UNIVERSITY OF MEDICINE AND PHARMACY ''CAROL DAVILA'', BUCHAREST

DOCTORAL SCHOOL
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"Research on quality of life in families with children or adolescents with neuro-disabilities of ante- and peri-natal/ congenital origin compared to families with members with acquired disabling neuropediatric status"

PHD THESIS SUMMARY

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INTRODUCTION

The Ph.D. thesis entitled "Research on quality of life in families with children or adolescents with neuro-disabilities of ante- and peri-natal/ congenital origin compared to families with members with acquired disabling neuropediatric status" is a scientific intervention carried out with the aim of assess the extent to which the congenital versus (vs.) acquired neuropathological context has an impact on the quality of life (QOL) of families with children or adolescents with consecutive neurodisabilities and to objectify the found results, through a comprehensive analysis.

Even if in the international literature there are published results that provide information about QOL in families with children or adolescents with neurodisabilities, the lack of comparative studies of QOL between families with children or adolescents with disabling neuropathology, determined by problems arising in the development of the conception product, during intrauterine or immediately after birth and, respectively, families with such minor members, with temporary or permanent damage to the brain, occurring in childhood or adolescence, from external or internal causes (traumatic or non-traumatic), makes this subject have potential for exploration and related availability for elements of originality of this Thesis.

I.GENERAL PART

Chapter 1. THEORETICAL ASPECTS RELEVANT TO THE RESEARCHED PATHOLOGY

1.1. Current synthetic data on disabling neuropathology of ante- and peri-natal/ congenital origin

Among neurodisabling pathologies of ante- and peri-natal/ congenital origin, from the file of Centrului Național Clinic de Recuperare Neuropsihomotorie Copii "Dr. Nicolae Robănescu" (CNCRNC "Dr. N. Robănescu") were used those which were part of study Group 1 of this research: Cerebral Palsy (CP) and spinal muscular atrophy (SMA).

1.2. Current synthetic data on acquired disabling neuropediatric conditions

Among the disabling neuropediatric conditions acquired, those from the CNCRNC "Dr. N. Robănescu" file were used, which were part of study Group 2 of the present research: traumatic brain injury (TBI), brain tumors and, respectively, stroke (AVC).

1.3. Definitions and conceptual aspects of disability, with emphasis on neurodisability

Eurostat, the European Union that produces statistics in member countries, advances the percentage of 6.1% people with disabilities in Romania.[1]. When disability is caused by neurological impairments, the term used by specialists is neurodisability.

Motor, sensory and/ or intellectual disabilities limit the ability of a child or adolescent to perform various activities and interact properly with the environment, including the family [2].

1.4. Current synthetic data regarding the quality of life in families with children and/ or adolescents with disabling neuropathology of ante- and peri-natal/ congenital origin

Synthesizing the data we extracted from the literature, we could say that the following variables (without considering that we have exhausted their identification and enumeration) can influence the QOL of the family with children and/ or adolescents with disabling neuropathology of ante- and peri-natal origin/ congenital: the lack of psycho-emotional balance [3], he stigma of different functioning of the child [3], the long waiting time until a diagnosis is established [4], the level of education of the parents [5,6], characteristics of the child, the parents , environmental factors [7–9], intellectual disability of the child [10], anxiety and depression of relatives [11], low socio-economic status of the family [11], worry about the future [12].

1.5. Current synthetic data on quality of life in families with children and/ or adolescents with disabling acquired neuropathology

Synthesizing the data extracted from the literature, we could say that among the variables that can influence the QOL of the family with children and/ or adolescents with acquired disabling neuropathology are the following: cognitive and behavioral impairment of the child [13], family functioning before a traumatic event [14–16], the child's psychocognitive functioning [15], prognosis, and uncertain functional results [17]. It should be noted that the literature, from this point of view, does not provide variables identical to pathology of 1.4.

1.6. Cognitive emotional regulation strategies – impact on quality of life

Emotional regulation can be defined as "the attempts of individuals to influence the emotions they have, when they have them, and how these emotions are experienced and expressed" [18]. Emotional regulation strategies can be disturbed by the fatigue of those who fight to improve the condition of the child/ adolescent with disabilities, by the feeling

of powerlessness and lack of control, by the stress perceived, as a whole, by those involved, all of which lead to the impairment of the family's QOL [19]. The training of emotional regulation by recognizing, accepting and expressing emotions and the appropriateness of behaviors in problematic situations can contribute to increasing the ability to adapt in a positive manner to unfavorable situations and to improving relationships and social interaction in families with children/ adolescents with disabilities [20].

Chapter 2. FUNCTIONAL CLINICAL ASSESSMENT TOOLS, INCLUDING PSYCHOMETRIC, USED WITHIN DOCTORAL RESEARCH

We specify from the beginning of this chapter the fact that for all the questionnaires used in this doctoral study we either had express approval (eg: PedsQL-FIM, WHOQOL-BREF, CERQ) or were downloaded free of charge [e.g.: FAM (FIM + FAM)].

2.1. Evaluation, using the FAM scale (FIM + FAM), of the functional independence of the child(ren)/ adolescent(s) with disabling neuropathology

The Functional Assessment Measure (FAM) scale is a 30-item scale that can be used for nonspecific patient populations [21–23]. Independence, respectively dependence, are assessed on levels (from 1 to 7), which also represent the score that a person can obtain (1 – total assistance to 7 – complete independence) [21].

2.2. Evaluation, using the PedsQL-Family Impact Module (PedsQL-FIM) questionnaire, of the impact of the child and/ or adolescent neurodisability on the family.

The questionnaire contains 36 items divided into eight dimensions, measuring on the one hand the reported functioning of the interviewed parent and, on the other hand, the functioning of the family, reported by the parents. [24]. Higher scores in one or more dimensions represent better functioning for that dimension(s) [25].

2.3. Evaluation, using the WHOQOL-BREF scale, of the quality of life of the family with child(ren)/ adolescent(s) with disabling neuropathology

The WHOQOL-BREF contains two general items (Q1, which refers to the "general perception of the individual on the quality of life" and Q2, which refers to the "general perception of the individual on his health") and 24 items that measure satisfaction, divided into four areas. [26]. Higher scores indicate higher QOL [27].

2.4. Evaluation, using the CERQ questionnaire, of cognitive-emotional coping in families with child(ren)/ adolescent(s) with disabling neuropathology

CERQ, a tool with 36 items divided into 9 subscales (with 4 items each), includes strategies that can be used by a person following a negative, traumatic event, such as: "self-blame", "acceptance", "rumination", "positive refocusing", "refocusing on planning", "positive reappraisal", "putting into perspective", "catastrophizing", "blaming others" [28].

