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Evaluation of stress of parents of children with disability and without disability – pilot study

Ocena stresu rodziców dzieci niepełnosprawnych i bez niepełnosprawności – badanie pilotażowe

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STRESZCZENIE

OCENA STRESU RODZICÓW DZIECI NIEPEŁNOSPRAWNYCH I BEZ NIEPEŁNOSPRAWNOŚCI – BADANIE PILOTAŻOWE

Cel. Celem pracy było określenie poziomu stresu rodziców opiekujących się dzieckiem z niepełnosprawnością oraz rodziców dzieci pełnosprawnych.

Metody. Badanie pilotażowe trwało od października do listopada 2020 r. W badaniu wzięło udział 40 rodziców dzieci niepełnosprawnych i 40 rodziców dzieci pełnosprawnych. Jako narzędzie badawcze wykorzystano krótki formularz Parenting Stress Index 4 w wersji czeskiej (PSI 4 SF).

Wyniki. Stwierdzono, że rodzice dzieci z niepełnosprawnościami wykazują duży stres w porównaniu z grupą rodziców dzieci pełnosprawnych. Różnica w odczuwaniu stresu między grupami monitorowaną i kontrolną jest istotna statystycznie ($p<0,001$) we wszystkich podskalach oraz w ocenie ogólnej.

Wnioski. Opieka nad dzieckiem niepełnosprawnym wiąże się z dużym stresem. Pracownicy służby zdrowia powinni sporządzić mapę stresu rodzicielskiego i zaoferować rodzicom profesjonalną pomoc w opiece nad dzieckiem w razie potrzeby.

Słowa kluczowe: **niepełnosprawność, dziecko, stres, rodzice, PSI 4 SF**

ABSTRACT

EVALUATION OF STRESS OF PARENTS OF CHILDREN WITH DISABILITY AND WITHOUT DISABILITY – PILOT STUDY

Aim. The aim of the study was to determine the level of stress of parents caring for children with a disability and parents of children without a disability.

Methods. Pilot study was performed in the period from October to November 2020. A total number of 40 parents of children with a disability and 40 parents of children without a disability participated in this study. Parenting Stress Index 4 Short Form in Czech version (PSI 4 SF) has been used as a research tool.

Results. It has been found out that parents of children with a disability have high stress levels in comparison with the group of parents of children without a disability. The difference in the stress perception between the monitored group and the control group is statistically significant ($p<0.001$) in all subscales as well as in the overall evaluation.

Conclusion. Caring for a child with a disability is associated with high levels of stress. Healthcare professionals should identify parental stress and offer the parents professional help in caring for their child according to their needs.

Key words: **disability, child, stress, parents, PSI 4 SF**

INTRODUCTION

The family and its functioning are considered to be predictors of successful management of an illness, disability or handicap. Being a parent of a child with a chronic disease, developmental disability, or with risk of delayed development due to premature birth can be very stressful [1]. Stress significantly worsens the health condition of parents and contributes to the development of various diseases. It can come from life events, interpersonal relationships, worries, or work [2]. Studies have shown a direct correlation between parental stress and childhood behaviour, suggesting that increased levels of parental stress may directly contribute to a child's problem behaviour. High levels of parental stress are directly related to educational problems in children aged from two to six [3]. Providing care in home conditions entails certain physical, mental, as well as financial issues [4]. Families with children who are physically, mentally handicapped or have a combined disability are in a more serious situation than families with children without a disability. A child's chronic disability places special demands on parents, which leads to stress [5]. Higher stress in the parents of girls with Rett syndrome is reported by Perry et al. [6]. Evaluation and reduction of parental stress is essential for the well-being and quality of life of the child and family [7]. Another study [8,9] deals with the impacts of strain and stress in relation to birth defects and chronic diseases of children, showing higher depression levels and lower quality of life of parents. The strain and stress impact on parents with children with congenital heart defect may result negatively in the physical and mental health and wellbeing and may lead to a reduced quality of life [10].

AIM

The aim of the pilot study was to compare the stress of parents caring for children with a disability and parents of children without a disability.

