

# THE BURDEN OF INFORMAL CAREGIVERS IN PROVIDING CARE TO PATIENTS WITH ALZHEIMER'S DISEASE

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A. Study design/planning • B. Data collection/entry • C. Data analysis/statistics • D. Data interpretation • E. Preparation of manuscript • F. Literature analysis/search • G. Funds collection

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SUBMITTED: 30.06.2022

ACCEPTED: 18.07.2022

DOI: <https://doi.org/10.5114/ppiel.2022.119881>

## ABSTRACT

**Introduction:** The increase of average life expectancy, and thus the increase of the number of elderly people, is the source of various health problems associated with old age, which include dementia diseases. The most frequent type of dementia is Alzheimer's disease (AD).

**Aim of the study:** The assessment of the degree of the informal caregivers' burden in providing care to patients with AD.

**Material and methods:** The study group comprised 100 persons providing informal care to persons with AD and 100 persons with diagnosed AD. The studies were conducted between December 2017 and September 2019 among caregivers and the people with AD under their care remaining in their residential environment and using day care centres in the Lesser Poland and the Silesia Province. Prior to that, consent was obtained from the Bioethics Committee in Bielsko-Biała (2017/11/16/1) and from medical facilities and day care centres.

**Results and conclusions:** A medium level of burden was demonstrated among all caregivers of patients with AD. Decreased functional capacity of the persons receiving care in the scope of the activities of daily living resulted in the increase of the burden in the domain of disappointment among the caregivers. The caregivers providing care to patients with AD, in cases where the persons receiving care used day care centres, experienced an increase of burden in the emotional involvement domain in the case of better functional capacity of the persons receiving care in the scope of activities of daily living (ADL).

**Key words:** Alzheimer's disease, burden, daily life fatigue, informal caregiver.

## INTRODUCTION

The increase of average life expectancy and, thus, an increase of the number of elderly people, is the source of various health problems associated with old age, which include diseases associated with dementia. The most frequent type of dementia is Alzheimer's disease (AD). Thanks to the introduction of innovative diagnosing methods, it is a more and more frequently diagnosed chronic disease correlated with age.

Among the general population of Poland, over 9 million people are 60 years old and over. The share of people in the age of at least 60 years demonstrates an increasing trend, from 14.7% in 1989 to 24.2% in 2017. The increase of the number of people in elderly age refers not only to Poland but also to Europe. This phenomenon is defined as "the greying of Europe" or the "silver economy", and it presents particular countries with new tasks in the area of politics, economy, and economic activity [1, 2].

Providing care to a chronically ill family member with AD is a burden to the caregiver, who faces vari-

ous problems from the side of the person they provide care to. The contemporary definition of burden takes into consideration the physical, emotional, material, and social costs resulting from providing care to a chronically ill person. Increasingly, neutral expressions are used, such as 'care experience' or 'consequences of caring', instead of 'care burden' [3, 4].

The literature interchangeably uses the terms 'informal caregiver' or 'family caregiver' providing non-professional care. The term 'family caregiver' or 'family care' is a notion that is narrower and limited to persons who are relatives of the person receiving care, whereas an 'informal caregiver' or 'informal care' includes both people from the family as well as non-relatives, who undertake care activities [5].

## AIM OF THE STUDY

The aim of the paper was the assessment of the degree of the informal caregivers' burden in providing care to patients with AD.

## MATERIAL AND METHODS

The study group comprised 100 persons providing informal care to persons with AD and 100 persons with diagnosed AD. The studies were carried out in the period from December 2017 to September 2019 among caregivers and the people with AD under their care remaining at their environment of residence (group A – 50 caregivers and 50 patients) and those using day care centres (group B – 50 caregivers and 50 patients) in the Lesser Poland Province and the Silesia Province. Before commencing the studies, consent was obtained from the Bioethics Committee in Bielsko-Biała (2017/11/16/1) and from medical facilities and centres running day care centres.

