Selected aspects of the quality of life of caregivers of people with Alzheimer's disease-preliminary study

Wybrane aspekty jakości życia opiekunów osób z chorobą Alzheimera – doniesienie wstępne

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Abstract

Introduction: Alzheimer's disease is a degeneration of the brain, most often occurring in people over 65 years of age. The disease process is based on the mechanism of deposition of proteins with a pathological beta-fold structure in the brain, causing irreversible damage. The progression of the disease contributes to a drastic reduction in the autonomy of the patient and the need for constant third-party care. Aim: The aim of the study was to examine the quality of life of caregivers of people with Alzheimer's disease. Material and methods: The diagnostic survey method was used as the research method. The research technique enabling collecting the necessary data was a questionnaire of our authorship and the Sense of Burden Questionnaire. The survey was conducted online, among people who provide care for people with Alzheimer's disease. The research group consisted of one hundred people, including 76 women and 24 men. Results: Time caring for a person with Alzheimer's disease ranged from up to 2 years (42%), followed by 2 to 5 years (40%). The smallest group of respondents were people who had been providing care for more than 5 years -18%. More than half of the respondents admitted that they devote less than 6 hours to caring for a sick person (54% of respondents). Every fourth respondent was in the range of 6-12 hours, and every fifth devoted more than 12 hours to a patient (21% of respondents). The vast majority of respondents did not take care of the patient on their own (76%). Conclusions: The quality of life of a caregiver depends on the time devoted to care, the level of stress and fatigue, the form of care provided, the deficit of support - especially psychological support - and the health of the caregiver. Gender, age, education, employment status of the caregiver do not affect the quality of life of the respondents. (Gerontol Pol 2024; 32; 69-78) doi: 10.53139/GP.20243211

Keywords: Alzheimer's disease, quality of life of caregivers, neurodegenerative disease, support

Streszczenie

Wstęp: Choroba Alzheimera to zwyrodnienie mózgu, występujące najczęściej u osób po 65. roku życia. Proces chorobowy opiera się na mechanizmie odkładania się w mózgu białek o patologicznej strukturze beta-fałdowej, powodując nieodwracalne uszkodzenia. Postęp choroby przyczynia się do drastycznego ograniczenia autonomii osoby chorej i konieczności pozostawania pod ciągłą opieką osób trzecich. Cel: Celem pracy było zbadanie jakości życia opiekunów osób chorych na Alzheimera. Materiał i metody: Jako metodę badawczą wykorzystano metodę sondażu diagnostycznego. Techniką badawczą umożliwiającą zebranie niezbędnych danych był kwestionariusz ankiety własnego autorstwa oraz Kwestionariusz Poczucia Obciążenia. Badanie zostało przeprowadzone online, wśród osób, które opiekują się osobami z chorobą Alzheimera. Grupa badana liczyła sto osób, w tym 76 kobiet i 24 mężczyzn. Wyniki: Czas opieki nad osobą z chorobą Alzheimera wynosił od 2 lat (42%), następnie od 2 do 5 lat (40%). Najmniejszą grupę badanych stanowiły osoby, które sprawowały opiekę dłużej niż 5 lat – 18%. Ponad połowa badanych przyznała, że poświęca mniej niż 6 godzin na opiekę nad chorym (54% badanych). Co czwarty badany mieścił się w przedziale 6-12 godzin, a co piąty poświęcał pacjentowi więcej niż 12 godzin (21% badanych). Zdecydowana większość badanych nie opiekowała się pacjentem samodzielnie (76%). Wnioski: Jakość życia opiekuna zależy od czasu poświęconego na opiekę, poziomu stresu i zmęczenia, formy sprawowanej opieki, deficytu wsparcia – zwłaszcza psychologicznego – oraz stanu zdrowia opiekuna. Płeć, wiek, wykształcenie, status zawodowy opiekuna nie mają wpływu na jakość życia badanych. (Gerontol Pol 2024; 32; 69-78) doi: 10.53139/GP.20243211

Słowa kluczowe: choroba Alzheimera, jakość życia opiekunów, choroba neurodegeneracyjna, wsparcie

