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Research article

Further detailed objectification within comparative analysis of quality of life - based on some sociodemographic characteristics/parameters and related statistical analysis - between mothers of children with congenital versus acquired neuropathology

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Abstract: This study aimed to determine whether there is a difference in quality of life between mothers of children with congenital neuropathology and, respectively, those with acquired neuropathology based on some sociodemographic characteristics/parameters, taking into account data from the specialized literature on the influence of sociodemographic characteristics/parameters on mothers with disabled children. 85 subjects (divided into two groups, congenital and acquired) were included in the study conducted at the National Clinical Centre of Neurorehabilitation for Children "Dr. N. Robanescu. To objectify – if existing – such differences, as mentioned above, we used the clinical, functional quantified evaluation instrument PedsQL- Family Impact Module (PedsQL-FIM). According to our data, there were statistically significant differences between groups for physical functioning, emotional functioning, communication, and worry. There were no statistically significant differences between the groups for daily activity, social functioning, cognitive functioning, and family relationships. We also found weak negative correlations between the following dimensions of PedsQL-FIM: emotional functioning, social functioning, and communication) and education for the former group; a weak positive correlation between worry and education, a weak negative correlation between emotional functioning and income level, and two moderate negative correlations between social functioning, daily activities, and income level for the latter group. We can conclude that the variable education had the most significant influence on the quality of life for mothers of children with congenital neuropathology, in contrast, the variable income level had the most significant influence on mothers of children with acquired neuropathology.

Keywords: sociodemographic characteristics, quality of life, disability

1. Introduction

Due to concerns about improving living conditions, optimizing therapeutic interventions, and providing support for children and their families, the specialized literature offers an increasing number of tools meant to measure the various dimensions of quality of life (QOL) in families with disabled children [1,2].

"One in 10 children worldwide live with disabilities", according to a report by the United Nations International Children's Emergency Fund (UNICEF) [3].

In the United States, a census revealed that children with disabilities increased from 3.9% in the year 2008 to 4.3% in the year 2019 [4].

In Romania, according to data from the National Institute of Statistics (in the year 2019), the prevalence of chronic diseases (probably at least part of them generating correlating disabilities) in children aged 0 to 19 years was 16.61% [5].

Limited access to school, difficulties with social integration and restricted participation in various social activities, a lack of sustained programs for children with disabilities, on the one hand, and the affected family structure, on the other, all contribute to the child's and his/her family's QOL [6–11].

Many studies have examined sociodemographic characteristics (such as education, marital status, place of residence, and income) and have linked them to QOL in families with disabled children [12–15] but not with comparative statistical analysis.

According to some research, parental education is a good predictor of QOL[16,17], and the presence of a disabled child can have a more significant impact on marriage than it would in a family with healthy children, due to the care costs and psycho-emotional challenges that a family with a disabled child(ren) must overcome [10,12,18,19].

The costs of caring for a disabled child often put a burden on the family's finances because (frequently) the mother stays at home to take care of the respective child(ren) [9,20–22].

The benefits a family may experience depend on their level of access to health services [23].

Is there a difference in the QOL between mothers of children with congenital neuropathology and mothers of children with acquired neuropathology based on some sociodemographic characteristics/parameters? This research question was addressed using data from the specialized literature on the influence of sociodemo-graphic characteristics/parameters on the family having a child(ren) with disabilities.

2. Materials and Methods

Study design

This comparative cross-sectional study that included 85 subjects (mothers of children with disabilities) was conducted at the National Clinical Centre of Neurorehabilitation for Children "Dr. N. Robanescu" between December 2019 and April 2022. There were 47 mothers of children with congenital neuropathology (Group 1, comprising cerebral palsy) and 38 mothers of children with acquired neuropathology (Group 2, comprising traumatic brain injury).

Questionnaire

Health-related QOL is measured with PedsQL-FIM, a standardized, multidimensional instrument that considers parents' concerns about their child's health [24]. The 36 items of the questionnaire are organized into 8 dimensions as follows: Physical Functioning (PF) - 6 items, Emotional Functioning (EF) - 5 items, Social Functioning (SF) - 4 items, Cognitive Functioning (CF) - 5 items, Communication (CO) - 3 items, Worry (WO) - 5 items, Daily Activities (DA) - 3 items, and Family Relationships (FR) - 5 items [24]. The mean scores are calculated for each dimension using a 5-point response scale (Likert - type scale) [24].

