

## Analysis of Selected Determinants of Burden in Caregivers of People With Alzheimer's Disease

### Analiza wybranych czynników determinujących obciążenie wśród opiekunów osób chorych na chorobę Alzheimera

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#### Abstract

**Introduction.** Alzheimer's disease is one of the most common neurodegenerative diseases. This condition is progressive in nature. In Europe, Alzheimer's disease is estimated to affect mainly people over the age of 60. It is estimated that currently, around 357,000 people in Poland suffer from Alzheimer's disease, which is a 5% increase compared to 2014.

**Aim.** The aim of this study is to assess the level of burden and analyse the factors determining this burden among family caregivers of individuals with Alzheimer's disease.

**Material and Methods.** The study included 100 caregivers and patients with Alzheimer's disease. The research was conducted at the Provincial Specialist Hospital in Wrocław and the Alzheimer's Disease Treatment Centre in Ścinawa from 1 November 2023 to 1 March 2024. The study sample consisted of 89 women and 11 men, aged 30–81 years. Participants provided written consent for the study, had no cognitive impairments, and were under the age of 90. Two participants were excluded due to advanced age. The study employed a diagnostic survey method using a questionnaire technique. Data were collected using an author-developed sociodemographic questionnaire with 10 questions concerning age, support from relatives, relationship to the patient, and the time spent caring for the patient. The questionnaire was anonymous and completed in the presence of the researcher. Additionally, four standardised questionnaires were used: the Global Deterioration Scale (GDS), the Instrumental Activities of Daily Living (IADL) Scale, the Caregiver Burden Scale (CB Scale), and the Mini-COPE Inventory for Measuring Coping with Stress.

**Results.** The analysis of the research material revealed that in most cases, caregivers of people with Alzheimer's disease experience high levels of burden in 4 out of 5 assessed areas. Only in the "environment" area is the burden at a medium level. A higher degree of clinical symptoms in Alzheimer's patients correlated with a greater burden on caregivers. Furthermore, a lower ability of the Alzheimer's patient to perform activities of daily living, as measured by the IADL scale, was associated with a higher burden on the caregiver. The amount of time spent caring for the patient did not affect the caregiver's burden ( $p > 0.05$ ). Caregivers who had been caring for the patient for more than 12 years exhibited the lowest level of burden.

**Conclusions.** The difficulties associated with the burden of care for caregivers of people with AD represent a significant clinical, social and also economic problem. Moreover, they significantly reduce the quality of life of caregivers, often taking away the joy of caring for loved ones with Alzheimer's disease. (JNNN 2024;13(4):147–155)

**Key Words:** Alzheimer's disease, care burden, caregiver, quality of life

#### Streszczenie

**Wstęp.** Choroba Alzheimera jest jedną z najczęściej występujących chorób neurodegeneracyjnych. Schorzenie to występuje w charakterze postępującym. Określa się, że na chorobę Alzheimera chorują w Europie głównie osoby powyżej 60 roku życia. Zakłada się, że w Polsce na chorobę Alzheimera obecnie choruje około 357 tys. osób i jest to liczba wyższa o 5% niż w 2014 r.

**Cel.** Celem pracy jest ocena stopnia obciążenia oraz analiza czynników determinujących to obciążenie wśród opiekunów rodzinnych osób chorych na Alzheimera.

