

FACTORS THAT HAVE A NEGATIVE IMPACT ON QUALITY OF LIFE IN CHILDREN WITH ADHD

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Abstract

Attention deficit-hyperactivity disorder (ADHD) and cerebral palsy (CP) are chronic diseases with major impact on quality of life (QoL) of children and their families.

Using Family Quality of Life Survey (FQOLS) – the version addressed to the main caregiver of the child with disability, the present study aimed to analyze the influence of pharmacological treatment concerning the expression of satisfaction as key concept in the areas of life, compared to overall QoL and overall satisfaction on QoL, before administration of treatment and one year after.

The scores assigned to the satisfaction on each area were statistically analyzed with Wilcoxon test (a non-parametric test for means comparison between dependent samples). For correlation analysis of the satisfaction in each area of life with overall QoL and overall satisfaction on QoL, non-parametric Spearman test was applied.

Rezumat

Tulburarea hiperkinetică cu deficit de atenție (ADHD) și paralizia cerebrală (PC) sunt afecțiuni cronice având un impact major asupra calității vieții (CV) copiilor diagnosticați cu aceste boli, cât și asupra familiilor lor.

Studiul de față a avut ca scop analiza influenței tratamentului farmacologic în exprimarea satisfacției considerate ca și concept de bază în domeniile calității vieții, în comparație cu CV generală și satisfacția generală asupra CV, înainte de inițierea tratamentului medicamentos și după un an.

Scorurile au fost analizate statistic cu ajutorul testului non-parametric Wilcoxon. Pentru analiza corelației satisfacției în fiecare domeniu al CV cu CV generală și satisfacția generală asupra CV, s-a folosit coeficientul de corelație Spearman.

Keywords: attention deficit-hyperactivity disorder (ADHD), cerebral palsy (CP), quality of life (QoL), area of life.

Introduction

World Health Organization (WHO) defines QoL as “individuals’ perception of their position in life in the context of the culture and value

systems in which they live and in relation to their goals, expectations, standards and concerns” [8].

It is widely acknowledged that QoL is a multidimensional concept referring to physical, social, psychological and occupational dimensions. The concerns for assessing QoL increased in recent decades. With enhanced life expectancy of the patients with chronic disease, QoL issues have become more remarkable [7].

QoL is fundamentally a public health issue. Thus, it has become an important concern in clinical research lately, but the real challenge the researchers are facing with is finding the appropriate measurement tool and administration method. Achieving a high QoL is difficult and it can coexist with the illness [4].

As the use of QoL measurement in clinical practice has focused primarily on adult patients, there is a lack of information and data regarding these issues in pediatric clinical care. Talking about pediatric practice, communication can be a key issue because young children may not have the language skills necessary to accurately communicate verbally their healthcare needs to their physicians [12]. That is why sometimes physical and psychological effects which affect social functioning can be better understood from the perspective of parent by the use of QoL measures [3].

Childhood illness has changed dramatically during this century [10]. Chronic diseases affecting children like asthma, epilepsy, cerebral palsy (CP), ADHD persist even into adulthood.

Both CP and ADHD have a major impact on QoL of children and their families through the implications and consequences of the disease itself. No cure is currently available for ADHD and CP, but the pharmacological treatment can reduce and control the consequences on long-term and must be taken in consideration as part of primary care plan.

Materials and Methods

In this study, ADHD and CP patients were considered for collection of data. Both pathologies patients underwent specific pharmacologic treatment. The questionnaire was completed by the main caregiver before administration of specific treatment for each disease and one year (± 20 days) after date of first completion. The patients included in the study were selected from the database of the Pediatrics and Pediatric Neurology Department of „Victor Gomoiu” Children Clinical Hospital, Bucharest, Romania.

This study included 49 patients diagnosed with ADHD (38 males and 11 females, mean age 8.33 ± 2.258 years) and 31 patients diagnosed

with CP (13 males and 18 females, mean age 6.1 ± 2.587 years). The CP group patients were administered botulinum toxin injections, while the ADHD group received either atomoxetine or methylphenidate treatment. The study was approved by the Ethics Committee of „Victor Gomoiu” Children Clinical Hospital. For all the children in the study, the written consent was obtained from children’s parent for using the medical data, ensuring also privacy and identity protection of the subjects.

Questionnaire Management

In order to assess the QoL, Family Quality of Life Survey (FQOLS) – the version translated in Romanian and addressed to the main caregiver of the child with disability, the parent in our case. No need for approval from the authors was needed for the use of the survey.

FQOLS is structured as follows:

1. About Your Family chapter which introduces the family members
2. The next nine chapters address specific areas of life: health, financial well-being, family relationships, support from others, support from services, influence of values, careers, leisure and recreation and community integration.

Each of these nine chapters has two sections: Section A providing the context and containing questions that collect some general information and Section B which contains questions related to six key concepts: importance, opportunities, initiative, attainment, stability and satisfaction.

3. The final part asks for overall impressions on Family QoL [5].

The FQOLS was completed by the health professional with the main caregiver (face-to-face administration) so that the parent to have the possibility to ask any questions that might arise.