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Introduction

Alzheimer's disease is an ever-growing public health problem. According to the World Health Organization (WHO), about 44 million people in the world are currently struggling with Alzheimer's disease, and predictions indicate that this number will increase to 60 million in 2030, and in 2050 even to 115 [1]. It is a degenerative brain disease that occurs most often in people over the age of 65, causing what is known as dementia. The disease process is based on the mechanism of changes in amyloid precursor protein (APP) cleavage and production of the APP fragment beta-amyloid along with hyperphosphorylated tau protein aggregation coalesce which causes reduction in synaptic strength, synaptic loss, and neurodegeneration. Metabolic, vascular and inflammatory changes, as well as comorbid pathologies are key components of the disease process. The degradation of neurons progresses gradually, leading to a decrease in their number and disorders in nerve transmission. The course of the disease is progressive and incurable. Treatment is mainly based on symptomatic management, focusing on minimizing cognitive impairment. Its priority is to slow down the progression of the disease, stabilize the patient's mental and physical condition, and improve the quality of life. Multi-faceted treatment and rehabilitation is only possible in the early stage of the disease, therefore precise diagnosis is of paramount importance in selecting the appropriate treatment [2]. The progression of the disease leads to the need for constant care of the patient, and caregivers can experience many physical, economic, and emotional burdens. Increasing stress resulting from inadequate preparation of the caregiver, lack of institutional support or emotional problems resulting from difficulties in caring for the patient can affect the caregiver's quality of life.

Aim

The main objective of the study was to assess the quality of life of caregivers of people with Alzheimer's disease. The assessment of the caregiver's quality of life was considered through the prism of the patient's functioning, which closely correlated with the occurring care problems.

Material and methods

The survey was conducted from September 2022 to March 2023 among 100 people caring for patients diagnosed with Alzheimer's disease. The survey was posted on forums: "Alzheimer's and related diseases... Support group for caregivers and families.", "Caregivers of seniors". A diagnostic survey method and a survey technique were used to conduct the study. The research tool was the authors' questionnaire and the Sense of Burden Questionnaire (KPO) by P. Raś, G. Opała, S. Ochudło [3], which was conducted after obtaining permission for its use. The KPO was used to assess the sense of burden of the surveyed caregivers, taking into account personal limitations (questions 1-7), material and social limitations (questions 16-20), negative emotions (questions 8-12) and lack of energy – loss of control (questions 13-15). In the KPO, 0 to 60 points can be obtained, where -0 points indicates no burden on the caregiver, and 60 points corresponds to the greatest sense of burden. Each of the respondents could give one answer to the questions: never, sometimes, often or always. The answers were scored consecutively: never - 0, sometimes - 1, often - 2, always - 3. The authors' questionnaire consisted of 22 questions, including questions that allowed to characterize the study group (age, gender, place of residence, education, employment status, degree of kinship with the patient) and questions related to the studied subject (the form of support they have, disruptions at work caused by caring for the patient or the level of stress). The calculations were performed using the SPSS Statistica 25.0 statistical package. To deepen the analysis of the obtained results, the Chi-square statistical test and the Mann-Whitney test were used. In the analyses, p=0.05 was used as the level of significance.

Results

The largest groups were people under 35 years of age (30%) and those aged 35-54 (28%). The smallest group were people aged over 75 (2%). The main place of residence of the respondents was the countryside (56%). The majority of respondents declared higher education (47%), those with secondary education accounted for 32%, with vocational education 18% and with primary education 3% of the respondents. More than half of the respondents worked full-time (63%), 12% of respondents part-time, and pensioners accounted for 13%. 8% of the respondents were forced to resign from their current jobs, while 4% of the respondents declared a complete lack of employment. The majority of respondents cared for their mother or father (45%), 15% of respondents cared for their partner or spouse, and 7% of respondents cared for their offspring. A different type of kinship was characteristic of 33% of the respondents. Time of caring for a person with Alzheimer's disease ranged from up to 2 years (42%), followed by 2 to

5 years (40%). The smallest group of respondents were people who had been providing care for more than 5 years – 18%. More than half of the respondents admitted that they devote less than 6 hours to caring for the patient (54% of respondents). Every fourth respondent was in the range of 6-12 hours, and every fifth devoted more than 12 hours to the patient (21% of respondents). The vast majority of respondents did not take care of the patient on their own (76%).