**Materiał i metody.** Badaniem objęto 100 opiekunów oraz pacjentów z chorobą Alzheimera. Badanie przeprowadzono w Wojewódzkim Szpitalu Specjalistycznym we Wrocławiu oraz w Ośrodku leczenia choroby Alzheimera w Ścinawie w okresie od 1 listopada 2023 r. do 1 marca 2024 r. W badaniu wzięło udział 89 kobiet oraz 11 mężczyzn, w przedziale wiekowym 30–81 lat. Osoby badane wykazały pisemną zgodę na badania, nie miały żadnych dysfunkcji układu poznawczego oraz powyżej 90 lat. Dwie osoby zostały wyłączone z badań ze względu na zbyt duży wiek. W pracy zastosowano metodę sondażu diagnostycznego, technikę ankiety. Badania prowadzone były za pomocą autorskiego kwestionariusza ankiety socjodemograficznej, który zawierał 10 pytań dotyczących m.in. wieku, wsparcia osób bliskich, powinowactwa z chorym oraz czasu jaki poświęca na opiekę nad pacjentem. Ankieta była w pełni anonimowa i wypełniana w obecności badacza. Ponadto w pracy wykorzystano 4 kwestionariusze standaryzowane tj. Globalna Skala Deterioracji (GDS), Skala Złożonych Czynności Dnia Codziennego (IADL), Skala Obciążenia Opiekuna (CB Scale) oraz Inwentarz do Pomiaru Radzenia sobie za Stresem (Mini — COPE).

**Wyniki.** Analiza materiału badawczego wykazała, że w większości sytuacji opiekunowie osób cierpiących na Alzheimera odczuwają wysokie obciążenie związane z opieką nad chorymi w 4 z 5 badanych obszarów. Jedynie w obszarze „otoczenie” jest to średni poziom obciążenia. Wyższy stopień nasilenia objawów klinicznych u pacjenta z chorobą Alzheimera korelował z większym obciążeniem opiekunów. Ponadto im mniejsza zdolność samodzielnego funkcjonowania osoby chorej na Alzheimera w skali IADL tym większe jest obciążenie opiekuna. Czas opieki sprawowanej nad chorym nie ma wpływu na obciążenie jakiego doświadcza opiekun ( $p>0,05$ ). Opiekunowie sprawujący opiekę nad chorym  $>12$  lat wykazywali najmniejszy poziom obciążenia.

**Wnioski.** Trudności związane z obciążeniem opieką opiekunów osób chorujących na AD stanowią istotny problem kliniczny, społeczny a także ekonomiczny. Co więcej w istotny sposób wpływają na obniżenie jakości życia opiekunów niejednokrotnie odbierając im radość czerpaną z opieki nad najbliższymi chorującymi na chorobę Alzheimera. (PNN 2024;13(4):147–155)

**Słowa kluczowe:** choroba Alzheimera, obciążenie opieką, opiekun, jakość życia

## Introduction

The optimal environment for a person suffering from Alzheimer's disease is their own home, which should be adapted to the deteriorating psychophysical condition of the patient. Caregivers should be supported by general practitioners, medical specialists, nurses, physiotherapists, neuropsychologists, as well as receive support from government institutions and non-governmental organisations.

The primary goal of caring for a patient with Alzheimer's disease is to improve quality of life, maintain independence in daily activities, and ensure a sense of security. Families who assume the role of caregivers but lack adequate professional training may experience significant physical and psychological burdens [1].

In Poland, the family plays the main role in caring for patients with Alzheimer's disease. This is related to behavioural patterns derived from cultural norms. Informal care is the preferred form of care for the elderly, also due to the shortage of facilities providing care for Alzheimer's patients. In Polish culture, the family performs a crucial role in providing care for the elderly and disabled, fulfilling fundamental caregiving functions [2].

Caring for a patient with Alzheimer's disease brings about numerous changes in the caregiver's life, affecting social functioning, family life, and professional activities. Caregivers often have to completely give up or reduce their working hours, which negatively impacts the well-being of the entire family. Additionally, long-term caregiving can lead to social isolation of caregivers. In Poland, there is no financial support for caregivers of

Alzheimer's patients, so only a small percentage of families can afford any form of support from professional caregivers. Only a small fraction of families can financially manage the costs of hiring a professional caregiver, rehabilitation therapist, or psychologist. The prolonged stress associated with caregiving negatively affects the mental and physical health of caregivers [3].

The primary aim is to assess the level of burden and analyse the factors determining this burden among family caregivers of individuals with Alzheimer's disease.

