

The Burden on Caregivers of the Elderly to Care for Patients with Nervous System Diseases

Obciążenie opiekunów osób starszych opieką nad pacjentami ze schorzeniami układu nerwowego

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Abstract

Introduction. Previous studies have shown that the level of care burden depends primarily on the mental state and functional ability of patients, i.e. on factors on the patient's part. Other reports point to factors also related to the caregiver.

Aim. The aim of the study was to analyse the impact of selected factors on the burden on informal caregivers in caring for geriatric patients with nervous system diseases.

Material and Methods. The research was conducted at the Geriatrics Clinic of the University Hospital no. 1 of Dr A. Jurasz in Bydgoszcz on a group of 117 informal caregivers and 117 patients with nervous system diseases under their care at home. The prospective studies used survey techniques as well as observation and measurement. The Negative Impact of Care Scale (NIC) included in the COPE-index was used to assess the caregiver's burden with care. The Barthel scale and Lawton's IADL scale were used to assess patients' deficits in basic activities of daily living. To assess the intensity of depression symptoms in older people, the Geriatric Depression Scale — GDS was used.

Results. The socio-demographic factors determining caregiver burden (NIC) include: caregiver's age ($p=0.00$), place of care ($p=0.03$), caregiver's self-assessment of health ($p=0.00$) and experience in providing care ($p=0.03$). However, there was no significant ($p>0.05$) impact of variables such as gender, place of residence, marital status, caregiver's education and degree of relationship with the patient on the burden of care. The analysis also showed that caregivers feel a negative overload in connection with caring for a patient with a functional impairment (BI and IADL $p=0.01$) and with vascular disease and dementia ($p=0.01$).

Conclusions. More than half of the surveyed caregivers show a high degree of burden in caring for geriatric patients with nervous system diseases. Caregiver burden is determined by the following factors: the age of the caregiver, the place of care, the caregiver's self-assessment of health and the experience of providing care. Caregivers feel a negative overload due to caring for patients with functional deficits, vascular disease and dementia. (JNNS 2023;12(2):84–91)

Key Words: Barthel Index Scale, caregiver burden, COPE-index, elderly, Geriatric Depression Scale, Lawton Instrumental Activities of Daily Living (IADL) Scale, nervous system diseases

Streszczenie

Wstęp. W dotychczasowych badaniach wykazano, że poziom obciążenia opieką zależy przede wszystkim od stanu psychicznego i sprawności funkcjonalnej chorych, czyli od czynników ze strony pacjenta. Inne doniesienia wskazują, na czynniki związane również z opiekunem.

Cel. Celem pracy była analiza wpływu wybranych czynników na stopień obciążenia opiekunów nieformalnych, opieką nad pacjentami geriatrycznymi ze schorzeniami układu nerwowego.

Materiał i metody. Badania przeprowadzono w Klinice Geriatrii Szpitala Uniwersyteckiego nr 1. im. dr. A. Jurasza w Bydgoszczy na grupie 117 opiekunów nieformalnych oraz 117 pacjentów z chorobami układu nerwowego, będących pod ich opieką w środowisku domowym. W prospektywnych badaniach posłużono się techniką ankietową oraz obserwacją i pomiarem. Do oceny stopnia obciążenia opiekuna opieką wykorzystano Skalę Negatywnego Wpływu Opieki (NWO) wchodzącą w skład COPE-index. Do oceny pacjentów — ich deficytu w zakresie podstawowych czynności dnia codziennego zastosowano skalę Barthel oraz skalą IADL Lawtona. W ocenie natężenia symptomów depresji u osób w starszym wieku, zastosowano Geriatryczną Skalę Depresji — GDS.

Wyniki. Wśród czynników socjo-demograficznych, determinujących obciążenie opiekuna (NWO), można wymienić: wiek opiekuna ($p=0,00$), miejsce sprawowania opieki ($p=0,03$), samoocenę stanu zdrowia opiekuna ($p=0,00$) oraz doświadczenie w sprawowaniu opieki ($p=0,03$). Nie stwierdzono natomiast, istotnego ($p>0,05$) wpływu takich zmiennych jak: płeć, miejsce zamieszkania, stan cywilny, wykształcenie opiekuna oraz stopnień pokrewieństwa z pacjentem na obciążenie opieką. Analiza wykazała również, że opiekunowie odczuwają negatywne przeciążenie w związku z opieką nad pacjentem z deficytem sprawności funkcjonalnej (BI i IADL $p=0,01$) oraz obciążonym chorobą naczyniową i zespołem otępiennym ($p=0,01$).