To assess the burden of the caregivers of patients with AD, the diagnostic poll method was applied, with the survey technique, and with the use of our own survey questionnaire as well as a standardised research tool: the Caregiver Burden Scale (CB-Scale). The patients with AD were assessed using standardised scales: the Instrumental Activities of Daily Living Scale (IADL), the Activities of Daily Living Scale (ADL), and the Abbreviated Mental Test score (AMTS).

The statistical analysis applied elements of descriptive statistics. In reference to ordinal variables and qualitative variables, the number ( $n$ ) and percentage (%) were applied. Spearman's rank correlation coefficient and the multiple correlation coefficient were used for dependence-related analyses. The significance of the correlation coefficient was tested using Student's  $t$ -test. When appropriate, the multiple regression equation was constructed in reference to the dependence of one variable on other variables (one or several) assuming the most simple, rectilinear shape of the dependence. The analysis of the significance of differences between the mean values in the compared groups was carried out using Student's  $t$ -test, the Mann-Whitney  $U$  test, and the chi-squared

( $\chi^2$ ) test. The significance level adopted in all the analyses was  $\alpha = 0.05$ .

## RESULTS

The disease duration in the persons with AD receiving care for both groups in total (group A and B) was on average 5.0 years. In group A it was 5.8 years and in group B it was 4.2 years. The most numerous group of persons taking care of patients with AD were their children. The persons receiving care were mothers of the caregivers – 44.0% ( $n = 22$ ) in group A vs. 40.0% ( $n = 20$ ) in group B, and fathers – 8.0% ( $n = 4$ ) in group A vs. 6.0% ( $n = 3$ ) in group B. Another group of persons receiving care were spouses: husbands with AD were 24.0% ( $n = 12$ ) of persons in group A and B and wives – 6.0% ( $n = 3$ ) in group A vs. 16.0% ( $n = 8$ ) in group B.

The assessment of the functioning of the persons receiving care according to the IADL (according to Lawton) demonstrated severe disability in almost 3/4 of patients with AD – 72.0% ( $n = 72$ ). In group A in the IADL scale 86.0% ( $n = 43$ ) persons did not perform any instrumental activity, and in group B this was 58.0% ( $n = 29$ ). In the scope of the assessment of the ADL (according to Katz) 43.0% ( $n = 43$ ) of the persons were patients with severe disability in both groups (group A and B). Among the persons receiving care who stayed at home, in group A 66.0% ( $n = 33$ ) demonstrated severe disability, whereas in group B severe disability was demonstrated by 20.0% ( $n = 10$ ) of persons. More than a half – 56.0% ( $n = 56$ ) – of all 100 persons receiving care obtained results according to the Abbreviated Mental Test score (AMTS, according to Hodgkinson), which indicated severe impairment of mental capacity (Table 1).

Women constituted the vast majority of caregivers in the group of persons with AD receiving care who stayed at home (group A) – 86.0% ( $n = 43$ ) as

**Table 1.** The basic statistical parameters of the assessment of the physical state of the persons receiving care

Patient's physical and mental health state	Group	$n$	$\bar{x}$	SD	95% confidence interval of the mean	Me	Mo	Min	Max	Mann-Whitney $U$ test
IADL	A	50	0.26	0.85	(0.02-0.50)	0	0 (43)	0	5	$Z = -3.018$ , $p = 0.0025$
	B	50	0.64	1.05	(0.34-0.94)	0	0 (29)	0	5	
	General	100	0.45	0.97	(0.26-0.64)	0	0 (72)	0	5	
ADL	A	50	1.68	2.13	(1.07-2.29)	0	0 (27)	0	6	$Z = -4.988$ , $p = 0.0000$
	B	50	3.80	1.41	(3.40-4.20)	4	4 (15)	1	6	
	General	100	2.74	2.09	(2.32-3.16)	3	0 (27)	0	6	
AMTS	A	50	1.36	1.87	(0.83-1.89)	0	0 (30)	0	5	$Z = -6.034$ , $p = 0.0000$
	B	50	4.62	2.54	(3.90-5.34)	5	5 (10)	0	10	
	General	100	2.99	2.76	(2.44-3.54)	3	0 (33)	0	10	