The symptoms of Alzheimer's disease correlate closely with the severity of the disease. Memory impairment was the symptom most frequently chosen by respondents (95%). The next most frequently selected symptoms were concentration disorders (78%), cognitive impairment, forgetting the names of relatives (77%), difficulties in performing activities of daily living (68%) and mood disorders (59%). Much less frequently the respondents declared the presence of such symptoms as: withdrawal from social contacts, hobbies, resignation from work – 46%, problems with speaking and writing - 37%, urinary and fecal incontinence - 31%, and increased muscle tension, slowness of movement – 27%. More than half of the respondents (58%) admitted that the care they provide to a sick person "slightly" interferes with their work/housework. The same percentage of respondents marked the answers "even a lot" and "very much" - they accounted for 19% of the respondents in both cases. Only 4% of people said that their work was not affected in any way by the care they provided. In the question about the occurrence of problems related to work or daily activities resulting from emotional problems, more than half of the people surveyed chose the answer "a little" (63%). One in five respondents indicated the answer "even a lot", while 10% of respondents admitted that they felt very serious problems related to their work or daily activities resulting from emotional problems. Only 6% of respondents said they had no problems of this nature. Exactly half of the respondents described their worries and stress at the average level. 37% of the respondents indicated a high level, while a very high level of worries and stress was declared by 4% of the respondents. Only 9% of respondents had no worries related to their role in caring for a person with Alzheimer's disease. Half of the respondents said that they did not receive a satisfactory amount and form of patient care support. Over 30% of respondents (32%) believed that the form and amount of support was satisfactory for them. No clear opinion on the subject was expressed by 18% of respondents. Almost 60% of respondents (58%) admitted that they felt the greatest deficit of support in the psychological sphere, 21% of the respondents indicated the physical sphere whereas 16% indicated the deficiency in material support. The fewest respondents expressed deficits in information support. Due to the variety of forms of support available, a multiple-choice question was used. More than half of those surveyed (56%) admitted that they use care services available in their places of residence. Nearly half (47%) reported they benefited from support groups, societies and centers created specifically for people with Alzheimer's disease. Significantly fewer people used social assistance (29%) and permanent, periodic or targeted benefits (29%). The smallest group were people who did not use any of the above-mentioned forms of support (22%). When asked about their subjective assessment of their health, 40% of respondents admitted that their current state of health was "a little worse than before they started caregiving" and 36% did not find much difference. Deterioration of health was noticed by 15% of respondents, while 9% of respondents admitted that their health condition is now better than before taking care. Moderate satisfaction with one's own health was expressed by 44% of the respondents, while moderate dissatisfaction concerned 29%. 16% of respondents had no opinion about their own health. Those who were very satisfied accounted for 6%. The smallest group were people very dissatisfied with their current health – 5%. Half of the surveyed group declared a medium level of overload related to caring for a person with Alzheimer's disease, while 35% of the respondents felt a definite overload of care. No opinion on the subject was expressed by 9% of respondents. Only 6% of the respondents did not think that they were overburdened with care. Due to the many components that could affect the ability to perform daily activities, a multiple-choice question format was used. Rest or sleep deprivation was one of the most frequently selected responses – 65%. Next were limited social contacts and difficulties meeting new people (59%), developing skills and hobbies, learning (51%), performing their current professional job (46%) or eating properly (43%). Only 14% of the respondents stated that caring for a sick person does not limit their daily activities. More than half of those surveyed said their health or emotional problems affected their usual activities, contacts with family, friends, neighbors and other social groups (62%). One in four respondents did not notice any of these problems in themselves, while 12% did not express any opinion on the subject. The last question of the author's survey allowed for a holistic view of the quality of life of the respondents. More than 40% of respondents (43%) described their quality of life as "neither good nor bad". A good quality of life was declared by 39% of respondents, while a poor quality of life was admitted by 15% of respondents.

In the KPO, the average score of the sense of burden with care was 24.68 in the range of 7-43 points. The highest average score was related to personal limitations – care fatigue, while the lowest sense of burden was related to lack of energy – loss of control (table I).

