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Quality of life of families with children with intellectual and developmental disabilities: Family health domain

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ABSTRACT

Introduction: The most general definition of quality of life states that "quality of life is the degree of what makes life good." Contemporary disability research increasingly relies on examining the quality of life of the whole family. Health and developmental outcomes are affected by the health of children and their environment. The objective of this study is to determine the difference in quality of life between families with children with disabilities and families with children without disabilities in the area of family health.

Methods: The Family Quality of Life Questionnaire was used to assess quality of life. The test group consisted of 41 families of children with intellectual disabilities and developmental disabilities who use day care centers. The control group consisted of 69 families of children without disabilities whose members are employed in day care centers.

Results: A statistically significant difference was found in the quality of life of families of children with disabilities and families of children without disabilities in the area of family health within the concept of satisfaction with family health ($p = 0.0001$), with respondents in the test group reporting a lower mean score of 3.1 ± 0.86 compared to subjects in the control group 3.94 ± 0.62. None of the respondents in the test group reported being very satisfied with family health, while for most respondents in both groups, 38 (92.8%) in the test group and 66 (95.7%) in the control group, family health was very important for quality of life.

Conclusion: A statistically significant difference was found in the quality of life of families of children with disabilities and families of children without disabilities within the concept of achievement, the concept of satisfaction with family health and the determination is a statistically significant difference in relation to the existence of health services in the place of residence.

Keywords: Family quality of life; children with intellectual and developmental disabilities; family health

INTRODUCTION

Quality of life is a concept that the scientific community, especially from the fields of psychology, philosophy, sociology, and medicine, began to deal with in the 70s of the twentieth century. Since then, several millions of scientific publications have been published mentioning quality of life, and over a hundred definitions of this concept (1).

The World Health Organization defines quality of life as "a person's perception of his or her life situation in the context of the culture and value systems in which he or she lives and in relation to his or her goals, expectations, norms, and concerns. It is a broad concept that is influenced in complex ways by physical health, mental state, personal beliefs, social relationships, and relationship to key features of the environment" (2). Quality of life is a concept that aims to capture the well-being of a population or an individual, in terms of both positive and negative elements within the totality of their existence at a given time (3).

The most general definition of quality of life states that quality of life is the degree of what makes life good. The life of a person with a disability, like the life of a person without a disability, is made good by the right to work, the right to healthcare, the right to live without barriers, and the right to know one's rights (4).

Contemporary research on disability increasingly relies on examining the quality of life of the whole family. The construct of family quality of life (FQOL) addresses the needs of all family members, goes beyond the needs of one member with a disability, that is, the mother-child dyad, and emphasizes family strengths and priorities (5). FQOL is about the extent to which individuals experience their own quality of life in the family context and how the family as a whole is able to pursue its important opportunities and

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achieve its goals in the community and society of which it is a part (6).

The study of the quality of life of families after the birth of a child with a disability shows an imbalance in the family system, ignorance of aspects of health and education, negative feelings, and need for adaptation, for which they need support programs (7). The birth of a child with a disability or the occurrence of a disability due to an illness or injury results in the neglect of the needs of parents, siblings, and other family members, which creates special circumstances for this family. These families face significant challenges such as the availability of medical care, the quality of medical care, maintaining their own health, and the health of the child with a disability. Caring for a child with developmental disabilities requires additional social, emotional, and physical resources. Research on the quality of life of families will provide recommendations to state institutions about support services that need to be changed and improved.

Health represents a state of dynamic equilibrium between the individual and his or her physical and social environment and consists of biopsychosocial components of the individual and environmental-social components (8).

Children's health and developmental outcomes are influenced by the health of the family and the environment created. There is limited understanding of the factors that contribute to good family health and that can indicate family capacity and assessment (5).

Health-related quality of life is a comprehensive concept of a health outcome that encompasses various dimensions of health and functioning that contribute to a person's overall well-being and quality of life. In addition to assessing physical and psychological well-being, health-related quality of life evaluations also assess several other important components of health, such as role and social functioning. Health-related quality of life differs from many other assessments of health status in its multidimensional nature and in its focus on the subjective experience of health. It also emphasizes individuals' perceptions of their own functioning and well-being rather than focusing on an objective assessment of health (9).

