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FAMILY QUALITY OF LIFE: PARENTS OF CHILDREN WITH DISABILITIES

Abstract:

In recent years, there has been a growing emphasis on researching quality of life, particularly within families that include members with disabilities. Family Quality of Life (FQOL) has gained prominence in special education as researchers seek to understand and improve the well-being of these families. This study aims to present findings on the quality of life of parents raising children with disabilities.

Using a quantitative research approach and the validated BCFQOL tool, we surveyed 205 parents. The results were unexpectedly positive, showing generally higher levels of quality of life among participants. However, challenges were identified in specific dimensions such as "Emotional well-being," and "Material well-being".

Keywords: *parents, child with disabilities, family quality of life.*

Introduction

In the 1970s, researchers in psychology, philosophy, sociology, and medicine began studying the concept of quality of life (QoL). Since then, numerous scientific publications have addressed this topic, offering many definitions of the concept (Schalock, 2004). According to the World Health Organization (2012), quality of life (QoL) is defined as "an individual's perception of their position in life in the context of the value systems and culture where they live and concerning their purposes, standards, concerns, and expectations. It can be a broad-ranging concept influenced in a complicated way by the person's physical well-being, mental state, individual opinions, social connections, and their correlation to notable specifications of their environment." It encompasses a broad concept influenced by a person's physical health, mental state, personal beliefs, social relationships, and their connection to significant aspects of their environment. Eckermann (2012) indicated that definitions of quality of life typically focus on two main areas: reaching a consensus on what constitutes a satisfactory life and integrating both subjective elements, such as personal feelings and beliefs, and objective indicators, which are measurable factors, into the concept of quality of life (Sirgy et al., 2006).

Over the past three decades, there has been growing importance placed on family quality of life (FQoL) in research concerning individuals with disabilities. Namely, FQoL is an extension of individual QoL. According to Summers et al. (2005), for families with children with disabilities, FQoL reflects the overall experiences of family members, which can be positive or negative, based on the support and services they receive. This concept significantly influences policy development, directs service provision, and aims to improve outcomes for both children with disabilities and their families.

After birth, parents usually take on the primary role of caring for a child with a disability, becoming their long-term caregiver (Juhás, 2015). According to parents, caring for a child with a disability is often seen as difficult, requiring significant time, effort, and patience, which can impact their ability to meet their own basic personal needs (Hoefman et al.,2014). In general, a child's disability has a negative impact on the physical and psychological well-being of their parents, which can lead to a diminished overall quality of life (Sulaimani et al., 2023).

Caring for children with disabilities presents significant challenges for parents, often resulting in a range of mental health issues such as heightened stress, increased anxiety, depression, and potential physical health concerns. These challenges are more prevalent among parents of children with disabilities compared to those raising typically developing children (Al-Farsi et al., 2016). Moreover, families caring for children with disabilities frequently face financial obstacles, including underemployment and an elevated risk of living in poverty. These difficulties primarily stem from the high costs associated with childcare, including medical services and specialized equipment. Additionally, balancing parental employment with caregiving responsibilities further complicates their financial circumstances. Recent studies also suggest that misunderstandings about the causes of children's disabilities and the stress of managing behavioral challenges in disabled children contribute to marital conflict and dissatisfaction, potentially increasing the likelihood of divorce among parents (Al-Farsi et al., 2016).

Globally, 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 (Shivers and Resor, 2020), intelectual (Čolić et al., 2019; Dizdarevic et al., 2020; Staunton et al., 2020) or combined disability (Kolcic, 2018), the results confirm the negative impact of children's disability on the quality of life of their parents. Despite the extensive research on Family Quality of Life (FQOL) in special education worldwide, there is a significant gap in studies focusing specifically on FQOL among families of children with disabilities in our country. This study aims to investigate and fill this gap by examining FQOL within these families in the Macedonian context.

Methodology

The study included 205 parents of children with disabilities. Data was collected using the "family sociodemographic profile" form and the Beach Center Family Quality of Life (BCFQoLS) scale. The "family sociodemographic profile" form was developed to gather information on parents' gender, age, marital status, educational level, and employment status, as well as details about their child's disability type, age, and school attendance.

