

# Quality of Life in Parents of Children with Cerebral Palsy

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## Abstract

*Introduction:* When a child with disability, especially with cerebral palsy, is born into a family, there is a significant burden on the parents that directly impacts their quality of life. We believe the quality of life of a family with a child with cerebral palsy deserves research attention.

*Aim:* Therefore, in 2018 we carried out research aimed at examining the quality of life in parents of children with cerebral palsy.

*Method:* The research used a validated tool of a quantitative research strategy – a standardized QOL questionnaire, Family Quality of Life Scale – known as “FQOL”. The research sample consisted of parents with children with cerebral palsy. The total size of the sample was 98 respondents, 12 fathers (12.2%) and 86 mothers (87.8%).

*Results:* Average score by the respondents reached 94.0918 points, indicating higher quality of life in respondents than presumed. Further investigation revealed lower quality of life of respondents in five statements (items 3, 9, 13, 15). The research further examined statistically significant differences in quality of life in respondents depending on the researched socio-demographic indicators. Age-related statistically significant differences in quality of life were confirmed for the researched categories ( $t = -2.341$ ,  $p = 0.021$ ), family status ( $F = 3.476$ ,  $p = 0.019$ ) and region ( $\chi^2 = 15.39$ ,  $p = 0.031$ ). Statistically significant correlation was identified between quality of life in respondents and the age of their child with cerebral palsy ( $0.288$ ,  $p = 0.004$ ).

*Conclusion:* In spite of a relatively high score pointing at a higher level of experienced quality of life of the respondents, the research pointed to two areas of life where the parents of children with cerebral palsy experienced a lower level of quality of life, area of support and leisure-time activities of the parents.

**Keywords:** cerebral palsy, informal care givers, parents, quality of life

## Introduction

When a child with disability is born into a family, there is a significant burden on the parents. It involves emotional and practical challenges of how to organize family life. From the very birth of a child with disability, family life must be fully adjusted to the child's needs. The care primarily lies with the parents (Juhásová, 2015) who become the child's long-term care givers. The burden linked to the birth of a child with disability thus primarily lies with the parents (Olawale, Deih, & Yaadar, 2013; Pousada et al., 2013). Often, the parents must sacrifice their interests, social and work life and limit themselves solely to the care for their child with disability (Leung & Li-Tsang, 2003). This specifically applies to children with cerebral palsy.

Cerebral palsy has a significantly negative impact on a child's development. Often, the child is fully dependent on care and assistance from the family. The child's progress, achieved level of independence and quality of life is fully dependent on the commitment and dedication of the family.

Naturally, such a situation brings along a plenitude of emotional and social problems for the family with a child with cerebral palsy to deal with.

Prevendárová (1998) underpins that with a child with cerebral palsy in a family certain essential family functions are disrupted. An example could be its economic viability that is under heavy pressure. Often, the family budget is on the edge due to the high cost of rehabilitation, medical aids, transport of a child, etc. The family's relaxation options are also compromised – since care for a child with cerebral palsy requires continuous contact. Family socializing is eroded since the parents do not have time for developing and maintaining social relations when providing 24/7 care to their child. Vágnerová (2004) and Valenta, Michalík and Lečbych (2012) concluded that a family with a child with cerebral palsy has a different social identity than a family without a child with disability. When a child with cerebral palsy is born, this changes the lifestyle of everybody in a family since family life needs to be adapted to the child's capacities and needs. It is not only family lifestyle that changes. There are also changes in family behaviour, potentially a disruption of family interactions (Miller, 2005) or interactions with the social environment.

One of the most severely impacted areas of family life is emotional experiences, mostly those of the parents. They can experience feelings of panic, anxiety, despair or even anger, indifference and apathy (Vijesh & Sukumaran, 2007). International research points to a higher level of stress, depression and tension in parents of children with cerebral palsy (Cheshire, Barlow, & Powel, 2010; Cowen & Reed, 2002; Mobarak, 2000). The main sources of stress for parents raising a child with cerebral palsy result from providing care for a disabled child, gaining adequate professional support and assistance in meeting the child's needs. Further challenges include raising the child, arranging for education, potential prejudice-based social attitudes and others (Benson, 2006; Petalas, Hastings, Nash, Lloyd, & Dowey, 2009; Rao & Beidel, 2009). The health complications of the child combined with frequent visits to health care institutions or hospitalizations are additional potential stressors.