## Materials and Methods

The study involved 100 caregivers and patients with Alzheimer's disease. The research was conducted at the Provincial Specialist Hospital in Wrocław and the Alzheimer's Disease Treatment Centre in Ścinawa from 1 November 2023 to 1 March 2024. The study sample consisted of 89 women and 11 men, aged 30–81 years. Participants provided written consent for the study, had no cognitive impairments, and were under the age of 90. Two participants were excluded due to advanced age. The study employed a diagnostic survey method using a questionnaire technique. Data were collected using an author-developed sociodemographic questionnaire with 10 questions concerning age, support from relatives, relationship to the patient, and the time spent caring for the patient. The questionnaire was anonymous and completed in the presence of the researcher. Additionally, four standardised questionnaires were used: the Global

Deterioration Scale (GDS), the Instrumental Activities of Daily Living (IADL) Scale, the Caregiver Burden Scale (CB Scale), and the Mini-COPE Inventory for Measuring Coping with Stress. The study results were subjected to statistical analysis. To verify the hypotheses, statistical analyses were performed using IBM SPSS Statistics v. 25 package. Basic descriptive statistics were analysed, along with the Kolmogorov–Smirnov test, frequency analysis, Spearman's rank correlation, Pearson's correlation, Kruskal–Wallis tests, and one-way analysis of variance with a between-group design. The standard threshold of  $\alpha=0.05$  was considered as the significance level.

## Results

Based on the Spearman's rank correlation analysis, four statistically significant relationships were observed. Higher levels of clinical symptoms in patients were associated with increased caregiver burden in the following dimensions: overall burden, social isolation, disappointment, and environment. The strength of the first two correlations was moderately high, while the last two were weak. The correlation between clinical symptoms and emotional commitment was not statistically significant. The results defining the relationships are presented below in tabular form (Table 1).

**Table 1.** Severity of the patient's clinical symptoms and the level of caregiver burden

Variable	Clinical symptoms
Overall burden	0.38**
Social isolation	0.33**
Disappointment	0.23*
Emotional commitment	0.06
Environment	0.23*

\* $p<0.05$ ; \*\* $p<0.001$

In the next step, it was decided to verify the second research hypothesis, which assumed that a lower level of independence of a patient with Alzheimer's would be associated with a higher level of caregiver burden. Pearson correlation analyses were conducted to test this hypothesis. All the correlations tested proved to be statistically significant. The lower the patient's level of independence, the higher caregiver burden across all five dimensions. The strength of the relationship for overall burden was high, for emotional involvement was low, and the remaining three relationships were moderately strong. The results defining the relationships are presented below in tabular form (Table 2).

**Table 2.** Patient independence and caregiver burden

Variable	Patient independence
Overall burden	−0.51**
Social isolation	−0.44**
Disappointment	−0.46**
Emotional commitment	−0.24*
Environment	−0.39**

\* $p<0.05$ ; \*\* $p<0.001$

In the next step, it was decided to verify the third research hypothesis, which assumed that a longer duration of caring for a patient with Alzheimer's would be associated with higher levels of caregiving burden. To test this hypothesis, Kruskal–Wallis tests were performed due to the significant imbalance among the compared groups. Four statistically significant results were observed for overall burden, social isolation, disappointment, and emotional involvement scales, as shown in Table 3. Post-hoc analyses using the Dunn–Sidak test were conducted to further explore these relationships. The results defining the relationships are presented below in tabular form Table 3).

Regarding the overall burden scale, three statistically significant differences were noted. Caregivers with 6–12 years of caregiving experience exhibited a higher burden compared to those caring for less than a year ( $p=0.002$ )

**Table 3.** Duration of caregiving and caregiver burden

Variable	<year (N=14)		1–6 years (N=64)		6–12 years (N=17)		>12 years (N=5)		H	p
	M	SD	M	SD	M	SD	M	SD		
Overall burden	2.63	0.55	3.21	0.56	3.27	0.61	2.68	0.70	14.91	0.002
Social isolation	2.31	0.93	3.01	0.72	3.10	0.78	2.47	1.10	8.37	0.039
Disappointment	2.47	0.72	2.95	0.68	3.32	0.52	2.00	0.68	17.56	0.001
Emotional commitment	2.36	0.99	2.70	0.82	3.02	0.89	1.87	0.77	8.58	0.035
Environment	2.33	0.74	2.40	0.77	2.80	0.68	2.33	0.41	5.52	0.138

