



Differences in well-being of informal caregivers: a comparative cross-sectional study of Polish caregivers

Magdalena Mucha^A✉, Magdalena Leszko^B, Andrzej Potemkowski^C

University of Szczecin, Institute of Psychology, Krakowska 69, 71-017 Szczecin, Poland

^A ORCID: 0000-0002-1429-6370; ^B ORCID: 0000-0002-9985-0325; ^C ORCID: 0000-0001-8162-8649

✉ magda.mucha96@gmail.com

ABSTRACT

Introduction: The diagnosis of dementia can significantly affect all aspects of a caregiver's life. Although providing care can be a positive experience, it can also have serious negative consequences for the caregiver's mental and physical health. As caregiving tasks accumulate as the disease progresses, caregivers may choose to place a disease-affected family member in a nursing home.

The aim of this study was to examine differences in depression and caregiver burden among caregivers based on their parents' care setting (home vs. nursing home).

Materials and methods: A total of 100 caregivers participated in the study. Data collection included care-recipient and informal

caregiver's demographic characteristics, duration of care, levels of depression, and caregiver burden.

Results: Caregivers who decided to place a parent in a nursing home reported significantly lower levels of overall subjective caregiver burden than caregivers who provided care at home, $t(98) = 2.884$; $p = 0.004$. No significant differences were found in their levels of depression.

Conclusions: Healthcare professionals should be alert to symptoms of caregiver burden and depression among caregivers and refer them to appropriate resources for help and assistance.

Keywords: Alzheimer's disease; caregiving; nursing home placement.

INTRODUCTION

In 2019, the population of adults aged 65 or above in Poland represented 18.8% of the population [1]. Due to declining fertility rates and increasing life expectancy, it is projected that by 2050 the number of individuals aged 65 and above will constitute 32.7% of the Polish population [2]. An aging population will affect the country in many ways. For example, it may place an increased burden on Poland's healthcare system as older adults are at risk of multiple, comorbid chronic health conditions which impact their physical and mental health as well as their ability to live independently [3]. One of the most prevalent diseases among older adults is Alzheimer's disease (AD) which is the most common form of dementia [4, 5]. Progressive in nature, it is a neurodegenerative brain disorder that encompasses a variety of symptoms including significant memory impairment, difficulty solving problems, an impaired ability to perform activities of daily living, and a gradual loss of communication [6, 7]. It is estimated that nearly half a million Polish people (7.9% of all individuals age 65 and older) may currently be affected by AD or related dementia. This number is projected to quadruple by 2050 [8]. Increasing age is the greatest risk factor for AD; therefore, the number of individuals affected by this disease will grow as the population of older adults continues to increase [9].

Alzheimer's disease and other chronic health conditions are among the major causes of adult mortality and disability and require a long period of treatment and ongoing medical care [10]. An increasing number of individuals with chronic degenerative diseases and long-term disabilities present challenges, not only

for Poland's healthcare system but also for family members who often become informal caregivers. Studies demonstrate that most individuals with AD (80%) live at home and are cared for by their family members – predominantly by a spouse or adult children [11]. This rate is higher in Poland, where about 90% of people affected by dementia live at home and only a small percentage (an estimated 1% or less) receive long-term care in an institutional setting [12]. In comparison, the average in other European countries is 4.2% [13]. However, it is estimated that the proportion of older adults living in long-term facilities will increase mainly because of the shrinking pool of informal caregivers [14].

Caregiving refers to activities and experiences involved in providing care, help, and assistance to people who are unable to provide for themselves [15] and might be a source of positive feelings such as fulfillment, enjoyment, and the satisfaction of meeting an obligation of providing care to a loved one [16]. However, attending to the needs of an individual with AD has more often been linked to adverse consequences for a caregiver's well-being and feelings of being trapped in caregiving responsibilities. The physical and emotional demands associated with providing care, such as lifting or dealing with aggressive behavior, impose a significant burden on caregivers and are associated with increased anxiety, mortality, depression, physical fatigue, and financial burdens [17]. Caregiving may also lead to caregiver burden, which is defined as a state resulting from the action of taking care of a dependent or older person that threatens the physical and mental health of the caregiver [18].

One of the most notable and detrimental outcomes of caregiver burden is depression [19]. Depression is a very serious

and alarming consequence of caregiver burden as depressed caregivers have been found to be more likely to have coexisting anxiety disorders, substance abuse or dependence issues, and may be at risk for chronic health conditions [20]. Additionally, caregiver burden may lead to an expedited placement of the care recipient in a long-term care institution [21].