$n$  – number of people,  $\bar{x}$  – mean (average), SD – standard deviation, Me – median, Mo – moda, Min – minimum, Max – maximum, IADL – Instrumental Activities of Daily Living, ADL – Activities of Daily Living, AMTS – Abbreviated Mental Test Score by Hodgkinson, Group A – the patients with Alzheimer's disease under their care remaining at their environment of residence, Group B – the patients with Alzheimer's disease using day care centres

well as the persons with AD using day care centres (group B) – 78.0%. The age of the caregivers of patients with AD ranged between 32 and 84 years (min: 32, max: 84). In group A 52.0% (n = 26) of the caregivers of patients with AD limited the time devoted to professional work, and among the caregivers in group B this limitation referred to 48.0% (n = 24) of persons. A lack of help in the care provided to patients with AD was declared by 21.0% (n = 21) of all caregivers. The vast majority of caregivers, 79.0% (n = 79), received help in the scope of the care provided to the patient. The analysed caregivers in groups A and B devoted a comparable number of hours to care provided to the patient with AD: on average it was 71.3% of the day (24 h) in both groups.

The total result of the caregiver burden according to the Caregiver Burden Scale (CB-Scale) indicated a medium level of burden of the persons providing care to patients with AD (2.77 points). A high level of caregiver burden referred to the subscale of general strain in group A and group B of the analysed subjects (3.07 points vs. 3.16 points). The mean of the social isolation subscale from the CB-Scale in group A indicated a medium level of burden (2.78 points), whereas in group B the level of caregiver burden was high (3.03 points). In subsequent subscales of the CB-Scale the results indicated medium caregiver burden, in group A and group B, in the following areas: dis-

appointment (2.84 points vs. 2.82 points), emotional involvement (2.15 points vs. 2.51 points), and environment (2.05 points vs. 2.10 points) (Table 2).

The results of the studies demonstrated the existence of a negative statistical dependence between the caregiver burden according to the CB-Scale in the domain of disappointment and the functional status of the person receiving care in the scope of the ADL (R = -0.2349) in the studied group (Group A and B). The disappointment of the caregiver increased in a situation of lower capacity in the scope of the ADL in a patient with AD. It was found, however, that the correlation of the subscale of emotional involvement and ADL for the studied group (group A and B) was positive (R = 0.2420). The emotional involvement of the caregiver increased together with better functionality of the person receiving care in the scope of the ADL. Moreover, negative statistical significance of the caregiver burden according to the CB-Scale was demonstrated in group B for the subscale of disappointment and ADL (R = -0.4395) and the functional status in the scope of the IADL in the persons receiving care (R = -0.2994). The level of burden of the caregivers from group B according to the CB-Scale in the scope of the disappointment domain increased with the deterioration of the functionality of the patients with AD in the scope of the activities of daily living and the instrumental activities of daily living (Table 3).

**Table 2.** The mean of the level of caregiver burden according to the Caregiver Burden Scale (CB-Scale) depending on the place of stay of the person receiving care

CB-Scale	Group A	Group B	General	Student's t-test	
	x	x	x	Value of t	Probability p
General strain	3.07	3.16	3.12	-0.757	0.4508
Social isolation	2.78	3.03	2.90	-1.458	0.1480
Disappointment	2.84	2.82	2.83	0.088	0.9297
Emotional involvement	2.15	2.51	2.33	-2.178	0.0318
Environment	2.05	2.10	2.08	-0.323	0.7476
Total Score CB-Scale	2.71	2.83	2.77	-1.096	0.2757

CB-Scale – Caregiver Burden Scale, Group A – Caregivers of the patients with Alzheimer's disease under their care remaining at their environment of residence, Group B – Caregivers of the patients with Alzheimer's disease using day care centres, x – arithmetic mean/arithmetic average

