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The effect of targeted interventions on the unmet needs of healthcare and social support services in patients with progressive neurological disease: interventional control study

Wpływ celowanych interwencji na niezaspokojone potrzeby z zakresu opieki zdrowotnej i pomocy społecznej u pacjentów z postępującą chorobą neurologiczną: interwencyjne badanie kontrolne

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STRESZCZENIE

WPŁYW CELOWANYCH INTERWENCJI NA NIEZASPOKOJONE POTRZEBY Z ZAKRESU OPIEKI ZDROWOTNEJ I POMOCY SPOŁECZNEJ U PACJENTÓW Z POSTĘPUJĄCĄ CHOROBĄ NEUROLOGICZNĄ: INTERWENCYJNE BADANIE KONTROLNE

Wstęp. Ważnym priorytetem świadczonej opieki jest koncentracja na jakości życia pacjentów i ich rodzin oraz troska o potrzeby biopsycho-społeczne i duchowe pacjentów.

Cel pracy. Celem było zidentyfikowanie niezaspokojonych potrzeb pacjentów i określenie wpływu ukierunkowanych interwencji na niezaspokojone potrzeby pacjentów.

Materiał i metody. Próba składała się z 151 pacjentów z postępującą chorobą neurologiczną (PChN). Do zbierania danych wykorzystano kwestionariusz NPCS.

Wyniki. Najwięcej niezaspokojonych potrzeb zidentyfikowano w obszarze rehabilitacji, zarówno pod względem częstotliwości (78,8%), jak i intensywności (73,5%), wsparcia rodziny (52,3%), zapewnienia opieki zastępczej w miejscu zamieszkania (38,4%), potrzeby opieki osobistej (35,7%) i specjalistycznego leczenia pielęgniarskiego (33,7%). Ukierunkowana interwencja zmniejszyła niezaspokojone potrzeby pacjentów włączonych do badania interwencyjnego.

Wnioski. Zrozumienie czynników, które determinują rodzaj i stopień niezaspokojonych potrzeb pacjentów z PChN, ma zasadnicze znaczenie dla zapewnienia odpowiedniej opieki wielodyscyplinarnej.

Słowa kluczowe: **interwencja, potrzeba, pielęgniarka, postępująca choroba neurologiczna, wsparcie**

ABSTRACT

THE EFFECT OF TARGETED INTERVENTIONS ON THE UNMET NEEDS OF HEALTHCARE AND SOCIAL SUPPORT SERVICES IN PATIENTS WITH PROGRESSIVE NEUROLOGICAL DISEASE: INTERVENTIONAL CONTROL STUDY

Introduction. An important priority of provided care is the focus on the quality of life of the patients and their families and care for bio-psycho-social and spiritual needs of the patients.

Aim. The aim was to identify the unmet needs of patients and to determine the impact of targeted interventions on the unmet needs of patients.

Material and methods. The sample consisted of 151 patients with PND. The NPCS questionnaire was used for data collection.

Results. Most unmet needs were identified in the area of rehabilitation, both with respect to frequency (78.8%) as well as intensity (73.5%), family support (52.3%), provision of residential respite care (38.4 %), need of personal care (35.7%), and specialized nursing treatment (33.7%). Targeted intervention reduced the unmet needs in patients included in the interventional study.

Conclusions. Understanding the factors which determine the type and degree of unmet needs of patients with PND is essential for providing suitable multidisciplinary care.

Key words: **intervention, need, nurse, progressive neurological disease, support**

INTRODUCTION

Focusing on the quality of life and care for the bio-psycho-social and spiritual needs of patients and their families is an important priority of the care provided. Progressive neurological diseases (PND), such as Parkinson's disease (PD), motor neurone disease (MND) and multiple sclerosis (MS), also have a major impact on the quality of life of patients and their families [1]. The diagnosis itself may not be the positively determining factor of one's needs, therefore it is necessary to use a different way to identify the needs for providing care [2]. The chronic and still deteriorating motion handicap causes a range of health-related as well as psychosocial problems to the patients and their families, and requires multidisciplinary approach and cooperation [3]. The unmet needs substantially lower the patients' quality of life [4], therefore their identification is crucial to provide targeted healthcare services and support and to provide individualized care. To provide nursing treatment focused on the patient, specific unmet needs of patients with PND factors that affect them need to be identified. The assessment of the needs enables the patients to clarify to which level their needs are or are not satisfied. Also, it helps the multidisciplinary team determine where it is necessary to target the intervention [5,6]. The evaluation of health needs includes the need assessment and unmet need measurement [7]. Calvert et al. [8] found out that patients with neurological disease were provided with fewer health and social services than their needs demanded. Moreover, a research on people with health disabilities revealed that the unmet needs regarding healthcare occurred, to greater extent, among them when compared to people without any health disability [9].