To evaluate Family Quality of Life (FQoL), the Beach Center Family Quality of Life Scale (BCFQoLS) was utilized (Hoffman et al., 2006), which has been translated into Macedonian. This tool comprises a 25-item questionnaire that encompasses five domains: family interaction (6 items), parenting (6 items), emotional wellbeing (4 items), physical/material (5 items), and disability-related support (4 items). Responses were recorded on a Likert scale ranging from 1 (very dissatisfied) to 5 (very satisfied) to gauge levels of satisfaction. A higher score indicates a higher quality of life for the family, while a lower score indicates the opposite. The findings were presented using mean and standard deviation (SD), as well as absolute frequency and percentage. T-test were used in the analysis of the relationship between the answers to a certain group of questions.

Results

Table 1 presents the distribution of participants based on various sociodemographic variables. The average age of parents is 36.5 (+7,607) years.

Most respondents are women (69.8%), married (67.8%), with higher education (57.1%) and employed (79.5%).

Table 1: Sociodemographic characteristic of parents

	N	%
Gender		
Female	143	69.8
Male	62	30.2
Total	205	100
Marital status		
married	139	67.8
divorced	62	30.2
widow	4	2
Total	205	100
Level of education		
Primary	2	1
High	78	38
Higher education	8	3.9
Faculty	117	57.1
Total	205	100
Working status		
Yes	37	18
No	163	79.5
Retired	5	2.5
Total	205	100

The average age of children with disabilities is 9.1 years, with a standard deviation of 4.014 years. The largest proportion of children have autism spectrum disorder (29.7%), while the smallest proportion have hearing impairment (4.4%). Ten parents (4.9%) were uncertain about specifying their child's disability. Half of the children attend primary education (see Table 2).

Table 2: Demographic characteristics of the children

Type of disability		
Speech problems	28	13.6
Specific learning disabilities	9	4.4
Autism spectrum disorder	61	29.7
Visual	10	4.9
Hearing	9	4.4
Physical	18	8.8
Intellectual	32	15.6

Combined	28	13.7
Unspecified	10	4.9
Total	205	100
Education		
Preschool	55	26.8
Primary	113	55.1
High	26	1.,7
Daily centre	11	5.4
Total	205	100

The BCFQOL scale is widely used with various samples from different cultures (Balcells-Balcells et al., 2020; Kyzar et al., 2020). The average scores for the five domains of the scale are shown in the following tables.

Table 3: Domains Family interaction

Items	*M*	*SD*
My family enjoys spending time together.	4.68	0.568
My family members talk openly with each other.	4.35	0.871
My family solves problems together.	4.36	0.843
My family members support each other to accomplish goals.	4.33	0.832
My family members show that they love and care for each other.	4.55	0.749
My family is able to handle life's ups and downs.	3.7	0.819

In the first subscale of family interaction, the statement "*My family is able to handle life's ups and downs,*" had the lowest average rating, while the statement "*My family enjoys spending time together,*" had the highest rating (Table 3).

Table 4: Domains Parenting

Items	*M*	*SD*
My family members help the child learn to be independent.	4.57	0.641
My family members help the child with school work and activities.	4.3	0.894
My family members teach the child how to get along with others.	4.6	0.675
Adults in our family teach the child to make good decisions.	4.52	0.696
Adults in my family know other people in the child's lives (friends, teachers, etc.).	4.56	0.651
Adults in my family have time to take care of the individual needs of every child.	3.46	1.002

For parents of children with disabilities, the most challenging task was to support the statement: "*Adults in my family have time to take care of the individual needs of every child*." On the other hand, it was easiest for them to agree with the statement: " *My family members teach the child how to get along with others*." (Table 4).

Table 5: Domains Emotional wellbeing

Items	*M*	*SD*
My family has the support we need to relieve stress.	3.89	0.904
My family members have friends or others who provide support.	3.8	1.040
My family members have some time to pursue our own interests.	3.33	0.988
My family has outside help available to us to take care of special needs of all family members.	3.37	1.236

In the emotional well-being subscale, parents least support the statement: "*My family members have some time to pursue our own interests*," while most support the statement: "*My family has the support we need to relieve stress*." (Table 5).