Wnioski. Przeszło połowa badanych opiekunów wykazuje wysoki stopień obciążenia opieką nad pacjentami geriatrycznymi ze schorzeniami układu nerwowego. Obciążenie opiekunów jest determinowane przez następujące czynniki: wiek opiekuna, miejsce sprawowania opieki, samoocenę stanu zdrowia opiekuna oraz doświadczenie w sprawowaniu opieki. Opiekunowie odczuwają negatywne przeciążenie w związku z opieką nad pacjentem z deficytem sprawności funkcjonalnej, obciążonym chorobą naczyniową i zespołem otępiennym. (PNN 2023;12(2):84–91)

Słowa kluczowe: skala Barthel, obciążenie opiekuna opieką, COPE-index, osoba starsza, Geriatryczna Skala Depresji, Skala Oceny Złożonych Czynności Życia Codziennego (IADL), schorzenia układu nerwowego

Introduction

Over the last 25 years, a slowdown in demographic development and significant changes in the age structure of its inhabitants have been observed in Poland. The ongoing process of demographic aging of the population is primarily the result of increasing life expectancy and low fertility levels and is a social problem not only in Poland, but also in most European societies. There are many health problems in the elderly population, and the deterioration of health with age results in limitations in everyday life, the need for external support and an increased intensity of use of health care services. Age, regardless of other conditions, is the main risk factor for chronic diseases.

An informal caregiver for an elderly person is a person who takes care of a senior for more than 4 hours a week and does not receive remuneration for this [1]. As part of care, he provides regular, lasting, physical and emotional support and assistance in everyday activities to an elderly person whose psychophysical condition can be described as poor [2]. The basic forms of care include: emotional support, instrumental activities performed at home and outside, care and hygiene, establishing and coordinating contacts with institutions [3]. Most informal caregivers combine care with professional responsibilities. This group shows psychological burdens, such as stress, a sense of helplessness, and a negative impact on personal and social life. Burden is defined as physical problems (time and costs spent on care) resulting mainly from the functional state of the patient, mental problems (emotional disorders) related to coping with a stressful situation, such as caring for a sick person, social problems (limited social contacts) manifested by in the caregiver's

relationships with other people and financial ones, resulting from interruption of professional work, costs of treatment and rehabilitation of the patient [4,5]. Previous studies have shown that the level of burden depends primarily on the mental state and functional ability of patients, i.e. on factors on the part of the patient. Other reports indicate factors also related to the caregiver [6].

The aim of the study was to analyse the impact of selected factors on the burden on informal caregivers in caring for geriatric patients with nervous system diseases.

Material and Methods

Material

The research was conducted at the Geriatrics Clinic of the University Hospital no. 1 of Dr A. Jurasz in Bydgoszcz on a group of 117 informal caregivers and 117 patients with nervous system disease under their care at home. The criteria for selecting a caregiver were: acting as an informal caregiver in the family for the studied patients and consenting to participate in the study. The criteria for selecting patients under care were: hospitalization in the geriatric department, 65 years of age or older (old age limit according to the UN), no disorders of consciousness, comprehensive geriatric assessment performed and consent to participate in the study. The characteristics of the study groups are presented in Table 1.

Table 1. Characteristics of the study group

Variable	Caregivers		Patients	
	N	%	N	%
1	2	3	4	5
Gender				
Women	86	73.5	91	77.8
Men	31	26.5	26	22.2
Age				
Under 50 year	38	32.5	–	–
51–64 years	55	47.0	–	–
Over 65 years	24	20.5	–	–
65–74 years	–	–	28	23.9
75–89 years	–	–	86	73.5
90 years and more	–	–	3	2.6
Place of residence				
City	79	67.5	83	70.9
Village	38	32.5	34	29.1
Marital status				
Single	27	23.1	38	32.5
Relationship	90	76.9	79	67.5
Education				
Elementary	0	0	11	9.5
Vocation	28	23.9	48	41.0
Secondary	48	41.0	37	31.6
Higher	41	35.1	21	17.9
Relationship to patient				
Spouse	37	31.6	–	–
Child	48	41.0	–	–
Other member of family	11	9.5	–	–
Other person	21	17.9	–	–
Place of care				
In the same apartment	57	48.7	–	–
In the same house	38	32.5	–	–
Near	19	16.2	–	–
Access by transport	3	2.6	–	–
Self-assessment of health status				
Very good	9	7.7	–	–
Good	36	30.8	–	–
Average	61	52.1	–	–
Bad	10	8.6	–	–
Very bad	1	0.8	–	–
Experience in care				
First	91	77.8	–	–
Next	26	22.2	–	–

