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Quality of Life of the Person Taking Care of a Child Diagnosed with Spina Bifida

Jakość życia osoby sprawującej opiekę nad dzieckiem, u którego zdiagnozowano rozszczep kręgosłupa

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Abstract

Introduction. Birth of a disabled child, constitutes a large and initially insoluble problem particularly for parents. Assistance should be offered by relatives but above all by experts.

Aim. Assessment of the quality of life of caregivers taking care at home of children diagnosed with spina bifida.

Material and Methods. The valid questionnaire containing a modified and standardized tool — the Index of the caregiver's quality of life was applied as a method for collecting empirical data. The scale includes 26 items that reflect the perception of the situation by the caregiver. Grade 4 expressed the greatest burden. The surveyed group consisted of 60 respondents who care at home for children diagnosed with spina bifida. The index of the quality of life was assessed in terms of the following statistical data: caregiver's family relationship to the child, duration of care of a disabled child and the degree of burden perception by the caregiver, depending on the age of the child.

Results. Based on the analysis of the data there has not been revealed a statistically significant relationship between the caregiver's family relationship to a disabled child and their level of subjective quality ($p>0.05$). A statistically significant relationship has not been confirmed between the duration of the care of a disabled child and caregiver's burden perception measured, as well as between the age of the disabled child and the caregiver's performance evaluation ($p>0.05$).

Conclusions. The research results are consistent with the results obtained by several other authors who argue that performance of care often depends on the condition of the disabled child, access to the child and also on the child's age. (JNNN 2014;3(4):148–152)

Key Words: child, quality of life, caregiver, spina bifida

Streszczenie

Wstęp. Narodziny niepełnosprawnego dziecka stanowią początkowo dla rodziców duży i nierozwiązywalny problem. Rodzicom powinna zostać zaoferowana pomoc nie tylko ze strony bliskich, ale przede wszystkim specjalistów.
Cel. Ocena jakości życia opiekunów sprawujących opiekę domową nad dzieckiem, u którego zdiagnozowano rozszczep kręgosłupa.

Materiał i metody. Jako metodę zbierania danych empirycznych wykorzystano odpowiedni kwestionariusz, który zawierał zmodyfikowane oraz znormalizowane narzędzie — Wskaźnik jakości życia opiekuna. Przedmiotowa skala zawiera 26 elementów, które odzwierciedlają stopień odczuwania sytuacji przez opiekuna. Stopień czwarty oznacza najwyższy poziom ciężaru odczuwanego przez opiekuna. Badaniu poddano 60 respondentów, sprawujących domową opiekę nad dzieckiem, u którego zdiagnozowano rozszczep kręgosłupa. Ocenę jakości życia przeprowadzono w oparciu o następujące kryteria demograficzne: relację rodzinną między opiekunem a dzieckiem, okres sprawowania opieki nad niepełnosprawnym dzieckiem, stopień odczuwania przez opiekunów obciążenia związanego z wiekiem dziecka.

Wyniki. Na podstawie analizy otrzymanych danych nie stwierdzono statystycznie istotnego związku między relacją rodzinną opiekuna do dziecka niepełnosprawnego a poziomem subiektywnej oceny jakości ($p>0,05$). Nie potwierdzona została również statystycznie istotna zależność między czasem trwania opieki nad dzieckiem niepełnosprawnym a zmierzonym obciążeniem opiekuna, podobnie jak między wiekiem niepełnosprawnego dziecka a oceną opieki sprawowanej przez osobę opiekującą ($p>0,05$).