We also collected information regarding marital status, residence, education, and income, levels (the first and the third items are from the preamble of the World Health Organization Quality of Life Instrument—Short Form, WHOQOL - BREF).

Regarding education, the subjects were asked to choose one of the following answer options: "none at all" or "Less than high school" or "High school" or "University" to the following next question, i.e., "What is the highest education you received?"

"What is your marital status?" was the question with answer options: "Single parent" (including also "Separated" or "Divorced" or "Widowed) or "Married" (including "Living as married", also).

Regarding residence, we considered the following answer options: rural/ urban.

Subjects were also asked to answer the following question "How do you appreciate the income of your family?" They chose an answer between "insufficient", "acceptable", or "comfortable".

Ethical Consideration

The Ethics Committee of the National Center for Neurorehabilitation for Children "Dr. N. Robanescu" in Bucharest, Romania, approved the study (protocol code 8739, date of approval 28.10.2019).

Subjects signed an informed consent form explaining specific aspects of the study before enrolling.

Statistical Analysis

The qualitative variables' descriptive statistics (education, marital status, residence, and income level) were cross-tabulated as numbers (n), and percentages (%), and the relationships between pairs of these variables were evaluated using Fisher's exact test.

To ensure that the data for the analysed groups had a normal distribution, we performed the Kolmogorov-Smirnov test. For variables with a data distribution that could be considered as normal, the t-test was used. For those where the data were not normally distributed was used Mann–Whitney U test (for the equality of medians) [25]. A p-value < 0.05 (and calculated confidence interval was afferent to a 95% level of trust) was considered statistically significant.

Spearman's rho correlations between the dimensions of PedsQL-FIM and sociodemographic characteristics/parameters were also performed. The Spearman correlation coefficient, which measures how closely two variables are related, ranges in value from -1 to 1[25].

All analyzes were performed with Excel and SPSS - version 22 - soft.

3. Results

We have analyzed two research groups regarding education level, marital status, residence, and income level. Table 1 summarizes the results we obtained.

38 of all mothers included in the study representing (44.70%) had a high school degree, more than those with another education background. 65 (76.47%) of them are married and 57 (67.05%) have an acceptable income level.

When the sociodemographic characteristics/parameters of the respondents were compared between the two groups of mothers (Group 1 and Group 2), no significant difference ($p > 0.05$) was found, as shown in Table 1.

Analysis of PedsQL-FIM Dimensions

We found that a higher percentage of mothers having children with congenital neuropathology were more likely to report feeling tired during the day (85% vs. 74% with acquired neuropathology) or when woke in the morning (68% vs. 47%), or when to do the things they like to do (62% vs. 45%).

They were more likely to experience headaches (60% vs. 50%) or feel physically weak (68% vs. 55%) and sick to the stomach (37% vs. 30%).

Table 1. Sociodemographic characteristics/parameters of the groups.

Characteristic	Group1	Group2	Total	p-Value
Education	**n (%)**	**n (%)**	**n (%)**	
University	7 (14.89)	10 (26.32)	17 (20.00)	
High school	24 (51.07)	14 (36.84)	38 (44.70)	**0.322**
Less than high school	16 (34.04)	14 (36.84)	30 (35.30)	
None at all	0 (0.0)	0 (0.0)	0 (0.0)	
Marital status				
Married	33 (70.21)	32 (84.21)	65 (76.47)	**0.198**
Single parent	14 (29.79)	6 (15.79)	20 (23.53)	
Residence				
Urban	18 (38.29)	23 (60.52)	41 (48.24)	**0.051**
Rural	29 (61.71)	15 (39.48)	44 (51.76)	
Income level				
Insufficient	5 (10.63)	4 (10.52)	9 (10.58)	
Acceptable	33 (70.21)	24 (63.15)	57 (67.05)	**0.712**
Comfortable	9 (19.14)	10 (26.31)	19 (22.35)	

We noticed that they feel more anxious (77% vs. 29%), sad (79% vs. 61%), angry (68% vs. 39%), frustrated (57% vs. 29%), and helpless or hopeless (66% vs. 42%) than mothers from Group 2.