M — mean; SD — standard deviation; H — Kruskal–Wallis test result; p — significance level

and those caring for more than 12 years ( $p=0.048$ ). Additionally, caregivers with 1–6 years of experience showed a higher burden than those caring for less than a year ( $p=0.001$ ). Other differences were not statistically significant. In terms of the social isolation scale, two significant differences were noted. Caregivers with less than a year of experience reported lower levels of burden compared to those caring for 1–6 years ( $p=0.011$ ) and 6–12 years ( $p=0.014$ ). Other differences were not statistically significant. In the disappointment scale, four statistically significant differences were observed. Caregivers with 6–12 years of experience reported a higher burden than those caring for less than a year ( $p=0.001$ ) and those caring for more than 12 years ( $p=0.001$ ). Similarly, those with 1–6 years of experience showed a higher burden than those caring for less than a year ( $p=0.029$ ) those caring for more than 12 years ( $p=0.013$ ). Other differences were not statistically significant. There were three statistically significant differences on the emotional involvement scale. Caregivers with 6–12 years of experience reported higher burden levels than those caring for less than a year ( $p=0.035$ ) and those caring for more than 12 years ( $p=0.011$ ). Caregivers with 1–6 years of experience reported higher emotional involvement compared to those caring for more than 12 years ( $p=0.045$ ). Other differences were not statistically significant. Regarding the environment scale, the Kruskal–Wallis test result was not statistically significant. The obtained results do not support the third hypothesis. Although caregivers with 1–6 and 6–12 years of experience generally reported higher burden levels than those caring for less than a year, caregivers with over 12 years of experience reported lower burden levels. Therefore, the relationship between caregiving duration and burden was not linear.

The fourth research hypothesis was then verified, which assumed that caregivers of individuals with Alzheimer's disease judge the support they receive from social services and NGOs to be insufficient. Frequency analyses were performed. As shown, the majority of respondents indicated that they either never or only occasionally received support in both dimensions. Support from health care and social services was rated slightly better than that from NGOs. These findings support the fourth research hypothesis. The results defining the relationships are presented below in tabular form (Table 4).

Next, the fifth research hypothesis was examined, which proposed that caregivers' stress-coping strategies would be linked to the level of independence of the person with Alzheimer's. Pearson correlation analyses were performed. As shown, only one statistically significant relationship was found. Higher patient independence was associated with a lower level of behavioural disengagement, although the strength of this correlation was weak. Other correlations were not

**Table 4.** Level of support received from social services and NGOs

Variable	Do you feel you receive sufficient support from health care and social services?	Can you rely on support and help from NGOs?
Never	43	62
Sometimes	41	31
Often	14	4
Always	2	3

statistically significant. These results provide only limited support for the fifth hypothesis — of the fourteen analyses conducted, only one proved statistically significant. The results defining the relationships are presented below in tabular form (Table 5).

**Table 5.** Level of caregivers' stress-coping strategies and the patient's level of independence

Variable	Patient independence
Active coping	−0.16
Planning	−0.11
Positive revaluation	0.17
Acceptance	−0.19
Sense of humour	0.07
Turning to religion	0.02
Seeking emotional support	0.11
Seeking instrumental support	−0.02
Moving on to something else	0.01
Denial	−0.12
Abreaction	−0.13
Psychoactive substance use	0.07
Behavioural disengagement	−0.25*
Self-blame	−0.04