The sum of the items of each strategy is compared with the reference values related to the questionnaire manual; high scores represent the dominant strategy(s) chosen by the patient. [29].

II. PERSONAL CONTRIBUTION

Chapter 3. WORKING HYPOTHESIS AND OVERALL GOALS

To perform the research, we started from the following hypotheses:

1. Between families with children or adolescents with congenital neurodisabilities and families with children or adolescents who develop neurodisabilities after a period of normal life (acquired), differences in QOL can be assumed.

2. Between families with children or adolescents with congenital neurodisabilities and families with children or adolescents with acquired neurodisabilities, differences can be assumed regarding strategies for cognitive regulation of emotions.

The general/ main objective of this research is to conduct a comparative study between two groups, representing:

- mothers of neuropediatric patients with congenital disabling pathology – Group 1;
- mothers of neuropediatric patients with acquired disabling pathology – Group 2.

Chapter 4. GENERAL RESEARCH METHODOLOGY

The personal research carried out in this doctoral thesis consists of five studies.

4.1. Material and research methods

This doctoral research occurred over a period of approximately four years, approximately 2019–2023 within the CNCRNC "Dr. N. Robănescu", in two target groups: one that includes mothers of neuropediatric patients with congenital disabling pathology and one including mothers of neuropediatric patients with acquired disabling pathology (we emphasize the fact that in the meaning of the term families with such neuropediatric patients, we could evaluate only their mothers), both groups being clinically functionally evaluated, including psychometrically through the scales mentioned above.

4.2. Characteristics of the study groups

4.2.1. Inclusion criteria

- school-age children or teenagers with neurodisabilities;

- family members – the mother – adults (1st, 2nd degree relatives) who live together.

4.2.2. Exclusion criteria

- teenagers over 18 years old;

- family members who live and care for children with neurodisabilities and who present with psychocognitive status.

4.3. Ethical considerations

The entire doctoral clinical research was carried out within the CNCRNC "Dr. N. Robănescu" and its development received the approval of the Ethics Commission no. 8739/ 28.10.2019 within this institution. The enrolment of subjects in the study was carried out only after obtaining informed consent from the patient's parent/ legal representative.

Statistical analysis

SPSS (Statistical Package for the Social Sciences) version 22 and Microsoft Excel 2016 were used for statistical processing of the primary data.

Descriptive and elementary statistical calculations were also used: averages, medians, standard deviations of the values of the measured parameters; the Kolmogorov-Smirnov normality test, according to which if the data had a normal distribution, we used parametric t tests; if they had an abnormal distribution, we used nonparametric Mann-Whitney U tests; rank correlation coefficient (Spearman) [30–35].

Chapter 5. STUDY I: SYSTEMATIC REVIEW OF LITERATURE IN THE THESIS FIELD

5.1. Introduction (Working hypothesis and overall goals)

This first study – a systematic review of the related literature – was carried out with the aim of increasing the knowledge related to the subject of the Doctoral Thesis and to appreciate if there is potential for further exploration and related availability for elements of originality of the theme.

5.2. Material and method or Patients and methods

In order to know the existing data in the literature related to the subject, we interrogated, using contextually keywords, respectively, combinations/ "syntaxes" of keywords (presented in detail in the Thesis), the following internationally recognised medical databases:: NCBI/ PubMed [36], NCBI/ PMC [36], Elsevier [37], PEDro [38], to

which the Google Scholar browser was added free. The ISI Web of Knowledge/ Science database [39] checked whether articles significant in terms of content in relation to the topic of the doctoral thesis were published in ISI indexed journals.

For this purpose, we used the standardized methodology, internationally accepted, Preferred Reporting Items for Systematic Reviews and Meta-Analyses – PRISMA [40] – without performing the last possible stage of this meta-analysis, since this approach exceeds the proposed bibliographic exploratory purpose.

5.3 Results

Using these words, key word combinations/ syntax resulted in the first stage of querying the 4 databases, 397 articles of which 395 in PMC and 2 in PEDro. After using the PRISMA article filtering algorithm, 7 articles were selected in the direct and final quantitative analysis, which were checked and the extracted information can be found in the thesis, including the related bibliographic references.

5.4. Discussions and partial conclusions (sectoral)

Even after the extensive contextual search using several key word combinations/ "syntaxes", we can claim that we have not found a detailed approach sufficient as a volume of works (articles whose content refers approximately defined the issue we propose to study) so that we can appreciate that the chosen topic is still insufficiently addressed in the literature and therefore deserves an additional analysis.

Chapter 6. STUDY II: RESEARCH ON EMOTION REGULATION STRATEGIES AND DOMAINS OF QUALITY OF LIFE IN FAMILIES WITH CHILDREN/ ADOLESCENTS WITH SPINAL MUSCULAR ATROPHY

6.1. Introduction (Working hypothesis and overall goals)

In this study, analyzing families with children and/ or adolescents with SMA, we sought an answer to the question: can there be correlations between QOL domains and emotion regulation strategies? If they exist, we are interested in what quantitative, statistically objective level they can.

6.2. Material and method or Patients and methods

The study carried out in CNCRNC "Dr. N. Robănescu" included 33 mothers of children and/ or adolescents with SMA, who were surveyed using:PedsQL-FIM [25] and, respectively, CERQ [28], Romanian versions.

6.3. Results

We calculated reversed scores (as required by the PedsQL-FIM questionnaire) to find values corresponding to better functioning for each domain and CERQ scores to see what percentage of respondents chose a very high score in response to a specific strategy.

The analysis of the Spearman correlation coefficient (rho) showed generally weak and moderate, positive correlations [31] between the domains of the PedsQL-FIM questionnaire, but there were also 3 high, positive correlations (details in Thesis). The Spearman rho correlation coefficient showed that there were generally positive, weak correlations between the CERQ subscales [31], with 5 positive, moderate correlations (details in Thesis) [31].

Between the PedsQL-FIM domains and the CERQ subscales of the data analysis, negative, moderate, and weak correlations resulted [31].

6.4. Discussions and partial conclusions (sectoral)

Statistically analyzing the data of the PedsQL-FIM questionnaire, we found that the field "family relations" had the highest frequency of high scores (which, according to the interpretation of the authors of the questionnaire, indicated a better QOL for the respective subscale), being chosen by 7 of the respondents, representing 21.2% of the total number of mothers who considered that they had no "problems with family relationships, including communication, stress and conflicts between family members and difficulties in making decisions and solving problems as a family"[25]. At the same time, only one respondent representing 3% of mothers scored the highest for the domains of physical functioning, emotional functioning, and worry.