It was difficult for them to discuss their child's health with others (66% vs. 32%) or communicate their feelings to professionals (62% vs. 26%). They believe that people do not understand their family's condition (64% vs 55%).

Mothers from Group 1 are more concerned about the efficacy of treatment (72% vs. 47%) and the side effects of drugs/medical treatments (68% vs. 55%). They are also more concerned about how others will react to their child's illness (57% vs. 37%) or the influence the child's condition will have on family members (51% vs. 34%). They are concerned for the child'future (85% vs. 76%).

We compared the data for the dimensions of PedsQL- FIM to find differences in the QOL between a family with children with congenital versus acquired neuropathology.

Kolmogorov-Smirnov test verified if there was a normal distribution of data for our groups. Thus, p values = Sig. should be > 0.05 (actually, the threshold represents 0.2 acceptance of normality; the point of 0.05 represents categorical rejection).

Table 2. Calculation of the p-value for 2 groups (congenital and acquired)

One-Sample Kolmogorov-Smirnov Test

diagnosis		PF	EF	SF	CF	CO	WO	DA	FR
Group 1	Asymp. Sig. (2-tailed)	0.200[c,d]	0.070[c]	**0.020[c]**	**0.032[c]**	0.200[c,d]	0.200[c,d]	0.053[c]	**0.016[c]**
Group 2	Asymp. Sig. (2-tailed)	0.200[c,d]	0.079[c]	**0.004[c]**	**0.011[c]**	**0.023[c]**	0.132[c]	0.074[c]	**0.003[c]**

a.The test distribution is normal. b.Calculated from the data.

c.Lilliefors Significance Correction. d.This is a lower bound of the true significance.

Legend: PF = Physical Functioning, EF = Emotional Functioning, SF = Social Functioning, CF = Cognitive Functioning, CO = Communication, WO = Worry, DA = Daily Activities, and FR = Family Relationships

Our findings indicate a normal distribution of data for Group 1 variables, except for social functioning (p =0.020), cognitive functioning (p = 0.032), and family relationships (p

= 0.016) (Table 2). Social functioning (p = 0.004), cognitive functioning (p = 0.011), communication (p = 0.023), and family relationships (p = 0.003) are the variables in which the Kolmogorov-Smirnov test rejects the normality of data for Group 2 (Table 2).

We used t-test to verifiy statistically significant differences between groups for variables with a normal data distribution (physical functioning, emotional functioning, worry, and daily activities).

Table 3. Calculation of the p-value using the t-test for four PedsQL- FIM variables

Independent Sample Test										
		Levene's test for the equality of variances		t-test for the equality of means						
									95% confidence interval of the difference	
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	Lower	Upper
PF	Equal variances assumed	4.860	**0.030**	2.320	83	0.023	0.41	0.17	0.05	0.77
	Equal variances not assumed			2.418	80.335	**0.018**	0.41	0.17	0.07	0.76
EF	Equal variances assumed	1.802	0.183	2.699	83	**0.008**	0.55	0.20	0.14	0.96
	Equal variances not assumed			2.770	82.917	0.007	0.55	0.20	0.15	0.95
WO	Equal variances assumed	7.034	**0.010**	2.825	83	0.006	0.61	0.21	0.18	1.04
	Equal variances not assumed			2.937	80.901	**0.004**	0.61	0.20	0.19	1.02
DA	Equal variances assumed	.000	0.998	1.926	83	0.058	0.44	0.23	-0.01	0.90
	Equal variances not assumed			1.945	81.803	0.055	0.44	0.22	-0.01	0.89

Legend: PF = Physical Functioning, EF = Emotional Functioning, WO = Worry, DA = Daily Activities

The following variables show statistically significant differences between the groups: PF (p = 0.018), EF (p = 0.008), and WO (p = 0.04) according to Table 3. There are no statistically significant differences between the groups for the DA variable (Table 3).

Using the Mann-Whitney U test for variables with non-normally distributed data, we found statistically significant differences between groups for the CO variable (p = 0.009) (Table 4).