\* $p<0.05$

The next step was to verify the sixth research hypothesis, which proposed that the stress-coping strategies used by caregivers of individuals with Alzheimer's disease are linked to the level of care-related burden they experience. Pearson correlation analyses were conducted to test this hypothesis. As shown in Table 6, eighteen statistically significant relationships were identified. The level of overall burden negatively correlated with the positive revaluation strategy and positively correlated with abreaction and behavioural disengagement. This means that the more caregivers utilised positive revaluation, the lower their overall burden, while greater use of abreaction and behavioural disengagement was associated with a higher overall burden. The strength of the first



correlation was moderately high, while the strengths of the other two correlations were weak. The social isolation scale negatively correlated with positive revaluation and seeking emotional support, while it positively correlated with abreaction. These relationships were of low strength. The disappointment scale negatively correlated with positive revaluation, sense of humour, and seeking emotional support, while it positively correlated with denial and abreaction. The latter relationship was moderately strong, while the others were of low strength. The emotional involvement scale negatively correlated with seeking emotional support and positively correlated with turning to religion, psychoactive substance use, behavioural disengagement, and abreaction. The latter relationship was moderately strong, while the others were of low strength. The environment scale correlated positively with the level of psychoactive substance use and behavioural disengagement. The strength of these relationships was low. Other correlations were not statistically significant. These results provide only limited support for the sixth hypothesis — of the seventy analyses conducted, nineteen proved statistically significant. The results defining the relationships are presented below in tabular form (Table 6).

In the final step, the seventh research hypothesis was verified, which assumed that the stress-coping strategies of caregivers of individuals with Alzheimer's are related to the level of the patient's clinical symptoms. Spearman's rank correlation analyses were performed. As shown in Table 12, only two statistically significant relationships were observed. Higher levels of clinical symptoms were associated with higher levels of acceptance and

behavioural disengagement. The strength of these relationships was low. Other correlations were not statistically significant. These results provide only limited support for the seventh hypothesis — of the fourteen analyses conducted, only two proved statistically significant. The results defining the relationships are presented below in tabular form (Table 7).

**Table 7.** Level of caregivers' stress coping strategies and the level of the patient's clinical symptoms

Variable	Clinical symptoms
Active coping	0.12
Planning	0.18
Positive revaluation	−0.01
Acceptance	0.28**
Sense of humour	0.09
Turning to religion	−0.01
Seeking emotional support	−0.02
Seeking instrumental support	−0.10
Moving on to something else	−0.06
Denial	−0.02
Abreaction	0.04
Psychoactive substance use	−0.08
Behavioural disengagement	0.24*
Self-blame	0.04

\* $p < 0.05$ ; \*\* $p < 0.01$

**Table 6.** Level of caregivers' stress-coping strategies and the level of care-related burden

Variable	Overall burden	Social isolation	Disappointment	Emotional commitment	Environment
Active coping	0.19	0.12	0.13	0.14	0.12
Planning	0.15	0.10	0.09	0.15	0.14
Positive revaluation	−0.33***	−0.24*	−0.28**	−0.19	−0.16
Acceptance	0.19	0.14	0.08	0.02	0.02
Sense of humour	−0.14	−0.14	−0.21*	−0.19	−0.02
Turning to religion	−0.05	0.03	0.10	0.22*	−0.02
Seeking emotional support	−0.19	−0.24*	−0.28**	−0.21*	−0.09
Seeking instrumental support	−0.10	−0.12	−0.05	−0.05	0.01
Moving on to something else	0.03	0.04	0.09	0.16	0.08
Denial	−0.04	0	0.20*	0.16	0.10
Abreaction	0.21*	0.21*	0.41***	0.43***	0.17
Psychoactive substance use	0.05	0.07	0.08	0.24*	0.20*
Behavioural disengagement	0.22*	0.09	0.19	0.24*	0.27**
Self-blame	−0.13	−0.16	−0.10	−0.15	0.07

\* $p < 0.05$ ; \*\* $p < 0.01$ ; \*\*\* $p < 0.001$

## Discussion

Caring for a patient with Alzheimer's disease is incredibly burdensome across many aspects of life. Alzheimer's is a progressive condition, where, as the disease advances, the patient will require more care and greater financial contribution from the caregiver.

