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Original research article

Factors influencing the quality of life of parents raising a child with a disability

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Abstract

Objectives: The aim of the paper is to present the results of research aimed at determining the quality of life of parents of a child with a disability.

Theoretical base: Quality of life, as a multidimensional and multidisciplinary concept, is an important research area in social work. In Slovakia, at least 2,500 children are born with a disability every year. This situation is a long-term burden for parents and the extended family that significantly affects their quality of life.

Methods: To reach our goal, we have chosen a quantitative research strategy using a valid research tool, the standardized Family Quality of Life Scale.

Results: Results of the research indicate a higher level of quality of life of the respondents than we expected. However, a reduced quality of life of the respondents was found in the dimensions of the scale *"Parenting"*, *"Family interaction"* and *"Emotional well-being"*. The research also confirmed that there are statistically significant differences in the quality of life of respondents depending on marital status, self-governing region, and education.

Keywords: Emotional support; Parenting; Satisfaction with the quality of life; Social quality of life of parents; Support

Introduction

Quality of life studies (QoL) have become widespread over the last three decades and are an area of interest for many fields of science (Cummins, 2005; Davis et al. 2009; Memisevic et al., 2017; Schalock, 2000). The notion of quality of life is often connected with the issue of disability, most frequently in relation to the life of the family or the parents of a child with a disability themselves. This is due to the fact that after the birth, the care for a child with disability is mainly in the hands of the parents themselves (Emerson and Hatton, 2008; Juhás, 2015), who become their long-term care-givers. Parents must largely sacrifice their interests, social or professional life, and limit it predominantly to caring for their child with a disability (Beighton and Wills, 2016; Leung and Li-Tsang, 2003). For this reason, the birth of a child with a disability is a stressful situation, especially for parents (Beighton and Wills, 2016; Cooper, 1991; Ellis et al., 2000; Elmstähl et al., 1996).

For the purpose of this paper, we refer to the "bio-psycho-social model" based on the International Classification of Functioning, Disability and Health (IFC, 2001) when defining the notion of *disability*. It is a concept that goes beyond the dichotomic view of disability as an individual medical or structural and social problem, and perceives it as a "dynamic interaction between health conditions and contextual – both personal and environmental – factors" (Repková and Sedláková, 2014). Slovak legislation describes disability as *"any mental, physical, temporary, long-term or permanent disorder or handicap that prevents persons with a disability from adapting to the typical demands of life"* (Ministry of Labour..., 2022). The terminological definition of "person with disability" is not unambiguous. The most recent Act 317/2010 Coll. defines "persons with disability as having long-term physical, mental, intellectual or sensory disorders which, along with interaction with various obstacles, may prevent them from effectively contributing to society on an equal basis with others". In cases of children with a disability, we are also confronted with conceptual diversity. The same child is referred to as a child with a disability, a child with a disadvantage (Act 245/2008 Coll.), a child with an unfavourable health condition (Act 600/2003 Coll.) or a child/student with special needs. The authors Repková and Sedláková (2014) emphasise that this so-called "terminological labyrinth" concerns mainly legislation. With respect to the classification of disability under the Convention on the Rights of Persons with Disability, the basic division recognizes physical, intellectual, sensory and combined disability (Krhutová, 2011). This division is complemented or internally differentiated by several authors (Kuzníková et al., 2011; Michalík et al., 2011).

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However, research in several countries around the world does not differ significantly when it comes to knowledge of the quality of life of parents who have children with a disability, depending on the type of the child's disability. Regardless of whether it concerns physical (Chalipat et al., 2016; Pousada et al., 2013; Shivers and Resor, 2020), intelectual (Čolić et al., 2019; Dizdarevic et al., 2020; Misura and Memisevic, 2017; Singh et al., 2016; Staunton et al., 2020) or combined disability (Kolcic, 2018; Leung and Li-Tsang, 2003), the results confirm the negative impact of children's disability on the quality of life of their parents. Variations in the quality of parents' life related to the type of disability are caused by the degree and extent of the child's disability (Dizdarevic et al., 2020; Haimour and Abu-Hawwash, 2012; Huang et al. 2014; Jenaro et al., 2020; Leung and Li-Tsang, 2003; Pineio et al., 2020).