Interpreting the results of the CERQ questionnaire showed that the highest score obtained by 10 of the mothers surveyed (representing 30.3% of the total of the mothers surveyed) was for the "positive refocusing" strategy. Also, 9 mothers (27.3% of total respondents) gave a "very high" score for the "putting into perspective" strategy; 8 mothers (24.2% of total respondents) gave a "very high" score for the "acceptance" strategy.

According to the results, two of the surveyed mothers (6.1% of the total respondents for each strategy) gave the highest scores for each of the maladaptive strategies, "self-blame" and "blame others". The remaining 31 mothers (93.9% of all respondents) considered that other people cannot be blamed for what happened to them (the scores obtained were medium to low). Furthermore, for the "blaming others" strategy, 19 mothers were assigned the lowest score. For our respondents, the better the communication (including other people's understanding of the family situation, discussions with them about the health status of the child/ adolescent, communication with health professionals),

the better the social functioning (which includes sense of belonging, receiving support from others and finding time and/ or energy for social activities). Harmony and communication within the family lead to the ability to perform household duties properly. When cognitive functions, expressed by focusing attention, the ability to store and update information, and the ability to think quickly are not affected, household activities do not require additional effort.

Of interest: we found moderate positive correlations between two maladaptive strategies (catastrophising and self-blame) that we identified in the literature as anxiety-related strategies [41]. The cause could be the stress given by the severity of the disease/ disability in families with children/ adolescents with SMA.

Our study suggests that the lower the emotional functioning, the more intense the rumination (the more anxious, sad, angry or frustrated, helpless or hopeless mothers feel, the more they think about their situation).

The results we obtained are consistent with the literature, where it is appreciated that high scores for rumination are associated with emotional problems [29].

The moderate negative correlation between communication and self-blame could be explained as follows: the more other people understand the family's situation, while overcoming difficulties in talking about their child's health and communicating with health professionals, the more the feeling of guilt about their child's illness is lower. Between family relationships and self-blame and between family relationships and rumination, the negative correlation being weak, we cannot appreciate the extent to which the two strategies influence the relationships that are established in families with children/ adolescents with SMA from our group. We also found that cognitive functioning is little influenced by mothers' thoughts and concerns about their child's condition. The weak negative correlation between social function and self-blame could indicate that when mothers are intensely concerned with their own responsibility for the child's illness there is a decrease in social relationships and involvement in social activities. Although in general the correlations that were established were weak and moderate, the maladaptive strategies used by mothers in our study could be determined by the stress given by the severity of the illness/ disability, and the adaptive strategies (acceptance, refocusing on planning, perspective taking, positive reappraisal) could show that there is interest in finding solutions to improve the QOL of children and/ or adolescents with SMA and their whole family.

Chapter 7. STUDY III: COMPARATIVE ANALYSIS OF THE QUALITY OF LIFE IN FAMILIES HAVING CHILDREN OR ADOLESCENTS WITH CONGENITAL VERSUS ACQUIRED, DISABLING NEUROPATHOLOGY

7.1. Introduction (Working hypothesis and overall goals)

The results of this study related to the scientific approach to the compilation of the special part of the Doctorate Thesis were published in Children journal (Basel), 2022, 9(5), FI=2.863, ISSN 2227-9067, authors: M. V. Morcov, L. Pădure, C. G. Morcov, A. Mirea, M. Ghiță, and G. Onose [42].

Our study aimed to investigate whether there is any difference between the QOL of a family that has children or adolescents with congenital neuropathology and that of children or adolescents with acquired neuropathology.

7.2. Material and method or Patients and methods

66 subjects [Group 1 – consisting of 31 mothers of pediatric patients with congenital disabling neuropathology (PC of prenatal and perinatal origin) and Group 2 – consisting of 35 mothers of pediatric patients with acquired disabling neuropathology (traumatic brain injury after car accidents)] hospitalized at CNCRNC "Dr N. Robănescu" completed: PedsQL-FIM [25], WHOQL-BRIEF [27], and CERQ [28], Romanian versions.

Basic demographic data were also collected, including education, marital status, residence, age of their children, length of time between the time of the accident and the mother's questionnaire (for acquired neuropathology) and severity of impairment, respectively. Patient observation sheets were used to obtain information on the severity of the acquired condition.

7.3. Results

Based on the mean ranks, the Mann–Whitney U test calculated a value of $p = 0.686$ for the variable level of education, $p = 0.084$ for marital status, and $p = 0.988$ for residence. The three p values being >0.05 show that there are no statistically significant differences between the groups based on sociodemographic parameters.

Data analysis for PedsQL-FIM

Using the parametric t test, $p < 0.05$ values were obtained for emotional functioning ($p = 0.034$), communication ($p = 0.042$) and worry ($p = 0.036$), indicating that there were significant differences between the two groups. For physical functioning, we cannot say the same; we can only say that the number of analysed cases is too small to draw (statistically) a conclusion.

The Mann–Whitney U test showed that the variables social functioning (p = 0.489), cognitive functioning (p = 0.199) and daily activities (p = 0.103), family relationships (p = 0.057) all had p values > 0.05, indicating that there are no statistically significant differences between the groups for these dimensions.

Data analysis for WHOQOL-BREF

To determine whether there were statistically significant differences between the groups for the psychological health variable, we used the parametric t-test. I noticed that both the averages are apparently "close" to each other; the average for Group 1 is 14.96 and for Group 2 it is 14.40. Thus, these results (p = 0.383) are not surprising and do not suggest any differences between the groups in terms of psychological health.

The Mann–Whitney U test for the variables physical health (p = 0.370) and environment (p = 0.479) indicated that there were no statistically significant differences between the groups for these domains. For social relations, p = 0.058, which shows us that the difference is also not statistically significant for this variable.

Data analysis for CERQ

The Mann–Whitney U test showed that there were no statistically significant differences between groups for self-blame (p = 0.430), positive reappraisal (p = 0.075), catastrophizing (p = 0.679), and blaming others (p = 0.226). Regarding positive refocusing (p = 0.023) and putting into perspective (p = 0.031), statistically significant differences were found between groups, with Group 1 having a higher mean rank than Group 2 for both variables.

7.4. Discussions and partial conclusions (sectoral)

We found no comparative research on QOL in families having children with congenital vs. acquired neurological disorders. We believe that the importance of this study comes from the fact that no one has done anything like it before.