With the anticipated increase of individuals with AD, the growing costs of long-term institutional residential care, and the shortage of long-term care beds in these facilities [22], informal caregiving continues to be a crucial part of the health-care system that enables older adults to stay at home as long as possible. Although a number of studies have established that the consequences of providing care include depression, impaired health habits, and physical exhaustion [23], most studies focus on caregivers who provide care at home. Little is known about mental health outcomes among caregivers who have decided to place their care-recipient in a nursing home. It is also unclear whether there are differences in health outcomes between caregivers of institutionalized and noninstitutionalized individuals with dementia. The available evidence suggests that caring for an individual affected by AD can exert a considerable physical and mental toll; therefore, one can assume that caregivers who choose a nursing home placement are at a lower risk for depression and caregiver burden. A few studies, however, have shown that depression and caregiver burden can persist and even worsen after the placement of the care-recipient in a nursing home [24].

The current study examined mental health outcomes among caregivers of individuals with AD. Specifically, we assessed predictors of caregiver burden and depression and analyzed the differences between caregivers who chose to place a care recipient in a long-term care facility and those who continued to provide care at home. We anticipated that the residential location of a care-recipient (home vs. a nursing home) significantly impacts the caregiver's health outcomes. We hypothesized that providing in-home care would be associated with higher levels of depression and caregiver burden because these caregivers are more often exposed to behavioral problems and have more caregiving responsibilities than caregivers who chose to institutionalize a care recipient. To the best of our knowledge, no other study in Poland has analyzed the differences between caregivers based on the location status of their care-recipient.

MATERIALS AND METHODS

Procedure

Participants took part in this study on a voluntary basis. The materials were hand-delivered to the participants' homes or to 2 nursing homes located in Szczecin and Rokito (Poland). Eligible participants were at least 18 years of age and the primary caregiver to a care-recipient. In July through November 2019, participants were approached by a research assistant who explained the conditions of participation (including confidentiality and the right to withdraw from the study). Upon giving informed consent, participants completed questionnaires. There

were no financial incentives for participation. Prior to data collection, ethics approval for data collection was provided by the Institutional Review Board of the University of Szczecin (No. KB 7/2019). Primary analyses examined the distribution, means, and standard deviations. Differences between caregivers were examined using an independent samples t-test. Data analysis was conducted using SPSS 23.0.

Participants

A total of 100 caregivers completed the questionnaires. Of them, 50 caregivers provided care at home. Participants were 73% female and 27% male. Their age ranged between 34–77, with a mean age of 54.5 (SD = 9.83). All participants in this sample were Caucasian which reflects the composition of the geographical area.

Measures

Depression was assessed with the Polish version of the Beck Depression Inventory (BDI). The BDI is a 21-item self-reporting measure using a 4-point scale indicating the degree of severity. The items are rated from 0 (not at all) to 3 (extreme form of each symptom). The statements express feelings common in depression (e.g., sense of failure, guilt, low self-worth, and suicidal ideation). The score is calculated by adding the ratings for the 21 items together, with a maximum total score of 63. Higher scores indicate a higher severity of depression [25]. The psychometric analyses of the Polish translation indicated very high reliability and validity, are fully equivalent to the original version, and proved to be a very useful tool for use in scientific research and clinical practice to measure depression among Polish-speaking participants [26].

Caregiver burden was assessed using a questionnaire called the Subjective Caregiver Burden (Kwestionariusz Poczucia Obciążenia – KPO) [27]. The KPO is a 20-item instrument for measuring subjective burden in informal caregivers of individuals with dementia. The instrument consists of 4 subscales:

1. personal restrictions (measures the extent to which caregiving activities have impacted aspects of the caregiver's life, for example, lack of free time),
2. social and financial constraints (measures the extent to which social and financial aspects of life were altered or strained as a result of caregiving),
3. negative emotions (measures negative emotions that caregivers experience such as shame, guilt, anger, anxiety, or sadness),
4. fatigue – lack of control (measures the degree of caregiving satisfaction, feeling of losing control over one's life).

Each item is a statement that is rated on a 4-point scale with the values "never" (0), "sometimes" (1), "often" (2), and "always" (3). The result can be obtained for each of the subscales as a total score. The total score ranges 0–60 points, with higher values indicating a greater caregiver burden. Cronbach's alpha was satisfactory (0.70).

Caregiver's demographic characteristics

Caregiver demographics included the caregiver's age, kin relationship to the care-recipient (a son or daughter), number of

siblings, employment status, financial status (bad, average, good, very good), education, duration of care (in months), and housing situation (institutionalized vs. noninstitutionalized). Education consisted of 3 categories: less than a high school diploma, high school graduate or equivalent, and college degree or higher. If care was provided at home, we asked whether the caregiver and care-receiver resided in flat/house or if they lived separately and if they had ever considered placing a parent in a nursing home. Caregivers were also asked to rate their care-recipient's mental and physical health on a scale from 1 (very poor) to 5 (very good). The demographics of the care-recipients were also collected and included age, gender, and educational attainment.