The above-mentioned studies jointly claim that the birth of a child with a disability is a stressful situation, both emotionally and in terms of the organisation of family life. From the moment the child is born, family life fundamentally changes and adapts to the child's needs. Children with a disability become the sole focus of their parents (Slaná et al., 2017) which, according to the parents' opinion, directly affects their quality of life (Kotzampopoulou, 2015). The quality of life of families with a child with a disability is also affected by the constant changes associated with meeting the specific needs of the child, and this in turn limits the ability of these families to meet the needs of other members. Parents are confronted with restrictions on working life or education, social life, leisure and so on (Chalipat et al., 2016; Dardas and Ahmad, 2014; Leung and Li-Tsang, 2003; Pousada et al., 2013). Moreover, they have to deal not only with the problems associated with the child's disability, but also with the maintenance and running of the whole household, while tending to further requirements of everyday life (Olawale et al., 2013). According to Witzanyová and Velemínský (2019), parents also tend to change their lifestyle and values.

The part of parents' life which covers emotional experience and emotional well-being is particularly affected, since they may experience feelings of panic, anxiety, helplessness, or even anger, indifference, and apathy (Vijesh and Sukumaran, 2007). Feelings of failure and guilt are also often present (Dervishaliaj, 2013; Jenaro et al., 2020). Research from abroad shows that parents of children with a disability are more likely to exhibit signs of stress, depression and tension (Chakraborty et al. , 2019; Cheshire et al., 2010; Dobríková et al., 2015; Huang et al. 2014; Hung et al., 2004; Jenaro et al., 2020; Parkes et al., 2011; Pousada et al., 2013). Chakraborty et al. (2019) confirm that stress negatively affects the overall quality of life, regardless of whether this concerns physical or intellectual disability. Parents experience stress associated with providing for a child with a disability, in particular, as a result of the increased requirements for the provision of care, the actual parental role and the responsibility attached to it, the manifestations of the child's behaviour and/or the child's cognitive problems, the presence of health issues, and the fulfilment of the child's needs as related to education and training. Parents may also experience stress in relation to social attitudes resulting from prejudices that the family might have to face, as well as with finding adequate professional assistance and support while, at the same time, not receiving sufficient social support in the form of benefits (Benson, 2006; Jenaro et al., 2020; Olawale et al., 2013; Petalas et al., 2009; Pousada et al., 2013; Rao and Beidel, 2009). The adverse effects on the relationship between parents (Leutar and Oršulić, 2015) has also been proven. The risk of the parents' marriage falling apart along with the impending threat of poverty are other confirmed factors that directly affect the quality of life, as well as the life satisfaction of parents of children with a disability (Džamonja Ignjatović, 2019; Shivers and Resor, 2020).

A child's disability can also bring positive effects on the life of the family. Studies based on qualitative research strategies have identified three types of positive effects. The first group consists of intrapersonal factors, which influence the parents directly, such as personal empowerment, growth, change of priorities, stronger appreciation of life, and increased spirituality and/or religiosity. The second group consists of interpersonal factors related to the surroundings, such as more meaningful relationships with others, extended personal and social networks, child's positive impact on others/community, feelings of unity and closeness of the family, increased mutual tolerance and understanding. The third group comprises factors related to children as a source of positivity and happiness, including in relation to their achievements. The positive aspects identified above are mainly composed of coping strategies focused on relevance. However, even in case of these qualitative studies, from the beginning of the interview parents mainly verbalized the negative effects of disability that influenced their lives and which coincided with the above findings (Beighton and Wills, 2016).

The above-mentioned factors indicate that families with children with a disability are subject to an enormous burden, and this directly affects the quality of life of individual family members, especially parents. It is important to mention that the quality of life of parents of children with a disability is interlinked with the quality of life of the disabled child and other family members (Child Care Research Network, 2002; Kotzampopoulou, 2015; Parkes et al., 2011). Dervishaliaj (2013) states that parental stress reciprocally affects their child with a disability. The more dissatisfied the parents are, the more stress they feel, and consequently they meet the child's needs to a lesser extent, lowering the quality of their child's life. This is why we consider it important to pay attention to the topic of the quality of life of a family with a child with a disability, as well as to the factors affecting their quality of life. As a result, a better understanding of the quality of life and the factors affecting it can help to provide more direct assistance to the affected families. In light of this, we carried out research aimed at assessing the quality of life of parents of a child with a disability.