Table 6: Domains Phisical/Material wellbeing

Items	*M*	*SD*
Family members have needed transportation.	3.85	0.972
My family gets medical care when needed.	3.76	1.058
My family feels safe at home, work, school, and in our neighborhood.	3.87	0.939
My family can get necessary regular medical examination.	4.22	1.111
My family has a way to take care of our expenses.	3.49	1.198

The statement with the lowest level of agreement among parents regarding physical/material well-being is: "*My family has a way to take care of our expenses*" (Table 6).

Table 7: Domains Disability-related support

Items	*M*	*SD*
My family member with a disability has support to accomplish goals at school or at work place.	4.19	1.004
My child has support to accomplish goals at home.	4.62	0.634
My child has support to make friends.	4.22	0.846
My family has good relationships with professionals who provide services and support to my child.	4.34	0.970

On the scale of support related to disability, parents are most satisfied with the statement that " *My child has support to accomplish goals at home*".

Table 8: Average score of five sub-scales and overall scale

	M	*SD*
Family interaction	4.32	0.780
Parenting	4.33	0.759
Emotional well-being	3.59	1.042
Material well-being	3.83	1.055
Disability-related supports	4.34	0.863
Overall scale	4.08	0.899

As shown in Table 8, the highest satisfaction according to the average score per question was recorded on the sub-scale of disability-related supports, with a mean of 4.34, while the lowest satisfaction was on the sub-scale of emotional well-being, with a mean of 3.59. The satisfaction levels on the overall scale and the five sub-scales rank as follows: disability-related supports > parenting > family interaction > overall scale > material well-being > emotional well-being.

Table 9: Paired sample T test of satisfaction among the overall scale and its five sub-scales

	Mean difference	*T*	*p*
Family interaction	0.083	3.127	0.0019
Parenting	0.082	3.0423	0.0025
Emotional well-being	0.096	5.0978	0.0001
Material well-being	0.097	2.5824	0.0102
Disability-related supports	0.087	2.9872	0.0030

Paired sample t-tests were conducted to compare satisfaction levels between the mean of the overall scale and the means of each of the five subscales (see Table 9). The results indicate that all subscales significantly differ from the overall scale ($p < .005$).

Discussion

This study aimed to evaluate the quality of life experienced by parents of children with disabilities. The birth of a child with a disability is recognized as a major factor that disrupts family dynamics (Witzanyová and Veleminský, 2019), influencing both family and the well-being of individual family members, particularly parents (Romeo et al., 2010).

The review of all responses and analysis of the average values for each scale indicate that the "Emotional well-being" subscale has the lowest average scores, suggesting reduced quality of life for parents of children with disabilities. Furthermore, this scale had the lowest mean score in the study by Molnárová Letovancová and Slaná (2022), indicating that families in the Czech sample also face challenges in achieving satisfaction in this area. The overall emotional well-being of the family is a critical aspect that requires special attention. According to Meral and colleagues (2013), emotional support plays a significant role in improving psychosocial health, reducing stress, and promoting a positive life approach among parents of children with disabilities.

Generally, parents in this survey highlighted emotional well-being as the area where satisfaction was lowest. Emotional well-being, often discussed in the context of disability issues, as mentioned earlier in this paper, aligns with the results in this study. Specifically, the results align with other studies indicating that low emotional well-being among parents is associated with decreased life satisfaction, increased anxiety, and depression (Cheshire et al., 2010), as well as higher levels of stress (Butcher et al., 2008). For example, Parks and colleagues (2011) found that parents of children with cerebral palsy experienced stress levels five times higher than those in the general population.

Macedonian families of children with disabilities generally express satisfaction with their family's quality of life, as measured by the BCFQOL (M = 4.08; SD = 0.899). It is interesting to note that according to the average responses, the subscale for family interaction ranks third, although the differences between the top two are very small. Particularly, the first question in this subscale received the highest average score among all 25 questions (*My family enjoys spending time together*; M = 4.68).

Conclusion

Family quality of life is crucial for parents of children with disabilities. Assessing the quality of family life provides a framework for identifying, evaluating, and improving social services and policies designed for them.

Academic literature on quality of life often focuses on individuals with disabilities to define their specific needs. However, it is important to emphasize that parents of children with disabilities are also deeply affected by their child's condition, and their quality of life also requires attention. Emotional support is essential to help them cope with the stress and psychological challenges of managing their family's difficult circumstances. While many families typically seek help from informal sources such as friends and relatives, there are situations where these networks are insufficient, making it necessary to provide professional assistance.

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