

An Assessment of the Burden on Polish Caregivers of Patients With Dementia: A Preliminary Study

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Abstract

Introduction: The aim of the study was to assess the level of burden of caregivers of persons with dementia and to analyze the factors related to the sense of burden. **Methods:** The study group consisted of 58 caregivers with an average age of 54.7 (\pm 12.6) and 45 (78%) were women. The Caregiver Burden Scale, the Beck Depression Inventory (BDI), the Berlin Social Support Scale (BSSS), and the Satisfaction with Life Scale (SWLS) were used. **Results:** In the study group, 93% could rely on help in caring for the patient, provided mainly by the family. Most caregivers demonstrated a medium level of burden (2.63 \pm 0.61). A significant correlation was found between the level of caregiver burden and caregiving frequency, BSSS, BDI, and SWLS. **Conclusions:** A lot of factors influence the caregivers' burden. It appears necessary to take into consideration the cultural, religious, and economic distinctiveness of the country in question.

Keywords

caregiver burden, dementia, social support, satisfaction with life, depression symptoms, elderly

Introduction

One of the most frequent mental problems affecting elderly people is cognitive impairment.^{1,2} In Poland, 92% of elderly people with dementia are cared for at home from diagnosis until death, and 44% of caregivers provide care on their own, without any support from other people.³ As a consequence, caregivers are at high risk of experiencing negative physical, psychosomatic, psychosocial effects as well as a financial burden; together these negative effects of caregiving are termed the caregiver burden.^{4,5} As Poland is one of the fastest aging countries in Europe, the problem of caring for elderly members of Polish society is bound to increase over time. The situation is exacerbated by strong outward migration of young people. Poland is facing the enormous problem of providing care for elderly citizens who are unable to manage without assistance.

Polish policy on care for senior citizens during the 2014 to 2020 period fails to address the needs not only of patients with Alzheimer's disease and other dementia but also of their caregivers. Due to a shortage of specialist facilities and an inefficient long-term care system, only 8% of Polish caregivers, mainly those in large cities, receive support from state institutions, whereas in the Scandinavian countries, this figure is as high as 50%.^{6,7} Hence in Poland, the main burden of caring for a patient with cognitive impairment falls on the family; most often the role of caregiver is assumed by adult children (53.6%) or a spouse (39.8%) who may also have age-related health problems.⁸⁻¹⁰ What is more, caring for a patient with dementia

is significantly more burdensome than taking care of a person with another chronic illness or physical disabilities.^{11,12}

A number of studies have shown that the perceived burden on the caregiver and its impact on his or her health depends on various factors, including patient age, the severity of dementia, caregiver age, the duration of caregiving, and the mental and physical fitness of the caregiver.^{10,12-14} As a result of the Resources for Enhancing Alzheimer's Caregiver Health (REACH) study and other transcultural studies (conducted in different countries and ethnic groups), the basic model of stress and coping in caregivers, developed by Aranda and Knight (behavioral problems—burden—caregivers' health), has been supplemented by related factors such as cultural values, coping styles, and social support.¹⁵⁻²⁰ Similarly, studies carried out in 8 European countries have demonstrated that the burden perceived by caregivers of people with dementia is influenced by a wide range of factors.^{21,22}

Poland is currently undergoing rapid socioeconomic and demographic changes. The Western model of starting families

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late in life, currently dominant in Poland, as well as the decreasing number of children being born, the increasing number of 1-person households, social pressure, and a very conservative mentality, mean that families are increasingly burdened by the care for elderly people. There is an urgent demand for research designed to identify the needs of families providing care to relatives with dementia and the problems they face. Therefore, the aim of this study was to assess the level of burden on caregivers of persons with dementia and to analyze the factors that affect perceptions of burden.

Methods

Design of the Study

This study presents the results of the first observational part of the project, which was carried out in Wrocław, in 2015. The project "Alzheimer's Cafe—a place for meeting, support, and social integration" was cofunded by the Municipality of Wrocław and run by the Foundation for Seniors Activation. The project lasted for a year and encompassed caregivers' participation in an information training, support group sessions, and individual consultations with a psychotherapist.