**Table 3.** The basic statistical parameters of the assessment of the physical state of the persons receiving care

CB-Scale	Group A			Group B			General		
	ADL	IADL	AMTS	ADL	IADL	AMTS	ADL	IADL	AMTS
General strain	-0.1893	-0.0258	-0.2350	-0.1055	-0.0895	-0.1099	-0.0518	-0.0324	-0.0905
Social isolation	-0.1122	0.0636	-0.0621	-0.1680	-0.1852	-0.0020	-0.0301	-0.0450	0.0690
Disappointment	-0.2231	-0.0418	-0.2510	-0.4395	-0.2994	-0.2294	-0.2349	-0.1792	-0.1890
Emotional involvement	0.1806	0.1406	0.1066	0.0696	-0.1771	-0.0993	0.2420	0.0317	0.1240
Environment	-0.0006	-0.0156	0.0189	-0.0792	-0.0628	-0.1432	0.0252	-0.0322	-0.0368
Total Score CB-Scale	-0.1153	0.0006	-0.1344	-0.1956	-0.2332	-0.1445	-0.0475	-0.0882	-0.0568

Group A – Caregivers of the patients with Alzheimer's disease under their care remaining at their environment of residence, Group B – Caregivers of the patients with Alzheimer's disease using day care centres, ADL – Activities of Daily Living, IADL – Instrumental Activities of Daily Living, AMTS – Abbreviated Mental Test Score by Hodgkinson, CB-Scale – Caregiver Burden Scale

## DISCUSSION

Despite the development of medical sciences, there is still a lack of effective treatment for persons with the chronic disease of Alzheimer's. In the world and in Europe, the life expectancy constantly increases, which is connected with the likelihood of the occurrence of diseases associated with dementia, including AD, among the elderly. The World Health Organization (WHO) estimates that in 2030 there will be 75.6 million people suffering from diseases associated with dementia, and in 2050 this number will increase to 135.5 million [6].

The family remains the largest group of informal caregivers providing care to elderly people and those suffering from chronic diseases [7, 8]. Alzheimer's disease, as a chronic disease that progresses and causes limitations to an individual's functioning, means the necessity to adapt to the new situation of family members. Care provided to persons with AD is difficult, it requires patience, understanding, and knowledge of the diagnosis and the course of the disease. Providing care to a patient with AD is not only limited to support or the performance of initially more difficult, and then simple, daily activities by the caregivers for the persons receiving care. The actions of caregivers are conditioned by maintaining the best possible quality of life of the persons receiving care. This is expressed in ensuring safety for patients with AD, maintaining and stimulating their preserved skills and interests as well as their individual mental needs [9]. Niedorys *et al.* [10] describe that a lack of knowledge and abilities in the scope of care activities are problems impacting the level of the caregiver burden. Informal caregivers frequently do not have prior preparation to the undertaken care activities. According to Kosińska *et al.* [11], the element that causes the greatest difficulty to caregivers of chronically ill patients are activities associated with maintaining body hygiene, such as bathing, washing, changing diapers, changing underwear, feeding the patient, or procedures with bed sores. Due to this, the care provided by informal caregivers is not free of trial and error. Caregivers experience various difficulties associated not only with the persons receiving care, but also with their own functioning. Undertaking care may be associated with the necessity to limit or resign from professional work or social life, and it may be connected with conflicts in the family, as well as financial, mental, and physical burden or the co-existence of somatic conditions. Our own studies have also shown the necessity to resign or limit the time for the professional work of the caregivers.

In literature there is much evidence for the presence of health problems occurring in caregivers of patients with AD and the negative implications resulting from the care that is being provided [3, 8, 10, 12].