We hypothesized that the occurrence of a disabling event at a certain point in life could lead to a breach in previously normal life, and as a result, both coping strategies and QOL would be different from those of mothers with children with congenital deficiencies. From our results, we appreciate that for the family, regardless of when the insult appears, at birth or after a period of normal development, it is a shock and a permanent challenge in the fight with the child's disability.

Having no comparative studies in the specialized literature to refer to, based on our statistical analysis, we find that regardless of the type of impairment, congenital or acquired, the domains of social, cognitive functioning, and daily activity were equally

appreciated by both groups. Given the significant parental burden caused by the physical and psychosocial difficulties of children with a congenital or acquired disease, we can appreciate that family structure, social, emotional, and relational functioning are similarly disrupted.

Since the result of our comparative analysis for the domains: family relations (PedsQL-FIM) and social relations (WHOQOL-BREF) has no statistical significance, we cannot clearly appreciate which group has a better situation for these domains.

Taking into account the duration of care and the severity of the disease we could explain why most of the QOL parameters are almost comparable in the two studied groups.

When completing the three questionnaires, the results allowed us to draw some conclusions regarding coping strategies.

Analyzing the mean score on the CERQ scale for each strategy, we found that it was higher for Group 1, except for catastrophizing, where the mean score was higher for Group 2.

The highest scoring strategies that appear to be most frequently chosen by mothers are: putting into perspective (45.1%) for Group 1 and catastrophizing (48.5%) for Group 2.

Considering that there are statistically significant differences between the groups in terms of strategies: positive reorientation and putting into perspective – that is, the situation in Group 1 is different from that in Group 2 – we can appreciate that the perspective on life in families with children/ adolescents with congenital impairment were more prone to change, in the sense of more frequent use of adaptive coping strategies by mothers in Group 1.

According to the findings made from the analysis of our questionnaire, we can state that for mothers of patients with traumatic brain injuries (acquired neuropathology), QOL expressed by emotional functioning, communication, and concern is different from that of mothers of patients with CP (congenital neuropathology): on average, better for the mothers in Group 2. At the same time, the choice of adaptive coping strategies leads us to consider that they are psychological support for the family in the fight against their children's illness and in the extension of the recovery treatment.

Chapter 8. STUDY IV: ADDITIONAL, DETAILED OBJECTIVE – BASED ON SPECIFICATIONS AND CHARACTERISTICS/ SOCIODEMOGRAPHIC PARAMETERS AND RELATED STATISTICAL PROCESSING – WITHIN THE

COMPARATIVE ANALYSIS OF THE QUALITY OF LIFE IN FAMILIES HAVING CHILDREN OR ADOLESCENTS WITH CONGENITAL VERSUS ACQUIRED, DISABLING NEUROPATHOLOGY

8.1. Introduction (Working hypothesis and overall goals)

Starting from data found in the specialized literature regarding the influence of sociodemographic characteristics/ parameters on the family that has a child(ren)/ teenagers with disabilities, we set out to investigate if there is a difference in QOL between mothers of children/ teenagers with congenital neuropathology and mothers of children/ adolescents with acquired neuropathology based on such characteristics/ parameters.

8.2. Material and method or Patients and methods

This cross-sectional comparative study that included 85 subjects [47 mothers of pediatric patients with congenital disabling neuropathology (CP) – Group 1 and 38 mothers of pediatric patients with acquired disabling neuropathology (TCD) – Group 2] was conducted at CNCRNC "Dr. N. Robănescu" between December 2019 and April 2022. Health-related QOL was measured using the PedsQL-FIM. We also collected information on marital status, residence, education, and perceived income level.

8.3. Results

Comparing the groups (Group 1 and Group 2) according to the sociodemographic characteristics/ parameters did not reveal any statistically significant difference between the groups, p being > 0.05.

To check if there were statistically significant differences between Group 1 and Group 2 regarding QOL, we compared the data of the PedsQL-FIM dimensions. The parametric t-test found statistically significant differences between groups for the following variables: physical functioning ($p = 0.018$), emotional functioning ($p = 0.008$), and worry ($p = 0.004$). For the daily activities variable, there were no statistically significant differences between the groups.

Using the Mann–Whitney U test for variables where the normal distribution of data was rejected (social functioning, cognitive functioning, communication and family relationships) we found statistically significant differences between groups only for the communication variable ($p = 0.009$). For the other three variables, social functioning, cognitive functioning, and family relationships, there were no statistically significant differences between the groups, $p > 0.05$.

To objectify – if any – associations between PedsQL-FIM dimensions and sociodemographic characteristics/ parameters within each group we used Spearman's rho

correlation coefficient. According to the findings, we found three 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) in Group 1.

Within Group 2, we 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). We also found two moderate negative correlations between social function and perceived income level (rho = - 0.534, p = 0.001), daily activity and perceived income level (rho = - 0.405, p = 0.012).

8.4. Discussions and partial conclusions (sectoral)

Although numerous studies in the literature have examined the influence of sociodemographic characteristics/ parameters on families with children/ adolescents with neurodisabilities, we have not found any study that comparatively analyzes the effects of these characteristics/ parameters on the QOL of families with children/ adolescents with congenital vs. acquired neurodisabilities, to which we relate our results.

Moreover, the sociodemographic variables that influenced some of the PedsQL-FIM dimensions (for which statistically significant correlations were obtained), were not the same for the two groups: education (for Group 1) and perceived level, respectively of income (for Group 2). There was, however, a correlation between education and worry in Group 2.

Therefore, the reference to the literature was carried out for each group separately.

For mothers in Group 1, a higher level of education meant a lower social function, that is, they felt more alone, without support from others, and did not have time and energy for social activities. According to the answers given by the mothers in Group 2, the higher the family income, the less stressed or helpless the mother feels, accumulates less frustration and does not worry much about her child's future. Mothers from Group 2 also believe that high incomes do not reduce the time needed to carry out family activities.

It is interesting that in our study we could not establish statistically significant correlations between residence and PedsQL-FIM dimensions, although it is known from the literature that access to treatment for rural families is usually limited [43–45].

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

Chapter 9. STUDY V: FINAL DATA (with additional numerical augmentation of the studied patient groups) ON THE COMPARATIVE ANALYSIS OF THE QUALITY OF LIFE IN FAMILIES HAVING CHILDREN OR ADOLESCENTS WITH CONGENITAL VERSUS ACQUIRED, DISABLING NEUROPATHOLOGY

9.1 Introduction (Working hypothesis and overall goals)

Starting from the conclusions of previous studies and further expanding the groups (which would allow mathematical processing with greater statistical power and therefore with additional increased reliability), we believe that we could obtain results and, consequently, conclusions with greater relevance for the entire approach in our comparative doctoral research on the QOL of mothers of children/ adolescents with congenital vs acquired, disabling neuropathology.