It is often assumed that people who have a disabled family member have greater difficulty managing a family life and are more likely to suffer from stress and depression (10). Children adapt best to chronic illness. Families of children with disabilities often experience increased levels of emotional and financial stress and isolation (11). Parents cite the prejudice they encounter toward children with disabilities as a particular source of stress, not only among the general public but also among health care, education, and social service workers (12). When children have a higher degree of disability, it also affects the physical and mental health of their parents. Health care professionals should be more aware of the needs of these parents. It is necessary to organize a higher level of support and various interventions to improve their physical and psychological well-being. Various empowerment programs such as coping skills, stress management, positive thinking training, and support groups can help relieve stress and perceive their feelings differently (13). The aim of this study is to determine the difference of quality of life of families with children who have disabilities and families of children without disabilities in relation to the domain of family health.

METHODS

The study was designed as a descriptive-analytic cross-sectional study and was conducted from December 1, 2021, to February 20, 2022.

The study was conducted in 6 day care centers in the northern, central, and southern regions of Montenegro. The sample consisted of the main caregivers of families of children with developmental disabilities who attended day care centers for children with developmental disabilities and families of children without disabilities whose members are employed in day care centers for children with developmental disabilities.

Test group – 41 families of children with mental retardation and developmental disabilities, aged 6-18, attending day care centers for children with developmental disabilities. The respondents of the test group were family members of children with severe and serious forms of psychomotor disorders, children with multiple disabilities, who, according to the assessment of the centers for social work, that is, the advisory commission, cannot be included in any kind of inclusive education. Included were 19 families of children with autism, 13 families of children with cerebral palsy, six families of children with Sy Down, three families of children with epilepsy.

Control group – 69 families of children without mental retardation and developmental disabilities, aged 6-18 years, whose members are employed in day care centers for children with developmental disabilities.

One member/primary caregiver from each family was included in the study.

Analysis of the questionnaires revealed that of the 121 respondents who signed consent to participate in the study and completed the questionnaires, 11 did not meet the criteria for participation in the study because they did not have children aged 6–18 years in their family.

By studying the quality of life in health, we will determine if there is a difference in the health of the families of children with and without disabilities, but also evaluate the existing health services and the need for new ones. We can use the data obtained in the design of public policies in the field of health and social care. The concepts of quality of life and FQOL for people with disabilities are increasingly being studied as an important framework to: assess families' needs for supports and services, target organizational changes and service delivery systems, and evaluate the quality of family outcomes (14).

FQOL Survey Questionnaire FQOL Survey – General Population Version, based on an approved adaptation of the FQOL Survey – General Version, for families with members without intellectual disabilities (15).

The purpose/theoretical basis of the FQOL Survey – General Version is to collect FQOL data from families with one or more members with intellectual disabilities and to help families better understand their particular needs and the state of family life. The respondents are parents. Areas examined are: Health, finances, family relationships, support from others, support from disability-related services, influence of values, career and career planning, leisure and recreation, and community interaction. Response options/scoring techniques: Six core concepts: Importance: 1 = hardly important, 3 = somewhat important, and 5 = very important; Opportunity, Initiative, and Realization: 1 = hardly important, 3 = somewhat important, and 5 = very important; Stability: 1 = much deterioration, 3 = about the same, and 5 = much improvement. Satisfaction: 1 = very dissatisfied and 5 = very satisfied. Mean for each domain ranged from 1 to 5. Number of items/psychometric properties: 54 items, coefficient alpha = 0.60-0.92 (16).

All 6-day care centers that participated in the study obtained approval from their ethics committees and provided informed consent to participate in the study. Consent to voluntarily participate in the study was confirmed by the respondents with their written informed consent.

The Cronbach's alpha value of 0.791 indicates that the questionnaire has good reliability, while the factorial analysis with principal component analysis and $p = 0.014$ mean that the structure of the questionnaire is represented by the data.