AIM

The aim of the research was to analyse the unmet needs of chronically neurologically ill patients and to find out which of them affect them and to find out the effect of the intervention on the unmet needs.

MATERIALS AND METHODS

We performed an intervention study – randomized control study design. A randomized control study is the most common type of an intervention study.

Participants

The sample consisted of 151 patients meeting the following criteria: diagnosis of selected PND according to ICD-10 – Parkinson's disease (G-20), multiple sclerosis (G-35), motor neuron disease (G-12.2); older than 18 years; PPS (Palliative Performance Scale) ≤ 70 points; good cognitive status (MMSE ≥ 24 points); consent to cooperation.

The study included patients from four institutions in the Moravian-Silesian Region of the Czech Republic. Based on these criteria, the physician or nurse selected suitable patients, who were asked to be included in the study. Thereafter, they were randomly assigned to an intervention or control group.

Ethical Aspects

The study respects Helsinki declaration from 1975 (and its 2004 and 2008 revisions). At the same time, it was approved and the approval of the ethics committee of the University Hospital Ostrava was granted (10 June 2016, No. 486/2016). All patients were informed of the study details and provided informed consent prior to enrolment in the study.

Intervention

The multidisciplinary team provided interventions. Patients were contacted at a regular outpatient check-up and were randomly assigned by a physician to an intervention or control group. The physician then assessed the functional status of the patients (PPS - Palliative Performance Scale [10], ADL - Activity of Daily Living [11]) and the nurse assessed the individual needs of health and social services. The coordinator then offered the services of a multidisciplinary team (doctor, nurse, psychologist, social worker, priest, physiotherapist, speech therapist and occupational therapist) and a targeted intervention was carried out on the basis of unmet needs. The individual consultation usually lasted 45-60 minutes. The consultations took place according to the patient's request in the outpatient clinic, in the institution or at the client's home.

The physician consultation was focused on symptom management, medication adjustments, setting a care plan and treatment goals in individual phases of the disease. Physiotherapist and occupational therapist set functional goals, respiratory or cognitive rehabilitation, care focused on spasticity and locomotion, timely provision of appropriate aids. The speech therapist helped solve problems with speech and swallowing. The psychologist provided psychosocial support and psychotherapy. The social worker consulted on the possibility of financial support and the provision of social services.

Patients in the control group received standard care (regular check-up by a neurologist in an outpatient clinic or institution). After 3 months, the nurse reassessed the individual needs of health and social services. Patients were offered the opportunity to consult with a multidisciplinary team.

Data Collection

To evaluate the needs of care, the NPCS scale was used (The Needs and Provision Complexity Scale) [2]. NPCS covers 16 areas that are evaluated. First, the actual need of care is assessed (NPCS, part A) and then the level of provided services, the so called received care (NPCS, part B). The questions are the same both in part A and part B. Part A and part B are assessed by a physician or another health professional. The overall score ranges 0-50 points and is analysed on six subscales (A-F) assembled in two major areas: 1. needs of health and personal care (score: 0-25 points), and 2. needs of social care and support (score: 0-25 points). Area 1 "needs of health and personal care" includes three partial scales: A. healthcare (0-6 points),

B. personal care (0-10 points), and C. rehabilitation (0-9 points). Personal care represents one's care for himself or herself. Area 2 "needs of social care and support" includes three partial scales: D. social care and family support (0-13 points), E. aids (0-3 points), and F. environment (0-9 points). The difference between the evaluation of the actual needs of care and the provided services represents "the unmet needs". Higher scores in all areas mean greater need of services and more unmet needs.