Wnioski. Wyniki badania są zbieżne z wynikami uzyskanymi przez kilku innych autorów, którzy twierdzą, że sprawowanie opieki nad dzieckiem niepełnosprawnym często uzależnione jest od jego stanu, kontaktu z dzieckiem, jak również wieku dziecka. (PNN 2014;3(4):148–152)

Słowa kluczowe: dziecko, jakość życia, opiekun, rozszczep kręgosłupa

Introduction

Spina bifida — unconnected vertebral arch. Spina bifida is a term often used for defining developmental disorders of the spine during intrauterine life (spina bifida), which may or may not be associated with the development of neural tube defects — neural tube defects (NTD) [1]. It is a congenital disability that can be considered as a stressful event in a person's life, and its effect on life quality varies considerably. Child's parents, and later the child himself, learn to cope with his disability and help him. It requires a great amount of patience, knowledge, abilities, skills, discipline and willingness to learn. Overcoming these barriers allows the family to survive and more efficiently fulfill the quality of life [2].

Guaranteeing to the child with spina bifida and to his family a high quality of life is a challenging task in our country. Since this requires a multifaceted professional approach as well as deep commitment. The family needs long-term instrumental, psychological support, life sustaining, and orientation to cope with a disabled child. Some of them affect this situation and so does the nurse, who is from the beginning of diagnosis in direct contact not only with the child, but also with his parents and it is her role to help them cope with situational problems.

The aim of our study was to assess caregiver's burden connected with care of a child diagnosed with spina bifida and to identify differences in the quality of life of caregivers in terms of demographics (family caregiver's relationship to the child, duration of care of a disabled child and the degree of perception of burden by caregivers, depending on age).

Material and Methods

Selection of respondents in the study group was carried out within a specific group of children diagnosed with spina bifida (from the database of the neurosurgical clinic). The surveyed group consisted of caregivers — parents of children diagnosed with spina bifida. Questionnaires were distributed by Slovak mail to respondents all over the country. Out of the 60 respondents the group consisted of 50 mothers and 10 fathers, of whom 49 parents were married, 6 respondents were single and 5 parents lived with a partner.

The questionnaire included a modified standardized tool — the caregiver's quality of life Index, which included

included scaled items that reflect their situation with those individual statements: (one at all, at least 2, 3 moderate, 4 very much). From Barthel's test we investigated the extent to which a child with spina bifida is self-sufficient in daily activities and items of general categorical identification of respondents (child's age, family relationship, duration of child care and family status).

The interpretation of the results included in the tables for the summary statistics indicated rates of 2 central tendencies (mean values) and arithmetic mean (\bar{x}) as well as median and 1 rate variability (scatter) values, standard deviation (SD — standard deviation).

In order to test the working hypothesis there were selected appropriate statistical tests. To test the hypotheses regarding the variable data (data scaled score) Student's t-test as well as the pair test were applied. The hypotheses concerning the relative multiplication test was used proportionally. Next, the 'null' hypothesis was tested i.e., argument, where the compared variables are statistically significantly different (the difference is zero). For each test the significance level of 0.05 (5) was chosen, indicating the probability that the hypothesis is rejected, which in fact is the case. The acceptance or rejection of hypotheses was decided by the p-value, which represents the critical level of significance. For a truly statistically significant dependence, respectively the difference is considered to be such a result, if the p-value is less than 0.05.

Results

The total number of respondents in the questionnaire included 50 mothers and 10 fathers, we focused on the feeling of exhaustion of caregivers taking care of children diagnosed with spina bifida. Only 12% of mothers who responded did not feel exhausted at all, almost 24% reported slight exhaustion. A slight feeling of exhaustion occurs in 60% of fathers, 34% reported the feeling of moderate exhaustion whereas 26% of mothers and 20% of fathers felt very exhausted.

Table 1. Feeling of exhaustion referring to the mother and father in terms of family relationship to the child taken care of

	Mother	Father
Mean value of	1.0	0.4
P (T<=t) (2)	0.0501	

Based on the test results based on the use of two elective t-test, the correlation in the perception of the feeling of exhaustion by mothers and fathers of children with disabilities was similar, but not confirmed. P-value of 0.0501 is greater than the specified significance level ($p > 0.05$).