The above indicates that a family with a child with cerebral palsy is subjected to an enormous burden that directly impacts the quality of life (hereinafter the "QOL") of its members, mainly parents. Kotzampopoulou (2015) notes that a well-functioning society needs each and every family to be stable and well-functioning. At the same time the QOL of parents with children with health disabilities is linked to the QOL of the disabled child and other family members. Thus we believe the QOL of a family with a child with a health disability, in our case a family with a child with cerebral palsy, deserves research attention. Therefore, in 2018 we carried out research aimed at examining the QOL in parents with children with cerebral palsy.

## **Aim**

The main aim of the research was to benchmark the quality of life in parents of children with cerebral palsy. Partially, we focused on the correlation between QOL in parents of the child with cerebral palsy, the sex and age of the research respondents, age of the child with cerebral palsy and the number of children in the family.

## Method

### *Research sample*

The sample consisted of parents with children with cerebral palsy. A non-probability sampling was used as the selection method. The selection was made based on pre-defined criteria. Enrolment criteria included the following:

- Parents of children with cerebral palsy;
- Age above 18 years;
- Shared household;
- Intensive spent time.

Parents who receive service of early childhood intervention in centres were asked to participate in the survey. There were two options for answering the questionnaire: online (via email with the URL) or via conventional mail. Respondents were requested to complete the questionnaire during the survey period, January 1 to January 31, 2018.

The total size of the sample was 98 respondents, age 27 to 52 years. The research group consisted of 12 fathers (12.2%) and 86 mothers (87.8%). For more information on the sample, see Table 1.

Tab. 1 **Socio-demographic characteristics of the sample (n = 98)**

<b>Variable</b>		<b>Frequency (n)</b>	<b>Percent (%)</b>
<b>Gender</b>	Male	12	12.2
	Female	86	87.8
<b>Age</b>	18–34	37	37.8
	35–44	38	38.8
	45–64	23	23.5
<b>Marital status</b>	Single	21	21.4
	Married	64	65.3
	Divorced	11	11.2
	Separated	2	2.0
	With a partner	64	65.3
	Without a partner	34	34.7
<b>Education</b>	Higher education	59	60.2
	University education	39	39.8
<b>Number of respondent's children with cerebral palsy</b>	1	92	93.9
	2	6	6.1
<b>Age of respondent's children with cerebral palsy</b>	1–6	62	63.3
	7–14	14	14.3
	15+	22	22.4

### *The tool*

The research used a validated tool of a quantitative research strategy – a standardized QOL questionnaire, *Family Quality of Life Scale* – known as “FQOL”. The FQOL Scale was developed by a research team from the University of Kansas in 2003. The initial framework for scale development resulted from extensive literature reviews, focus groups, and individual interviews with family members of children with disabilities, individuals with disabilities, service providers, and administrators of service agencies. Now this scale assesses families’ perceptions of their satisfaction with different aspects of family quality of life. It consists of twenty-five statements that are assessed through a Likert-type scale from “very unsatisfied” to “very satisfied” (Hoffman, Marquis, Poston, Summers, & Turnbull, 2006).

With a view to meet research goals, the research questionnaire not only contained a standardized scale but also another series of questions examining demographic and socio-economic data. Collected data was processed with IBM SPSS Statistics software in 22.0.0.

## **Results**

Initially, we subjected the FQOL scale to a reliability test which showed a very high level of reliability ( $\alpha = 0.943$ ). The SPSS programme analysed and evaluated the average score of the research respondents, the total value of which was 94.0918 points.

Examining the respondents’ answers more meticulously and following the average values of all items on the scale one by one it became evident that the average score was clearly higher only in four statements (items 8, 12, 23, 24)<sup>1</sup> that pointed to a higher QOL level. The lowest average score, pointing to a lower quality of life was identified in item No. 9 (My family members have some time to pursue our own interests, mean [m] = 3.0816, standard deviation [SD] = 1.224), No. 3 (My family has the support we need to relieve stress, m = 3.2143, SD = 1.123), No. 13 (My family has outside help available to us to take care of special needs of all family members, m = 3.2347, SD = 0.917) and No. 15 (My family gets medical care when needed, m = 3.357, SD = 1.177) (Figure 1).