Participants

The study group was made up of informal caregivers living in Wrocław who, having read the information published in the local media, applied to take part in the project (first-come-first-served basis) in order to receive information support (a one-off, free training course for 60 people on providing care to a patient with dementia) and who met the following inclusion criteria: written consent for participation in the study, declaration that the participant is the closest caregiver of a patient with dementia and receives no financial compensation on that account, and willing to participate in the training. The exclusion criteria were also applied: caring for a person with illness other than dementia, previous experience of caring for a patient with dementia, and patient's stay in a hospital or another care facility during the caregiver's involvement with the project. Participants who met the inclusion criteria were interviewed once in the Foundation's office by a psychologist. They received instructions and filled in an information questionnaire and measuring instruments independently. Next informal caregivers participated in an information training. The final study group comprised 58 caregivers (2 persons failed to attend the training). The characteristics of the study group and the patients are shown in Table 1.

Measuring Instruments

An information questionnaire and Polish versions of the Caregiver Burden Scale (CBS), the Beck Depression Inventory (BDI), the Berlin Social Support Scale (BSSS), and the Satisfaction with Life Scale (SWLS) were used.

The CBS consists of 22 items and is commonly used in Poland to measure the burden on caregivers of patients with

Table 1. Characteristics of the Studied Group of Caregivers and the Patients With Dementia.

Baseline characteristics	n (%)
Caregivers' age	
Mean (SD)	54.7 (12.6)
Range	21-78
Caregivers' gender	
Female	45 (78)
Male	13 (22)
Caregivers	
Daughter	34 (59)
Son	3 (5)
Daughter-in-law	2 (3)
Spouse	8 (14)
Grandchildren	7 (12)
Other	4 (7)
Caregiving duration, years	
1-5	34 (59)
6-10	13 (22)
11-14	11 (19)
Mean (SD)	4.9 (3.5)
Persons assisting caregivers	
Family	45 (83)
A professional	4 (7)
Family and a professional	2 (4)
Others	3 (6)
Caregiving frequency	
Daily	31 (53)
2-3 Times a week	23 (40)
Occasionally	4 (7)
Patients' age	
Mean (SD)	81.1 (7.6)
Range	58-94
Illness duration, years	
1-5	29 (50)
6-10	14 (24)
11-14	12 (21)
≥ 15	3 (5)
Mean (SD)	5.6 (3.9)

Abbreviation: SD, standard deviation.

dementia. The original version has satisfactory psychometric properties.²³ The Polish adaptation was developed by Jaracz and Grabowska-Fudala. Higher scores indicate a higher burden on the respondent. The following categories of burden were adopted: low level (1.00-1.99 points), medium level (2.00-2.99 points), and high level (3.00-4.00 points).⁹

The BDI contains 21 items that relate the most significant symptoms of depression. The Polish version of the BDI is a translation of the original tool with very good psychometric properties (Cronbach's α was .95 for a clinical trial and .93 for a control group). The first 13 questions focus on cognitive-affective aspects and the remaining questions relate to somatic symptoms that accompany mood disorders. The applicable standards are as follows: 0 to 11 points = no depressive disorders, and higher total scores indicate more severe depressive symptoms.²⁴

The BSSS measures cognitive and behavioral dimensions of social support. This questionnaire consists of 4 independent

Table 2. Dependence of the Burden on Received Assistance and Frequency of Care.

Feature	Category	The Caregiver Burden Scale (CBS)				Student's <i>t</i> Test /ANOVA	
		Mean	SD	Minimum	Maximum	<i>t/F</i>	<i>P</i>
Assistance received	Yes	2.60	0.61	1.09	3.77	1.52	.223
	No	2.99	0.52	2.32	3.50		
Caregiving frequency	Daily	2.79	0.68	1.09	3.77	3.32	.044
	2-3 Times a week	2.51	0.47	1.55	3.14		
	Occasionally	2.09	0.22	1.91	2.41		

Abbreviations: ANOVA, analysis of variance; CBS, Caregiver Burden Scale; SD, standard deviation. $P < .05$. statistically significant. The values in boldface are statistically significant.

scales of social support: BSSS I = perceived available support, BSSS II = need for support, BSSS III = seeking of support, and BSSS IV = support currently received. It was adapted for Polish conditions by Łuszczynska et al and has satisfactory psychometric properties (Cronbach's α ranges from .71 to .90).²⁵

The SWLS measures subjective sense of life satisfaction. The higher the score, the more satisfied with life the respondent is. This study uses raw results of Polish standards: 5 to 17 = low satisfaction, 18 to 23 = average satisfaction, 24 to 35 = high satisfaction. The psychometric properties of the Polish version are satisfactory and similar to the original.^{26,27}

Procedure of Data Collection

Data were collected from the participants at the time of entry to the project. The participants were informed of the purpose of the study, the rules for participation, and the possibility of withdrawing at any stage of the study without consequences. The study was observational and participants were not exposed to any risks. The surveys did not involve any interventions or structured experiments. Approval to conduct the study was obtained from the Bioethics Committee of the University School of Physical Education in Wrocław.