The main objective of the research was to define *the quality of life of the parents raising a child with a disability*. A partial objective was to find out whether there are differences in the quality of life of parents of a child with a disability depending on gender, family status, domicile, age of a parent, age of a child with a disability and the child's diagnosis or type of disability.

Materials and methods

To meet our objective, we decided to apply a quantitative research strategy using a valid research tool, namely the standardized *Family Quality of Life Scale* (FQOL). This questionnaire aims to determine the satisfaction of families with children with a disability via diverse aspects of quality of life. The questionnaire consists of 25 statements, which are assessed on a 5-degree Likert scale, from "very dissatisfied" to "very satisfied". Statements are grouped into five dimensions. Throughout its development, the scale has undergone several stages of testing and analysis. Of the originally studied 10 dimensions,

the authors from the Beach Center on Disability developed a scale of 5 dimensions, namely: *family interaction, parenting, emotional well-being, physical/material well-being*, and *disability-related support* (Hoffman et al., 2006).

For the purpose of our research, we have complemented the FQOL scale with questions concerning demographic and socioeconomic data. All data obtained were subsequently processed via IBM SPSS Statistics v. 22.0.0.

The normality of the distribution was tested via Kolmogorov–Smirnov test, followed by the Kruskall–Wallis and Mann–Whitney U test.

Research sample

In order to determine a research sample, we applied a non-random targeted selection. The sample selected for our research consisted of parents raising a child with a disability. The initial selection criteria were:

- a parent of a child with a disability;
- age over 18;
- living in the same household;
- with a child up to 18 years of age.

When calculating the research sample size, we relied on statistics about the number of children with a disability between 0 and 18 years of age. Due to the absence of one comprehensive set of statistics that provides such data, we decided to use the summary statistical reports of the Association of Providers and Supporters of Early Intervention and the statistical report of the Centre of Scientific and Technical Information of the Slovak Republic CVTI SR (CVTI SR, 2019; Fričová et al., 2018), according to which there are approximately 73,383 children with a disability in Slovakia between the age of 0 and 18. Approximately the same number of families are primary care-takers of children with a disability. It was always just one parent from a family with a child with a disability who participated in our research. According to our calculation, the size of the research sample totalled at 382 respondents, with the confidence rate set at 95% and the confidence interval at 5. Finally, 550 respondents participated in our research. To facilitate contact with the parents, we asked for cooperation from the centres of special-pedagogical counselling, early intervention centres, social service centres guaranteeing the provision of early intervention services, day care centres, as well as specialized schools. The distribution and collection of questionnaires took place during the first six months of 2019. Subsequently, the accumulated research data were analysed.

A total of 550 respondents between 18 and 65 participated in our research. The research sample consisted of 69 men (12.5%) and 481 women (87.5%). For further demographic data, see Table 1.

As indicated in the initial criteria for the selection of the research sample, we conducted the research with parents of children with a disability aged between 0 and 18. Distribution of disability as well as the age of children is shown in Table 2.

The research study was conducted in accordance with the Ethical Principles of Human Research adopted by the American Psychological Association (APA). Respondents submitted their informed consent before the start of the research. Each respondent was informed about the research objectives, procedures, and use of research data. At the same time, respondents were allowed to obtain the research results published in the research report if they were interested. Participation in the research was voluntary. Particular attention was paid to maintaining the anonymity and confidentiality of the respondent.