Table I. Sense of burden of care for the study group

Factor	A component of the sense of burden	Average score
I	Personal limitations – Care fatigue	10.48
II	Material and social constraints	6.39
III	Negative emotions	4.16
IV	Lack of energy – loss of control	3.65
Total		24.68

Next, an attempt was made to determine what variables affect a caregiver's quality of life. Taking gender into account, the majority of respondents, regardless of gender, described their quality of life as "good" or "neither good nor bad." The percentage of women who rated their quality of life as "good" was slightly higher than the percentage of men. Analysis using the chi-square test showed no statistically significant difference according to the gender of the caregiver (chi-square = 3.79, p = 0.434). In the next step, the quality of life of caregivers was analyzed according to age. The quality of life of the respondents varied according to age groups, but these differences were not statistically significant (chi--square = 3.79, p = 0.434). Then, the caregiver's quality of life was analyzed depending on their education. The results of the analysis did not show a significant relationship between these two variables (p>0.05). Caregivers with primary education mainly described their quality of life as "neither good nor bad" (66.7%), as did those with secondary education (56.3%). In the case of higher education, 48.9% of caregivers described their quality of life as "good". Among those with vocational education, 38.9% marked the answer "good", while 33.3% of caregivers declared "bad" quality of life.

Taking into account the employment status and the caregiver's quality of life, no significant relationship was found (p>0.05). Caregivers without employment, those working part-time and those who had to give up their jobs to take care of the patient declared "neither good nor bad" quality of life. 46.2% of pensioners described their quality of life as "bad". Those who worked full-time jobs reported a "good" quality of life in 46%. It was also examined whether there is a correlation between the amount of time spent caring for the patient and the quality of life of the caregiver. Respondents who spent less than 6 hours caring for a sick person were more likely to rate their quality of life as "good" or "very good". In contrast, respondents who spent more than 12 hours on patient care were more likely to indicate a "bad" or "very bad" answer. The chi-square analysis showed a statistically significant relationship between the amount of time spent on care and the assessment of quality of life (chi-square = 18.9, p = 0.015) (table II).

Next, the effect of the length of care on the caregiver's quality of life was analyzed. The majority of respondents, regardless of the length of time they had been caring for the patient, described their quality of life as "good" or "neither good nor bad". Despite the lack of significant statistical correlations (chi-square = 10.81, p = 0.212), it was observed that in the case of care up to 2 years, caregivers showed "neither good nor bad" (42.9%) and "good" (42.9%) quality of life. In the case of the duration of care between 2-5 years, 47.5% of respondents described their quality of life as "neither good nor bad". For caregivers providing care for more than 5 years, quality of life was mainly described as "neither good nor bad" (33.3%), "good" (33.3%) and "bad" (33.3%).

Table II. The relationship between time spent caring and quality of life

			Wha	at is you	ır qualit					
	Neither good nor bad	Very good	Very bad	Good	Bad	Total	Pearson's Chi-square	р		
	6-12	n	14	0	0	9	2	25		
	hours	%	56.0	0.0	0.0	36.0	8.0	100.0		
How much time do	less than 6 hours	n	19	2	1	27	5	54		
you devote to caring for a sick person?		%	35.2	3.7	1.9	50.0	9.3	100.0		
ioi a sick person?	more	n	10	0	0	3	8	21	18.9	0.015
	than 12 hours	%	47.6	0.0	0.0	14.3	38.1	100.0		
Total		n	43	2	1	39	15	100		
		%	43.0	2.0	1.0	39.0	15.0	100.0		

Legend: n- number of observations; p- level of statistical significance. % - percent

Analyzing the impact of the form of care provided on the assessment of the caregiver's quality of life, it was found that there is a significant correlation between these two variables. As many as 45.8% of those providing care on their own could not define their own quality of life, while 33.3% of the respondents described their quality of life as "bad". Those receiving assistance in caring for the sick mainly declared a "good" quality of life (44.7%) (table III).