9.2 Material and method/ Patients and methods

The comparative study carried out within the CNCRNC "Dr. N. Robănescu" included, in total, 152 subjects (87 mothers of neuropediatric patients with congenital disabling pathology – Group 1 and 65 mothers of neuropediatric patients with acquired disabling pathology – Group 2).

To carry out this study, the following were administered: the FAM scale (FIM + FAM); the PedsQL-FIM questionnaire; the WHOQOL-BREF scale; the CERQ questionnaire.

9.3. Results

The statistical analysis of the data was performed in 2 stages:

A. The stage of the comparative analysis, by groups, of the values measured with each individual assessment tool;

B. The stage of analysing possible correlations between the values of the variables quantified with the assessment tools used in this research.

A. To carry out the **comparative statistical analysis**, at this stage, we interpreted the data of each clinical functional assessment tool, including psychometric [FAM (FIM + FAM), PedsQL-FIM, WHOQOL-BREF, CERQ].

A1. Comparative analysis of FAM scale scores (FIM + FAM).

Unlike the other three questionnaires that interview mothers strictly in relation to their own functioning or coping strategy, this instrument indirectly assesses mothers' emotional status through their answers related to the questions in the FAM scale (FIM + FAM) related to their child's/ teenager neurodysfunctional status.

A.1.1. Comparison of the Motor domain subscores

Using the Mann-Whitney U test, a value p = 0.098 is calculated attached to the statement: "the distributions of the values of the motor domain subscore, by groups, differ from each other", which is not confirmed.

A.1.2. Comparison of the Cognitive domain subscores

The Mann-Whitney U test calculated a value p = 0.133 attached to the statement: "the distributions of the values of the subscore of the cognitive domain, by groups, differ from each other" which is not confirmed.

A.2. Comparative analysis of the scores of the two groups for the 8 dimensions/ variables of the PedsQL-FIM questionnaire.

A.2.1. Dimension Physical functioning

The calculated averages are 56.03 for Group 1 and 62.81 for Group 2, respectively, and the parametric t test calculated a value p = 0.037 attached to the statement "Group 1 has a different physical functioning from Group 2", confirming that Group 2 has an average better situation.

A.2.2. Dimension Emotional Functioning

The average ranks are 67.47 for Group 1 and 88.59 for Group 2.

Based on these ranks, the Mann-Whitney U test calculated a value p = 0.003, so we can say that "Group 2 has a higher average rank than Group 1", a statement that is statistically significant.

A.2.3. Dimension Social Functioning

The average ranks are 74.21 for Group 1 and 79.57 for Group 2.

The Mann-Whitney U test calculated a value p = 0.456 which is statistically insignificant (p > 0.05), which does not confirm the statement: "Group 1 has a different situation from Group 2".

A.2.4. Dimension Cognitive Functioning

The calculated average ranks are 72.65 for Group 1, respectively 81.65 for Group 2. The Mann-Whitney U test calculated a value p = 0.210, statistically insignificant (p > 0.05), which does not confirm the statement: "Group 1 has a different situation from Group 2".

A.2.5. Dimension Communication

The calculated average ranks are 67.05 for Group 1, respectively 89.15 for Group 2. Based on these ranks, the Mann-Whitney U test calculated a p value = 0.002, so we can say that "Group 1 has a different situation than Group 2", statement which is statistically significant (Group 2 having the better situation based on average ranks).

A.2.6. Dimension Concern

The calculated averages are 45.87 for Group 1 and 56.30 for Group 2, respectively, and the parametric t test calculated a value p = 0.013, attached to the statement "Group 1 has a different level of concern than Group 2", which confirms it (Group 2 having on average a better situation than Group 1).

A.2.7. Dimension Daily activities

The average ranks calculated are 68.97 for Group 1, respectively 86.58 for Group 2. The Mann-Whitney U test calculated a p-value = 0.014, so we can state that "Group 1 has a different situation from Group 2", a statement that is significant from a statistical point of view (Group 2 has on average a better situation than Group 1).

A.2.8. Dimension Family Relationship

The calculated average ranks are 72.29 for Group 1, respectively, 82.14 for Group 2. The Mann-Whitney U test calculated a value p = 0.166, attached to the statement: "Group 1 has a different situation from Group 2" which it does not confirm.

A.3. Comparative analysis of scores for each domain of the WHOQOL-BREF scale.

Before performing the comparative analysis of the domains of the WHOQOL-BREF scale, we separately examined the first and second items of the scale, respectively, Q1 and Q2, to find out what the general perception of QOL and health is in the studied groups.

Analysing question Q1 regarding the general perception of QOL, we could see that the percentage of those who rated QOL as very good is approximately equal in both groups, discretely in favour of Group 1 (11.5% versus 10.8%).

The average ranks calculated are 76.26 for Group 1, respectively 76.82 for Group 2. The Mann-Whitney U test calculated a value p = 0.930, attached to the statement: "the average ranks of the groups differ from each other" which it does not confirm.

Analyzing the question Q2 regarding the general perception of health, we could see that the percentage of those who appreciated that they are very satisfied with their health is slightly higher for Group 1 (11.5% versus 9.2%).

The calculated average ranks are 75.79 for Group 1, respectively 77.45 for Group 2. The Mann-Whitney U test calculated a value p = 0.795, attached to the statement: "the average ranks of the groups differ from each other" which it does not confirm.

Comparative analysis of WHOQOL-BREF scale domains

A.3.1 Domain Physical Health

The calculated average ranks are 73.34 for Group 1, respectively 80.73 for Group 2. Using the Mann-Whitney U test, the value p = 0.302 was calculated, attached to the statement "Group 1 has a different situation from Group 2", which is not confirmed.

A.3.2. Domain Psychological Health

The calculated average ranks are 74.33 for Group 1, respectively 79.41 for Group 2. The Mann-Whitney U test calculated the value p = 0.476, attached to the statement "Group 1 has a different situation from Group 2" which is not confirmed.

A.3.3. Domain Social Relations

The calculated average ranks are 72.20 for Group 1, respectively 82.25 for Group 2. The Mann-Whitney U test calculated the value p = 0.159, attached to the statement "Group 1 has a different situation from Group 2" which is not confirmed.