Table 1. Representation of respondents based on monitored demographic characteristics

	N	%
Gender		
woman	481	87.5
man	69	12.5
Age		
18–34	182	33.1
35–44	272	49.5
45–65	96	17.4
Self-governing region		
Banská Bystrica	135	24.5
Bratislava	27	4.9
Kosice	96	17.5
Nitra	33	6.0
Prešov	62	11.3
Trenčín	63	11.5
Trnava	63	11.5
Žilina	71	12.9
Place of residence		
town	304	55.3
municipality	246	44.7
Marital status		
single/single	90	16.4
married/married	373	67.8
divorced	62	11.3
separated/separated	8	1.5
other	17	3.1

Table 2. Distribution of respondents' children based on demographic features

	N	%
Type of disability		
physical	144	26.2
intellectual	249	45.3
combined	157	28.5
Age		
0–3	78	14.2
4–7	210	38.2
8–11	138	25.1
12–15	73	13.3
16–18	51	9.3

Results

At the beginning of the evaluation of the FQOL scale, we subjected the range itself to reliability testing. This showed a very sound degree of scale reliability (Cronbach's alpha = 0.951). In the SPSS programme, we calculated the average score achieved by our respondents showing their overall quality of life. It may have ranged from 25 to 125 points, while the applicable rule dictates that the higher the score, the better the quality of life. The average score was 92.6963 points, indicating a better quality of life for our respondents. We also evaluated the average score for each dimension of the scale. The results show the satisfaction of respondents and their perceived quality of life in relation to the individual dimensions studied. The lowest scores, indicating lower satisfaction, were recorded for *"Emotional Well-being"* and *"Parenthood"*. The highest satisfaction of respondents was recorded for the area *"Social support in relation to the child's disability"* (see Table 3).

Table 3. Comparison of the average score in relation to dimensions (descriptive statistics)

	N	Minimum	Maximum	Mean (M)	Std. deviation (SD)
Family interaction	550	6.00	30.00	22.8564	4.91673
Parenting	550	6.00	30.00	22.1527	4.69530
Emotional wellbeing	550	4.00	20.00	13.5473	3.41546
Physical material wellbeing	550	5.00	25.00	18.7109	4.06931
Disability related support	550	4.00	20.00	15.4109	3.40554
Valid *N* (listwise)	550				

A more detailed examination of responses aimed at monitoring the average values of all items of the scale individually, show that the lowest average score indicating a reduced quality of life was achieved by respondents in statements falling within the dimension *"Emotional well-being"*, namely for statements number 9 (Members of my family have time to devote to their own interests, M = 3.2164, SD = 1.19139), 13 (Members of my family enjoy external support, thanks to which they can take care of the special needs of all family members. M = 3.2709, SD = 1.06324), and 3 (My family has the support it needs to eliminate stress. M = 3.3709, SD = 1.09506). The average score for individual items of the scale can be found in Table 4.

In the next part of the research, we confirmed the existence of statistically significant differences in the overall quality of life with regard to marital status (χ^2 = 12.879, p = 0.012), self-governing region (χ^2 = 39.125, p = 0.000), and education (χ^2 = 63.405, p = 0.000). The highest quality of life in relation to marital status was shown by the parents of children with a disability who were married, and the lowest quality of life was found in single parents. Parents with secondary education

Table 4. Average score for each FQOL scale item

	Mean (M)	Std. deviation (SD)
1. My family enjoys spending time together	3.6964	1.10166
2. Members of my family help children to be independent	3.6436	1.05422
3. My family has the support it needs to eliminate stress	**3.3709**	**1.09506**
4. My family has friends and other people who provide it with support	3.6891	1.05222
5. Members of my family help children with homework and other activities	3.6709	1.16525
6. Members of my family have a way of getting to where they need to	3.6709	1.13516
7. Members of my family talk openly to each other	3.9018	1.02314
8. Members of my family teach children how to get along with others	3.8891	1.01916
9. Members of my family have time to devote themselves to their own interests	**3.2164**	**1.19139**
10. My family solves problems together	3.8527	1.02169
11. Members of my family support others in achieving their goals	3.7491	1.08925
12. It is obvious that members of my family love and care for others	4.0127	0.99444
13. Members of my family receive external support thanks to which they take care of the special needs of all family members	**3.2709**	**1.06324**
14. Adults in my family teach children how to make the right choices	3.7527	0.94702
15. My family receives the necessary medical care when needed	3.6382	1.09228
16. My family knows how to handle expenses	3.7200	1.06858
17. Adults in my family know other people involved in the lives of their children (friends. teachers. etc.)	3.7255	0.97467
18. My family is able to cope with life's challenges and mistakes	3.6436	0.97524
19. Adults in my family have time to take care of each child's individual needs	3.4709	1.05843
20. My family is getting the necessary dental care	3.7636	1.11234
21. My family feels safe at home, at work, at school and in the neighbourhood (in my neighbourhood)	3.9182	1.00211
22. A member of my family who has a disability is encouraged to achieve his/her goals at school or work	3.8400	1.04360
23. A member of my family who has a disability is encouraged to achieve his/her goals at home	4.0200	0.98696
24. A member of my family who has a disability is encouraged to have friends	3.9055	1.00914
25. My family has good relationships with service providers who provide assistance and support to a family member with a disability	3.6455	1.05397