Table 1. Continued

	1	2	3	4	5
Diagnosed disease (dominant disease)*					
Vascular disease (stroke)	–	–	–	31	26.5
Dementia (dementia syndromes, Alzheimer's disease)	–	–	–	69	59.0
Diseases of the pyramidal system (parkinsonian syndromes, Parkinson's disease)	–	–	–	18	15.4
Degenerative changes in the spine	–	–	–	28	23.9
Proliferative disease (brain tumor)	–	–	–	2	1.8

N — number of observations, % — percent, *multiple selection

Methods

The prospective studies used survey techniques as well as observation and measurement. The Negative Impact of Care Scale, part of the COPE-index, was used to assess the caregiver's burden with care. Full assessment tool — COPE-index is an initial screening tool for identifying the needs of caregivers and emphasizes the caregiver's subjective assessment of their situation and circumstances of providing care. The tool consists of 15 questions in three subscales: Negative Impact of Care (NIC) — 7 questions, Positive Value of Care (PVC) — 4 questions and Quality of Support (QS) — 4 questions. The last question on the COPE-index scale is an open question. The Negative Impact of Care subscale consists of 7 questions to which the caregiver answers according to a four-point Likert scale. The values obtained by the respondent are in the range of 7–28 points, and the higher the values obtained, the higher the level of care burden. For the purposes of statistical analyses, the following caregiver qualification criteria were adopted: 7–10 points — no or low care burden and 11–28 points — high care burden. The Cronbach's alpha reliability coefficient for the entire COPE-index tool is 0.82 [7,8].

The data was supplemented with sociodemographic indicators characterizing the caregiver with an original questionnaire assessing patients' informal caregivers.

The Barthel scale was used to assess the degree of patients' deficit in basic activities of daily living. The Barthel Scale (Barthel Index — BI) was published in 1965 and is still the most common method of assessing activities of daily living (ADL). By awarding a certain number of points 0, 5, 10, 15, the ability of self-service is assessed. When assigning a score, 10 daily activities are assessed. The internal consistency coefficient for the

original version of the scale, according to various studies, ranges from 0.87 to 0.90; validity coefficient in relation to other scales from 0.65 to 0.69. For the purposes of statistical analyses, the following patient qualification criteria were adopted: 86–100 points — the patient copes well with everyday activities; 21–85 points — the patient is partially unable to cope with everyday activities; 0–20 points — the patient cannot independently perform most everyday activities [9–11].

The Lawton Instrumental ADL Scale (IADL) was used to assess complex activities of daily living in hospitalized patients. Scoring in individual areas ranges from 3 points — without help, to 1 point — completely unable to cope with a given area. For the purposes of statistical analyses, the following patient qualification criteria were adopted: 27–23 points — high degree of efficiency; 22–14 points — average level of fitness and 13–9 points — low degree of efficiency. The loss of IADL function does not eliminate the possibility of living independently, but it determines the area of assistance that must be provided by caregivers in order for the disabled person to remain in the home environment. The reliability rating of the original scale is high. The inter-rater reliability coefficient for the overall scale is 0.87 [12–14].

To assess the intensity of depression symptoms in older people, the Geriatric Depression Scale (GDS) was used. The full version of the scale consists of 30 short questions with two answer options (yes/no). The Geriatric Depression Scale has also been translated into Polish and is one of the most frequently used screening tools for assessing depression in old age. For the purposes of statistical analyses, the following patient qualification criteria were adopted: 0–10 points — no depression, 11–20 points — slight depression and 21–30 points — severe depression. The reliability of the original version of the GDS was estimated using Cronbach's α coefficient ($\alpha=0.94$) and split-half reliability using the Spearman–Brown formula ($r=0.94$). The sensitivity and specificity of the GDS scale were 84 and 95%, respectively [15–17].