The study involved 100 Alzheimer's patients and 100 caregivers. The vast majority of caregivers were women, accounting for 89% of respondents. Among the patients, women also predominated, constituting 63% of those studied. In the study by Szewczyk M. and colleagues, 71% of caregivers were female, and among the patients, this percentage was as high as 81% [4]. According to a 2022 report from the National Health Fund (NFZ) in Poland, 357,000 patients were diagnosed with Alzheimer's disease, of which 72% were women [5]. Research by Scheyer O. and colleagues indicates that women constitute two-thirds of Alzheimer's patients, with hormonal changes during menopause cited as the main reason. Peri- and postmenopausal women show reduced cerebral metabolism and increased amyloid-beta deposition in the brain, which is one of the main factors in the development of Alzheimer's disease [6]. Similar conclusions were reached by Li R. and Singh M. in their research. The higher prevalence of Alzheimer's disease among women is mainly influenced by hormonal differences between women and men. In post-menopausal women, there is a rapid decline in estrogen levels, while in men, the reduction of testosterone is gradual. Estrogens are responsible for inhibiting the synthesis of beta amyloid, the deposition of which occurs in Alzheimer's disease, and also increase dopamine activity [7].

The results of our study showed that age and gender do not affect the severity of the disease. However, Ann M. Kolanowski and colleagues concluded that both gender and age influence the faster progression of the disease. It turns out that not only are women more likely to develop Alzheimer's disease, but they also experience more rapid progression of symptoms. This is influenced by an increased susceptibility to stress. Additionally, with age, women with dementia experience greater dependence compared to men, despite having fewer comorbidities [8]. Resnick B. and co-authors, on the other hand, present in their study that women with dementia are more frequently diagnosed with depressive disorders. Female patients show increased occurrences of anxiety and sadness compared to men, regardless of co-existing depression. Men with dementia have a significantly higher incidence of aggressive behaviour [9].

According to the Alzheimer's Association report titled "Alzheimer's Disease Facts and Figures", about two-thirds of all caregivers of Alzheimer's patients are women. Female caregivers may experience higher levels of burden, depression, and deterioration of health compared to male

caregivers. This is due to the fact that women spend more time with the patient and take on more caregiving tasks. This is linked to social constructs, where caregiving tasks are more often assigned to women as unpaid work [10].

Another aspect of the study was to examine whether the severity of Alzheimer's symptoms affects the burden perceived by the caregiver. The results of our study showed that the greater the severity of AD symptoms, the greater the burden experienced by the caregiver. The highest scores were observed in the subscale of overall burden ( $p < 0.001$ ) and the subscale of social isolation ( $p < 0.001$ ). Only the score in the emotional commitment subscale was not statistically significant ( $p > 0.05$ ). Similar results were obtained by Grabowska-Fudala B. and colleagues, who also confirmed the above thesis. The highest scores were recorded in the subscales of disappointment, overall burden, and environment. No significant results were found in the emotional commitment and social isolation subscales [11].

According to the results of the conducted study, both the lower level of patient independence and the higher severity of the disease contribute to an increased burden on the caregiver. Similar results were obtained by Kawano Y. and colleagues, where it was also found that both low patient scores on the IADL scale and severe AD negatively impact the burden experienced by the caregiver [12].

Our own study showed that the length of time a patient was cared for did not affect the level of perceived burden on the caregiver. The largest group of caregivers were those providing care for 1–6 years (64%). The results in the 1–6 year and 6–12 year groups were similar and indicated a higher level of burden, while the group caregiving for more than 12 years showed the lowest level of burden. Patyk-Rybka A., in her Ph.D. dissertation, also did not find statistically significant relationships between the duration of caregiving and the caregiver's burden [13]. Grabowska-Fudala B. and colleagues found a significant correlation between longer caregiving periods and increased caregiver burden [11].