and parents from the Žilina, Košice and Trnava regions also showed the highest quality of life. The lowest quality of life of respondents was associated with basic education and the Prešov self-governing region.

We also looked at differences in quality of life depending on sociodemographic data for individual dimensions of the scale. The results, with minimal variations, coincided with those related to the overall quality of life. We paid more attention to the dimensions in which respondents showed the lowest and highest satisfaction.

The dimension *"Emotional well-being"* confirmed statistically significant differences in satisfaction with the emotional well-being of respondents, depending on the self-governing region ($\chi^2 = 37.217$, $p = 0.000$) and education ($\chi^2 = 14.599$, $p = 0.001$). The highest satisfaction with emotional well-being was expressed by parents from the Žilina and Košice self-governing regions, and the lowest by respondents from the Bratislava region. In relation to education, respondents with secondary education were the most satisfied in the area of emotional well-being. Similarly, the existence of statistically significant differences was confirmed in the satisfaction of respondents in the area of *"Parenthood"* depending on marital status ($\chi^2 = 9.898$, $p = 0.042$), self-governing region ($\chi^2 = 34.919$, $p = 0.000$), and education ($\chi^2 = 54.368$, $p = 0.000$). Again, the highest quality of life or the highest satisfaction in the area of perceived emotional well-being was expressed by respondents from the Žilina and Trnava regions, respectively, married respondents and those with higher education. The lowest satisfaction in the field of parenting was expressed by respondents from the Prešov region and those who were unmarried with basic education.

According to the results of the research, respondents were most satisfied with the area of *"Social Support"* compared to other dimensions of quality of life. Testing confirmed statistically significant differences in satisfaction with the social support of our respondents depending on their place of residence ($Z = -2.321$, $p = 0.020$), marital status ($\chi^2 = 16.913$, $p = 0.002$), self-governing region ($\chi^2 = 20.576$, $p = 0.004$) and education ($\chi^2 = 52.181$, $p = 0.000$). The highest scores were achieved by married respondents living in the city, with secondary education and respondents living in the Žilina, Košice, and Trnava regions. The lowest scores, proving lower satisfaction in the field of social support, were shown by single respondents with basic education living in the Prešov region.

In our research, we also looked at whether the quality of life and satisfaction of respondents with its individual aspects was influenced by the type of disability. This connection has not been confirmed in our research, thus we assume that respondents' quality of life is influenced by the very existence of a disability, regardless of its type.

Discussion

The aim of our research was to define the quality of life of parents of a child with a disability. The birth of a child with a disability is considered to be a factor that significantly disrupts the previous functioning of the family (Okurowska-Zawada et al., 2011; Witzanyová and Veleminský, 2019), not only in terms of the family organization, but also in experiencing an event in the life of a family that has direct impact on the quality of life of its individual members, especially the parents (Davis et al., 2009; Romeo et al., 2010). Our research showed that the areas of emotional well-being and parenting were the most affected when it comes to the quality of life of our respondents.

