

Correlation between depression and burden observed in informal caregivers of people suffering from dementia with time spent on caregiving and dementia severity

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Abstract. – OBJECTIVE: The aim of the study is to compare data on the examined population of informal caregivers of people suffering from dementia with previous studies, as well as to assess the correlation between (i) depression determined on the basis of the Center for Epidemiologic Studies Depression Scale and (ii) caregiver burden measured by means of the Zarit Caregiver Burden Scale and some chosen parameters, such as total time devoted to caregiving, time of caregiving in hours per week and level of dementia severity measured by Global Deterioration Scale.

PATIENTS AND METHODS: 41 informal caregivers of people suffering from dementia from different backgrounds were evaluated using the Zarit Caregiver Burden Scale and the Center for Epidemiologic Studies Depression Scale. Demographic data about the time devoted to caregiving and the number of hours spend on caregiving weekly were gathered. The type of dementia and its stage were registered using the Global Deterioration Scale (GDS). With the aid of the Statistica StatSoft program, mutual correlations between the parameters were measured. The study was conducted within the framework of AAL UnderstAID – a platform that supports and helps to understand and assist caregivers in the care of a relative with dementia. The international project is co-

founded by the Joint Programme Ambient Assisted Living (Grant code: ESR-aal 2012 5 107).

RESULTS: No significant correlations between the level of depression severity evaluated in caregivers and the total time of taking care of a demented person or time of caregiving in hours per week were observed. Similarly, no significant correlation between depression severity level and dementia severity level measured on the GDS scale were noted. There was also no significant correlation between Zarit Caregiver Burden Scale scores and the above-mentioned parameters.

CONCLUSIONS: The level of depression among caregivers do not depend on socio-demographic factors.

Key Words:

Dementia, Zarit Caregiver Burden Scale, Depression, Informal caregivers, Caregiving.

Introduction

Dementia is a broad category that includes a number of symptoms resulting from different brain disorders. It is characterized by an impairment of higher cortical functions, such as mem-

ory, orientation, reasoning, etc. The impairment of cognitive functions can co-occur with different emotional disorders. For this reason, dementia is a very complicated condition and giving its precise definition is often poses difficulty. Also assessing the level of dementia severity, its progress or loss of different functions is problematic. Owing to an increased life span and improved healthcare standards, the number of people suffering from dementia is growing. This leads to various costs and expenses. Apart from the financial ones, incurred by both the diseased person together with his or her family and the whole society, also emotional costs should be mentioned, which are borne mainly by the relatives of the diseased person, the caregivers in particular. During the last few years, many crucial findings about the burden of caregiving to the chronically ill and other negative effects of such caregiving has been published. The results vary among countries and alter over time, which results from many different factors, e.g. cultural, financial or organizational. It is also difficult to compare the results because different studies make use of different methodologies. In this study, information concerning demographic data is given. Also the impact of the patient's clinical condition and some other factors on the informal caregiver of a demented person is discussed in the paper.

Patients and Methods

The study was conducted within the framework of AAL UnderstAID – a platform that supports and helps to understand and assist caregivers in the care of a relative with dementia. The international project is co-founded by the Joint Programme Ambient Assisted Living (Grant code: ESR-aal 2012 5 107). Its aim is to create an internet platform for caregivers of people with different types of dementia. For the purposes of the study, it was necessary to establish what kind of situations cause most difficulties to informal caregivers during their caregiving. Inclusion criteria were as follows: consent to participate in the study and declaration of being an informal, i.e. unpaid, caregiver to a demented person. In medical documentation dementia had to be diagnosed for subjects to be included in the study. 41 caregivers from Poland participated in the study. The participants were residents of the city of Poznan and the community of Koziegłowy in Wielkopol-

ska Region. They were interviewed and the questionnaires described further below were filled in.

In the study, a set of questionnaires created for the purposes of the grant was used. The set included a depression questionnaire – Center for Epidemiologic Studies Depression Scale (CES-D) and a burden questionnaire – Zarit Caregiver Burden Scale (ZCBS). The ZCBS questionnaire includes 22 items scored on a 4-point scale. The total of 0-20 points means that there is little or no burden, 21-40: mild to moderate burden, 41-60: moderate to severe burden, and 61-88: severe burden. The CES-D scale is a 20-item scale scored from 1 to 3 points. Possible results range from 0 to 60 points and 16 points or above indicate depression. The level of dementia was evaluated by means of the Global Deterioration Scale. The scale developed in the 1982 by Reisberg et al allows to assign a patient into one out of seven stages of dementia (Reisberg B, Ferris SH, de Leon MJ, Crook T. The Global Deterioration Scale for assessment of primary degenerative dementia. *Am J Psychiatry* 1982; 139: 1136-1139). At stage 1, no cognitive impairments are observed, stage 2 – very mild cognitive impairments are present, stage 3 – mild cognitive impairments are present, stage 4 – there are moderate cognitive impairments present, stage 5 – moderately severe cognitive impairments are observed, stage 6 – severe cognitive impairments are present, the patient is dependent on his or her caregiver, stage 7 – there are very severe cognitive impairments, the patient losses any verbal or motor abilities.