The relationship between quality of life and the declared level of stress and worry was also examined. More than 40% of respondents described their quality of life as "neither good nor bad", 39% as "good", 15% as "bad". In terms of worry and stress levels: 50% of respondents reported very high levels of worry and stress, 48% indicated medium levels of worry and stress, 45.9% of respondents reported high levels of worry and stress. It is worth noting that 77.8% of people with low levels

Table III. The form of care and the quality of life of the respondents

			What	is your d		Desween's				
			Neither good nor bad	Very good	Very bad	Good	Bad	Total	Pearson's Chi-square	р
	Nia	n	32	2	1	34	7	76		
Is the patient cared for	No	%	42.1	2.6	1.3	44.7	9.2	100.0	10.75	0.000
independently?	\ \ \ 	n	11	0	0	5	8	24		
	Yes	%	45.8	0.0	0.0	20.8	33.3	100.0		0.029
Total n %		n	43	2	1	39	15	100		
		%	43.0	2.0	1.0	39.0	15.0	100.0		

Legend: n- number of observations; p- level of statistical significance. % - percent

Table IV. The level of stress/worries and the quality of life of the respondents

			What is	s your (quality	of life?				
	Neither good nor bad	Very good	Very bad	Good	Bad	Total	Pearson's Chi-square	р		
	Very	n	2	0	0	1	1	4		
	high	%	50.0	0.0	0.0	25.0	25.0	100.0		0.041
At what level do you	Low	n	0	0	0	7	2	9	21.68	
describe your worries		%	0.0	0.0	0.0	77.8	22.2	100.0		
and the level of stress that accompanies	Medium	n	24	1	0	23	2	50		
them?		%	48.0	2.0	0.0	46.0	4.0	100.0		
	I Carla	n	17	1	1	8	10	37		
	High	%	45.9	2.7	2.7	21.6	27.0	100.0		
Total n		n	43	2	1	39	15	100		
		%	43.0	2.0	1.0	39.0	15.0	100.0		

Legend: n- number of observations; p- level of statistical significance. % - percent

Table V. Relationship between perceived support and quality of life

		What	is your	quality	of life?			Pearson's		
	Neither good nor bad	Very good	Very bad	Good	Bad	Total	Chi-square	р		
	Dhysiaal	n	8	1	0	5	7	21		
	Physical	%	38.1	4.8	0.0	23.8	33.3	100.0		
	Information	n	3	0	0	1	1	5		
In which area of sup-		%	60.0	0.0	0.0	20.0	20.0	100.0		
port do you feel the biggest deficit?	Material	n	3	0	0	10	3	16	10.70	0.10
		%	18.8	0.0	0.0	62.5	18.8	100.0	16.72	0.16
	Davido da sia al	n	29	1	1	23	4	58		
	Psychological	%	50.0	1.7	1.7	39.7	6.9	100.0		
Tatal			43	2	1	39	15	100		
Total		%	43.0	2.0	1.0	39.0	15.0	100.0		

Legend: n- number of observations; p- level of statistical significance. % - percent

of worry and stress described their quality of life as "good." In contrast, a higher percentage of those with high levels of worry and stress described their quality of life as "neither good, nor bad" or "bad". The differences were statistically significant (p<0.05) (table IV).

The next step was to examine the impact of available forms of support for caregivers on their quality of life. The results indicate that there is no statistically significant difference between areas of support and overall quality of life (p=0.16). In the case of caregivers experiencing a deficit in physical support, the quality of life was declared to be "neither good nor bad" (38.1%). Deficiencies in informational and psychological support, as well as in physical support, contributed to the indication of "neither good nor bad" quality of life. Only in the case of deficits in material support a higher percentage of caregivers with a "good" quality of life (62.5%) was observed (table V).

The answers to the question "Do you think that you receive a satisfactory amount and form of support in caring for a sick person? in reference to the quality of life

of the caregiver were also analyzed. Most people who do not feel that they receive a satisfactory amount and form of support in caring for a patient rate their quality of life as "neither good, nor bad" or "bad". In contrast, the majority of people who believe that they receive a satisfactory amount and form of support rate their quality of life as "good". The results of the chi-square test indicate a significant statistical difference between the answers to the question about support in patient care and the overall quality of life (p=0.015) (table VI).