Data Analysis

The study group was characterized using the following descriptive statistics: mean, standard deviation, minimum and maximum values, and, in the case of qualitative variables, numbers and percentages. The significance of differences between mean values was evaluated using the Student's *t* test for independent samples or, for comparisons of more than 2 means, the 1-way analysis of variance (ANOVA). Pearson's linear correlation coefficient was used to describe correlations between continuous variables, and the nonparametric χ^2 test was used to assess relationships between categorical variables. The significance threshold was set at $P < .05$. The calculations were carried out using the STATISTICA 12 software of StatSoft.

Results

The study group consisted of 58 caregivers (13 men, 22%). The mean ages of caregivers and patients were, respectively, 54.7 (\pm

Table 3. Correlation Between the Level of the Caregivers' Depression and the Level of Their Burden.

Caregiver Burden Scale (CBS)	Depression			χ^2 test	
	None	Mild	Moderately Severe	χ^2	<i>P</i>
Low	7	1	0	17.68	.024
Medium	17	19	0		
Very high	2	11	1		

Abbreviation: CBS, Caregiver Burden Scale. $P < .05$. statistically significant.

12.6) and 81.1 (\pm 7.6) years (Table 1). In the large majority of cases (78%), the caregivers were women, usually daughters. The duration of the illness and the period of providing care were different, but it was usually for a period of a few years. The vast majority of caregivers ($n = 54$, 93% of the group) could depend on the assistance of other persons (mainly family members = 83%). In over a half of the cases (53%), care was provided on a daily basis and the caregivers lived with their relatives with dementia.

The CBS

Caregiver burden as evaluated by the CBS ranged from 1.09 to 3.78 points. Most caregivers (62%) reported a medium level of burden (2.63 ± 0.61). The age of caregivers, the age of patients, and the period of care did not seem to impact the caregivers' level of burden. The mean burden was higher for caregivers who did not receive any assistance than for those who did, but the difference was not statistically significant due to the high variance in burden. Caregiver burden was, however, influenced by caregiving frequency. Caregivers providing daily care reported a higher burden than occasional caregivers (Table 2).

The BDI

The mean BDI score was 12.9 (\pm 7.6). No cases of severe depression were detected in the caregiver group, and only 1 person reported moderate symptoms of depression. The majority of the remainder reported mild symptoms of depression ($n = 31$, 53%). There was a relationship between severity of caregiver depression symptoms and caregiver burden ($r = .64$; $P < .0001$; Table 3). Severity of caregiver depression symptoms

Table 4. Comparison of Features With Continuous Distributions in Groups of Caregivers With Extremely High and Low Levels of Burden (in the CBS).

Feature	Low Burden (n = 8)	High Burden (n = 14)	Student's <i>t</i> Test	
	Mean (SD)	Mean (SD)	<i>t</i>	<i>P</i>
Caregiver's age	54.3 (17.3)	56.0 (10.5)	-0.30	.770
Patient's age	77.3 (8.5)	82.9 (6.4)	-1.75	.095
Illness duration	4.6 (3.4)	6.8 (4.3)	-0.98	.341
Caregiving duration	5.8 (4.8)	5.1 (3.8)	0.34	.739
BDI—emotional sum (13 questions)	2.1 (2.1)	12.1 (4.0)	-6.56	< .001
BDI—somatic sum (8 questions)	3.6 (2.3)	6.6 (3.8)	-1.97	.063
BDI—total (21 questions)	5.8 (3.8)	18.6 (7.2)	-4.69	< .001
Perceived available support (BSSS I)	30.8 (1.8)	25.6 (5.7)	2.43	.025
Need for support (BSSS II)	12.3 (4.2)	11.8 (1.7)	0.37	.718
Support seeking (BSSS III)	16.4 (5.3)	15.8 (3.1)	0.33	.745
Support currently received (BSSS IV)	49.0 (8.2)	36.5 (14.4)	2.24	.036
BSSS total	108.4 (11.1)	89.7 (20.9)	2.33	.030
SWLS	24.0 (4.4)	16.4 (7.0)	2.78	.011

Abbreviations: BDI, Beck Depression Inventory; BSSS, Berlin Social Support Scale; CBS, Caregiver Burden Scale; SD, standard deviation; SWLS, Satisfaction With Life Scale.

P < .05, statistically significant. The values in boldface are statistically significant.

Table 5. Comparison of Features With Discrete Distributions in Groups of Caregivers With Extremely High and Low Levels of Burden (in the CBS).