The questionnaire examines the degree to which family QoL is enjoyable, meaningful and supported by resources that are important to all family members and meets a score from 1 (minimum) to 5 (maximum) for each question.

Respondents met the following eligibility criteria: the main caregiver of the child with disability (ADHD, PC), ability to read, cooperation and understanding while filling in the questionnaire.

The purpose of this study was to assess the satisfaction as key point on each area of life (health, financial well-being, family relationships, support from others, support from services, influence of values, careers, leisure and recreation and community integration) from parent’s perspective, before and after administration of pharmacological treatment to the child with ADHD or CP whose medical condition influences QoL of the

entire family overall QoL and to correlate it with overall QoL and overall satisfaction on QoL also.

Results and Discussion

For both CP and ADHD groups, the scores assigned to the satisfaction as key concept were statistically analyzed for the nine areas of life. Descriptive statistics for the scores determined before treatment initiation and after treatment for each disease group – CP group and ADHD group are presented in Table I.

Table I
Descriptive statistics of the scores for satisfaction in the nine key areas for the ADHD and CP groups *before and after* administration of pharmacological treatment

#	Area of life	Mean		Std. Deviation		Minimum		Maximum	
		ADHD	PC	ADHD	PC	ADHD	PC	ADHD	PC
Before treatment	Health of the family	1.84	1.71	0.717	0.693	1	1	4	3
	Financial well-being	1.86	1.84	0.612	0.638	1	1	3	4
	Family relationships	1.88	2.42	0.564	0.807	1	1	3	4
	Support from other people	2.27	2.13	0.605	0.718	1	1	4	4
	Support from disability related services	2.1	2.06	0.586	0.629	1	1	3	3
	Influence of values	3.06	3.1	0.775	0.908	2	2	4	5
	Careers and preparing for careers	2.57	2.29	0.764	0.643	1	1	4	4
	Leisure and recreation	2.22	2.16	0.621	0.583	1	1	4	3
	Community interaction	2.29	2	0.645	0.516	1	1	4	3
	Overall QoL	1.94	2.1	0.475	0.301	1	2	3	3
After treatment	Overall satisfaction on QoL	2.16	1.97	0.426	0.482	1	1	3	3
	Health of the family	4.08	4.13	0.607	0.499	3	3	5	5
	Financial well-being	3.76	3.58	0.751	0.62	1	2	5	5
	Family relationships	4.22	4.23	0.587	0.56	3	3	5	5
	Support from other people	3.55	3.77	0.647	0.617	2	2	5	5
	Support from disability related services	4.02	3.68	0.559	0.541	3	2	5	4
	Influence of values	3.51	3.48	0.545	0.677	2	2	4	5
	Careers and preparing for careers	3.71	3.61	0.577	0.558	2	3	5	5
	Leisure and recreation	4.1	3.87	0.549	0.619	3	2	5	5
	Community interaction	3.71	3.55	0.54	0.506	3	3	5	4
	Overall QoL	3.45	3.45	0.709	0.768	2	2	5	5
	Overall satisfaction on QoL	3.94	3.58	0.517	0.62	2	2	5	4

The Wilcoxon test (a non-parametric test for means comparison between dependent samples) was applied for the scores assigned to satisfaction regarding each area of life to both disease groups CP and

ADHD in order to test the difference between the two time points, before and after pharmacological treatment. The results are presented in Table II.

Table II

Wilcoxon test in ADHD and CP groups for the scores regarding each area of life at two time points

Area of Life	Wilcoxon statistic Z		p	
	ADHD	CP	ADHD	CP
Health of the family	-6.247	-4.983	< 0.001	< 0.001
Financial well-being	-6.030	-4.796	< 0.001	< 0.001
Family relationships	-6.214	-4.689	< 0.001	< 0.001
Support from other people	-5.697	-4.956	< 0.001	< 0.001
Support from disability related services	-5.985	-4.845	< 0.001	< 0.001
Influence of values	-3.947	-2.972	< 0.001	< 0.01
Careers and preparing for careers	-5.457	-4.862	< 0.001	< 0.001
Leisure and recreation	-6.229	-5.069	< 0.001	< 0.001
Community interaction	-6.033	-4.949	< 0.001	< 0.001
Overall QoL	-5.963	-4.665	< 0.001	< 0.001
Overall satisfaction on QoL	-6.420	-4.919	< 0.001	< 0.001

Wilcoxon statistic Z, applied to the comparison between the two time points of the scores for satisfaction in each area of life, resulted in associated statistical significance ($p < 0.01$) for all the areas for both CP and ADHD groups, for the difference between the two time points – before and after treatment. We can conclude that the decision of accepting and administration of treatment influenced the scores assigned to the satisfaction in all areas of life considered in this study.

For the correlation analysis, the non-parametric Spearman correlation coefficient was applied. The score for satisfaction in each area of life was tested for significant correlation with the score assigned for overall QoL and overall satisfaction on QoL, before and after administration of pharmacologic treatment, in both disease groups. The results are presented in Table III and Table IV.