The analysis of the impact of satisfaction with one's own health in the context of the caregiver's quality of life showed that there is a statistically significant difference between the assessment of satisfaction with one's own health and the overall quality of life (p=0.001). People who are more satisfied with their own health tend to express a higher quality of life (table VII).

Analyzing the question "What is your quality of life?" in relation to the results obtained in the KPO, a fundamental relationship was observed between people's assessment of their quality of life and their personal limita-

Table VI. The amount and form of support received and the quality of life of caregivers

			What i	s your d	quality	of life?			Deersen's	
	Neither good nor bad	Very good	Very bad	Good	Bad	Total	Pearson's Chi-square	р		
Do you think that you	No	n	28	0	1	13	8	50		
receive a satisfactory	No	%	56.0	0.0	2.0	26.0	16.0	100.0		
amount and form of sup-	I don't	n	4	2	0	9	3	18		
port in caring for the patient? (Psychological.	have an opinion	%	22.2	11.1	0.0	50.0	16.7	100.0	18.99	0.015
physical. material. infor-	V	n	11	0	0	17	4	32		
mational support)	Yes	%	34.4	0.0	0.0	53.1	12.5	100.0		
T-1-1		n	43	2	1	39	15	100		
Iotai	Total		43.0	2.0	1.0	39.0	15.0	100.0		

Legend: n- number of observations; p- level of statistical significance. % - percent

Table VII. The relationship between satisfaction with one's own health and one's quality of life

			What	is your c	quality o	of life?			Deersen's	
			Neither good nor bad	Very good	Very bad	Good	Bad	Total	Pearson's Chi-square	р
	Very dissatis-	n	1	0	0	2	2	5		
	fied	%	20.0	0.0	0.0	40.0	40.0	100.0		
	\/om/ potintiad	n	0	2	0	2	2	6		
How satisfied	Very satisfied	%	0.0	33.3	0.0	33.3	33.3	100.0	50.05	0.001
are you with	I don't have an opinion	n	10	0	0	5	1	16		
your current		%	62.5	0.0	0.0	31.3	6.3	100.0		
health?	Moderately	n	15	0	0	6	8	29	53.95	0.001
	dissatisfied	%	51.7	0.0	0.0	20.7	27.6	100.0		
	Moderately	n	17	0	1	24	2	44		
	satisfied	%	38.6	0.0	2.3	54.5	4.5	100.0		
Total		n	43	2	1	39	15	100		
10	ıaı	%	43.0	2.0	1.0	39.0	15.0	100.0		

Legend: n- number of observations; p- level of statistical significance. % - percent

Table VIII. The sense of burden and the assessment of the quality of life of the respondents

What is your qu	uality of life?	Personal limitations	Material and social constraints	Negative emotions	Lack of energy
	Average	11.4884	6.5581	4.5349	3.6512
Neither good nor bad	N	43	43	43	43
	SD	3.39728	2.32279	2.06269	1.02082
	Average	13.0000	9.0000	7.0000	4.5000
Very good	N	2	2	2	2
	SD	7.07107	2.82843	2.82843	0.70711
	Average	7.0000	2.0000	6.0000	3.0000
Very bad	N	1	1	1	1
voly bad	SD				
	Average	8.4872	5.4872	3.0513	3.0513
Good	N	39	39	39	39
	SD	3.74076	2.02448	1.66936	0.93153
D. I	Average	12.6667	8.2000	5.4667	4.3333
Bad	N	15	15	15	15
	SD	5.13624	1.85934	1.64172	0.72375
Total	Average	10.4800	6.3900	4.1600	3.6500
Total	N	100	100	100	100
	SD	4.18144	2.36513	2.08273	0.98857
Н		4.882	6.227	7.126	3.419
р		0.001	0.000	0.000	0.012

Legend: n- number of observations; p- the level of statistical significance; SD-standard deviation; H- Kruskal-Wallis test result

tions, material and social constraints, and lack of energy. The less satisfied people are with their quality of life, the higher the scores they obtain (table VIII).

Discussion

Caring for someone with Alzheimer's disease is difficult and multidimensional. Constant stress, lack of institutional support or the enormity of emotional problems resulting from difficulties in caring for a patient particularly affect the quality of life possessed so far.