Ethical Considerations

The study was conducted in accordance with the ethical principles and requirements of the Declaration of Helsinki, and the study participants were familiarized with the study conditions and gave their informed consent to participate.

Data Analysis

The results were processed using Microsoft Excel and STATISTICA (CM UMK license). The statistical study used quantitative and value statistics, as well as statistical

description methods: location measure — arithmetic mean (M), median — (Me), diversity measure — standard deviation (SD), minimum value (Min), maximum value (Max). Appropriate correlation tests were also used. A significance level of $p<0.05$ was considered statistically significant in this study.

Results

More than half of the surveyed caregivers (68 people — 58%) show a high degree of burden in caring for geriatric patients with nervous system diseases (Table 2).

The youngest caregiver was 21 years old and the oldest was 88 years old. The analysis of the age categories of caregivers indicates that the majority of caregivers (55 people — 47%) were in the age group of 51–64. The place of care for the patient was an apartment shared by the caregiver and the patient (57 people — 49%). It can be noticed that the caregiver's care burden was related to the distance of the place of residence. It turns out that experience in caring for a patient determines the level of burden on the caregiver. For 91 people (78%) of the surveyed group of caregivers, this was their first experience. Most caregivers assess their health as average (61 people — 52%). Self-assessment of very good and good health concerns 45 people, i.e. 38% of the respondents (Table 1). Sociodemographic factors determining caregiver burden (NIC) include: caregiver's age ($p=0.00$), place of care ($p=0.03$), caregiver's self-assessment of health ($p=0.00$) and experience in providing care ($p=0.03$). However, there was no significant ($p>0.05$) impact of variables such as gender, place of residence, marital status, caregiver's education and degree of relationship with the patient on the burden of care. The analysis also showed that caregivers feel a negative overload in connection with caring for a patient with vascular disease and dementia ($p=0.01$) (Table 2 and 3).

In the clinimetric assessment of patients using functional scales, it was found that on the BI scale, the vast majority (89 people — 76%) were patients who could not cope with everyday activities. Similarly, in terms of complex activities of daily living (IADL), the largest group were patients with medium (64 people — 55%) and low (42 people — 36%) levels of fitness (Table 2). The analysis showed that as the patient's functional ability on the BI and IADL scales decreases, the caregiver's burden (NIC) increases — negative correlation at $p=0.01$. In the case of correlation between the GDS scale and NIC, no statistically significant correlation was observed ($p>0.05$) (Table 4).

Table 2. Clinimetric assessment of caregivers and patients

Variable	Caregivers		Patients	
	N	%	N	%
Negative Impact of Care (NIC) COPE-index*				
7–10 (low load range)	49	42.0	–	–
11–28 (high load range)	68	58.0	–	–
Barthel Index — BI**				
86–100 points — Mild functional impairment	–	–	8	6.9
21–85 points — Moderate functional impairment	–	–	89	76.0
0–20 points — Very severe functional impairment	–	–	20	17.1
Lawton Instrumental ADL Scale***				
27–23 points — high level of functional impairment	–	–	11	9.4
22–14 points — moderate level of functional impairment	–	–	64	54.7
13–9 points — low level of functional impairment	–	–	42	35.9
Geriatric Depression Scale — GDS****				
0–10 points — no depression	–	–	83	70.9
11–20 points — mild depression	–	–	34	29.1
21–30 points — severe depression	–	–	0	0

N — number of observations, % — percent, *M — 14.2, Me — 14.0, SD — 1.75, Min — 7, Max — 26, **M — 43.0, Me — 40.0, SD — 21.90, Min — 20, Max — 100, ***M — 16.7, Me — 15.0, SD — 2.20, Min — 9, Max — 26, ****M — 14.2, Me — 14.0, SD — 2.70, Min — 0, Max — 20

Table 3. Selected sociodemographic variables and the Negative Impact of Care (NIC)

Variable vs. NIC COPE-index	Correlation coefficient	p
Gender caregiver	–0.071	>0.05
Age caregiver	0.328	0.00
Place of residence caregiver	–0.074	>0.05
Marital status caregiver	0.081	>0.05
Education caregiver	0.006	>0.05
Relationship to patient	0.038	>0.05
Place of care	0.345	0.03
Self-assessment of health status caregiver	0.413	0.00
Experience in care	–0.370	0.03
Diagnosed disease (dominant disease)	0.413	0.01

p — level of statistical significance

Table 4. Correlations between clinimetric assessment and the Negative Impact of Care (NIC)

Variables vs. NIC COPE-index	Correlation coefficient	p
Barthel Index — BI	–0.861	0.01
Lawton Instrumental ADL Scale	–0.940	0.01
Geriatric Depression Scale — GDS	0.455	>0.05

p — level of statistical significance

Discussion

The study aimed to analyse the impact of selected factors on the burden on informal caregivers of caring for geriatric patients with nervous system diseases.