Disease progression was assessed using 13 questions, to which the physician answered YES or NO. 1 point was awarded for each answer YES. The total score ranged from 0 to 13 points. More points means more disease progression.

Data Analysis

Basic descriptive statistics were used – mean, standard deviation, relative and absolute frequencies; a nonparametric Wilcoxon two-sample test for independent samples (Mann-Whitney U test) and Wilcoxon's singed-rank test were used to compare the difference between groups. The relationship between unmet needs and selected factors was determined using Spearman's correlation coefficient. Statistical significance was tested with a significance level of $p < 0.05$. It was used to evaluate the data using SPSS v. 24.0 software (IBM, Armonk, NY, USA).

RESULTS

Sociodemographic Characteristic of the Sample

A total of 151 respondents were included in the study (98 patients in intervention group and 53 patients in control group). The average age of respondents was 63.9 years (SD=12.8). The sociographic characteristics of the sample are provided in Table 1.

Graph 1. overviews the needs of the patients (no needs, needs met and unmet needs). Most unmet needs were identified in the area of rehabilitation both with respect to frequency (78.8%) and intensity (73.5%), family support (52.3%), securing residential respite care (38.4%), need of personal care (35.7%), and specialized nursing care (33.7%).

Correlation between the Actual Needs of Care and Selected Factors

Furthermore, we focused on the correlation between the individual domains of needs in the NPCS questionnaire and selected factors (the ability to perform activities of daily living, functional state, cognitive functions, progression, disease duration, and age).

Through correlation, a connection was identified between the domain of the health and personal care need, need of social care and support, total score of needs and the selected factors (PPS, ADL). There was also found an association between better score for activity of daily living, functional state, and the lower score of the needs in the given areas (Tab. 2).

Tab. 1. Sociodemographic and health characteristics of the sample

Sociodemograp. characteristics	Intervent. N=98	control N=53	total N=151	Health status	Intervent. N=98	control N=53	total N=151
Age N (%)				**Length of diseases/care**			
mean (SD)	62.6(13.4)	66.3(11.5)	63.9 (12.8)	Mean(SD)	16.4(11.6)	10.1(7.7)	14.1(10.8)
Min–max	38-90	43-91	38-91	Min-max	2-37	2-30	2-37
Gender N (%)				**Activity of daily living (ADL)**			
Man	39 (39.8)	22 (41.5)	61 (40.4)	Mean(SD)	58.4(19.7)	57.2(22.3)	58.1(21.0)
Women	59 (60.2)	31 (58.8)	90 (59.6)	Min-max	10-80	10-80	10-80
Marital status N (%)				**Palliative Performance scale (PPS)**			
Single	11 (11.2)	3 (5.7)	14 (9.3)	Mean(SD)	56.8(11.4)	55.8(10.3)	56.4(11.0)
Married	48 (49.0)	31 (58.5)	79 (52.3)	Min-max	30-70	30-70	30-70
Divorced	20 (20.4)	6 (11.3)	26 (17.2)	**MMSE**			
Widowed	19 (19.4)	13 (24.5)	32 (21.2)	Mean(SD)	27.5 (2.2)	27.5(1.9)	27.5 (2.1)
Employment N (%)				Min-max	24-30	24-30	24-30
Employee	3 (3.1)	2 (3.8)	5 (3.3)	**Progression**			
Unemployed	0 (0)	0 (0.0)	0 (0.0)	Mean(SD)	4.8 (2.3)	5.0 (2.3)	4.9 (1.6)
Invalid pens.	48 (49.0)	21 (39.6)	69 (45.7)	Min-max	0-11	0-9	0-11
Old-age pen.	47 (48.0)	30 (56.6)	77 (51.0)	**Type of disease**			
Other	0 (0)	0 (0.0)	0 (0.0)	MS	54 (55.1)	34 (64.2)	88 (58.3)
Children N (%)				PD	42 (42.9)	16 (30.2)	58 (38.4)
Yes	84 (85.7)	48 (90.6)	132 (87.4)	MND	2 (2.0)	3 (5.6)	5 (3.3)

MS – Multiple sclerosis, PD – Parkinson's disease, MND – Motor neuron disease

The patients who had been facing the disease for longer time, had more needs in the domains of personal care (r = 0.279), rehabilitation (r = 0.365), family support (r = 0.298), aids (r = 0.347), and the surroundings (r = 0.250).