Feature	Category	Caregiver Burden		χ^2 test	
		Low	High	χ^2	<i>P</i>
Gender	Female	6	10	0.03	.856
	Male	2	4		
Caregiving frequency	daily	3	12	5.46	.020
	2 to 3 Times per week/occasionally	5	2		
Assistance received	Yes	8	12	1.26	.262
	No	0	2		
Frequency of assistance received	Never	0	3	2.12	.346
	Often	6	9		
	Sometimes/hardly ever	2	2		

Abbreviation: CBS, Caregiver Burden Scale.

P < .05, statistically significant. The values in boldface are statistically significant.

was not correlated with the patient age, illness duration, or caregiving duration.

The BSSS

The mean total BSSS score was 97.3 (\pm 15.7) and the mean scores on the subscales were as follows: perceived available support (BSSS I): 27.6 (\pm 4.5); need for support (BSSS II): 11.9 (\pm 2.4); seeking support (BSSS III): 16.1 (\pm 3.3); and support currently received (BSSS IV): 42.1 (\pm 10.8). Caregiver burden was negatively correlated with perception of received social support ($r = -.35$; $P = .007$). Burden was negatively correlated with only 2 of the subscales: perceived available support ($r = -.42$; $P = .001$) and support currently

received ($r = -.32$; $P = .015$). Additionally, BSSS was negatively correlated with BDI score ($r = -0.41$; $P = .001$). There were weak, nonsignificant negative correlations between BSSS score and patient age, illness duration, and caregiving duration.

The SWLS

In the caregiver group, SWLS score ranged from 5 to 33. The mean score was 19.9 (\pm 6.4) points. We classified caregivers into 2 groups of similar size, based on the SWLS score. The group with low life satisfaction ($n = 22$, 38%) reported a higher mean burden than the group with high life satisfaction ($n = 21$, 36%; $P < .0001$). This result was corroborated by the strong negative correlation between burden and SWLS score ($r = -0.48$; $P = .0001$). Neither caregiver age nor caregiving duration was associated with reported satisfaction with life.

In order to evaluate the associations between perceived caregiver burden and the other variables measured, we compared 2 groups of caregivers, those with extremely low CBS scores ($n = 8$) and those with high CBS scores ($n = 14$). The results are presented in Tables 4 and 5.

Discussion

This study demonstrates that as many as 83% of caregivers who took part in our research receive help from their family but not from the institutions established for this purpose. Walczak found that despite experiencing negative emotions and frustration, the large majority of caregivers (86%) would not consider placing the patient in a permanent care facility or discontinuing their care (72%).²⁸ Similarly, Gustaw et al found that despite the emotional crises and somatic problems, 63% of respondents were convinced that their loved one should stay at home

throughout his or her illness.⁸ These findings reflect Polish people's strong sense of duty to provide care for aging parents and the social pressure to do so, which is reinforced by the Catholic religion. Additionally, Poland currently faces a very particular situation: institutionalization of chronically ill elderly people is still not socially accepted, but vigorous economic development, sociocultural changes, and adoption of the so-called "western lifestyle" have resulted in a transition from "familism" to individualism. Unfortunately, the Polish social security system is not prepared for the changes. There is a severe shortage of day care places and beds in long-term care facilities, meaning that even if a family decides to place a relative in a care institution, there is usually a waiting period of over a year.

The majority of caregivers (62%) in this study reported a medium burden, as did caregivers in Swedish and American studies.^{29,30} However, a study of 172 caregivers from Cyprus carried out by Papastavrou et al and a study of caregivers for patients with Alzheimer's disease by Grabowska-Fudala et al both reported high caregiver burden.^{9,31} Such varied results of caregiver burden suggest that it is influenced by a range of factors, perhaps including economic, religious, and cultural factors. It is probable that the medium level of caregiver burden reported by caregivers in our study reflects the fact that the group consisted of people who were actively seeking help with their problems and thus had demonstrated an active approach to coping with stress, which has been shown to reduce caregiver burden.^{32,33}

We also observed a relatively low level of depression symptoms in our caregiver group. It is possible that the strong influence of the Catholic religion (over 90% of Polish people still declare an affiliation to Catholicism) may lend an additional emotional and spiritual dimension to the task of caring for a sick relative. Morano and King found that caregivers of patients with Alzheimer's disease with higher levels of religiosity reported significantly lower levels of depression.³⁴ The caregivers in our study could rely on other family members' help, indeed we are thankful to the family members for this help, enabling the caregivers to participate in our study. The correlation analysis showed that caregiver support is negatively correlated with depressive symptoms. An earlier study by Clay et al reported a similar finding that higher satisfaction with social support was associated with fewer depressive symptoms and increased levels of life satisfaction.¹⁹ The correlation analysis also showed that depressive symptoms—in particular, the emotional symptoms—were associated with perceived burden. This finding is consistent with other studies which have concluded that depression in a caregiver is related to a higher sense of burden.^{13,14} Moreover, Huang et al emphasize that emotion-focused coping strategies are a marker of caregiver burden.³⁵

