

ORIGINAL PAPER

ASSOCIATION BETWEEN BURDEN AND DEPRESSION IN CAREGIVERS OF DEMENTIA PATIENTS

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Abstract

Aim: The pilot study aimed to determine the association between burden and depression in caregivers caring for dementia patients. **Design:** Quantitative research; a cross-sectional study. **Methods:** Data were collected using a set of standardized questionnaires. Patients' performance in activities of daily living was assessed using the Barthel scale. The subset for caregivers included the Zarit Burden Interview, Caregiver Strain Index and Beck Depression Inventory. **Results:** The pilot study sample comprised 100 lay caregivers of dementia patients. More than 50% of caregivers of patients with moderate to severe dementia experienced moderate to severe burden as compared with those caring for individuals with mild or minimal depression. The median burden scores were 54 and 38 in caregivers with and without depression, respectively. There was no statistically significant difference in burden scores with respect to depression. There were positive correlations between depression measured with the Beck Depression Inventory and both Zarit Burden Interview scores (0.4898) and Caregiver Strain Index scores (0.3379). **Conclusion:** The pilot study results confirm that caregivers are at risk for the development of depression associated with burden of care for dementia patients. It is essential to pay attention to carers, testing them regularly to assess both caregiver burden and the development of depression.

Keywords: caregiver burden, caregiver depression, dementia patient.

Introduction

Today, dementia is a global problem no longer affecting developed countries only. This phenomenon is linked to longer life expectancy and the related general ageing of the population. In individuals over 65 years of age, the risk of developing dementia is 5%. This risk increases, reaching 10% at the age of 75; among patients older than 90 years of age, as many as 50% manifest clear symptoms of dementia. In the Czech Republic, 150,000 people have senile dementia; that number is estimated to exceed 250,000 by 2050 (Pidrman, 2007).

Globally, the situation is similar to that in the Czech Republic. There are 5.4 million people diagnosed with dementia currently living in the USA; their number is estimated to reach 7.7 million by 2030 (Bekhet, 2013).

In the past, the needs of dementia sufferers were relatively thoroughly studied; however, relatives

caring for up to 80% of them were neglected (Zvěřová, 2010).

Caregiver burden has only been researched since the mid-1980s. Mainly in the USA, numerous studies and survey have been concerned with family caregivers' feelings, needs and health, confirming that cognitive deficit results in lowering the quality of life of both patients and their carers.

Family members caring for dementia patients describe their feelings as permanent stress and frustration, often resulting in illness of caregivers themselves who are no longer able to care for their relatives; this, in turn, often means premature institutionalization of patients.

Many studies have shown that problems most frequently affecting caregivers range from simple physical tiredness, to family and work problems, feelings of inadequacy and incompetence, to sleep disturbances, depression and anxiety.

Helping a cognitively impaired person may disrupt every individual's emotional resources to such extent that the carer is often defined as a "hidden patient".

The indirect consequences of caregiving include, in particular, chronic stress associated with patient care and lower socioeconomic status of the family, due to

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either the patient's disability or the fact that the caregiver has to leave their job because of increasingly demanding care. Caregiver burden is associated with depression, morbidity and lower quality of life; more frequently, they visit doctors for multiple chronic problems and use many medicines (Bayer, Reban, 2004).

Caregivers more often develop depression; while in females, the increased prevalence is more or less stable, in males, the issue becomes worse in the course of caregiving. Additional problems include disturbed sleep and increased morbidity. Also associated are frustration and disappointment over the health and social system (Schulz, Beach, 1999).

Spouses caring for patients with dementia were estimated to be four times more likely to develop dementia than spouses of cognitively well partners (Joling et al., 2010). Many studies have shown that informal caregivers are more frequently diagnosed with clinical depression and higher levels of depression symptoms compared to non-carers.

A meta-analysis integrating the results of 127 studies published or presented in 1982–2005 showed that interventions for family caregivers had significant but small effects on burden, depressive syndrome, subjective well-being, ability/knowledge and symptoms of care recipient (Pinquart, Sörensen, 2006). Recently, numerous studies have been concerned with psychosocial health of patients' partners but long-term and systematic care for them is mostly lacking (Spruytte, Van Audenhove, Lammertyn, 2001).

In the Czech Republic and Slovakia, several studies on caregiver burden have been performed. The very first researcher investigating caregiver burden in the Czech Republic was Eva Topinková who translated and validated the Zarit Burden Interview. She showed that among Czech caregivers, patient care was subjectively perceived as more burdensome by females who also reported more subjective health problems compared to males. Based on the survey results, some recommendations were proposed to lower caregiver burden and to improve the quality of life of both carers and the elderly receiving care (Topinková, 1995).