After checking the received questionnaires, the data were entered into Microsoft Excel and entered into the statistical processing software MedCalc v12.7, which is designed for use in biomedical research. The results are presented in tabular and graphical form according to absolute number of cases, relative number of cases (percent), arithmetic mean with standard deviation, and range of values.

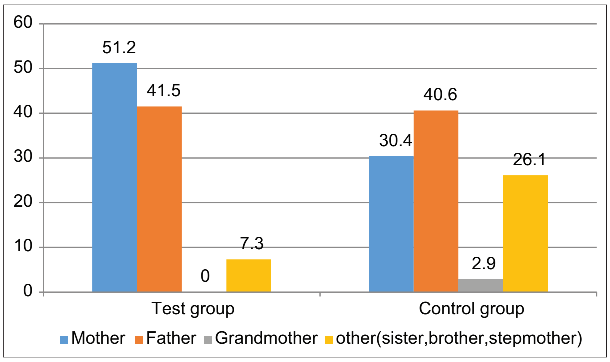
The results of the above tests are considered statistically significant at a confidence interval of 99.95% or at a value of $p < 0.05$.

RESULTS

A comparison of the number of respondents who completed the questionnaire shows a statistically significant difference in the sense that in the test group, the questionnaire was more often completed by mothers 21 (51.2%) and in the control group more often by fathers 33 (47.6%) (Graph 1).

Among the other members of the test group, fathers filled in the questionnaire in 17 (41.5%) cases, brother, stepmother, and sister in 1 (2.4%) case each. In the control group, mothers did so in 26 (37.4%), sisters in 8 (11.2%), and grandmothers in 2 (2.8%) cases (Graf 1).

The highest score in family health was given by control group respondents with 4.91 ± 0.51 for the concept of importance, and the lowest by test group respondents with 3.1 ± 0.86 for the concept of satisfaction (Table 1).



GRAPH 1. Comparison of who fills out the questionnaire according to groups.

Test group respondents rated the concept of family health performance with an average score of 3.71 ± 0.87, while control group respondents rated it with 4.04 ± 0.65 (Table 1).

There is a statistically significant difference in the area of family health within the concept of achievement $p = 0.023$ (Table 1).

Respondents in the test group rated the concept of satisfaction in the area of family health with an average rating of 3.1 ± 0.86, while respondents in the control group rated it with 3.94 ± 0.62.

There is a statistically significant difference in the area of family health within the concept of satisfaction $p = 0.0001$ (Table 1).

The largest percentage of respondents within the concept of the importance of family health to quality of life ranked it as very important: 38 (92.8%) respondents in the test group and 66 (95.7%) in the control group (Table 2).

There is no statistically significant difference between the groups when it comes to the concept of importance of family health for quality of life (Table 2).

Most respondents under the concept of opportunities to meet health needs indicate that there are some opportunities, namely, 19 (46.5%) of the test group and 43 (62.3%) of the control group. Sixteen (39.0%) respondents of the test groups and 20 (29.0%) of the control group declare that there are many opportunities (Table 3).

There is no statistically significant difference between the groups when it comes to the concept of opportunities (Table 3).

The concept of health maintenance initiative was rated as "quite" and "very" by most respondents in both groups, 17 (41.5%) and 19 (46.3%) in the test group and 31 (44.9%) and 30 (43.5%) in the control group (Table 4).

There is no statistically significant difference between the groups when it comes to the concept of initiative (Table 4).

Within the concept of achievement, the largest number of respondents in both groups rated the degree of enjoyment of good health as "quite," with 27 (65.9%) respondents in the test group and 49 (71.0%) in the control group (Table 5).

There is a statistically significant difference between the examined groups within the concept of achievement (Table 5).

Under the concept of family stability, the largest number of respondents 22 (53.7%) in the test group estimated that health will remain the same in the future, 12 (29.3%) that it will improve, 5 (12.2%) that it will improve a lot, and 2 (4.9%) that it will worsen (Table 6).