The authors own research analyzed the impact of selected factors on the quality of life of caregivers of people with Alzheimer's disease. Initially, we started with the analysis of the impact of gender, age and employment status. The analysis did not show a significant relationship between the quality of life of caregivers and the above factors. However, in the case of the gender of the respondents, it was shown that the percentage of women who rated their quality of life as good is slightly higher than the percentage of men. However, these differences were not statistically significant.

Another aspect examined was the relationship between the time spent caring for a patient and the assessment of the quality of one's own life. Statistical analysis showed a significant relationship between these two variables. Respondents who spent less than 6 hours on patient care were more likely to rate their quality of life as good or very good. In contrast, respondents who spent more than 12 hours on patient care were more likely to rate their quality of life as bad or very bad. Kaczmarek et al. also confirmed in their research the destructive impact of prolonged caregiving time on the caregiver's quality of life, both in terms of family and professional life [4]. Caring for a patient had a negative impact on relationships with the caregiver's partner (71%) and family members (71%). Similar results were presented by Szala et al. [5]. They did not specifically analyze the link between the duration of care and the assessment of health but instead they focused on the results of the KPO. However, when considering the available data, they found that the longer the duration of care, the greater the sense of burden, especially in terms of personal limitations and fatigue. Kachaniuk et al. in their analysis also proved a correlation between the length of time spent providing care and the quality of life [6]. They agreed with the fact that as caregiving time increases, the quality of life of the caregiver decreases. Having additional support from family, friends or institutions would greatly facilitate the care given. People who care for Alzheimer's patients often

have to give up their entire lives – from their daily routine, their job or social contacts. Everything is subordinated to the needs of the person under their care. This indicates the need to focus not only on the needs of the patient, but also on the person of the caregiver. Introducing diversified assistance, significantly supporting the caregiver, could distinctly improve their quality of life.

An important aspect of our own research affecting the quality of life was the form of care provided. As many as 45.8% of respondents providing care on their own could not define their quality of life, while 33.3% of respondents described their quality of life as bad. Those receiving assistance in caring for a sick person mainly declared a good quality of life (44.7%). In a study by Mazurkiewicz's, as many as 80.95% of respondents admitted that family support in the care of the patient was important to them [7]. More than half of them declared that they did not receive help and support from friends or institutions, which had a significant impact on their quality of life. Providing round-the-clock care is associated with an increased sense of responsibility for the patient. In the long term, it can lead to anxious and even aggressive behavior. Therefore, it can be concluded that independent care has a negative impact on the quality of life of the caregiver.

Analyzing the respondents' educational background, no significant impact on the caregiver's quality of life was shown. In the study by Kaczmarek et al. 80% of respondents were well-educated [4]. Thus, the education held may have influenced a greater awareness of responsibility and the scope of activities in the care of the patient. A broader knowledge of the course of the disease could have significantly affected the caregiver's quality of life. In addition, a high level of education certainly allowed caregivers to expand their financial capabilities, making it easier to cover the costs of care. An unfavorable financial situation undoubtedly affects the caregiver's standard of living, favoring the accumulation of negative emotions and stress. In a study by Serrano--Aguilar et al. it was shown that a lower quality of life was closely related to lower education and an unfavorable financial situation [8]. In contrast, a study conducted in the United States by Markowitz et al. found no correlation between poorer quality of life and variables such as age, level of education, housing conditions or length of care [9].

Support plays a key role in maintaining a person's mental health. It allows you to reduce stress, improve well-being, both mental and physical. The situation in which people caring for a chronically ill person find themselves is extremely difficult and stressful in psychological, financial and health aspects. In our own re-

search, half of the respondents declared that they do not receive a satisfactory amount of support in various areas of care. The vast majority of caregivers stated that they feel the greatest deficit in psychological support (58%), while the smallest in information support (5%). These characteristics of the research sample appear to be consistent with other studies describing the impact of available support on the lives of caregivers [10]. Similar results were observed in a study by Mazurkiewicz's [7]. The majority of caregivers (73.81%) declared deficits in psychological support, while the minority (30.95%) declared a lack of information support in patient care. On the other hand, a study by Szala also showed that the greatest deficits were found within psychological support [5].