It is mainly anxiety, depression, frustration and permanent stress that very often bring carers to doctors' offices; they become patients themselves and are no longer able to care for their demented relatives (Zvěřová, 2010).

In another study, Zvěřová (2013) claims that a so far underestimated aspect in our environment is proper communication and support to family caregivers from professional service providers. In the initial

phases of the disease, it is important to provide families with enough information on Alzheimer's disease itself, treatment options, social and legal issues. Caregivers need support, information and advice throughout the period of caring for a family member (Zvěřová, 2013).

In the Czech Republic, research on burden in caregivers of dementia patients is rather scarce.

Identifying the prevalence of caregiver burden may be a starting point for early detection of and prevention against potential impairment of mental functioning in carers, in cooperation with self-help groups, respite care services, day care centers, etc.

The present study is concerned with the impact of burden in lay carers for demented persons, namely the effect of age on caregiver burden, the effect of the carer-patient relationship, the impact of dementia on caregiver burden, the effect of age on positive aspects of carers and the impact of depressiveness on perceived caregiver burden. The pilot study aimed to determine the association between burden and depression in caregivers caring for dementia patients.

Aim

The pilot study aimed to determine the association between burden and depression in caregivers caring for dementia patients.

Methods

Design

Quantitative research; a cross-sectional study.

Sample

The sample comprised caregivers of dementia patients attending three outpatient psychiatric centers in Havířov and Karviná, psychiatric and geriatric wards of Havířov Hospital and SILOE, a Slezská Diakonie day service center in Ostrava – Nová Ves.

The inclusion criteria were caring for a person with dementia of any type as documented in the patient's medical records and confirmed by a psychiatrist or neurologist, consent to participation in the study, age over 18 years and having Czech as one's mother tongue.

Data collection

Data were collected between June 2016 and June 2017 using a set of standardized questionnaires. Patients' performance in activities of daily living (ADLs) was measured. The subset for caregivers included the Zarit Burden Interview, Caregiver Strain Index and Beck Depression Inventory. Before the study was started, the authors of the standardized

questionnaires were asked for permission to use and/or translate the instruments.

With the authors' permission, the Caregiver Strain Index was translated into Czech using the forward-backward translation method.

Patients' performance in ADLs was assessed using the Barthel scale. The variables addressed in the instrument are dressing, grooming, feeding, toilet use, etc. The scale yields a score of 0–100, with 0–40 points for high dependency, 45–60 points for moderate dependency, 65–95 points for low dependency and 100 points for independence (Mahoney, Barthel, 1965).

The Zarit Burden Interview by Zarit et al. (1980) was used to assess caregiver burden. Validity of the questionnaire in the culturally and historically different setting of the Czech Republic was confirmed by Topinková in 1995. The items are concerned with the physical, mental, social and financial aspects of caregivers. They are classified on a 0–4 scale (0 never, 1 rarely, 2 sometimes, 3 quite frequently, 4 nearly always). The total score is assessed, with higher scores suggesting higher burden (0–21 points for little or no burden, 21–40 points mild to moderate burden, 41–60 points for moderate to severe burden / high-risk association and 61–88 severe burden / high-risk association) (Topinková, 1995).

The Caregiver Strain Index consists of 13 items to be responded with yes/no answers. For each positive answer, one point is scored. A total score of seven or more points indicates high caregiver burden. The major domains include employment, financial, physical, social and time aspects. Caregiver burden is assessed in three areas: 1) objective burden limiting particular aspects of the caregiver's life (e.g. limiting caregiver's recreational activities or time for friends and relatives); 2) subjective caregiver burden (e.g. excessive demands from the care recipient or manipulation of the caregiver by the person receiving care) and 3) mental strain (e.g. stress resulting from the relationship between the caregiver and care recipient, anxiety and depression) (Robinson, 1983).

Patients' depression was measured with the Beck Depression Inventory. The scale is a screening test for assessing the severity of depression in already diagnosed patients and for detecting potential depression in the normal population. The questionnaire is concerned with affective, cognitive, motivational and physiological symptoms of depression; it measures the condition and not depressiveness as a personality feature. It consists of 21 items rated by the respondent on a 4-point scale to obtain a total score (0–13 points for minimal

depression, 14–19 points for mild depression, 20–28 points for moderate depression and 29–63 points for severe depression) (Beck et al., 1996).