The largest number of respondents, 40 (58.0%) in the control group, estimated that the family health status will remain the same in the future, 22 (31.9%) that it will improve, 4 (5.8%) that it will improve a lot, and 3 (4.3%) that it will worsen (Table 6).

There is no statistically significant difference between groups on the concept of family health stability in the future (Table 6).

TABLE 1. Family health domain concepts

Group	Importance	Opportunities	Initiative	Attainment	Stability	Satisfaction
Health						
T	4.83±0.7	3.44±0.81	4.27±0.87	3.71±0.87	3.49±0.78	3.1±0.86
C	4.91±0.51	3.36±0.69	4.29±0.75	4.04±0.65	3.39±0.67	3.94±0.62
p	0.471	0.597	0.891	0.023	0.493	0.0001

T-test group, C: Control group, *p*: Statistical significance

TABLE 2. Importance of family health for quality of life

Importance of family health for quality of life	Group				Total	
	Test group		Control group			
	n	%	n	%	n	%
Hardly importance at all	1	2.4	1	1.4	2	1.8
Somewhat important	1	2.4	0	0.0	1	0.9
Quite important	1	2.4	2	2.9	3	2.7
Very important	38	92.8	66	95.7	104	94.6
Total	41	100.0	69	100.0	110	100.0

χ^2=1.865; *P*=0.601

TABLE 3. Opportunities for health needs in the community

Opportunities for community health needs	Group				Total	
	Test group		Control group			
	n	%	n	%	n	%
Hardly one	1	2.4	1	1.4	2	1.8
Quite	2	4.8	1	1.4	3	2.7
Some	19	46.5	43	62.3	62	56.4
Many	16	39.0	20	29.0	36	32.7
Great many	3	7.3	4	5.9	7	6.4
Total	41	100.0	69	100.0	110	100.0

χ^2=3.297; *P*=0.509

TABLE 4. Initiative of family members to preserve or improve health

Initiative of family members	Group				Total	
	Test group		Control group			
	n	%	n	%	n	%
A little	3	7.3	2	2.9	5	4.5
Something	2	4.9	6	8.7	8	7.3
Quite	17	41.5	31	44.9	48	43.6
Very	19	46.3	30	43.5	49	44.6
Total	41	100.0	69	100.0	110	100.0

χ^2=1738; *P*=0.629

TABLE 5. The degree of enjoyment of good health

The degree of enjoyment of good health	Group				Total	
	Test group		Control group			
	n	%	n	%	n	%
Hardly at all	1	2.4	0	0.0	1	0.9
A little	4	9.8	3	4.3	7	6.4
Something	5	12.2	4	5.8	9	8.2
Quite	27	65.9	49	71.0	76	69.1
Very	4	9.8	4	5.8	17	15.5
Total	41	100.0	69	100.0	110	100.0

χ^2=15.624; *P*=0.024

TABLE 6. Stability of family health

Stability of family health	Group				Total	
	Test group		Control group			
	n	%	n	%	n	%
Get worse	2	4.9	3	4.3	5	4.5
Stay at the same	22	53.7	40	58.0	62	56.4
Improve	12	29.3	22	31.9	34	30.9
Greatly improve	5	12.2	4	5.8	9	8.2
Total	41	100.0	69	100.0	110	100.0

χ^2=1.444; *P*=0.965

TABLE 7. Satisfaction with family health

Satisfaction with family health	Group				Total	
	Test group		Control group			
	n	%	n	%	n	%
Very dissatisfied	1	2.4	0	0.0	1	0.9
Dissatisfied	10	24.4	1	1.4	11	10.0
Neither satisfied nor dissatisfied	14	34.1	12	17.4	26	23.6
Satisfied	16	39.0	46	66.7	62	56.4
Very satisfied	0	0.0	10	14.5	10	9.1
Total	41	100.0	69	100.0	110	100.0

χ^2=27.701; *P*=0.0001

Within the concept of satisfaction with family health in the test group, the largest number of respondents was 16 (39.0%) satisfied, 14 (34.1%) neither satisfied nor dissatisfied, 10 (24.4%) dissatisfied, and 1 (2.4%) very dissatisfied with family health (Table 7).