Lower parenting satisfaction and a more negative perception of parental role perceived by the researchers may also be related to the findings of other authors who argue that parents of children with disability may also harbour feelings of failure, helplessness, and guilt (Dervishaliaj, 2013). These are often associated with the fact that parents struggle with feelings of disappointment at the fact that a child with a disability was born to them (Li-Tsang et al., 2001; Schneider et al., 2001). For some parents, accepting a child is a long-term process, which deepens guilt. Stress and tension are also linked to the specific needs of children with a disability in the areas of treatment and rehabilitation, in the field of education and, in some cases, to the social pressure and prejudices faced by parents. These are obvious mainly in situations where, due to their disability, children fail to behave according to the norm, and consequently, their parents are prone to feeling shame and failure in their parental role (Benson, 2006; Olawale et al., 2013; Petalas et al., 2009; Rao and Beidel, 2009; Pousada et al., 2013). Ayrault (2001) claims that parents will start avoiding social contacts as a result of these situations, believing that even relatives or friends would not understand their child's needs. Parents therefore spend most of their time caring for the child, providing therapies, and exclusively fulfilling the needs of the child and not their own. The result is a decreased quality of life and increased psychological tension, which in turn also has an adverse effect on the relationship between parents (Leutar and Oršulić, 2015).

Respondents identified dimensions of emotional well-being as the area with the lowest satisfaction. Emotional well-being or emotional discomfort is often mentioned when it comes to issues of disability, as indicated in the introduction to this paper. Therefore, our findings are consistent with the results of several studies, showing that the impaired emotional well-being of parents manifests itself in lower life satisfaction, and higher levels of anxiety and depression (Cheshire et al., 2010), as well as perceived stress (Britner et al., 2003; Butcher et al., 2008; Skok et al., 2006; Wang and Jong, 2004). Parents of children with cerebral palsy have five times higher stress levels than the general population (Parkes et al., 2011). Parents of children with intellectual disability experience higher rates of anxiety (Gallagher et al., 2008). Stress, anxiety manifestations and a disrupted emotional well-being are, as proven by Raina et al. (2005), caused not only by the care of a child with a disability and the functioning of the family, but also by the behaviour of the child and disability-related features.

It is interesting to note that our research shows no relationship between the quality of life of a family with a child with a disability and the type of disability. This may be due to the fact that we monitored the type of disability, but not the level of functionality of the child. According to several studies, physical (Khalipat et al., 2016; Pousada et al., 2013; Shivers and Resor, 2020), intellectual (Čolić et al., 2019; Dizdarevic et al., 2020; Misura and Memisevic, 2017; Singh et al., 2016; Staunton et al., 2020) as well as combined disability (Kolcic, 2018; Leung and Li-Tsang, 2003) have a negative impact on the quality of life of parents. The internal deviations are then caused by the degree and extent of the child's disability (Dizdarevic et al., 2020; Haimour and Abu-Hawwash, 2012; Huang et al. 2014; Jenaro et al., 2020; Leung and Li-Tsang, 2003; Pineio et al., 2020). This is confirmed by earlier studies published by the authors Leonard et al. (1993), Browne and Bramston (1996), and Johnson (2000). According to their findings, the level of stress and anxiety was higher in parents of children with severe or multiple disability, which is also related to the findings of Leung and Li-Tsang (2003), who confirmed the existence of

a strong correlation between the level of functionality of children with disability and the quality of life of parents. Parents of children with a more pronounced functional disorder who are making slower progress are more frustrated and worried about their children's future. They also devote more time to childcare, which is related to the lack of fulfilment of their own needs, and consequently a poorer quality of life.

In addition to the factors mentioned above, the overall quality of life of our respondents was also affected by their marital status. The best quality of life was demonstrated by married respondents and the lowest by single ones. This finding may be related to the fact highlighted by Pousada et al. (2013), that stress and reduced emotional well-being are also caused by low levels of social support provided to parents. Given the results of our research, this relationship is an incentive for us to further examine to what extent social support can influence the individual emotional well-being of parents caring for their own child with a disability. Our results suggest that the reduced emotional well-being of our respondents was not so much related to the formal social support that, in the research scale, was associated with support from social service facilities, schools, or the availability of compensatory aids enabling children to function better in everyday life. Instead, it was associated with insufficient emotional support – a support that would help the parents minimise their stress, would help them reconcile family life with caring for their child with a disability and would help them find free time to meet their own personal needs. Nonetheless, our research showed that social support is an important factor that influences the quality of life of parents raising a child with a disability.