A.3.4. *Domain Environment*

The calculated average ranks are 73.57 for Group 1, respectively 80.42 for Group 2. The Mann-Whitney U test calculated the value p = 0.337, attached to the statement "Group 1 has a different situation from Group 2" which is not confirmed.

A.4. Comparative analysis of scores for each domain of the CERQ questionnaire.

A.4.1. Self-blame

Analyzing the two groups, we found that 12.6% of respondents for Group 1, respectively 15.4% for Group 2, chose self-blame as a strategy with a very high score. The Mann-Whitney U test calculated a value p = 0.423, statistically insignificant (p > 0.05), which does not confirm the statement: "Group 1 has a different situation from Group 2".

A.4.2. Acceptance

Analyzing the two groups, we found that 35.6% of respondents for Group 1, respectively 41.5% for Group 2 chose acceptance as a strategy with a very high score.

The Mann-Whitney U test calculated a value p = 0.259, statistically insignificant (p > 0.05), which does not confirm the statement: "Group 1 has a different situation from Group 2".

A.4.3. Rumination

Analyzing the two groups, we found that 21.8% of respondents for Group 1, respectively 23.1% for Group 2 chose rumination as a strategy with a very high score. The Mann-Whitney U test calculated a value p = 0.784, which is statistically insignificant (p > 0.05), which does not confirm the statement: "Group 1 has a different situation from Group 2".

A.4.4. Positive refocusing

Analysing the two groups, we found that 33.3% of respondents for Group 1, respectively 18.5% for Group 2 chose positive refocusing as a strategy with a very high score. The Mann-Whitney U test calculated a value p = 0.181, which is statistically insignificant (p > 0.05), which does not confirm the statement: "Group 1 has a different situation from Group 2".

A.4.5. Refocus on planning

Analyzing the two groups, we found that 19.5% of respondents for Group 1, respectively 30.8% for Group 2 chose refocusing on planning as a strategy with a very high score. The Mann-Whitney U test calculated a value of p = 0.490, which is statistically insignificant (p > 0.05), which does not confirm the statement: "Group 1 has a different situation from Group 2".

A.4.6. Positive reappraisal

Analysing the two groups, we found that 21.8% of respondents for Group 1, respectively 16.9% for Group 2 chose positive reevaluation as a strategy with a very high score. The Mann-Whitney U test calculated a value p = 0.326, which is statistically insignificant (p > 0.05), which does not confirm the statement: "Group 1 has a different situation from Group 2".

A.4.7. Putting it into perspective

Analysing the two groups, we found that 35.6% of respondents for Group 1, respectively 15.4% for Group 2, chose perspective as a strategy with a very high score. The Mann-Whitney U test calculated a value p = 0.065, which is statistically insignificant (p > 0.05), which does not confirm the statement: "Group 1 has a different situation from Group 2".

A.4.8. Catastrophizing

Analysing the two groups, we found that 42.5% of the respondents for Group 1, respectively 44.6% for Group 2, chose catastrophizing as a strategy with a very high score. We also found that no group scored very low. The Mann-Whitney U test calculated a value p = 0.817, which is statistically insignificant (p > 0.05), which does not confirm the statement: "Group 1 has a different situation from Group 2".

A.4.9. Blaming others

Analysing the two groups, we found that 26.4% of respondents for Group 1, respectively 30.8% for Group 2, chose blaming others as a strategy with a very high score. No group had a very low score.

The Mann-Whitney U test calculated a value p = 0.953, which is statistically insignificant p > 0.05), which does not confirm the statement: "Group 1 has a different situation from Group 2".

B. **Analysis stage through correlations** between the values of the quantified parameters with the evaluation tools used in our doctoral study.

B.1. Correlations between PedsQL-FIM and FAM

We conducted these correlations with the aim of finding out whether the QOL dimensions assessed with the PedsQL-FIM questionnaire are influenced by the severity of physical and cognitive impairment. According to the results, the Spearman rho correlation coefficient belongs to the interval [0.00; 0.30] and therefore we can consider the correlations found between PedsQL-FIM and FAM to be insignificant.

B.2. Correlations between PedsQL-FIM and WHOQOL-BREF

We aimed to correlate the values of the quantified parameters with two QOL assessment tools (PedsQL-FIM and WHOQOL-BREF) considering that there are facets of the domains of these questionnaires that are addressed in either one questionnaire or in the other, and the relationship between the two questionnaires would provide us with additional valuable information regarding the most comprehensive aspects of QOL. Furthermore, if PedsQL-FIM measures QOL by means of the health status of the child/ adolescents, WHOQOL-BREF brings clarifications regarding the perception of quality of life and health, without any specific mention related to the health of the child/ adolescents.

The Spearman rho correlation coefficient indicated weak, positive moderate correlations (detailed in Thesis). The rest of the values indicate uncorrelated pairs.

B.3. Correlations between PedsQL-FIM and CERQ

We aim to objectify the relationship, if any, between QOL dimensions and cognitive-emotional coping strategies for each group. We found that, for both groups, in general, the correlations established between PedsQL-FIM and CERQ are weak, negative correlations (detailed in the thesis).

B.4. Correlations between WHOQOL-BREF and FAM (FIM + FAM)

Two weak and positive correlations were found between the variables of the FAM scale (FIM + FAM) and of the WHOQOL-BREF questionnaire for Group 2: FAM (FIM + FAM) motor subscore and psychological health (rho = 0.392, p = 0.001), respectively, FAM (FIM + FAM) cognitive subscore and psychological health (rho = 0.333, p < 0.01).

The rest of the values indicate either negligible correlations or uncorrelated pairs.

B.5. Correlations between WHOQOL-BREF and CERQ

Analysis of correlations between the values of the WHOQOL-BREF and CERQ questionnaire values showed that there was only a weak and positive correlation for Group 1.

For Group 2, it was observed that there were some weak correlations, both negative and positive (detailed in the thesis).

For the rest of the values, we can say either that there were negligible correlations or that the pairs of values did not correlate.

B.6. Correlations between PedsQL-FIM/ WHOQOL-BREF and sociodemographic parameters

We found that between the dimensions/ domains of QOL (measured using the PedsQL-FIM and WHOQOL-BREF questionnaires) and the sociodemographic parameters, there was a weak, negative correlation for Group 2 between physical health and marital status (rho = - 0.401, p = 0.01). The rest of the pairs are uncorrelated.

9.4. Discussions and partial conclusions (sectoral)

I. FAM scale (FIM + FAM)

The data analysed showed us that most of the patients, regardless of which group they belonged to, need, to varying degrees, the support of other people and/ or some assistive devices to ensure functionality in the motor and cognitive domains.