Data analysis

Data were analyzed using basic descriptive statistics (the median, arithmetic mean, standard deviation and frequency tables). Distributions were compared with box plots (bottom of the box – 25th percentile; central line – median; top of the box – 75th percentile). Differences in qualitative parameters were assessed by the chi-squared test; if conditions for its use were not met, Fischer's exact test was used. The normality of distribution of metric parameters was checked with the Shapiro-Wilk test. Based on this test, non-parametric test were used for further analyses, namely the Mann-Whitney U test. Spearman's correlation coefficient was used to measure the strength of association.

The statistical tests were performed at a significance level of 0.05. Data were processed with the Stata v. 13 software.

Results

The pilot study sample comprised 100 lay caregivers of dementia patients and 100 patients with dementia cared for by them. Female caregivers prevailed (68%). The mean age of carers was 57.3 ± 17.07 years, with the youngest being 29 years old and the oldest being 87 years old. On average, they cared for patients for 4.0 ± 2.82 years, with the length of care ranging from six months to 20 years. On average, they spent 8.4 ± 7.42 hours a day caring for patients. The largest subgroup consisted of employed carers (54%), followed by retired carers. A majority of them had secondary education (59%).

In 62% of cases, caregivers and patients shared the same households. A total of 62 carers suffered from some diseases, with 32 having comorbidities. The most common conditions were hypertension and diabetes mellitus (Table 1). Treatment for depression was reported by 11% of participants.

The Caregiver Strain Index showed high burden in 63% of carers. The Beck Depression Inventory revealed no depression in 87% of caregivers and mild and moderate depression in 9% and 4%, respectively; none of them suffered from severe depression. The Barthel scale assessing ADLs showed high and moderate dependency in 59% and 21% of participants; only 3% were independent.

Table 2 shows correlations between age, length of care, time spent caring, burden and depression in caregivers and patients' condition.

Table 1 Characteristics of caregivers (n = 100)

Characteristic		n	%
Sex	female	68	68
	male	32	32
Disease	diabetes mellitus	23	23
	hypertension	42	42
	depression	11	11
	anxiety	11	11
	others	15	15
Depression in caregivers	minimal	87	87
	mild	9	9
	moderate	4	4
	severe	0	0
Caregiver burden	little or no	12	12
	mild to moderate	42	42
	moderate to severe	37	37
	severe	9	9

Table 2 Correlations between age, length of care, time spent caring, burden and depression in caregivers and patients' condition

	Age	Length of care	Time spent caring	Beck Depression Inventory	Caregiver Strain Index	Zarit Burden Interview
Age	1					
Care length	0.2707*	1				
Time	0.4343*	0.1691	1			
BDI	-0.1702	-0.0737	-0.0747	1		
Strain	-0.2432*	-0.1438	0.0116	0.3379*	1	
Burden	-0.2416*	-0.1032	0.0798	0.4898*	0.6110*	1
ADLs**	-0.0378	-0.0728	0.0358	-0.1768	-0.1494	-0.1312

*statistically significant correlation; **Barthel scale; BDI – Beck Depression Inventory; CSI – Caregiver Strain Index, ZBI – Zarit Burden Interview; ADLs – Activities of Daily Living

As seen from results in Table 2, age was positively correlated with care length and time spent caring; a possible explanation may be that the older people get, the fewer other tasks they have.

Age was negatively correlated with Zarit Burden Interview scores, that is, the younger the caregiver, the less burden; once again, this may be related to other tasks such as those at work. No significant correlation with care length was found.

There were positive correlations between depression measured with the Beck Depression Inventory and

both Zarit Burden Interview scores (0.4898) and Caregiver Strain Index scores (0.3379).

Caregiver Strain Index scores were strongly correlated with Zarit Burden Interview scores.

First, the association between depression in medical records and depression assessed with the Beck Depression Inventory. Among those treated for depression, 64% had minimal and 36% had mild to moderate depression as identified with the inventory (Table 3).

Table 3 Depression in carers assessed with the Beck Depression Inventory

Depression in medical records Beck Depression Inventory	No		Yes		Total	
	n	%	n	%	n	%
1 (0–13) minimal	80	90	7	64	87	87
2 (14–19) mild	6	7	3	27	9	9
3 (20–28) moderate	3	3	1	9	4	4
4 (29–63) severe	0	0	0	0	0	0
Total	89	100	11	100	100	100

Given the small number of depressed patients, burden scores were assessed instead of categories. The median burden scores were 54 and 38 in those with and without depression, respectively; however, there

was no statistically significant difference in burden scores with respect to depression (Table 4).