As the disease progressed, the needs also increased in the total score of the NPCS questionnaire (r = 0.297) and in the domains of health and personal care (r = 0.277), and social care and support (r = 0.226).

Correlation between the Unmet Needs and Selected Factors

Through correlation there was determined an association between the ability to perform the activities of daily living (measured by ADL) and the unmet needs in the total score of the health and personal care domain (r = -0.213), social care and support (r = -0.161), and in the total score of the NPCS questionnaire (r = -0.234), when the patients with greater dependence regarding the activities of daily living had more unmet needs in the given areas (Tab. 4). The patients in worse functional state had more unmet needs in the domain of social care and support (r = -0.246). The patients who had been facing the disease for longer time, had more unmet needs in the total score of the NPCS questionnaire (r = 0.219), and the disease progression also correlated with the unmet needs (r = 0.252) (Tab. 3).

Evaluation of the Differences in Unmet Needs Between the First and the Second Measuring in the Intervention Group and Control Group

When evaluating the differences between the first and the second measurements in the intervention group and the control group, a statistically significant difference was found in the total score of the health and personal care (p = 0.000), social care and support (p = 0.000) domains and in the overall NPCS questionnaire (p = 0.000). Fewer unmet needs were found in patients, in contrast to the control group, where there was no change (see Tab. 4).

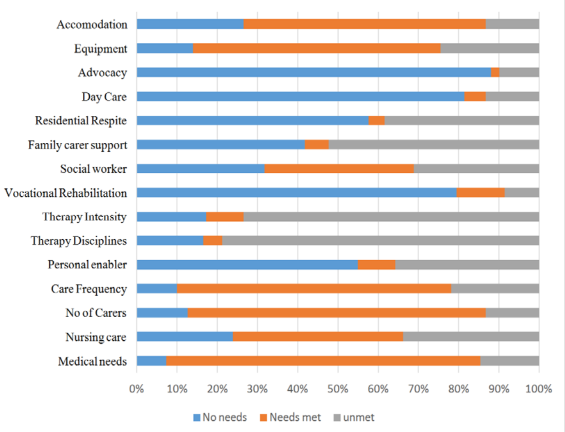

Fig 1. No needs, needs met and unmet needs of patients with PND

Tab. 2. Correlation of the actual needs and selected factors

	ADL	PPS	MMSE	Progression	Length	AGE
Health and personal care needs						
Health care	-0.223**	-0.249**	-0.058	0.152	0.001	-0.039
Personal care	-0.660**	-0.318**	-0.320**	0.218**	0.279**	0.134
Rehabilitation	-0.458**	-0.014	-0.089	0.188*	0.365**	-0.074
Total score	-0.225**	-0.020	0.003	0.277**	0.218**	-0.140
Social care and support needs						
Social/family support	-0.506**	-0.231**	-0.266**	0.101	0.298**	0.072
Equipment	-0.557**	-0.197*	-0.196*	0.294**	0.347**	-0.039
Environment	-0.449**	-0.246**	-0.187*	0.254**	0.250**	0.147
Total score	-0.225**	-0.344**	-0.154	0.226**	0.002	0.114
Total needs	-0.264**	-0.218**	-0.089	0.297**	0.126	-0.016

ADL - Activity of daily living, PPS - Palliative Performance scale, MMSE - Mini Mental State Examination

Tab. 3. Correlation between the unmet needs and selected factors

	ADL	PPS	MMSE	Progression	Length	AGE
Health and personal care needs						
Health care	-0.218*	-0.083	0.037	0.131	0.271*	-0.080
Personal care	-0.162	-0.131	-0.097	0.082	0.124	-0.075
Rehabilitation	-0.177*	0.126	0.022	0.239**	0.228*	-0.158
Total score	-0.213*	-0.016	-0.031	0.201**	0.266**	0.017
Social care and support needs						
Social/family support	-0.197*	-0.208*	-0.093	0.247**	0.183*	0.040
Equipment	-0.047	-0.233*	-0.033	0.224**	0.095	0.052
Environment	-0.221*	-0.223*	-0.110	0.084	0.048	0.126
Total score	-0.161*	-0.246*	-0.035	0.239**	0.120	-0.136
Total unmet needs	-0.234**	-0.125	-0.023	0.252**	0.219**	-0.080