Statistical Analysis

For the statistical analysis, arithmetic means and standard deviations (SD) were used. Spearman's rank correlation coefficient was applied to analyze the correlations. The value of $p < 0,05$ was assumed to be statistically significant. All calculations were performed using the SPSS Statistica package (SPSS ver. 22.0, Poznan, WLKP, Poland).

Results

Caregivers' Profile

The average age of caregivers was 61.68 years (range 25-88). The most relevant information that can be drawn from Table I is that there are gender differences observed. Female caregivers outnumber male caregivers (73.2% females versus 26.8% males). Most often caregivers were spouses ($n=18$, 43.9%), less often adult children ($n=12$,

29.3%) or daughters-in-law ($n=9$, 21.95%). The majority of the participants were married, with no children under 14 years old. 13 caregivers (more than 34%) were white-collar workers, whereas 5 caregivers (13.2%) were blue-collar workers. Most of the caregivers, i.e. 18 (47.4%), were retired. One person had the status of the unemployed. The average CES-D result was 16.72 (SD 8.88). For 25 caregivers, the result was 16 or below, while the result of above 16 points, i.e. the result indicating depression according to the questionnaire, was obtained for 16 subjects (39.02%). In the ZCBS questionnaire, the average result for the caregivers was 37.44 (SD 13.315), which means mild or moderate burden. The total time of caregiving in months was 70 months (SD 51.710) on average. The number of hours devoted to caregiving weekly was defined in ranges. The greatest number of caregivers, i.e. as many as 32 subjects (78%), reported more than 20 hours of caregiving per week. Ranges from 16 to 20, from 11 to 15 and from 6 to 10 hours per week were given by two subjects (4.9%) per each range. Three subjects (7.3%) took care of the demented person 5 hours a week.

Table I. Caregivers profile.

Gender	N	%
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Male	11	26.8
Female	30	73.2
Marital status		
Single	8	19.5
Married	32	78.0
Separated/divorced	1	2.4
Widow/er	0	0
Cohabiting	0	0
	Mean	Standard deviation
Caregiving time (months)	70.41	51.710
	N	%
Family relationship		
Spouse	18	43.9
Adult child	12	29.3
Father/mother in law	2	4.9
Nephew/Niece	0	0
Sibling	0	0
Others (daughter in law)	9	22
Hours per week of caregiving		
1-5	3	7.3
6-10	2	4.9
11-15	2	4.9
16-20	2	4.9
More than 20	32	78.0

Dementia Patients' Profile

In the majority of patients, severe and very severe dementia was observed. When analyzing the patients' profile, the data show that almost 80% of them was classified as GDS VI or VII, which means total dependence on the caregiver. Few patients presented with depression, stage I, III and IV according to the GDS scale. Detailed information about dementia level were presented in Table II.

Then, the correlation analysis was conducted. Based on the Spearman's correlation coefficient, no statistically significant correlation between the time of caregiving (in hours per week) and depression occurrence in the caregiver was observed ($r=-.018$, $p=0.912$). Also no statistically significant correlation between the time of caregiving (in months) and depression occurrence was proved by means of the Pearson's test ($r=-.064$, $p=0.70$). There was no statistically significant correlation between the GDS dementia stage and depression occurrence as well (Spearman's correlation coefficient?, $r=-.042$, $p=0.79$). Next, the correlation between caregiver burden measured in the ZCBS and the level of dementia severity determined in the GDS was analyzed. No statistically significant value was obtained ($r=-.130$, $p=0.419$). There was also no significant correlation between caregiver burden and the time of caregiving in hours per week (Spearman's correlation coefficient, $r=-.024$, $p=0.879$) and between caregiver burden and the total time of caregiving (Pearson's test, $r=-.203$, $p=0.215$).

Discussion

The number of people suffering from different types of dementia is growing as the society is getting older and the average life span is increasing. It was estimated that in 2000 there were ca. 25 mln dementia patients worldwide and it was predicted that the number will grow to 60 mln in 2030^{1,2}. In Poland, it is difficult to estimate the number of dementia patients. In 1999, it was determined at the level of ca. 200 thousand, but currently it may even

Table II. Patients GDS profile.