The results of studies carried out in the last decades at various scientific centres [3, 8, 10, 12, 13] confirm the existence of the informal caregivers' burden in the care provided to chronically ill patients, including those with AD. These results also point to the lowering of the quality of life of the caregivers and to the lack of received support. The obtained results of our own studies also prove the existence of burden among the caregivers providing care to patients with AD. The caregiver burden in the analysed group (in both group A and group B) indicate a medium level of burden. And the mean total score of caregiver burden (CB-Scale) was 2.77 points. The results of our own studies are consistent with the reports of Andrě and Elmstähl [8] and Pudelewicz *et al.* [14], who, based on the same research tools, demonstrated that informal caregivers experienced a medium level of care burden (2.13 points vs. 2.6 points). A medium sense of burden among caregivers of persons with AD disease was also found by Yu *et al.* [15] and Werner *et al.* [16]; in their studies they used different scales to measure the care burden, such as the Caregiver Burden Inventory and the Zarit Burden Interview Short Form. In the mentioned studies, Yu *et al.* [15] prove that the caregiver's sense of burden increases in the situation of a lower capacity level in the scope of cognitive functions among the patients with AD and the necessity for the caregivers to spend a higher number of hours with the persons receiving care. Similarly in the own studies, in both group A as well as in group B, the caregivers demonstrated an increase of the burden in the subscale disappointment while devoting a higher number of hours of care to the patient. Werner *et al.* [16] suggested that the stigmatization of the caregivers of patients with AD impacts the increase of their burden.

Scientific literature includes results of studies in which the level of caregiver burden was high. This is reported by Grabowska-Fudala *et al.* [17] and Abdollahpour *et al.* [18]. However, in the studies by Grabowska-Fudala *et al.* this was probably associated with the small group size ( $n = 38$ ) [17]. Subsequent reports by Galvin *et al.* [19] referred to caregivers of patients with dementia with Lewy bodies. It should be noticed that in the quoted studies by Abdollahpour *et al.* [18] and Galvin *et al.* [19] the research tool was adjusted to the country in which the studies were conducted, or its abbreviated version was used [18, 19].

The results of our own studies in particular subscales referring to social isolation, disappointment, emotional involvement, and environment demonstrate a medium level of caregiver burden (2.90 points – 2.08 points). In the analysed group of caregivers (group A and B) a high level of burden was demonstrated (3.12 points) in the subscale of general strain. Moreover, among the caregivers of persons who used day care centres, a high result (3.03 points) was ob-



tained in the social isolation subscale. The lowest level of burden was demonstrated in the subscale environment (2.08 points) in the analysed group of caregivers (group A and B). Similarly, in the already discussed report by Grabowska-Fudala *et al.* [17], a high level of burden was found in the subscales of general strain and social isolation (3.5 points and 3.7 points, respectively) and the lowest score in the environment domain (3.0 points). A report by Pudelewicz *et al.* [14] presented the highest level of burden in the subscale general strain (3.0 points) and the lowest one in the subscale environment (1.8 points), similarly to our study.

General strain means physical and mental fatigue of the caregiver and his or her feeling of responsibility resulting from the care in reference to the person receiving the care. It can be presumed that the obtained lowest burdens of caregivers in the subscale environment were associated with the fact that the caregivers did not report problems resulting from the movement of patients with AD both in the apartment as well as outside of it.

The studies conducted by Konerding *et al.* [20] in England, Finland, and Greece prove that the caregiver burden increases along with the physical and emotional problems of the persons providing care and the increase in the number of the weekly hours of care. Niedorys *et al.* [10], in turn, report that 1 in 4 informal caregivers of an elderly person suffers due to the negative influence of care, and especially this burden increases in caregivers of persons with AD and a lower level of self-care capacity.