According to the authors Ones et al. (2005) and Glenn et al. (2008), the degree of stress of parents is not so much related to the level of functioning of the child, but rather to their access to resources and support. This view is shared by our research results. The area of social support has been shown to have a significant impact on the overall quality of life of a parent with a child with a disability. In fact, our respondents were most satisfied with the area of social support. This was reflected in their answers related to the overall quality of life which scored significantly higher. Higher satisfaction with social support could also be influenced by the fact that contact with our respondents was mediated by institutions providing support to families with children with a disability, such as special-pedagogical counselling centres, early intervention centres, and social services guaranteeing the provision of early intervention, day care centres as well as special schools. In view of the above findings, we consider it essential that families with a child with a disability be provided with care and support that enables them to operate at the optimal level and live a quality life comparable to families with a child without a disability (Brown et al., 2006). Appropriate and high-quality support from family, professionals and services, can reduce parents' stress levels and increase their emotional well-being (Parkes et al., 2011).

Conclusions

Our research has shown that the birth of a child with a disability is associated with demanding care, which has a particularly negative affect on the emotional well-being of the parents. At the same time, it is an event in the lives of parents and the family that inevitably requires support from professionals, family and community. Social support appears to be an important factor that directly correlates with the quality of a family's life. We consider the findings of our research to be important. We see their importance in the fact that identifying factors affecting the quality of life of parents of children with disability may assist professionals in developing appropriate strategies or seeking support resources to help parents cope with their difficult life situation. Family interventions should then be aimed at strengthening parental competences to help them better cope with the requirements arising from caring for a child with a disability. Our findings have shown that, in addition to formal support, parents also need support which helps them, to not only meet the needs of their child with a disability, but also the needs of other family members. That is, they need emotional support that helps them reduce stress and the psychological burden they experience, which can accompany the family in their difficult life situation. Early intervention service, which is currently being developed, could be precisely the type of support that is needed. It aims to provide, inter alia, timely assistance to families with a child with a disability in the form of complex long-term guidance, and to support families with children in a way that contributes to the establishment of a cohesive and inclusive society.

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Ethical aspects and conflict of interests

The authors have no conflict of interests to declare.

Faktory ovplyvňujúce kvalitu života rodičov dieťaťa so zdravotným postihnutím

Súhrn
Cieľ: Cieľom príspevku je prezentácia výsledkov výskumu zameraného na zisťovanie kvality života rodičov dieťaťa so zdravotným postihnutím.
Teoretické východiská: Kvalita života ako multidimenzionálny a multidisciplinárny koncept je v sociálnej práci jednou z dôležitých výskumných oblastí. Ročne sa na Slovensku narodí minimálne 2 500 novorodencov so zdravotným postihnutím. Táto situácia predstavuje pre rodičov i širšiu rodinu dlhodobú záťaž, ktorá významne ovplyvňuje kvalitu ich života. Metódy: Pre naplnenie nášho cieľa sme si zvolili kvantitatívnu výskumnú stratégiu s využitím validného výskumného nástroja, a to štandardizovaného dotazníka kvality života rodiny – Family Quality of Life Scale.
Výsledky: Výsledky výskumu zaznamenali lepšiu úroveň spokojnosti respondentov s kvalitou ich života, ako sme predpokladali. Najväčšia miera spokojnosti respondentov bola spojená s dimenziou škály *„Sociálna podpora"* Znížená spokojnosť a teda nižšia kvalita života respondentov bola zistená pri dimenziách škály *„Emocionálna pohoda"* a *„Rodičovstvo"*. Výskum ďalej potvrdil, že existujú štatisticky významné rozdiely v kvalite života respondentov v závislosti od ich rodinného stavu, samosprávneho kraja a vzdelania.

Kľúčové slová: emocionálna pohoda; kvalita života rodičov; rodičovstvo; sociálna podpora; spokojnosť s kvalitou života

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