The association between caregiver burden and depression is illustrated in Figure 1.

Table 4 Presence of depression symptoms with respect to caregiver burden

Depression	n	median	Zarit Burden Interview score				p value*
			mean	SD	min.	max.	
no	89	38	38.4	14.41	10	67	0.0715
yes	11	54	47.5	12.44	27	62	

*Mann-Whitney U test; SD – standard deviation; min. – minimum; max. – maximum

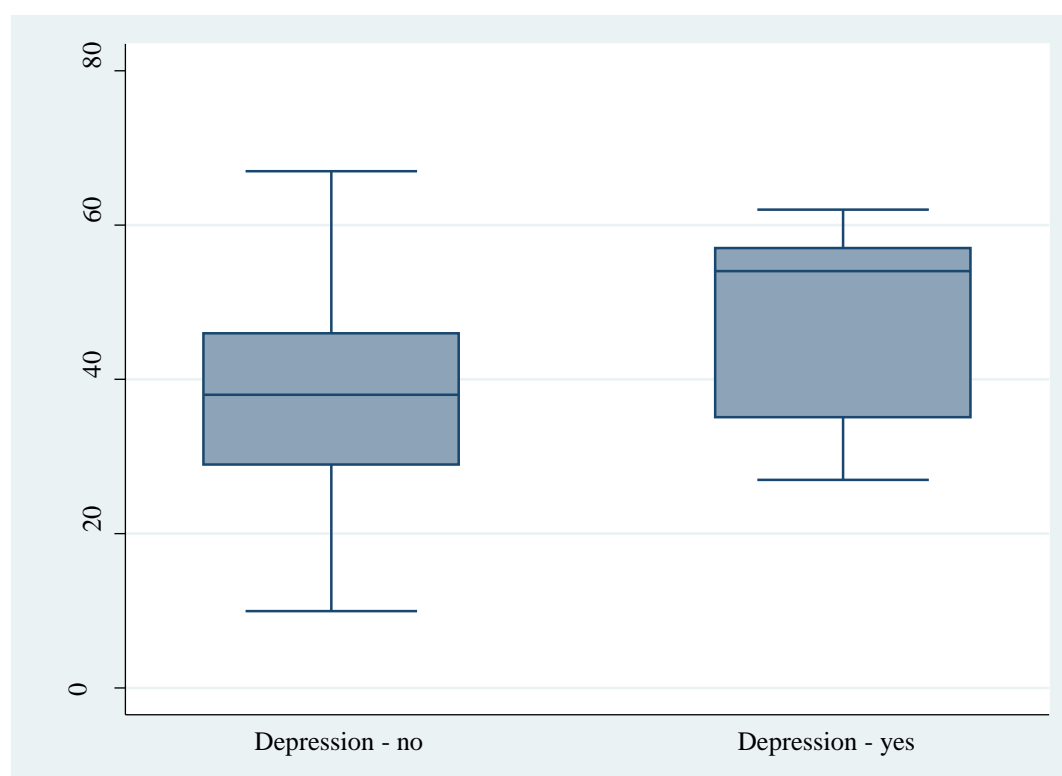


Figure 1 Association between caregiver burden and depression

Discussion

The present pilot study for a research project called Burden of Caregivers of Patients with Dementia focused on the association between burden and depression in those caring for dementia patients.

First, the association between depression in medical records and depression identified with the Beck Depression Inventory was assessed. The inventory showed minimal depression in 64% and mild to moderate depression in 36% of individuals treated for depression; this may be explained by the therapy.

The pilot study revealed that out of 89 participants untreated for depression, six (7%) and three (3%) had mild and moderate depression, respectively; none

of them suffered from severe depression. Among those treated for depression, three (27%) and one (9%) had mild and moderate depression. Seven participants (64%) were found to be free from depression with the test; no individuals showed symptoms of severe depression.

Given the small number of depressed patients, burden scores were assessed instead of categories.

The median burden scores were 54 and 38 in caregivers with and without depression, respectively; however, there was no statistically significant difference in burden scores with respect to depression.

There was a statistically significant correlation measured with Spearman's correlation coefficient ($r_s = 0.4898$) between burden and depression identified with the Beck Depression Inventory.