In the statistical data regarding the outlook on life there prevailed positive responses given by mothers. The average value of the responses in women — mothers is 3.48 and the standard deviation is 11.35. For fathers, our findings are different, where the arithmetic mean is 2.8 and the standard deviation is 1.12.

Based on our results, there is no statistically significant relationship between the family relationship of caregiver to a disabled child and their level of subjective quality.

In this study we investigated whether there is a statistically significant relationship between the duration of care of a disabled child and the degree of perception of burden by caregivers.

Based on the results of a p-value < 0.05 a correlation of the length of treatment was confirmed only with the feeling of exhaustion (p-value 0.027) and the awards and recognition (p-value 0.031). These two variables are directly dependent, ie the longer the treatment, the greater the feeling of exhaustion and need for more awards and recognition.

In Table 2 we present the statistical results in terms of length of the care of children with disabilities and strengthening family relationships. That connection is also confirmed by us, but indirectly (p-value 0.025), suggesting that the longer the care is, the less close family relationships are entailed. Length of care in our group ranged from 8 months to 14 years, median 5.6 years.

Table 2. Child birth and development of family ties

Correlation coefficient	-0.254
test statistic	-2.00
p-value of	0.025

Statistical test of the level of significance confirmed there is a correlation between the duration of care of a disabled child and feeling exhausted, support from child's family, intensity of accompanying the child to hospital and change life priorities in the family as the p-value < 0.05 .

The results confirm that there is statistically significant relationship between the duration of care of a disabled child and the burden perceived by the caregiver.

Table 3 presents the age of the children in the study group. The relationship between the age of the disabled child and the evaluation of the caregiver's performance was investigated.

Table 3. Age of children diagnosed with spina bifida

	Mean	Median	Standard Deviation
1 year	2.5	2.5	2.5
1–3 years	30	25	37.1
3–6 years	55.14	55	55.5
6–0 years	65.67	60	65.3
More than 10 years	53.33	60	58.5

Child's age and level of care is close to those in our findings only in the aspect regarding the degree of the caregiver's $p < 0.05$, statistical hypothesis in this case is dismissed. The other items (such as adaptation to change, financial stress, feeling of insecurity, family assistance) is greater than the level of significance rated at 0.05. The correlation coefficient concerning fatigue assessment is positive, thus directly linked — the older the child, the greater the feeling of exhaustion.

As far as the level of significance is concerned, p-value results show that there is no statistically significant relationship between the age of a disabled child and the evaluation of the care giver's performance.

Discussion

In our research, we focused on the quality of a caregiver's life taking care at home of a child diagnosed with spina bifida. Differences in caregivers' quality of life have been identified by us in terms of a caregiver's family relationship to the child, the duration of care of a disabled child and the degree of stress perception in caregivers conditioned on the age of the child. In the analysis of the problems we used the results of the crawl domestic and international electronic databases (Online Library, Medline). Based on our findings regarding caregivers' perceptions of the quality of life in terms of family relationships and the sense of exhaustion, we noticed statistically significant relationship between parents, but slightly more prevalent with mothers. Our results were compared to the results obtained by other authors [3], who found higher average range in fathers (1.92) than in mothers (1.85). The relationship of the disabled child to the father differs from that to child's mother, it is more abstract. Mothers in our culture are considered to be emotionally bound to the child and maternal love to the child can sometimes be seen as its own failure. In fact, it is an expression of helplessness and a call for assistance [4,5].

A chronically ill child constitutes a huge risk for the family affecting the stability of the marital relationship [3]. In the situation where both parents are involved in the care, those families were mostly considered to be

stable and functional [6]. Our research of the relationship between disabilities and family ties strengthening confirmed the relationship, but indirectly, implying that longer the care lasts, the less close family relationships become. Relationship between the duration of care of a disabled child and feeling exhausted, support from his family, intensity of accompanying the child to hospital and life changing priorities in the family, was not confirmed. Based on our results, there is a statistically significant correlation between the duration of care of a disabled child and level of caregiver's burden perceived.