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<sup>1</sup> Meaning of items of the FQOL Scale with the highest average score:

8. My family members teach the children how to get along with others.

12. My family members show that they love and care for each other.

23. My family member with a disability has support to accomplish goals at home.

24. My family member with a disability has support to make friends.

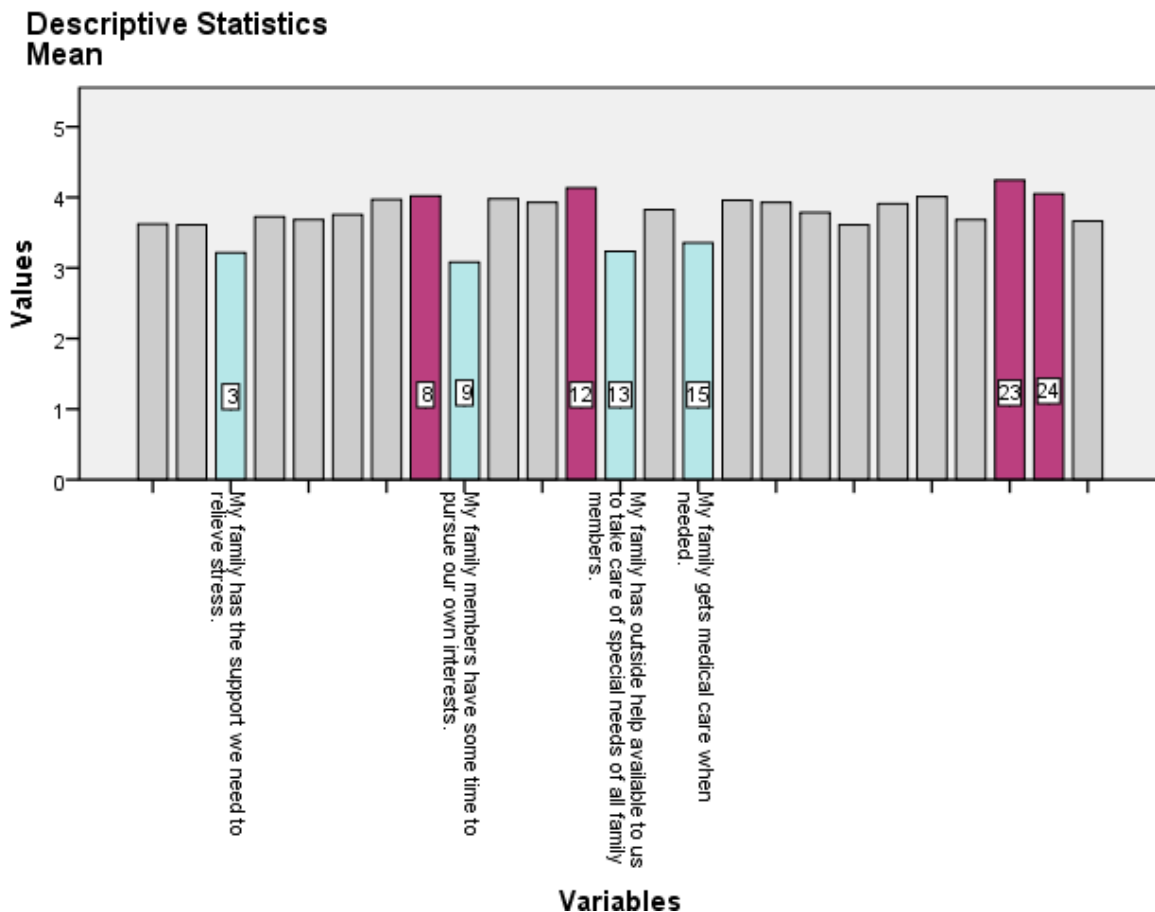


Fig. 1 Average score for each item on the scale

The research further examined statistically significant differences in quality of life in respondents depending on the researched socio-demographic indicators. Statistically significant differences in QOL were confirmed in the terms of age ( $t = -2.341$ ,  $p = 0.021$ ), family status ( $F = 3.476$ ,  $p = 0.019$ ) and region ( $\chi^2 = 15.39$ ,  $p = 0.031$ ). Statistically significant correlation was identified between QOL in respondents and the age of their child with cerebral palsy ( $0.288$ ,  $p = 0.004$ ).