Studies carried out at various scientific centres [21-23] describe that the presence of disorders in the cognitive realm in persons is associated with their lowered functional capacity. Rajtar-Zembaty *et al.* [22] showed that elderly persons with coexisting disorders in the cognitive realm demonstrated lower functional capacity. Staszczak-Gawęda *et al.* [23] indicate the limitation in functional capacity already in persons with a light degree of dementia. Białachowska [24] describes low functional capacity in the scope of the IADL and the ADL in persons with AD already at the moderate stage of the disease. The limitation in that study was a small group size ( $n = 19$ ). In that study, in nearly 3/4 of persons with AD the author demonstrated severe disability in the scope of the IADL and severe disability in the scope of the ADL in 43.0% of patients [24].

The results of our own studies have demonstrated in both groups (group A and group B) that 72.0% of patients with AD with various levels of mental disability did not perform any IADL, and 21.0% of such patients performed only one such activity. The persons receiving care remaining at the place of residence (group A) were characterized by severe impairment of mental capacity, which referred to 80.0% of the persons and limited the level of functionality in the scope of ADL in 66.0% of studied subjects. Persons with AD who used

day care centres demonstrated higher capacity in terms of both the IADL and the ADL, which may have been the result of the beneficial therapeutical impact as well as specific criteria of admission for the facility.

According to the studies by Rybka *et al.* [21], the ADL that caused the most difficulties to elderly persons were as follows: getting dressed and undressed, bathing the whole body, and moving from the bed to the chair. In the scope of IADL, the authors pointed to the loss of self-reliance of elderly persons, which started with problems associated with shopping, cleaning and tidying, as well as preparing meals.

The results of our own studies partially confirm the study results obtained by Rybka *et al.* [21]. The patients with AD were elderly people with significant deficits in the scope of the ADL referring to bathing the whole body, where this activity was performed independently by only 14.0%, getting dressed and undressed – 27.0%, and sphincter control – 40.0% of persons in the studied group (group A and B). Persons with AD demonstrated severe disability in the scope of the IADL.

Bartoszek *et al.* [25], Deluga *et al.* [26], Miyamoto *et al.* [27], and Fidecki *et al.* [28] reported that the deterioration of the functional and mental capacity of the patients significantly increases the burden of the caregivers and reduces their satisfaction from the care. Sansoni *et al.* [29], in turn, did not find any influence of the level of functional capacity of the patients with AD on the sense of burden among the caregivers. According to Grochowska [30], caregivers experiencing burden associated with the care were always or frequently taking care of elderly persons with a significantly lower level of capacity in the scope of ADL. The functionality level of elderly people was assessed by the author using the Barthel scale, according to which she demonstrated that over a half of the persons receiving care (53.1%) were in a state of moderate dependency, 26.5% were in a state of severe dependency, and the remaining persons receiving care were in a state of slight dependency [30].

Our own studies demonstrated an increase of the level of caregiver burden in the domain of disappointment in the situation of the lowering of the capacity of the persons receiving care in the scope of the ADL ( $R = -0.2349$ ). The burden associated with the emotional involvement of the caregiver increased together with the increase of the functionality of the patient with AD in the scope of ADL. The obtained results indicate that better functionality of the person receiving care does not always impact the reduction of the caregiver burden. In the situation of lower mental capacity, communicating with the patients and motivating them to undertake certain activities is difficult for the caregivers. This requires the caregivers to have patience and to use appropriate communication techniques.

## CONCLUSIONS

Among all caregivers of patients with AD, a medium level of burden was demonstrated. The factors determining the burden among the caregivers of persons with AD in the analysed group were, from the side of the persons receiving care, their capacity level in the scope of IADL and ADL, and the level of mental capacity; and from the side of the caregiver, the period of providing care and the time devoted to providing care during the day (day = 24 h), the necessity for constant presence, and kinship to the person receiving care.

The lowering of the functional capacity of the persons receiving care in the scope of the ADL resulted in the increase of the burden in the domain of disappointment in the caregivers.

The caregivers providing care to patients with AD, in the case of which the persons receiving care used day care centres, experienced an increase of burden in the emotional involvement domain in the case of better functional capacity of the persons receiving care in the scope of the ADL

### Disclosure

The authors declare no conflict of interest.

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