In the control group, the largest number of respondents was 46 (66.7%) satisfied, 12 (17.4%) neither satisfied nor dissatisfied, 10 (14.5%) very satisfied, and 1 (1.4%) dissatisfied with family health. None of the subjects in the test group reported being very satisfied with family health, while none of the subjects in the control group reported being very dissatisfied with family health (Table 7).

A statistically significant difference was found between the studied groups regarding the concept of satisfaction (Table 7).

The largest percentage, 30 (73.2%) respondents of the test group and 52 (75.4%) of the control group recognize as an obstacle the long wait for health services, then scheduling and receiving the service 16 (39.0%) respondents of the test group and 30 (43.5%) of the control group. Poor treatment by health professionals was recognized as an obstacle by 8 (19.5%) respondents test group and 8 (11.6%) control group (Table 8).

The availability of services at the place of residence was recognized as an obstacle to the realization of healthcare by 12 (29.3%) respondents in the test group and 6 (8.7%) in the control group (Table 8).

There is a statistically significant difference between the groups when it comes to the availability, that is, the existence of services in the place of residence (Table 8).

DISCUSSION

The questionnaires in the test group, that is, in front of the families of children with disabilities, were filled in by

TABLE 8. Barriers in the accessibility of healthcare

Barriers in the accessibility of healthcare	Group				Total		Chi-square	p-value
	Testna group		Control group					
	n	%	n	%	n	%		
Long wait for health service	30	73.2	52	75.4	82	74.5	$\chi^2=0.065$	*p*=0.485
Unknown treatment for health issue	6	14.6	6	8.7	12	10.9	$\chi^2=0.933$	*p*=0.255
Services not available in my area residence	12	29.3	6	8.7	18	16.4	$\chi^2=7.953$	*p*=0.006
Transportation is a problem	1	2.4	1	1.4	2	1.8	$\chi^2=0.141$	*p*=0.609
We can't making an appoitment easily, we have trouble getting around	16	39.0	30	43.5	46	41.8	$\chi^2=0.210$	*p*=0.399
We don't know where the services are health care	0	0.0	0	0.0	0	0.0	$\chi^2=2.348$	*p*=0.126
We do not understand about which health care professionals tell us about them	5	12.2	3	4.3	8	7.3		
Poor treatment by professionals health care	8	19.5	8	11.6	16	14.5	$\chi^2=1.271$	*p*=0.208
We have different beliefs about healthcare	3	7.3	10	14.5	13	11.8	$\chi^2=1.271$	*p*=0.208

TABLE 9. Statistically significant

Summary	
Statistically significant difference is confirmed	Statistically significant difference is not confirmed
The concept of the achievement	The concept of the importance
The concept of the satisfaction	The concept of the opportunities
Comparison of who fills out the questionnaire according to groups	The concept of the initiative
Health services not available in my area residence	The concept of the achievement
	The concept of stability
	the concept of satisfaction
	Long wait for health service
	Unknown treatment for health issue
	Transportation is a problem
	We can't making an appoitment easily, we have trouble getting around
	We don't know where the services are healthcare
	We do not understand about which healthcare professionals tell us about them
	Poor treatment by professionals healthcare
	We have different beliefs about healthcare

mothers in the largest percentage (51.2%), which once again confirms the mother-child dyad with disabilities and the role of the mother as the main and often the only caregiver of the child with disabilities.

In the study conducted in Latvia to investigate the quality of life of families with children with developmental disabilities, focusing on social policies to ensure the quality of life, 272 families participated, including 247 mothers, 11 grandmothers, 15 fathers, and one other person – the child's aunt. Moreover, this research also confirms that mothers care about a child with a disability and everything related to a child with a disability (17).

In a study that examined the relationship between FQOL and a family-centered approach in families with children with intellectual disabilities aged 0-18 years, in which 48 families participated, it was mainly mothers who reported on the quality of life of their families (18).