The results of our own study confirmed that people who do not receive satisfactory support tend to assess their quality of life as worse. In contrast, people who receive satisfactory support tend to rate their quality of life as good. Mazurkiewicz et al. [7] also confirmed in their research that the greater the generally available support, the higher the quality of life of the caregivers surveyed. Having the support of relatives, qualified medical staff or social organizations would significantly increase the comfort of life of the caregiver and affect the perception of their quality of life.

Questions from the self-generated questionnaire made it possible to identify factors that reduce the quality of life of the patient's caregiver. One of them was stress, which was present in half of the respondents at the medium level. As many as 37% of respondents declared a high level of stress and worry. In many studies, the presence of stress is an inseparable element of providing care [4,11]. Salon acknowledged in her study that caring for a person with dementia is definitely more burdensome and stressful than caring for people with other diseases [12].

A further analysis of our own research examined the correlation between the subjective assessment of caregivers' health and the quality of life. The results obtained suggest that the evaluation of satisfaction with one's own health may have an impact on the overall quality of life. People who were more satisfied with their own health tended to express a higher quality of life. The perception of one's own health can be influenced by a number of factors, such as the length of time spent providing care, lack of time for rest, limited social contacts or inability to perform one's current job. Stypińska et al. identified in their work factors that have a destructive effect on the psycho-physical state of the caregiver [13]. They listed: the severity of Alzheimer's disease in the patient, the feeling of loneliness, and the independence in perfor-

ming caregiving activities. They noted that the more people are involved in care, the lower the mental and physical burden on the caregiver. Caring for a sick person at the same time as fulfilling their everyday duties had a negative impact on the caregiver's quality of life. They showed that it was common for carers to prioritize the health and well-being of the patient over their own psycho-physical condition. Szala et al. also proved in their study that caring for a sick person significantly increases the risk of health problems and even death of the caregiver [5]. Care-enforced changes in the caregiver's life disrupt their previously held habits, reduce physical activity and sleep. It is necessary to introduce measures that would facilitate functioning of a caregiver while playing dual roles.

After obtaining results, we considered an additional issue, namely the influence of the type of family relationship between the caregiver and the patient and we confronted it with other studies. In our own study, care was mainly provided by children of patients (45%), followed by people with a different degree of kinship, spouses/ partners, and parents. In Szewczyczak's study, care was also most often provided by children, followed by spouses [11]. It is very difficult to determine exactly which of the family members usually becomes the main caregiver of the patient. In the case of the study conducted by Janion, it was determined that it is the spouse who is the main caregiver of the sick person (69.3%) [14]. This discrepancy between the obtained data may depend on the methods of selecting the research sample and the form of research conducted. It might seem that it is easier to reach the spouses of sick people who are retired than to children who are professionally active. On the other hand, online surveys are more accessible to younger people, in this case children of sick people.

The results of our own research confirm the current state of knowledge about the quality of life of the caregiver of a person suffering from Alzheimer's disease. The characteristics of the research sample seem to correspond to the statistics from studies on related topics. Differences in the balance of groups in terms of the age of the respondents can be seen as a discrepancy compared to some of the considered publications. On the other hand, it may indicate that younger people are more involved in caring for Alzheimer's patients. Confronting the results we have with other researchers' findings, suggests that special attention should be given to the issue of caregiver support. In the vast majority of studies, the lack of psycho-physical support for caregivers seems to be a significant problem.

A limitation of the study may be the form in which it was conducted - online, which may have affected the selection of the study group and thus the results. It would be worthwhile to broaden the scope of the study to include people who are not affiliated with online forums, but are caring for their loved ones with Alzheimer's disease.

Conclusions

- 1. The quality of life of a caregiver depends on the time spent caring for the patient.
- 2. Caregiver's stress and fatigue reduce the quality of life.
- 3. Providing care on one's own has a negative impact on the quality of life of the caregiver.
- 4. The lack of psychological support has a significant impact on the quality of life of caregivers.
- 5. The support one has, plays a key role in maintaining the caregiver's mental health. The more support available, the better the quality of life.
- 6. The quality of life of the caregiver is dependent on the state of his or her health.
- Gender, age, education, employment status of the caregiver do not affect the quality of life of the respondents.

Conflict of interest None

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