The research thus confirms that respondents over 35 years ( $m = 96.93$ ) demonstrated higher QOL than respondents under 35 years ( $m = 89.40$ ). Quality of life was also related to the age of their child with cerebral palsy. The research shows that QOL has a positive correlation with the age of a child with cerebral palsy. The lowest QOL was demonstrated by single respondents ( $m = 86.90$ ) and those who were separated from the partner ( $m = 82.50$ ). In the middle there were married respondents ( $m = 95.18$ ) and the highest QOL had divorced respondents ( $m = 103.54$ ). Statistically significant differences in QOL in the terms of the region show, that the highest QOL was demonstrated by respondents from the Košice region ( $m = 100.06$ ). Lower QOL had respondents from the Trnava region ( $m = 98.24$ ), the Prešov region ( $m = 92.86$ ), the Banská Bystrica region ( $m = 90.15$ ), the Žilina region ( $m = 90.00$ ), the Trenčín region ( $m = 87.00$ ), the Bratislava region ( $m = 79.50$ ) and the lowest QOL had respondents from the Nitra region ( $m = 71.75$ ).

Since the research shows that the lowest QOL in respondents was connected to areas that were the subject of items 3, 9, 13 and 15, we focused on identifying statistically significant differences in QOL based on social and demographic indicators, also in connection with the above statements. Testing confirmed statistically significant, age-related difference in the satisfaction of the respondents with the level of stress-alleviating support ( $Z = -2.00$ ,  $p = 0.045$ ). We also

demonstrated a statistically significant correlation between the age of the respondents and satisfaction with the amount of time available for personal interests (0.199,  $p = 0.049$ ), satisfaction with the amount of time available for personal interests and number of children with health disability (-0.253,  $p = 0.012$ ), and satisfaction with early provision of health care and the age of a child with health disability (0.283,  $p = 0.005$ ).

Married couples experienced the lowest level of external support ( $m = 45.62$ ). A higher level of satisfaction with the amount of external support was observed in unmarried respondents ( $m = 46.50$ ) and the highest in divorced respondents ( $m = 69.09$ ). Respondents above age 35 indicated a higher level of satisfaction with support in alleviating stress ( $m = 53.84$ ) than respondents below 35 years ( $m = 42.35$ ). Another age-related finding was that the higher the age of the respondents the higher the satisfaction rate with the amount of time they could devote to their own interests. Among respondents in our study, the level of satisfaction with time for personal interests directly and proportionally declined with the number of children with a health disability. Statistically significant correlation was also identified between the age of a child and the satisfaction of care givers with the adequacy of health care and its timeliness – the younger age of a child, the lower the satisfaction.

## **Discussion**

The research shows that overall deterioration in QOL can be observed primarily in mothers caring for children with cerebral palsy (Mugno, Ruta, D'Arrigo, & Mazzone, 2007). This is understandable by the fact that most of the care for a child with a health disability lies with mothers, and this frequently becomes their informal career (Kaya et al., 2010; Oh & Lee, 2009; Ones, Yilmaz, Cetinkaya, & Caglar, 2005).