Table 4. Calculation of the p-value using the Mann-Whitney U test

Test Statistics[a]

	SF	CF	CO	FR
Mann-Whitney U	809.000	773.500	601.000	741.500
Wilcoxon W	1550.000	1514.500	1342.000	1482.500
Z	-.746	-1.060	-2.598	-1.354
Asymp. Sig. (2-tailed)	0.456	0.289	**0.009**	0.176

a. Grouping Variable: Diagnosis

Legend: SF = Social Functioning, CF = Cognitive Functioning, CO = Communication, FR = Family Relationships

There were no statistically significant differences between the groups for social functioning, cognitive functioning, and family relationships, where p > 0.05 (Table 4).

We used Spearman's rho correlation test to objectify – if existing – associations between the PedsQL-FIM dimensions and sociodemographic characteristics/parameters within each group.

Table 5. Correlation between PedsQL-FIM dimensions and sociodemographic characteristics/parameters

Diagnosis		PedsQL-FIM dimensions		education	marital status	residence	income level
Group 1	Spearman's rho	PF	Correlation Coefficient	-0.181	0.050	0.029	-0.102
			Sig. (2-tailed)	0.223	0.739	0.846	0.495
		EF	Correlation Coefficient	**-0.338***	0.045	-0.186	0.070
			Sig. (2-tailed)	0.020	0.765	0.210	0.640
		SF	Correlation Coefficient	**-0.374****	0.191	-0.044	-0.178
			Sig. (2-tailed)	0.010	0.200	0.769	0.231
		CF	Correlation Coefficient	-0.171	-0.117	0.002	-0.133
			Sig. (2-tailed)	0.249	0.433	0.991	0.372
		CO	Correlation Coefficient	**-0.291***	0.098	-0.160	-0.099
			Sig. (2-tailed)	0.047	0.511	0.281	0.507
		WO	Correlation Coefficient	-0.180	0.165	-0.145	-0.041
			Sig. (2-tailed)	0.225	0.268	0.329	0.787
		DA	Correlation Coefficient	-0.153	0.107	0.034	-0.152
			Sig. (2-tailed)	0.304	0.473	0.820	0.308
		FR	Correlation Coefficient	-0.185	-0.007	0.005	-0.023
			Sig. (2-tailed)	0.213	0.963	0.974	0.878
Group 2	Spearman's rho	PF	Correlation Coefficient	-0.070	0.231	-0.052	-0.313
			Sig. (2-tailed)	0.674	0.162	0.757	0.056
		EF	Correlation Coefficient	0.063	0.185	0.143	**-0.327***
			Sig. (2-tailed)	0.707	0.265	0.391	0.045
		SF	Correlation Coefficient	0.215	0.195	0.037	**-0.534****
			Sig. (2-tailed)	0.196	0.240	0.825	0.001
		CF	Correlation Coefficient	0.141	0.083	0.032	-0.288
			Sig. (2-tailed)	0.400	0.621	0.848	0.080
		CO	Correlation Coefficient	-0.010	0.157	0.207	-0.317
			Sig. (2-tailed)	0.951	0.347	0.213	0.052
		WO	Correlation Coefficient	**0.332***	0.027	0.289	-0.140
			Sig. (2-tailed)	0.041	0.874	0.078	0.403
		DA	Correlation Coefficient	0.036	0.033	0.044	**-0.405***
			Sig. (2-tailed)	0.832	0.844	0.791	0.012
		FR	Correlation Coefficient	-0.057	0.131	-0.161	-0.206
			Sig. (2-tailed)	0.735	0.433	0.336	0.214

*. Correlation is significant at the 0.05 level (2-tailed).

**. Correlation is significant at the 0.01 level (2-tailed).

PF = Physical Functioning, EF = Emotional Functioning SF = Social Functioning, CF = Legend: Cognitive Functioning, CO = Communication, WO = Worry, DA = Daily Activities, and FR = Family Relationships

According to the findings in Table 5, we found 3 weak negative correlations between the following: emotional functioning and education (rho = - 0.338, p = 0.020), social functioning and education (rho = - 0.374, p = 0.010), and communication and education (rho = - 0.291, p = 0.047) for Group 1.

We also found a weak positive correlation between worry and education (rho = 0.332, p = 0.041), a weak negative correlation between emotional functioning and income level (rho = - 0.327, p = 0.045), and two moderate negative correlation between social functioning and income level (rho = - 0.534, p = 0.001), daily activity and income level (rho = - 0.405, p = 0.012) for Group 2.