In our study, burden was highest in caregivers who reported low life satisfaction, low perceived available support, and low support received currently. This indicates that caregivers have great needs in these areas. Our results are similar to those of other authors. Social support in the broad sense, from both

professionals and family members, leads to better mood and lower burden in caregivers.³⁶ Liu et al also showed that perceived social support had direct and indirect positive effects on caregivers' psychological health.³⁷ Although the obligation to provide home care for a sick family member may have a detrimental effect on caregivers, it may also give them a sense of satisfaction, a sense that they are fulfilling a duty to a loved one and a sense of being in control of the situation, which may reinforce their self-esteem and lend a special meaning to their efforts.⁸ Grochowska asked caregivers how frequently they derived a sense of satisfaction from providing care, 39% said they sometimes did, 36% reported that they often did, and 20% reported that they always did.³⁸

Further analysis of results showed that the caregiver burden was correlated with caregiving frequency rather than duration of caregiving. Caregivers who provided care every day had a higher sense of burden than occasional caregivers. Similar findings were recorded by Kim et al who found that a higher level of burden was observed in caregivers sharing the household with their relatives with dementia and those who took longer to care per week.³⁰

In countries where there is a strong cultural belief that families have an obligation to care for a relative with dementia, there may be a tendency to disregard the burden of caregiving. Informal caregivers will probably not seek or accept support unless they perceive the burden of caregiving as a problem.²² In such circumstances, it is crucial that medical staff and workers in the support sector (social workers and community caregivers) know the symptoms of caregiver burnout and use appropriate screening scales to assess symptoms of burnout. They must also take action in the initial stages of burnout, in order to prevent a complete burnout of the caregiver, which would result in a patient being placed in institutional care.

Very often caregivers' only chance to obtain information about the support available is during contact with medical staff. Rachel et al argued that caregivers' quality of life and the support they receive should routinely be discussed during medical visits.⁷ A competent person should ask the caregiver to consider these issues and tell him or her about the help and support available, especially the various types of support and therapeutic interventions that are helpful in increasing caregivers' knowledge, improving their mood, reducing stress, and delaying institutionalization of the patient.¹¹ Many studies have shown that educational programs for caregivers of people with dementia are effective,³⁹⁻⁴¹ but REACH I and REACH II demonstrated that active methods of supporting caregivers (skills training, role-playing, and interactive practice) were more effective than passive methods (receiving educational materials) in reducing caregiver burden and depression.⁴²

The diversity of the results obtained in studies analyzing factors affecting caregiver burden in caregivers of patients with dementia demonstrates the impossibility of creating a universal model of care for patients with dementia or a universal support scheme for informal caregivers. It is necessary to take into consideration the cultural, religious, and economic profile of the country in question. It is clear that in Poland, more funding

is needed to create new care facilities for patients with dementia, but a rapid expansion in social support in the broad sense for families and informal caregivers of patients with dementia is perhaps a higher priority, in order to adapt to the changing needs of an aging society.

This study has certain limitations. First of all, the instrument used to measure symptoms of depression is a screening instrument and does not provide a medical diagnosis. The study group consisted of caregivers for persons with dementia (not persons with dementia), so there is a lack of objective data on the functional state of the patients with dementia and the level of severity of their illness. The studied group of caregivers was not a representative group, as it consisted of people who were actively seeking help and support and signed up on their own initiative for training organized by the foundation. The study certainly needs to be continued and confirmed on a larger group of caregivers, and study tools should be supplemented with an assessment of stress coping styles and a stress biomarker measurement.

Conclusions

The studied group of caregivers, in most cases, demonstrated a medium level of burden, a moderate intensification of depressive symptoms, and a satisfaction with life similar to healthy persons of similar age with no such caregiving duties.

Of the caregivers taking part in the study, 93% could rely on help in caring for the patient, provided mainly by their family. In most cases (78%), the caregivers of patients with dementia were women.

A high sense of burden was related to caregiving frequency, low level of perceived available social support, low level of currently received social support, intensified symptoms of depression, and low satisfaction with life.

Declaration of Conflicting Interests

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