The length of care is related to the financial burden. The decision to care of chronically ill children at home often makes caregivers reduce or totally eliminate activities that could previously be an integral part of their lives. Many caregivers caring of a child diagnosed with spina bifida will not return to work or change the schedule of working time, unless it is allowed by their employers, but then the family is losing a part of their funding. On the other hand, the care of such a child with a disability requires increased expenses which include medicines, commuting of professionals or health and mobility aids.

In 2010 a median company in the Czech Republic carried out research among parents of disabled children. As the biggest problem in taking care of their disabled child the respondents mentioned lack of funding for the family, then of mobility aids and personal assistant. This group consisted of 30 respondents [7].

In our research, we asked each respondent to define a degree of financial burden of caring of such a child. Moderate financial burden was indicated by 38 parents whereas 62 parents considered their financial burden as very heavy. A caregiver's quality of life may be influenced by various factors. One of the factors being the age of the child. It has been assumed that with the increase of the child's age the burden on caregivers will be increased accordingly. In the past, the state preferred placing an disabled child to various institutions, where the child could be 'protected' from various family difficulties faced by the families taking care of disabled children. Nowadays, institutionalized care is considered to be expensive, often questioning the quality of care provided in these facilities and last but not least, one should also take into account the social isolation of the child. Today the non-institutionalized care is more popular, which may be associated with an increase of stress in the family. With the increase of age of a disabled child also there occur new worries and responsibilities. One of the inherent responsibilities of parents and of the chronically ill children themselves is compulsory schooling, where today everyone, not excluding disabled children can be educated at home. In our survey there participated caregivers of chronically ill children aged 3–6 years (58), aged 6–10 years (25), aged 1–3 years (8), there were 3

children under 1 year of age and 5 children over 10 years of age. 50 caregivers expressed moderate and high degree of concern and sense of insecurity of taking their child to school. Children with spina bifida, similarly to healthy children want to have friends and go to kindergarten or school, even if they are in wheelchairs [8].

Child's age and the level of care are related to our findings, only with a feeling of exhaustion. The other items (such as adaptation to change, financial stress, feelings of insecurity, family assistance) correlation coefficient in fatigue assessment is positive, thus closely linked with the principle — the older the child, the greater the feeling of exhaustion. The level of significance, however, shows us that there is no statistically significant relationship between the age of a disabled child and evaluation of caregiver's performance.

Conclusions

Family caregivers in Slovakia, similarly to other European countries, play an irreplaceable role in caring for children with disabilities. One's decision to become a caregiver and to take over the responsibility for one's child is a challenge to coping with which no one has been prepared. Obligations that they take, very often limit other life activities which has a definite impact on one's quality of life. The necessary assistance required in the performance of various activities related to the care is frequently received from their life partners, children, close family or friends. Managing caregiver's role can be specified as a process which is divided into stages in terms of the adoption to the caregiver's role, developmental needs of the child, the degree and extent of disability. Coping with this difficult task has a significant impact on the quality of life of family and of the caregiver of a disabled child diagnosed with spina bifida.

Implications for Nursing Practice

Based on the results obtained, of which the most significant are the findings concerning the feeling of exhaustion and fatigue in caregivers, we propose the following recommendations for practice:

1. In reference to the workplace, which specializes in treating children affected by spina bifida diagnosed, to organize regular meetings for fathers, during which they will be informed about the disease itself and the treatment of spina bifida, to emphasise their unique role in the overall care of the ill child and encourage them more effectively to carry out the activities associated with that treatment so that the burden on the individual caregiver could be reduced,

2. As regards the nursing practice, to educate, in cooperation with other health professionals who are dedicated to this issue, parents — caregivers on nursing care according to individual and particular needs of the child, regarding appropriate nutrition, the correct technique of catheterisation or flushing the colon,
3. In cooperation with self-help groups in the neighbourhood of families and with their help to organize meetings with the participation of experts, provide physiotherapy and psychological support, inquire from experts about respite and social support.

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