4. Discussion

The objective of this study was to compare the QOL of mothers of children with congenital versus acquired neuropathology based on some sociodemographic characteristics/parameters to find an answer to our research question.

Numerous types of research have examined the influence of sociodemographic characteristics/parameters on families with disabled children. However, as we demonstrated in the Introduction, we were unable to find a study that examined the effects of sociodemographic characteristics/parameters on families with children with congenital vs acquired disabilities in terms of QOL.

The outcomes we found when we compared the two groups from the perspective of sociodemographic characteristics/parameters cannot, therefore, be supported establishing a correspondence with other studies within the literature.

Sociodemographic characteristics / parameters (variables) differently influenced the dimensions of PedsQL-FIM in the two groups: education (for congenital neuropathology) and, respectively, income level (for acquired neuropathology) had statistically significant correlations.

Our study found that due to differences in the above-mentioned sociodemographic characteristics / parameters mentioned above, the quality of life of mothers whose children have congenital neuropathology is different from that of mothers whose children have acquired neuropathology.

According to the literature, parents can better control their emotions the more educated they are [26]. Our findings on the negative correlation between emotional function and mother's education for mothers having children with congenital neuropathology are consistent with those of Bumin and colleagues (2009). They analyze a group of mothers of children with various disabilities [27]. Thus, based on the findings, we discovered that the less educated the mother is, the more anxious she is, unhappy or furious she feels, accumulates frustrations, and feels helpless or hopeless.

We discovered in the literature that families with disabled children have more social opportunities when their education level is higher [28]. Our study found that the mothers from Group 1 felt more alone, without social support, and lacked the time and energy for social activities the more educated they were.

Our study revealed that mothers from Group 1 felt more alone, without social support, and lacked the time and energy for social activities as their children's education level increased.

According to the mothers from Group 2, our study's findings support some studies from the literature that focus on families of children with chronic conditions. The lower the family's income, the more stressed out they feel, feeling helpless, accumulating frustration, and worrying about the future of the disabled child [29,30].

We found that mothers from Group 2: the higher the level of education they have, the more they worry about the functionality of the treatments, the existence of side effects of the drugs or treatments applied, and how their child's future will be, how the family members would may be affected by the child's condition, and how others relate to the child's illness.

Our results show a negative, moderate correlation between daily activities and income. In contrast, in the literature, Park et al. (2002) showed that daily activities are carried out better when the financial situation is better in families with children with disabilities [15].

It is interesting that in our study, no statistically significant correlations were established between the residence and the PedsQL-FIM dimensions, as it is known that access to treatment for families in rural areas is usually limited [22,31,32].

Limitations of the study

Firstly, we only collected data from mothers, which makes the results reflect just their point of view, at least in terms of income level.

Secondly, due to the small number of subjects, we could not divide each group into subgroups (a stratification of subjects according to sociodemographic variables) to determine whether there were differences between subgroups for the same sociodemographic characteristic/parameters.

5. Conclusions

Our analysis of the two groups QOL dimensions revealed statistically significant differences between the two groups' levels of physical functioning, emotional functioning, communication, and worry – all the better for Group 2.

Based on the results of our study, we can conclude that for mothers from Group 1, the variable education had the most significant influence on QOL, in contrast for mothers from Group 2, the variable income level had the strongest impact.

The statistically significant correlations between sociodemographic variables and PedsQL-FIM dimensions differed between the two groups, with limited possibilities of comparisons related to these associations; so at this stage, we cannot explain the above-mentioned interesting findings.

Bigger sample size would increase statistical power, possibly allowing us to a deeper understanding of the results we obtained.

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Institutional Review Board Statement: The study was conducted following the Declaration of Helsinki and approved by the Ethics Committee of the National Clinical Centre of Neurorehabilitation for Children "Dr. N. Robanescu" Bucharest, Romania (protocol code 8739, date of approval 28.10.2019) for studies involving humans.

Informed Consent Statement: Informed consent was obtained from all subjects involved in the study. Subjects' participation in the survey was voluntary. After the patient's parent or legal representative signed the informed consent form, in which detailed details of the study were described, the patient was enrolled.

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Conflicts of Interest: The authors declare no conflict of interest.

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