Problems affecting caregivers range from simple physical tiredness, to family and work problems, feelings of inadequacy and incompetence, to sleep disturbances, depression and anxiety (Bayer, Reban, 2004). Caregivers of dementia patients are more frequently affected than those caring for patients with other conditions, with their problems being associated with many comorbidities (Schoenmakers, Buntinx, DeLepeleire, 2010). Informal care, especially when provided frequently or for a long time, has far-reaching consequences, such as depression, anxiety or mood disorder, leading to poor physical health (Tremont, 2011). Similarly, some studies conducted in the Czech Republic and Slovakia have shown mental burden in 53% and physical burden in 44% of persons caring for their relatives (Ondriová, Fertaľová, 2014).

Bártlová (2006) states that most caregivers immerse themselves in their roles so that they have no time for themselves or handling their own matters. Subconsciously, they take over the entire responsibility for the patients and the development of their condition; they consider deteriorations in their loved ones' health as their own failure (Bártlová, 2006).

Helping a person with cognitive impairment may disturb every individual's emotional resources to such extent that the carer is often defined as a "hidden patient" (Zvěřová, 2010). This was confirmed by a 2015 study of 30 patients with Alzheimer's disease and 30 family members providing them with long-term care. Assessments using the Zarit Burden Interview were repeated after eight months to show that the number of family caregivers with moderate or severe burden increased from 22 to 27. By the end of the study period, five out of 30 patients were institutionalized due to their caregivers' feeling that they could no longer cope with the burden. Twenty-two family caregivers (75%) sought professional psychiatric help in the course of the study (Zvěřová, 2015).

These findings are supported by results reported by many authors. According to a two-year longitudinal study, caregiver burden frequently leads to the development of depression (Schulz, Williamson, 1991). Bayer and Reban (2004) have confirmed that caregiver burden is associated with depression, morbidity and lower quality of life and that caregivers often visit physicians for numerous

chronic conditions and use many drugs (Bayer, Reban, 2004).

Prolonged stress associated with long-term care in immediate family caregivers is manifested, among others, by depression, disturbed sleep and increased morbidity (Spruytte, Van Audenhove, Lammertyn, 2001). Many studies have shown informal caregivers to be more commonly diagnosed with clinical depression and higher levels of depressive symptoms than non-carers (Ferrara et al., 2008; Brodaty, Donkin, 2009). The incidence of depression in spouses caring for dementia patients is estimated to be four times higher than in those having cognitively well partners (Joling et al., 2010).

Many caregivers of dementia patients state that for them, it is far more difficult to cope with psychological than physical challenges. Family members caring for demented individuals feel frustrated and stressed. Families caring for their ill loved ones deserve help. Family members need to want, be able and know how to care (Haškovcová, 2010). Caregivers should receive psychosocial intervention to help them identify the ways of providing care (Aneshensel et al., 2007). Caregivers with more support from their spouses and family members have been shown to be at a lower risk for depression (Thompson et al., 1993; Atienza, Collins, King, 2001). Also Majerníková, Ondriová, Fertaľová (2012) claim that it is essential that experts are able to assess the family situation by measuring the degree of caregiver burden. Individuals at risk for health problems due to their caregiver role are best identified by screening and assessing the degree of burden. Caregivers should be provided help to prevent care from becoming an overwhelming burden (Majerníková, Ondriová, Fertaľová, 2012).

Limitations of study

The main limitation is the small number of participants. In spite of the relatively small sample, however, the study showed that Czech caregivers are at risk for the development of depression. We assume that the correlation will be stronger after additional data are collected. Therefore, data continue to be collected, with the aim to obtain more questionnaires.

Conclusion

The pilot study results confirm that Czech caregivers are at risk for the development of depression associated with burden of care for dementia patients. More than 50% of caregivers of patients with moderate to severe dementia experienced moderate to severe burden as compared with those caring for individuals with mild or minimal depression. It is

therefore essential that health professionals also pay attention to carers, testing them regularly to assess both caregiver burden and the development of depression.

Ethical aspects and conflict of interest

The study was approved by the University of Ostrava Ethics Committee and Havířov Hospital Ethics Committee. Data were collected with consent from the Havířov Hospital management, the SILOE day center manager and the outpatient psychiatric center owners.

Before they filled out the questionnaires, the participants were informed about the purpose and focus of the study, its anonymity and personal data protection. Only questionnaires voluntarily and completely filled out by the participants were included in the study. Following electronic data processing, the questionnaires will be destroyed and electronic data will be stored safely. The authors are unaware of any conflict of interest.

Acknowledgements

Supported by SGS05/LF/2016-2017: Burden of caregivers of patients with dementia.

Author contribution

Conception and design (TK), data collection (TK), data analysis and interpretation (TK), manuscript draft (TK), critical revision of the manuscript (RZ), final approval of the manuscript (TK, RZ).

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