ADL - Activity of daily living, PPS - Palliative Performance scale, MMSE - Mini Mental State Examination

Tab. 4. Comparing the difference in the evaluation of individual unmet need domain during the first and the second measuring in patients included in the intervention group and the control sample

	Intervention				Control			
	Time I. med (IRQ)	Time II med (IRQ)	z	p*	Time I. med (IRQ)	Time II med (IRQ)	z	p*
Health and personal care needs								
Health care	1 (0-2)	0 (0-1)	-4.137	**0.000**	1 (0-1)	1 (0-1)	-0.333	0.739
Personal care	1 (0-2)	0 (0-1)	-3.677	**0.000**	1 (0-1)	1 (0-1)	-1.333	0.120
Rehabilitation	4 (2-6)	0 (0-1)	-7.164	**0.000**	4 (0-5)	4 (0-5)	0.000	1.000
Total score	6 (4-8)	1 (0-3)	-6.959	**0.000**	5 (0-6)	5 (0-6)	-0.663	0.507
Social care and support needs								
Social/family support	2 (1-3)	1 (0-2)	-4.686	**0.000**	1 (0-2)	1 (0-2)	-0.711	0.477
Equipment	0 (0-0)	0 (0-0)	-1.307	0.121	0 (0-1)	0 (0-1)	0.000	1.000
Environment	0 (0-0)	0 (0-0)	-0,933	0.351	0 (0-0)	0 (0-0)	-1.000	0.317
Total score	2 (1-4)	1 (0-2)	-5.088	**0.000**	1 (0-3)	1 (0-3)	-0.665	0.512
Total unmet needs	9 (6-11)	2 (1-4)	-7.071	**0.000**	7 (1-7)	7 (0-9)	-0.142	0.887

DISCUSSION

The evaluation of needs through standardized tools is performed to improve the effectivity of care and to identify the so-called unmet needs. Waller et al. [12] revealed that using these tools is efficient in case after the first measuring of an intervention is provided, which focuses on the unmet needs. The provided care thus becomes more efficient and faster. A range of previous studies focused on the unmet needs of patients with chronic disease [6-7,13], but also patients with progressive neurological disease where the unmet needs were identified in the physical as well as psychosocial areas. The evaluation of the unmet needs of health and social care and support might identify the impact of the disease on the individual domains of care which reflect the multidimensional effect of PND. In our research study, the most unmet needs of patients with PND were found in the area of rehabilitation. Other unmet needs were identified in the areas of personal care, securing the nursing care and social care. Also in the research of Siegert et al. [14] unmet needs were found in all areas monitored. Only a small fragment of the sample stated unmet needs of accommodation, but 40% of the respondents did not have their needs satisfied in the area of household equipment. Substantial deficiencies in satisfying the therapeutical needs in social, spiritual, emotional, and physical domains were also revealed by e.g. Buetow et al. [15] and Lee et al. [16]. Some researchers confirmed the mutual correlation between the unmet needs of health and social support and the quality of life of patients with long-term neurological states [17,18]. Calvert et al. [8] found out that patients with neurological disease received fewer health and social services than their needs demanded. Another research of people with health disability revealed that in this group of patients the unmet needs of health care occur to greater extent than among people without any health disability [14].

In our research we determined the positive impact of the provided intervention in patients included in the intervention sample. After the intervention, we found less unfulfilled patients. Care provided by a multidisciplinary team can help patients, improve the satisfaction of their unmet needs, and this approach can also be helpful in resolving their physical difficulties but also with emotional problems and can lead to follow-up health and social care based on the individual needs of the client.

CONCLUSIONS

A multidisciplinary team providing comprehensive patient-centered care can help patients and their families reduce unmet needs. We recommend conducting further research aimed at analysing the benefits of various interventions in patients with PND in a larger sample.

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