GDS stage	N	%
GDS 1	1	2.4
GDS 3	1	2.4
GDS 4	1	2.4
GDS 5	6	14.6
GDS 6	14	34.1

exceed 400 thousand patients^{3,4}. Both in Poland and worldwide, the majority of dementia patients are taken care of by their family members. To almost 92% of dementia patients in Poland, care is provided solely in the home-care setting and the role of caregivers is taken on by the patient's spouse or adult children⁵⁻⁷. In the population presented in this study, spouses constituted the largest group of caregivers (n=30; 73.2%). The second largest group were children (n=12) and daughters-in-law (n=9). The majority of caregivers were female (n=30; 73.2%). Grabowska-Fudała et al⁸ achieved similar results in her study, in which female caregivers comprised 86%. In a survey on the demography of caregivers of Alzheimer's patients carried out in 2003, in which 131 families of Alzheimer's patients were questioned, it was revealed that women constitute 81.7% of caregivers⁹. Similar tendencies can be observed in studies conducted in other countries, seemingly distant in terms of culture, such as Australia, where 84-85% caregivers are female, and China, where the percentage ranges between 66-74%¹⁰. In this study, the average age of the caregiver was 61.68 years and was higher than the value cited in Spisacka and Pluta study⁹, in which the average age was 57 years. In the Australian-Chinese study mentioned above, the caregivers age ranged from 60.5 among the Chinese population to 69 in Australia. In this study, the role of the caregiver is usually taken on by the spouse (43.9%) just like in the case of the Australian caregivers (74-77%). The number is lower for the Chinese caregivers though and it amounts to 46-57%¹⁰. Kowalska et al⁴, in her study, conducted in Poland ten years ago stated that care was most often provided by children (ca. 55%) and in the second place by the patients spouses (ca. 35%). Despite different cultural and social backgrounds, i.e. regardless of whether the family is regarded as a multigenerational institution and whether the duty to take care of the aged is dictated by tradition or law, as it is the case in China, or whether the caregiving process is divided between the family and some specialized institutions, which is the case in Australia, major tendencies remain the same. It could even be claimed that, as far as dementia is considered, the results of Polish studies together with the analysis of the caregiving process place Poland between the two countries mentioned above⁵. The CES-D questionnaire showed depression in 16 out of 41 interviewed caregivers (39.02%), which confirms the previous data gathered for Poland considering the issue – in the 1999 study, depression was observed in 47% of family member caregivers from among 42 families of

Alzheimer's patients¹¹. Similarly to the results of this study, the majority of caregivers took care of their demented relatives on a full-time basis – 65% of caregivers took care of their relatives 7 days a week, and 77% complained of the lack of rest¹¹. Unfortunately, all this means that over the last 15 years there has been no improvement in the system of care facilities for chronically ill patients with dementia.

The other factor that affects caregivers is caregiver burden. Pearlin et al¹² define it as physical, psychic, emotional and social difficulties that caregivers are exposed to. Contrary to expectations based on the analysis of the available literature, in this study no correlations between the occurrence of depression in caregivers and the clinical condition of caretakers, total time devoted to caregiving or the number of hours devoted to caregiving per week were observed⁸. Nevertheless, the authors are aware of the limitations of the conducted analysis, which were caused by a number of factors. Depression is a disease of multidimensional nature and it is difficult to diagnose on the basis of one test only, which may serve rather as a screening test to be verified by a specialist – the result of the test may be either confirmed during the specialist examination or it may be falsely positive or negative. Moreover, it follows from gathered information that at least 7 caregivers took drugs affecting the functioning of the central nervous system, e.g. antidepressant, sedative or soporific drugs, which might have also influenced the CES-D result. Next factors that may distort the results are the low awareness of the clinical picture of depression, as well as the unwillingness to receive psychiatric treatment. The latter was proven in a Polish multi-centre research study conducted in years 2000-2002. As many as 7289 patients of the primary healthcare filled in the Beck Depression Inventory. To the patients that scored ≥ 12 points (n=2995), psychiatric consultation was proposed. Only 51% of the subjects had the consultation¹³. Moreover, according to the literature, the caregivers of demented patients often disregard their own health and do not undertake treatment in the early stages of the disease¹⁴.

Owing to the complexity of the caregiver burden issue, some authors suggest the necessity for the division into objective and subjective burden. The former would involve time, as well as physical and financial efforts related to caregiving, whereas the latter would imply the caregiver's suffering associated with his or her emotional and social experiences¹⁵. Some authors have introduced the notions of emotional and physical burden. The former re-

sults from the new social situation that caregivers find themselves in and it includes both the negative and positive aspects, such as the loss of social bonds or lack of support from other people and satisfaction from taking on the new role, respectively. The latter is caused by the clinical condition of the caretaker¹⁶. Yet some other authors emphasize the indivisible nature of the burden understood as the emotional factor resulting from excessive burden associated with physical caregiving¹⁷. It is not only difficult to define the multidimensional notion of burden, but it is also hard to measure burden and precisely determine what factors influence the experienced burden to the greatest degree. The available literature states that the important factors are gender, upbringing and educational background of the caregiver¹⁸. Other factors associated with caregiver burden include the clinical condition of the caretaker (with an emphasis on psychiatric symptoms), behavioral disturbances, as well as the level of dependence of the diseased person on the caregiver with respect to daily chores¹⁹.

Conclusions

To recapitulate, similarly to this study, in their investigations into factors affecting caregiver burden or co-occurring depression many researchers have focused on socio-demographic data. It is true that such an approach is not deprived of its justification, it should be remembered though that different aspects of the caregiver-caretaker relationship are also influenced by cultural and neuro-psychological factors.

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Conflict of Interest

The Authors declare that they have no conflict of interests.

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