Vágnerová, Strnadová and Krejčíková (2009) also support this opinion. They believe that mothers of children with cerebral palsy are more affected by stress and stressful situations resulting from care for a child than fathers or other family members. The authors state that stress experienced by a mother impacts her quality of life and subsequently has a negative impact on the quality of life of other family members. These statements, however, have not been confirmed through our research – our testing did not statistically confirm significant differences between the QOL of men and women. Still, we did manage to confirm age-related dependence in QOL of parents with children with cerebral palsy. This finding was not only confirmed for the overall QOL, but also for satisfaction with leisure time. Parents over the age of 35 with children with cerebral palsy were more content with the time designated for their personal interests. Logically, this is closely related to another finding that the more children with cerebral palsy the parents had, the less they were satisfied in this area. There was also a correlation with the fact that the younger the child with cerebral palsy, the lower the parental satisfaction with the overall QOL and the lower the sense of support from the health care system, i.e. the parents tended to identify themselves with the statement they did not receive health care services when they needed them the most. Parents under the age of 35 reported feeling a lower level of support by the health care services and overall external support. It can be expected that the younger the child, the higher the stress and burden experienced by the parents. That leads to a lower sense of the quality of life. Our results are also confirmed by findings of Glenn, Cunningham, Poole, Reeves and Weindling (2008) and Ones, Yilmaz, Cetinkaya and Caglar (2005). They identified that the stress level in parents is not so much related to the functional level of their child but rather to whether they have access to resources and support. Koučová and Sikorová (2014) demonstrated that insufficient professional support offered

to the parents of children with disabilities may be a source of their stress. Both our and their research confirm that the source of stress in parents of a child with a health disability is a lack of time and freedom as a result of time-consuming, physically and emotionally demanding care for a child. Brown, Macadam-Crisp, Wang and Iarocci (2006) also underline the importance of support as a significant factor having influence on the QOL of a family with a child with a health disability. Findings of their survey showed that families' satisfaction and needs varied within the nine quality of life domains assessed, raising questions of support and care and the ability of families to pursue desired goals. The authors suggest that there is a need to both identify and provide measures of care and support that would enable families to function at an optimum level within their home and community so they may experience a quality life similar to that of families without a child with a disability (Brown et al., 2006). In the conditions of the Slovak Republic, the service of early intervention is perceived as this type of measures of care and support. The service aims at offering early support to families with a child with health disability through comprehensive services based in long-term accompaniment and support to families with those children in a way that contributes to building a cohesive and inclusive society (Slaná, Hromková, & Molnárová Letovancová, 2017).

## **Conclusion**

In spite of a relatively high score (94.0918) pointing at a higher level of experienced QOL of the respondents, the research pointed to two areas of life where the parents of children with cerebral palsy experienced a lower level of QOL. The research shows that raising a child with cerebral palsy is linked with time-consuming care that limits leisure-time activities of the parents and is a situation for the parents and the family that definitely requires support by professionals, extended family or community. The needed support would allow the parents and other family members to satisfy their needs, not only those of the child with cerebral palsy; the support would offer emotional assistance to the parents, decreasing the psychological burden and stress that accompanies the family in such a demanding situation. The early intervention service could represent this kind of support. Thus, early intervention could be a service that will contribute to increasing the QOL of families with children with health disabilities and to improving their functioning and participation in the society.

### *Survey limitations*

The size of the research sample was considered as a limitation of our survey.

## **Ethical Aspects and Conflict of Interest**

The authors of this article declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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## **Reference List**

Benson, P. R. (2006). The impact of child symptom severity on depressed mood among parents of children with ASD: The mediating role of stress proliferation. *Journal of Autism and Developmental Disorders*, 36, 685–695.