The Negative Impact of Care Scale, part of the COPE-index, was used to assess the caregiver's burden with care. The COPE-index is an initial screening tool for identifying the needs of caregivers and emphasizes the caregiver's subjective assessment of their situation and circumstances of providing care. It is a commonly used tool in research. Our own research shows that more than half of the surveyed caregivers (68 people — 58%) have a high level of care burden. Research conducted by Niedorys et al. [18] shows that caring for an elderly person has a negative impact on the burden of the informal caregiver, especially in the physical and emotional dimension. This is also confirmed by the results of studies by other authors, who show that caregivers were most exposed to burden [19,20]. Research conducted by Bartoszek et al. [21] also indicates that caregivers are overloaded with care. The obtained mean value in the area of Negative Care Impact (NIC) was 11.80 (SD=3.75). In the study by Niedorys et al. [18], it was 12.84 (SD=3.82) and in the study by Karczewska et al. [22], it was 11.9 (SD=4.2) and 8.9 (SD=2.7). The results obtained in our own research (14.2; SD=1.75) remain in values similar to those presented above. In a study conducted by Grabowska-Fudala and Jaracz [23], on a group of 30 pairs — caregivers and patients after diagnosed stroke, assessed using the Polish version of the Caregiver Burden Scale (CB Scale), it was found that the burden was greatest in the “general effort” subscale, regarding, among others, physical and mental fatigue and responsibility related to providing care, the lowest in the “emotional involvement” subscale.

The burden on caregivers is determined by a number of different factors. Our own research has shown that the sociodemographic factors determining caregiver burden (NIC) include: caregiver's age ($p=0.00$), place of care ($p=0.03$), caregiver's self-assessment of health ($p=0.00$) and experience in providing care ($p=0.03$). The results of the research conducted by Niedorys et al. [18] do not indicate that the degree of burden significantly correlates with the duration of care for the patient, including experience in providing care. Own research showed that such a correlation exists ($p=0.03$). Studies by other authors [24,25] also showed that the longer the duration of care, the greater the burden of care on the caregiver. Own research also observed that health status affects the burden of care ($p=0.00$). This is also confirmed by research conducted by Bartoszek et al. [26] and Vitaliano et al. [27], who note that with the duration of care, the somatic condition of caregivers

deteriorates, which makes them more susceptible to the negative effects of stress.

An important factor determining the caregiver's burden is the functional capacity of the patient/ward and the disease he/she is dealing with. Own research showed that on the BI scale, the vast majority (76%) were patients who could not cope with everyday activities. Similarly, in terms of complex activities of daily living (IADL), the largest group consisted of patients with an average (55%) and low (36%) level of fitness. It has been shown that as the patient's functional ability on the BI and IADL scales decreases, the caregiver's burden (NIC) increases ($p=0.01$). Similarly, in the study by Niedorys et al. [18], it was found that as the functional ability of patients deteriorates, the negative impact of care among caregivers increases significantly. Similar results are presented by the authors of other studies [28,29]. Own research also found that caregivers experience negative overload in connection with caring for patients with vascular disease and dementia ($p=0.01$). A similar position is presented by other authors who associate the negative burden of caregivers with various diseases of patients/wards, including dementia [18,30–32].

Conclusions

1. More than half of the surveyed caregivers show a high degree of burden in caring for geriatric patients with nervous system diseases.
2. The burden on caregivers is determined by the following factors: the age of the caregiver, the place of care, the caregiver's self-assessment of health and the experience of providing care.
3. Caregivers feel a negative overload due to caring for patients with functional deficits, vascular disease and dementia.


Implications for Nursing Practice

The conducted research has shown that the burden on informal caregivers is determined by factors such as: the caregiver's age, the place of care, the caregiver's self-assessment of the health status, experience in providing care, and the patient's functional ability and disease burden. Taking the above into account, when planning systems supporting informal caregivers, it is worth taking into account the above determinants of their burden.

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