However, it was not possible to assess in which of the groups the patients need help for care, movement, or for achieving psychosocial interaction. Also, our results could not establish which type of neurodisability, congenital or acquired, is associated with more difficulties in verbal and written expression, in performing cognitive processes (memory, attention, and executive functions) of children/ adolescents according to the responses of their mothers.

II. The PedsQL-FIM questionnaire

The analysis of the values/ variables/ parameters of the dimensions of the PedsQL-FIM questionnaire showed that for five of its dimensions (physical functioning, emotional functioning, communication, worry and daily activities) there were statistically significant differences between the two groups, the situation on average for Group 2 being better than for Group 1.

For the other 3 dimensions (social functioning, cognitive functioning, family relations), because no statistically significant differences were found between the two groups, we cannot appreciate which group has the better situation. Therefore, we cannot specify which group has more problems with social interaction, with maintaining attention

on tasks, with keeping and updating memorised information, or with the relationship within the family regarding communication between members, solving problems by mutual agreement.

III. The WHOQOL-BREF questionnaire

From the interpretation of the data of the PedsQL-FIM questionnaire (which refers to the impact that the child's health can have on the family) we could find that there are statistically significant differences between the two groups; in the case of the WHOQOL-BREF questionnaire (which aims to highlight how our respondents perceive their QOL and health in general, as well as aspects of their life in the last two weeks), we found no statistically significant differences between the two groups.

IV. CERQ questionnaire

Comparing the groups, we found that for two adaptive strategies (acceptance and refocusing on planning), more mothers in Group 2 gave a very high score and for the other three adaptive strategies (positive refocusing, positive reappraisal, and putting into perspective), more mothers in Group 1 gave a very high score.

In the case of maladaptive strategies, for self-blame in particular, more mothers in Group 2 gave a very high score. For the other three maladaptive strategies (rumination, catastrophizing and blaming others) the percentage of mothers who gave a very high score is slightly higher for Group 2.

However, for all the analyzed strategies the calculated p-values showed us that there are no statistically significant differences between the groups.

The analysis of the correlations between QOL and the functionality of the child or adolescent with neurodisability in relation to the level of assistance he needs, as well as between QOL and cognitive-emotional coping strategies, led to the following conclusions:

- for both groups, either negligible correlations or no correlations were observed between QOL measured with PedsQL-FIM and the severity of impairment (motor and cognitive) measured with FAM (FIM+FAM);

- the correlation between QOL and severity of impairment, even assessed with the WHOQOL-BREF questionnaire, did not provide new information (2 weak correlations for Group 2, the rest negligible correlations or uncorrelated pairs).

Some studies in the literature showed that the degree of severity of the child or adolescent's impairment does not influence the QOL of the relatives, in the sense of its decrease [13,46,47]; and the results of our doctoral research do not show the existence of a correlation between the severity of the child or adolescent's impairment and QOL.

The correlative analysis of the two QOL assessment tools: PedsQL-FIM and WHOQOL-BREF showed some correlations established between them, as follows:

- for Group 1, the relationship between physical, emotional, social functioning, communication and psychological health, as well as between communication and physical health, we could interpret them as follows: the more physically active, more confident they are, with social interactions and sharing their fears with other people the better their image and self-esteem;

- for Group 2, the relationship between emotional functioning, communication, family relationships and physical health, between emotional functioning, daily activities and psychological health, between family relationships, and social relationships or between social functioning and the environment can be interpreted as follows: the more mothers are confident, share their fears with other people, and interact effectively within the family, the more positive they are, the more able they are to carry out everyday activities; also, the more mothers interact with other people, actively participate in social life, the more secure they feel in everyday life, have easier access to information, appreciate health services more.

It is interesting to note for the correlation analysis between PedsQL-FIM and CERQ that, for Group 1, five of the PedsQL-FIM domains (emotional functioning, cognitive functioning, communication, worry, and daily activities) are correlated with all four maladaptive strategies (self-blame, rumination, catastrophising, and blaming others).

Correlations between PedsQL-FIM domains and adaptive strategies are either negligible or uncorrelated pairs.

The situation of Group 2 does not differ significantly from that of Group 1, with the mention that the most frequently used maladaptive strategy is self-blame and rumination is not found between the correlated pairs.

Analysis of correlations between WHOQOL-BREF and CERQ showed us:

- for Group 1, a single correlation related to the same adaptive strategy (positive refocusing), the rest being negligible correlations or uncorrelated pairs. We can interpret this correlation as follows: the better the psychological health, the more they can think of more pleasant things. We can also observe that the comparative analysis of the two groups for the CERQ questionnaire showed that positive refocusing was, on average, more used by Group 1;

- for Group 2, there is a correlation of two dimensions referring to the same adaptive strategy (positive reappraisal) and two other dimensions referring to 2 maladaptive strategies (self-blame and others-blame).

Analyzing the correlations between the variables of the two QOL assessment questionnaires and those of the CERQ, we found that in both questionnaires the two groups established correlations predominantly with maladaptive strategies.

To note for this final study is that no correlations were established between the primary data values from the QOL dimensions/ domains, measured with the PedsQL-FIM and WHOQOL-BREF questionnaires and the sociodemographic parameters that would provide information about any link between the variables.

In this final study, although the statistical power increased, the results obtained did not differ significantly from previous studies.

Chapter 10. FINAL CONCLUSIONS AND PERSONAL CONTRIBUTIONS

1. An objective of this research was a systematic literature review, materialized in Study I, which signaled, including through the relatively small number of qualified/ selected publications, that for the field addressed in the Thesis there is still potential for additional exploration.

2. Another objective was the analysis of the QOL domains of mothers with children or adolescents with congenital vs. acquired neurodisabilities, to quantitatively compare the two types of statuses.

a) The PedsQL-FIM questionnaire showed:

- in Study III, that the QOL dimensions for which there were differences between the two study groups were: emotional functioning, communication, and worry;

- in Study IV, after a first broadening of the groups, the differences found in Study III were preserved, to which the dimension of physical functioning was added [for this reason, in Study III, we concluded that the number of analysed cases was too small to draw (statistically) a conclusion];

- in Study V, although there was an additional numerical augmentation of the groups of mothers of neuropediatric patients, at least a theoretical premise: that through an increased statistical power we would highlight more defined statistical results; no significant changes to the previous results, regarding the variables taken into account, with one exception: daily activities - for which statistically significant differences between the two study groups were found in this study.