MATERIALS AND METHODS

The standardized tool Parenting Stress Index 4 Short Form was used to determine the level of stress. This questionnaire is also available in the Czech version under the authors' license conditions. PSI 4 SF measures stress in the parent-child system on the basis of parent's perception of the child's characteristics, the parent's personal characteristics and the interaction between the child and the parent. The questionnaire contains 36 items and the estimated completion time is less than ten minutes. There is a broad-spectrum use of this tool, especially in institutions where children are provided with health care, outpatient therapy, paediatric practice and it can also be used to monitor treatment results [11]. PSI – 4 SF is intended for parents of children aged from 1 month to 12 years. The evaluation is performed as a total of scores achieved in each area. The values exceeding 90 are considered to be clinically significant [12]. The items are assessed on a five-point Likert scale acquiring the total parental stress score ranging between 36 and 180. The score ≥ 90 indicates clinically significant stress levels. This questionnaire is used worldwide and a Czech licenced version was purchased from Psychological Assessment Resources (PAR, Inc.). The standardized tool was supplemented by basic demographic items, such as gender, age of the parent, age of the child. Written approvals of the medical facilities management with the conducted pilot study were obtained. Respondents were acquainted with voluntary participation and anonymity of the survey. The respondents expressed their consent to be included in the study by submitting the questionnaire to the pre-prepared boxes.

Sample of respondents

A total of 80 questionnaires were distributed to specialist children's clinics, spas, general practitioners' surgeries for children and adolescents, hospitals and child day care centres. Return of questionnaires was 100%. The research group consisted of 40 mothers of children with physical disabilities 21 (53%), with mental disabilities 14 (35%) and with combined disabilities 5 (13%), and 40 mothers of children without disabilities. The average age of mothers of children with disabilities was 34.6 years and 36.8 years for mothers of children without disabilities. The average age of fathers of children with disabilities was 36.6 years and fathers of children without disabilities 39.4 years. The average age of children with disabilities was 9.3 years and children without disabilities 10.0 years, see (Tab. 1.) Respondents' age data.

Tab. 1. Respondents' age data

Disability	Age	Quantity	Median	Arithmetic mean	sd	p-value.*
Yes	Mother	40	35.0	34.6	3.05	0.002
No		40	38.0	36.8	3.13	
Yes	Father	40	36.0	36.6	3.14	0.001
No		40	39.0	39.4	3.83	
Yes	Child	40	9.0	9.3	1.21	0.002
No		40	10.0	10.0	1.01	

Legend: *Wilcoxon signed-rank (Mann-Whitney) test for two selections, sd – standard deviation

Data analysis

Basic descriptive statistics was used to describe the data. Furthermore, non-parametric tests have been used – chi-square test, Fisher's exact test, Wilcoxon serial test (Mann-Whitney) test for two selections. The relationship between the dimensions was evaluated using the Spearman correlation coefficient. Cronbach's alpha has been used to verify the internal coherence for Parenting Stress Index 4 SF. Statistical tests were evaluated at a 5% significance level. Data processing was performed in the programme Stata, version 14.

RESULTS

The evaluation revealed that parents of children with disabilities showed more stress in all three subscales – Parental Distress (PD), Parent-Child Dysfunctional Interaction (P-CDI), Difficult Child (DC), than parents of children without disabilities. A statistically significant difference was found between the files, both in the individual subscales and in the overall evaluation (p<0.001) (Tab. 2). Based on the Total Stress score, it can be stated that 25 (63%) parents of children with disabilities show a high clinically significant level of stress, which already requires qualified professional help. There is no parent in this category in the control group. Higher levels of stress were reported by 10 parents (4%) in both groups. In the ranges that show low levels of stress, 11 parents (28%) were found in the group of parents of children with disabilities and 35 parents (88%) in the group of parents of children without disabilities. The lowest level of stress was found in 1 parent (3%) in the group of parents of children without disability (Tab. 3.).