- Brown, I. R., Macadam-Crisp, J., Wang, M., & Iarocci, G. (2006). Family quality of life when there is a child with a developmental disability. *Journal of Policy and Practice in Intellectual Disabilities*, 2006, 3(4), 238–245.
- Cheshire, A., Barlow, J. H., & Powell, L. A. (2010). The psychosocial well-being of parents of children with cerebral palsy: a comparison study. *Disability and Rehabilitation*, 32(20), 1673–1677.
- Cowen, P. S., & Reed, D. A. (2002). Effects of respite care for children with developmental disabilities: evaluation of an intervention for at risk families. *Public Health Nursing*, 2002, 19(4), 272–283.
- Glenn, S., Cunningham, C., Poole, H., Reeves, D., & Weindling, M. (2008). Maternal parenting stress and its correlates in families with a young child with cerebral palsy. *Child: Care, Health and Development*, 35(1), 71–78.
- Hoffman, L., Marquis, J., Poston, D., Summers, J. A., & Turnbull, A. (2006). Assessing family outcomes: psychometric evaluation of the beach centre family quality of life scale. *Journal of Marriage and Family*, 68(4), 1069–1083.
- Juhásová, A. (2015). Comparison of quality of life of families with children with disability and families with children without disability. *Procedia-Social and Behavioral Sciences*, 174, 3378–3384
- Kaya, K., Unsal-Delialioglu, S., Ordu-Gokkaya, N. K., Ozisler, Z., Ergun, N., Ozel, S., & Ucan, H. (2010). Musculo-skeletal pain, quality of life and depression in mothers of children with cerebral palsy. *Disability and Rehabilitation*, 32(20), 1666–1672.
- Kotzampopoulou, I. (2015). *Quality of life in families having children with disabilities: The parents' perspective* (thesis). Oslo: University in Oslo.
- Koučová, J., & Sikorová, L. (2014). Dopady tělesného postižení dítěte na psychickou pohodu rodičů. *Ošetrovatelstvo. Teória – výskum – vzdelávanie*, 4(1), 26–32.
- Leung, S. Y. C., & Li-Tsang, P. W. C. (2003). Quality of life of parents who have children with disabilities. *Hong Kong Journal of Occupational Therapy*, 13(1), 19–24.
- Miller, F. (2005). *Cerebral Palsy*. Berlín: Springer.
- Mobarak, R. (2000). Predictors of stress in mothers of children with cerebral palsy in Bangladesh. *Journal of Pediatric Psychology*, 25(6), 427–433.
- Mugno, D., Ruta, L., D'Arrigo, V. G., & Mazzone, L. (2007). Impairment of quality of life in parents of children and adolescents with pervasive developmental disorder. *Health and Quality of Life Outcomes*, 5(22), 22–30.
- Oh, H., & Lee, E. (2009). Caregiver burden and social support among mothers raising children with developmental disabilities in South Korea. *International Journal of Disability, Development and Education*, 56(2), 149–167.
- Olawale, A. O., Deih, N. A., & Yaadar, K. K. R. (2013). Psychological impact of cerebral palsy on families: the African perspective. *Journal of Neurosciences in Rural Practice*, 4(2), 159–163.
- Ones, K., Yilmaz, E., Cetinkaya, B., & Caglar, N. (2005). Assessment of the quality of life of mothers of children with cerebral palsy (primary caregivers). *Neurorehabilitation and Neural Repair*, 19(3), 232–237.
- Petalas, M. A., Hastings, R. R., Nash, S., Lloyd, T., & Dowey, A. (2009). Emotional and behavioral adjustment in siblings of children with intellectual disability with and without autism. *Autism*, 13(5), 471–483.



- Pousada, M., Guillamón, N., Hernández-Encuentra, E., Muñoz, E., Redolar, D., Boixadós, M., & Gómez-Zúñiga, B. (2013). Impact of caring for a child with cerebral palsy on the quality of life of parents: a systematic review of the literature. *Journal of Developmental and Physical Disabilities*, 25(5), 545–577.
- Prevendárová (1998). *Rodina s postihnutým dieťaťom*. Nové Zámky: Psychoprof.
- Rao, R. A., & Beidel, D. G. (2009). The impact of children with high-functioning autism on parental stress, sibling adjustment, and family functioning. *Behavior Modification*, 33(4), 437–451.
- Slaná, M., Hromková, M., & Molnárová Letovancová, K. (2017). *Včasná intervencia. Vývoj, súčasný stav a teoretické východiská*. Trnava: Váry s.r.o.
- Vágnerová, M. (2004). *Psychopatologie pro pomáhající profese*. (3rd ed.). Praha: Portál.
- Vágnerová, M., Strnadová, I., & Krejčová, L. (2009). *Náročné mateřství*. (1st ed.) Praha: Univerzita Praha.
- Valenta, M., Michalík, J., & Lečbych, M. (2012). *Mentální postižení: v pedagogickém, psychologickém a sociálně-právním kontextu*. (1st ed.) Praha: Grada.
- Vijesh, P. V., & Sukumaran, P. S. (2007). Stress among mothers of children with cerebral palsy attending special schools. *Asia Pacific Disability Rehabilitation Journal*, 18(1), 76–92.

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