In conclusion, we can find that there were statistically significant differences between the two studied groups, for the dimensions of quality of life: **physical functioning, emotional functioning, communication, worry, and daily activities**, showing that, overall, the situation was **better for Group 2** than for Group 1 – divergent from our working hypothesis – and for the dimensions – *social functioning, cognitive functioning, family relationships* – the group with the better situation could not be indicated, after the statistical analysis.

b) The WHOQOL-BREF questionnaire showed:

- in Study III, that there were no differences between the two groups, and thus we could not specify whether any of them had a better QOL;

- in Study V, even by enlarging the study groups, no new, additional information was obtained compared to that in Study III.

In conclusion, we can appreciate that for the groups studied, the WHOQOL-BREF questionnaire did not provide information that would allow us to specify in which group the QOL domains are more affected.

3. The objective of ranking the cognitive-emotional coping strategies, used by parents/ relatives (in the present clinical study doctorate of mothers), for psycho-emotional adaptation, was achieved using the CERQ questionnaire - which showed:

- in Study II, which included only mothers representing Group 1, that **positive refocusing and putting into perspective** were the most frequently chosen strategies;

-in Study III, that **positive refocusing and putting into perspective** are the strategies for which there were statistically significant differences between the two study groups;

- in Study V that although mothers of neuropediatric patients used adaptive and maladaptive cognitive-emotional coping strategies, there were no statistically significant differences between the groups. For two adaptive strategies: **acceptance and refocusing on planning**, several mothers in Group 2 gave a very high score, and for three adaptive strategies: **positive refocusing, positive reappraisal, and putting into perspective**, several mothers in Group 1 gave a very high score.

Therefore, the main attitudinal difference between the two groups was – without statistically significant differences objectified – the predominant option for the **acceptance** of mothers from Group 2

4. Analysis of the relationship between the severity of functional and cognitive impairment (FIM + FAM) of neuropediatric patients in the two groups and the QOL

domains of mothers with children or adolescents with neurodisabilities, another objective of this research, **led to our observations, consistent with those encountered in some studies in the literature** (the severity of the child or adolescent's affect does not cause a decrease in the QOL of the relatives).

5. Additionally, we proposed and investigated whether there is any difference in QOL between the mothers of children or adolescents with congenital neuropathology and that of mothers of children or adolescents with acquired, disabling neuropathology, based on some sociodemographic characteristics/ parameters, and we found the following:

- in Study IV, that **education influenced the QOL of mothers in Group 1** and the **perceived level of income influenced the QOL of mothers in Group 2**;

- in Study V, by expanding the samples studied, although we hoped to obtain new, more defined results, *they did not show* – except, in Group 2, a weak negative correlation: between physical health and marital status – *other influences of these characteristics/ parameters on QOL.*

Technical-economic advantages and disadvantages of this doctoral research

Among the advantages we mention:

- the possibility of carrying out our doctoral clinical study with minimal costs (derived from the multiplication of the forms related to the quantified evaluation tools used and, respectively, of the Informed Consent);

- obtaining the consent to use for this doctoral clinical study the Romanian version of the standardized, recognized and widely accepted international QOL evaluation tools: PedsQL-FIM and WHOQOL-BREF as well as the cognitive-emotional coping evaluation questionnaire (CERQ) free of charge under the usage licenses we have obtained.

Technical-methodological disadvantages and possible limitations of our doctoral clinical study:

- collecting data only from mothers (the only ones available for inclusion in this clinical trial) made the results reflect only their point of view;

- the quantified assessment tools, through the questions they contain, refer to a certain period of time (eg: the last month for PedsQL-FIM, the last 2 weeks for WHQOL-BREF). That is why we can consider that the reference of the respondents' answers to the required time limit could explain the lack of clearer results regarding the whole – including as a temporal range – especially considering the fact that the pathology of neuropediatric children/ adolescents whose mothers were questioned is chronic, not infrequently with lifelong sequelae.

The unsolved issues:

- a stratification of the groups according to the sociodemographic variables (e.g. trying to objectify, including through statistical analysis if there are differences between the level of education within the same study group) that we believe could provide more information about the mothers' QOL with neuropediatric children/adolescents with disabilities, being a possible future research direction, possibly postdoctoral;

- the inclusion in the clinical study, also **postdoctoral** – in two-parent families – of the **father**, in order to obtain information that reflects the QOL of the entire family with children/ adolescents, both with congenital and acquired neurodisabling conditions.

PERSONAL CONTRIBUTION:

- analyzing different medical databases (Elsevier, PubMed, PMC, PEDro, Scopus) to identify studies comparing QOL in families with children/ adolescents with congenital disabling conditions vs. acquired, we found that, practically, **there is no such research.** We also believe that the importance of our research primarily appears from the fact that, until now, no such clinical study has been carried out. Thus, both our general/ main objective and the secondary ones (with the mentioned limitations) have been achieved.

- we also consider that our doctoral research represents a starting point for future studies that will comparatively analyze QOL in families with children/ adolescents with congenital vs. acquired neurodisabling conditions, further exploring possible differences and/ or correlations between QOL dimensions/ domains and including emotion regulation strategies.

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Published scientific papers within the doctoral research:

1. Morcov, M.V., Pădure, L., Morcov, C.G., Onose, G. Findings regarding emotion regulation strategies and quality of life's domains in families having children with spinal muscular atrophy. Journal of Medicine and Life, 2021, 14(3): 390-96, https://medandlife.org/all-issues/2021/issue-3-2021/original-article-issue-3-2021/findings-regarding-emotion-regulation-strategies-and-quality-of-lifes-domains-in-families-having-children-with-spinal-muscular-atrophy/, (Capitolul 6, pp.73-84)

2. Morcov, M.V., Pădure, L., Morcov, C.G., Mirea, A., Ghiță, M., Onose, G. Comparative Analysis of the Quality of Life in Families with Children or Adolescents Having Congenital versus Acquired Neuropathology. Children, 2022, 9(5), 714. doi.org/10.3390/children9050714. Revista cotata ISI, FI=2.863, ISSN 2227-9067, https://www.mdpi.com/2227-9067/9/5/714, (Capitolul 7, pp.85-102)

3. Morcov, M. V., Pădure, L., Morcov, C. G., Onose, G. Further detailed objectification within comparative analysis of quality of life-based on some sociodemographic characteris-tics/parameters and related statistical analysis-between mothers of children with congenital versus acquired neuropathology. Balneo and PRM Research Journal, 2022, 13(3), 1-9, DOI 10.12680/balneo.2022.517, http://bioclima.ro/Balneo517.pdf , (Capitolul 8, pp.103-114)