Tab. 2. Evaluation of stress levels in subscales PSI 4 SF

Disability	Item	Quantity	Median	Arithmetic mean	sd	Min	Max	p-value.*
Yes	Parental Distress	40	88.0	82.5	12.47	50	94	<0.001
No		40	58.0	57.5	15.78	26	88	
Yes	Parent-Child Dysfunctional Interaction	40	86.0	82.3	11.65	48	94	<0.001
No		40	56.0	55.0	13.95	32	80	
Yes	Difficult Child	40	86.0	79.6	12.16	40	94	<0.001
No		40	52.0	51.8	14.77	26	82	
Yes	Total Stress	40	88.0	82.2	12.29	44	94	<0.001
No		40	54.0	54.0	14.70	24	80	

Legend: *Wilcoxon signed-rank (Mann-Whitney) test for two selections, sd – standard deviation

Tab. 3. Overall evaluation results

Handicap	Yes		No		Total	
Total Stress	Quantity	%	Quantity	%	Quantity	%
Low	0	0%	1	3%	1	1%
Medium	11	28%	35	88%	46	58%
High	4	10%	4	10%	8	10%
High threshold values	25	63%	0	0%	25	31%
Total	40	100%	40	100%	80	100%
Fisher's exact test, p<0.001						

DISCUSSION

When comparing the degree of stress between parents of children with disabilities and parents of children without disabilities, the biggest differences were found in the perception of high levels of stress. These 25 parents should be offered professional help or consultation in caring for their child and offered ways to eliminate the effects of stress and balance its effects on the body through coping strategies. Only 1 parent (3%) of the total number of respondents from the control group showed the lowest level of stress. When it comes to 4 parents in both groups, they showed high levels of stress and 11 parents of children with disabilities and 35 parents of children without disabilities showed lower levels of stress. A study conducted in Saudi Arabia investigated the levels of anxiety and depression in mothers of children with mental, physical or sensomotoric disabilities in comparison with a group of mothers of healthy children. Mothers of disabled children have been found to have higher levels of anxiety and depression and stress. Burden and chronic stress can cause mental (emotional disorders) and physical problems (low quality sleep). That is why medical help and support is very important not only for disabled children, but also for caregivers – parents of these children [13].

A study performed in Canada involved 68 parents of children suffering from a chronic disease or disability. The aim of this study was to investigate the parental role of children with complex care needs. The results revealed that parents performed more parental roles that are closely related to the care for a disabled child, e.g. they showed a greater need for sleep, they felt the need to monitor the child's breathing, they were tired of changing diapers at night. Parents further stated that they were aware that their child needed constant care and felt in a stressful situation that had an impact on their physical and mental health [14]. A study conducted in Italy focused on investigating parental stress in preschool children with ASD (autism spectrum disorder) compared to a group of physiologically developing children. The results revealed that parents of children with autism spectrum disorder experienced higher levels of stress compared to the control group. Dysfunctional behavior of children with ASD has a significantly negative impact on parental stress and also negatively affects and influences the well-being of the entire family [15]. Another study conducted in South Africa aimed to find out whether parents caring for a disabled child are more stressed. It has been found that parents caring for a disabled child experience more stress than parents caring for a child without a disability, regardless of socioeconomic status [16]. The results obtained in our research enable a more targeted focus of the interventions provided by the nurse. Educational interventions aimed at parents of children with disabilities should include procedures that increase the competence of parents, the certainty that they provide the best possible care to the child, procedures that reduce parental fear, anxiety and worry, increase resilience to stress, support family functioning, communication among family members and thus, improve the quality of life. Stress resistance can be increased through protective coping factors. Factors which can strengthen the resilience of parents of children with chronic diseases include all sources of material and psychosocial and coping strategies [2]. Nurse support towards parents also includes encouraging the confidence to overcome obstacles, motivating perseverance, encouraging acceptance of what cannot be changed, encouraging change of values, planning common goals, supporting

rituals, common activities of parents with children and presenting new possible activities with children or work--life balance of parents [17].

CONCLUSIONS

The results of this research survey have revealed that parents of children with disabilities experience a high degree of stress compared to parents of children without disabilities. The use of the Parenting Stress Index 4 Short Form questionnaire should be included as part of preventive examinations and regular inspections in children's outpatient clinics, hospitals and rehabilitation institutions and daycare facilities. The pediatric nurse acts as a connecting link between the parents, the doctor and the child. Therefore, the support of medical staff – mental, physical, emotional and social towards the parents of children with disabilities, especially support from nurses, is very important.

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