The concept of FQOL describes the quality of life of all family members and the family system as a whole, but usually includes only the parents' opinions. Siblings' opinions are included in parents' opinions, although research has shown that there is a discrepancy between parents' and siblings' views. Siblings of children with intellectual disabilities often define their quality of life as the quality of life of siblings with disabilities (19).

For most respondents in both groups, 38 (92.8%) in the test group and 66 (95.7%) in the control group, family health is very important to FQOL. For the majority of respondents in both groups, the ability to meet their health needs is rather limited and they expect the family's health status to remain stable. The level of health is higher for a significant number of respondents from the control group with very 13 (18.8%) than 4 (9.8%) from the test group. No respondent from the test group stated that they were very satisfied with the health of their family.

That a child's disability affects the health of family members, primarily parents, is also shown by the results of a study conducted in Croatia, according to which parents of children with profound developmental disabilities have poorer self-rated health in all dimensions of health compared to parents of healthy children, with the exception of physical health. Compared with the control group, 41% of parents of children with profound developmental disabilities and 30.2% of parents of healthy children reported suffering from a chronic disease (20).

As for the average rating of family health in the performance concept, a statistically significant difference was found between the studied groups (*p* = 0.023). Subjects in the test group reported a lower mean score of 3.71 ± 0.87, compared to subjects in the control group 4.04 ± 0.65.

A statistically significant difference was found in the mean score within the concept of satisfaction with family health ($p = 0.0001$), where subjects in the test group reported a lower mean score of 3.1 ± 0.86 compared to subjects in the control group 3.94 ± 0.62.

In a study conducted in Bosnia and Herzegovina among families of children with intellectual disabilities in health, the concept of importance was rated best with 4.93 ± 0.33 and the concept of stability was rated worst with 3.5 ± 08 (21).

A statistically significant difference ($p = 0.006$) between the studied groups was found in the availability of services at the place of residence, which is certainly related to the different level of development of the northern, central, and southern regions of Montenegro and the financial resources not equally distributed by the state.

Non-availability of health services at the place of residence could be one of the reasons for strong migration of population from northern to central and southern regions, which are better developed. In the northern region of Montenegro, negative net migration was recorded in 2021, amounting to 1267 persons. In the other two Montenegrin regions, positive net migration was recorded, and it was larger in the central region, where health services are the most developed (22). The lack of health services at the place of residence is one of the reasons for the migration of the population to the developed parts of the country. The results obtained point to the need to open support services equally in all regions.

A survey by the German Children's Network, which interviewed 1567 parents of children with chronic diseases and children with disabilities using a standardized online questionnaire that included children's health status diagnosis and severity, care burden, family and socioeconomic status, health status and health-related quality of life, and family impact, showed that higher care burden was associated with a greater risk of poor health-related quality of life (23).

Results from the survey of 533 parents of children with chronic conditions (10 diagnosis groups, children aged 1–19 years) revealed seriously lower health-related quality of life, which should receive attention and support if needed. An approach to pediatric care that focuses on the health of families of children with chronic conditions is recommended (24).

Timely action on a child's developmental difficulties provides a range of benefits, especially for the child, his or her family, and the system as a whole. To achieve such outcomes, it is necessary to develop an integrated model of early growth and development. To achieve an integrated model in early growth and development, mechanisms of professional and administrative collaboration must be established between healthcare, social service, and preschool education and training system agencies, at the level of an individual problem (25).

CONCLUSION

A statistically significant difference was found in the quality of life of families of children with disabilities and families of children without disabilities within the concept of achievement, the concept of satisfaction with family health, and the determination is a statistically significant difference in relation to the existence of health services in the place of residence. The results of the research show that it is necessary to work on the improvement of the health-care system to improve the quality of life of both families of people with disabilities and families of people without disabilities. The results of the research can be used in the development of public policies in the health-care system as well as in the creation of strategic documents to support families.

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CONFLICTS OF INTEREST

The authors declare no conflict of interest.

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