factors determining quality of life in parents of children with diagnosed cerebral palsy or autism.

Material and methods: The related research was conducted from April 2014 to December 2017. The individuals recruited for the study included 518 parents of children with the chronic conditions, receiving support from non-governmental organisations, as well as 195 parents of children with the chronic conditions, receiving no such support. The study was carried out using five research tools and a survey questionnaire designed by the author. Quality of life was assessed with SF-36 Quality of Life Questionnaire. Social support obtained was measured using the Interpersonal Support Evaluation List (ISEL – 40 v. GP). Caregiver burden was assessed in the parents with the New Burden Questionnaire for Families. On the other hand self-perceived satisfaction with life and ability to cope with difficulties were evaluated using Satisfaction with Life Scale (SWLS) and General Self-Efficacy Scale (GSES). The specially designed questionnaire was intended to provide selected sociodemographic data and information related to the subjects' self-assessed health status. Other items of the questionnaire focused on the child's characteristics, i.e. disease entity, age, sex, and intellectual disability level.

Results: The findings show that the parents taking care of children with chronic conditions reported a moderate quality of life (44.3%). Lower level of limitations was found in the domain of mental health (67.4%), compared to physical health (29.1%), which was additionally confirmed by a test of statistical significance ($p < 0.001$) applied to the relevant

indexes. In the study group, parental satisfaction with life was predominantly poor (N=336, i.e. 64.9%), while high level of satisfaction was reported only by 11.4% of the subjects (N=59). Nearly half of the parents in the study group (N=250, i.e. 48.3%) presented high level self-efficacy. Medium scores on this scale were obtained by 38.4% of the subjects (N=199), and low scores by 13.3% of the individuals (N=69). Social support in the relevant group of parents was assessed at a medium level 65.3%. The highest rating was found in the case of tangible support (74.3%), and the lowest in self-esteem support (57.3%). The study showed that majority of the parents in the study group (N=384, i.e.. 74.1%) reported medium caregiver burden.

Selected sociodemographic variables, such as age, education, housing conditions, and self-care performance were found to significantly ($p<0.05$) affect the quality of life in the parents of the children with chronic conditions. Likewise, demographic and clinical factors, such as the child's age and disease entity were shown to significantly ($p<0.05$) impact the caregivers' quality of life. A comparative analysis of the study group and the controls showed poorer quality of life in the study group than in the control group. Self-assessed caregiver burden was higher in the study group, while poorer perception of self-efficacy was more common in the controls. The parents in the study group presented higher overall rating of social support compared to the parents in the control group.

Conclusions: The current study shows that support received from non-governmental organisations corresponded to better perception of self-efficacy and ability to cope with difficult situations. The obtained support was also a determinant for higher rating of self-esteem support and tangible support, which significantly affected the quality of life of the parents of children with chronic conditions. Selected sociodemographic factors, such as age, education, housing conditions, and self-care performance affected the quality of life in the parents. Growing age and poorer housing conditions corresponded to lower quality of life. The parents with higher education and good self-care performance reported better quality of life. Furthermore, the parents of children over 10 years of age were found with poorer quality of life, particularly in the domains of overall health, physical and social performance, pain and vitality.

Keywords: quality of life, social support, caregiver, parents, autism, cerebral palsy.