Another determinant influencing caregiver burden is their engagement in professional work. The results of our own study showed that caregivers working full-time scored lower on the CBS scale than caregivers who were not employed and those working part-time. 36% of respondents worked full-time, 43% were not employed, and the remaining 21% worked part-time. In Patyk-Rybka A.'s PhD dissertation, only 29% of respondents were not engaged in professional work. Her findings suggest that, in the environment subscale, employed caregivers scored higher than those who were not working. However, no statistically significant differences were found in other areas of burden ( $p > 0.05$ ) [13]. In our study, caregivers who were employed had lower scores across all subscales, indicating a reduced burden. It should be noted that resigning from work or reducing work hours

negatively impacts the family budget, leading to additional stress for the caregiver [3].

According to the results of our own study, caregivers reported receiving insufficient support from social services, non-governmental organisations, and health care. In a study by Kaczmarek M. and colleagues, 56% of the respondents described the degree of information received as moderate, while 19% claimed not to have received any information related to the disease [14]. In a study by Mazurkiewicz A. and colleagues, 73.81% of respondents reported a lack of psychological support, 52.38% lacked physical support, 38.10% lacked material support, and 30.95% lacked informational support. Additionally, 59.52% of caregivers stated that they did not receive support from governmental or non-governmental organisations [15]. Based on a report by the Polish Alzheimer's Society, the lack of support felt by caregivers is not only a subjective but also an objective conclusion. The data show that Alzheimer's centres mainly operate in cities. This leads to caregivers living in rural areas, often struggling with transport exclusion, being isolated from receiving help. Furthermore, most centres operating in Poland are not funded by the state budget and rely on volunteer work [16]. Another significant problem is the insufficient number of geriatricians, which in 2016 was only 392 across the entire country. It should also be mentioned that there is an insufficient number of beds in geriatric wards, with 1,100 available, which equates to about 1.8 beds per 100,000 inhabitants. This compares with 75 beds in Belgium and 25 beds in Austria. Although the number of services provided in geriatrics is systematically increasing, it is still significantly insufficient. What is more, there are only about 20 specialised outpatient clinics or centres in Poland focusing on diagnosing and treating dementia disorders. Government data from the "Assumptions: Long term policy on seniority in Poland" shows that there are also too few long-term care facilities in the country. In 2014, there were a total of 543 facilities providing this type of care in Poland (i.e. ZOL (care and treatment centre) and ZPO (nursing and care centre)). The data presented in 2023 show that there are more than 10,000 patients awaiting admission to care and treatment centres (ZOL), with nearly 1,500 requiring urgent admission. For nursing and care centres, the waiting list includes over 3,000 people, with 600 in urgent need. The total number of long-term care beds in Poland is around 30,000 [17]. In our own study, 42% of respondents stated that they could never rely on health care or social services for help, and 62% reported that they had never received help from non-governmental organisations.

Children of the patients accounted for 54% of caregivers, followed by spouses at 16%. Similar results were achieved in the study by Kaczmarek M. and colleagues, where 44% of caregivers were children of the patients,

and 24% were spouses [14]. In a study by Karczewska B. and colleagues, 49% of caregivers were the patient's children, while 21% were their partners [18].

The final aspect examined in the self-designed questionnaire was the impact of the patient's degree of independence on the caregiver's stress. The results show that in the mini-COPE scale, only the "active coping" subscale was statistically significant ( $p < 0.05$ ). Contrary conclusions were drawn from the study of Rachel W. and colleagues, who claim that the progression of the disease and the resulting decrease in the patient's independence lead to increased stress for the caregiver. This is due to the increased time spent on caregiving and the greater physical effort required as the patient's disability worsens. Additionally, stress increases the likelihood of adverse events such as falls, wandering, the patient using gas or electricity, or aggressive behaviour [3].

Analysis of our own research showed that 57% of caregivers live in the same household as the patient. Higher results were reported by Karczewska B. and colleagues, where 78.8% of patients lived with their caregiver [18]. Living with the patient also entails the need to adapt the home to the patient's needs, which brings additional financial costs.