In CP group, the calculated non-parametric Spearman could not highlight a statistical significant correlation between the scores of satisfaction in each area of life and the scores for overall QoL or overall satisfaction on QoL before administration of pharmacologic treatment. This means that it couldn't be demonstrated that any of these areas of life influences overall QoL or overall satisfaction on QoL.

Table III
Non-parametric Spearman correlation in ADHD and CP groups
before administration of treatment

Area of life	Overall QoL				Overall satisfaction on QoL			
	ADHD	CP	ADHD	CP	ADHD	CP	ADHD	CP
	Correlation coefficient		p		Correlation coefficient		p	
Health of the family	-0.050	-0.180	0.732	0.331	0.042	-0.148	0.776	0.426
Financial well-being	0.030	0.297	0.838	0.104	0.000	-0.008	1.000	0.967
Family relationships	0.114	-0.075	0.434	0.687	0.159	-0.023	0.276	0.902
Support from other people	0.052	-0.062	0.720	0.741	-0.178	-0.033	0.221	0.860
Support from disability related services	0.087	-0.211	0.552	0.255	0.183	-0.115	0.208	0.539
Influence of values	0.176	0.103	0.227	0.582	-0.023	0.080	0.874	0.668
Careers and preparing for careers	0.328	0.028	0.021	0.880	0.071	-0.086	0.630	0.647
Leisure and recreation	0.031	0.094	0.835	0.616	0.288	0.126	0.045	0.500
Community interaction	0.206	0.215	0.156	0.246	0.070	-0.005	0.634	0.979

In ADHD group, the non-parametric Spearman highlighted a statistical significant correlation ($p < 0.05$) between the scores for satisfaction in “Careers and preparing for careers” area of life and overall QoL, before administration of pharmacologic treatment. Another statistical significant correlation ($p < 0.05$) resulted between the scores of satisfaction in “Leisure and recreation” and overall satisfaction on QoL, also before administration of pharmacologic treatment.

Table IV
Non-parametric Spearman correlation in ADHD and CP groups *after*
administration of treatment

Area of life	Overall QoL				Overall satisfaction on QoL			
	Correlation coefficient		p		Correlation coefficient		p	
	ADHD	CP	ADHD	CP	ADHD	CP	ADHD	CP
Health of the family	0.275	0.063	0.056	0.736	0.095	0.064	0.515	0.733
Financial well-being	0.312	0.274	0.029	0.136	0.292	-0.233	0.042	0.207
Family relationships	0.317	0.107	0.026	0.567	0.123	-0.048	0.399	0.796
Support from other people	0.070	0.351	0.631	0.053	0.177	0.230	0.224	0.214
Support from disability related services	0.093	0.206	0.523	0.266	0.083	-0.201	0.570	0.277
Influence of values	0.061	0.000	0.676	0.998	0.272	0.007	0.059	0.969
Careers and preparing for careers	0.157	0.423	0.281	0.018	0.222	0.604	0.125	0.000
Leisure and recreation	0.228	-0.004	0.115	0.982	0.343	0.406	0.016	0.024
Community interaction	-0.027	0.271	0.854	0.141	0.459	0.181	0.001	0.330

After administration of pharmacologic treatment, in CP group the non-parametric Spearman highlighted a statistical significant correlation ($p < 0.05$) between the scores of satisfaction in “Careers and preparing for

careers” area of life and overall QoL, and a statistical significant correlation ($p < 0.05$) between both “Careers and preparing for careers” and “Leisure and recreation” areas of life scores and overall satisfaction on QoL scores.

In ADHD group, the non-parametric Spearman highlighted also a statistical significant correlation ($p < 0.05$) between the scores of satisfaction in “Financial well-being” and “Family relationships” areas of life and overall QoL scores, and also a statistical significant correlation ($p < 0.05$) between “Financial well-being”, “Leisure and recreation” and “Community interaction” scores each in correlation with the overall satisfaction on QoL scores after administration of pharmacologic treatment.

Conclusions

ADHD and cerebral palsy (CP) are diseases with major impact on children’s and children’s family life and great impairment on quality of life (QoL). The decision of accepting the administration of pharmacologic treatment is a difficult one taking in consideration that neither ADHD nor CP can be cured, but the study demonstrated that treatment intervention influenced by a significant improvement the satisfaction in all area of life considered in this case after the disease being treated which is consistent with the hypothesis.

For CP group, “Careers and preparing for careers” and “Leisure and recreation” proved to have significant influence on QoL after administration of treatment which confirms the hypothesis also if we think that the consequences of this particular health condition can be ameliorated only if the disease is treated and thus the main caregiver can have a job and the patient may benefit from education and also an improvement of health condition provides an opportunity to enjoy of recreational activities for the family.

For ADHD group, treating the disease proved an improvement of satisfaction in more areas of life, like “Financial well-being”, “Family relationships”, “Leisure and recreation” and “Community interaction”. This also confirms the hypothesis that untreated ADHD can have long-term negative consequences at a psychological, social and economic level.

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