Our research analysis showed that education is related to the severity of the disease ( $p < 0.05$ ). The majority of patients had secondary education (56%), vocational education (21%), primary education (15%), while only 8% had higher education. Lower education is one of the factors increasing the risk of developing dementia. Having higher education is associated with greater cognitive reserve. Studies show that patients with higher cognitive reserve function better at similar stages of the disease. It is worth noting that cognitive reserve is influenced not only by education but also by creative hobbies, professional retraining, travelling, reading, or using modern devices. In complex tasks assessing various aspects of the planning process and with comparable cerebral metabolism values, patients with mild cognitive impairment and higher education performed worse than patients with lower education. However, individuals with higher education who developed dementia within two years showed more pronounced changes indicative of neurodegenerative disease in initial tests than those with lower education. Despite advanced neurodegenerative changes, patients with higher education were at a similar clinical level as those with lower education and much less advanced disease [19].

The results of our study lead to the conclusion that it is essential to reduce the burden on caregivers of people with Alzheimer's disease. It is crucial that the carer remains in good mental and physical health, as this affects their quality of life and the quality of the care they provide. It is important that measures are taken to provide caregivers with institutional and financial support and

to provide psychological support, as well as to create a database containing information on Alzheimer's disease. Similar conclusions were drawn by Kaczmarek M. and colleagues [14], Grabowska-Fudala B. and colleagues [11], Rachel W. and colleagues [3,20], and Mazurkiewicz A. and colleagues [15].

All the predictors of feelings of burden and the negative consequences of care presented in this paper contribute to the current understanding of the problem. Identifying these factors is important in order to be able to intervene early enough in the context of preventing excessive feelings of burden in caregivers of people with Alzheimer's disease. Reducing caregiver burden is associated with improving the quality of life for both caregivers and their family members.

## Conclusions

1. The patient's sex ( $p=0.341$ ) and age ( $p=0.925$ ) do not affect the severity of the disease.
2. In most cases, caregivers of people with Alzheimer's disease experience a high burden in 4 out of 5 areas studied. Only in the "environment" area is the burden at a medium level.
3. A higher degree of clinical symptom in a patient with Alzheimer's disease correlates with a greater burden on caregivers. In the overall burden and social isolation scales, the result indicated very high burden ( $p<0.001$ ). In the disappointment and environment scales, the result indicated medium burden ( $p<0.05$ ). Only the relationship between clinical symptoms and the emotional commitment scale was not statistically significant ( $p>0.05$ ).
4. The lower the patient's ability to function independently, as measured by the IADL scale, the greater the burden on the caregiver. All five scales (overall burden, social isolation, disappointment, emotional commitment, and environment) were statistically significant ( $p<0.05$ ).
5. The amount of time spent caring for the patient did not affect the caregiver's burden ( $p>0.05$ ). Caregivers who had been caring for the patient for more than 12 years exhibited the lowest level of burden.
6. Caregivers experience less burden when employed, however, only when working full-time. In the social isolation scale, emotional commitment scale, and environment scale, caregivers working part-time scored similar to those not employed.
7. Caregivers of people with Alzheimer's disease receive insufficient support from social services, non-governmental organisations, and health care.

8. The patient's lower level of independence does not affect the level of stress experienced by the caregiver. After examining 14 levels of the mini-COPE scale, only the "active coping" subscale was statistically significant ( $p<0.05$ ).

## Implications for Nursing Practice

All the predictors of feelings of burden and the negative consequences of care presented in these study results add up to the current picture of the problem. Identifying these factors is important in order to be able to intervene early enough in the context of preventing excessive feelings of burden in caregivers of people with Alzheimer's disease. Reducing caregiver burden is associated with improving the quality of life for both caregivers and their family members. This means that it is important to implement measures in nursing practice that prevent the effects of the care burden on caregivers and provide ongoing support and assistance in difficult situations.

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A — Concept and design of research, B — Collection and/or compilation of data,  
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