RESULTS

The means and standard deviations for all variables stratified by care-recipient location are presented in Table 1. The majority of caregivers ($n = 77$) lived in an urban area and 23 lived in a rural area. Daughters accounted for 73% of the sample and sons for 27%. The majority of caregivers (84%) reported working and only 16% were unemployed. In regard to their educational attainment, 38% had attained a bachelor's or higher degree and 45% had graduated from high school. Being in a bad financial situation was reported by 2% of caregivers, 8% reported to be in a very good financial situation, and the majority were either in an average (49%) or good (41%) situation. Of the total sample, 24% of the caregivers reported being an only child, 34% had a sibling, 20% had 2 siblings and 22% had more than 2 siblings. Care-recipients were 81.7 years old on average (standard deviation = 8.58, range 57–103) and the majority of them were female (82%).

Care-recipients who resided in a nursing home ($n = 50$) were there for 25 months on average (2 years and a month). The majority of caregivers reported visiting their parents twice a week.

Among caregivers who provided care at home ($n = 50$), 14 respondents stated that they were considering placing a care-recipient in a nursing home at some time in the future, whereas the majority ($n = 32$) stated that they would not choose this option. Four caregivers were undecided.

Caregivers' well-being

The survey also addressed caregiver burden and levels of depression among respondents. The preliminary results revealed that data were not normally distributed. Therefore, in order to determine whether or not caregivers differed significantly on the key study variables, Shapiro–Wilk tests were calculated.

Caregivers who decided to place a parent in a nursing home reported significantly lower levels of overall subjective

caregiver burden than caregivers who provided care at home, $t(98) = 2.884$; $p = 0.004$. In terms of the specific subscales of caregiver burden, significant differences were observed in the personal restriction and social and financial constraint subscales; caregivers who provided care at home felt that caregiving activities had impacted their personal, social and financial lives to a greater extent than caregivers who chose to place a parent in a nursing home. No statistically significant differences were found in caregivers' levels of depression, $t(98) = 0.308$; $p = 0.379$ (Tab. 2).

TABLE 1. Sample characteristics

Variable	All caregivers $n = 100$	Caregivers (at home) $n = 50$	Caregivers (nursing home) $n = 50$
	M (SD)	M (SD)	M (SD)
Age (in years)	54.5 (9.83)	56.5 (9.16)	52.58 (10.18)
Gender – n (%)			
male	27 (27)	14 (28)	13 (26)
female	73 (73)	36 (72)	37 (74)
Education – n (%)			
less than high school diploma	17 (17)	2 (4)	15 (30)
high-school graduate	45 (45)	20 (40)	25 (50)
college degree and higher	38 (38)	28 (56)	10 (20)
Employment status – n (%)			
employed	84 (84)	40 (80)	44 (88)
unemployed	16 (16)	10 (20)	6 (12)
Financial situation – n (%)			
bad	2 (2)	1 (2)	1 (2)
average	49 (49)	27 (54)	22 (44)
good	41 (41)	17 (34)	24 (48)
very good	8 (8)	5 (10)	3 (6)
Care-recipient's age (years)	81.74 (8.58)	82.08 (8.62)	52.58 (10.18)

Each item is a statement that is rated on a 4-point scale with the values “never” (0), “sometimes” (1), “often” (2), and “always” (3). A higher value of BDI indicates higher levels of depression.

Caregiver burden and depression among caregivers (n = 100)

Variable		M	SD	W	p	t(98)	p
KPO	home	22.36	11.43	0.952	0.041	2.884	0.004
	nursing home	16.78	7.53	0.956	0.058		
KPOS1	home	8.86	4.90	0.976	0.401	3.758	<0.001
	nursing home	5.72	3.30	0.946	0.023		
KPOS2	home	6.38	3.94	0.945	0.021	2.675	0.004
	nursing home	4.48	3.11	0.918	0.002		
KPOS3	home	3.68	2.83	0.934	0.008	0.278	0.391
	nursing home	3.54	2.15	0.939	0.013		
KPOS4	home	3.44	1.66	0.957	0.067	1.223	0.112
	nursing home	3.04	1.62	0.875	0.005		
BDI	home	13.08	10.34	0.938	0.012	0.308	0.379
	nursing home	12.52	7.62	0.973	0.307		

KPO – Kwestionariusz Poczucia Obciążenia (the Subjective Caregiver Burden); KPOS1 – the 1st subscale of KPO, measures personal restrictions; KPOS2 – the 2nd subscale of KPO, measures social and financial constraints; KPOS3 – the 3rd subscale of KPO, measures negative emotions; KPOS4 – the 4th subscale of KPO, measures fatigue – lack of control; BDI – the Beck Depression Inventory, a measure of depressive symptoms

DISCUSSION

Caregiving has become an important issue in an aging society. Caregivers are essential for individuals with chronic health conditions; however, caring for a parent may be a stressful experience and lead to significant consequences for one's mental and physical health [28]. With an increasing number of older adults and an increasing prevalence of chronic health conditions, it becomes more critical for healthcare professionals to understand the challenges of caregivers who provide care to their disease-affected parents.

Our study builds on previous studies investigating the effects of care provided by familial caregivers. The purpose of this study was to assess the differences in caregiver burden and depression levels based on the caregivers' choice of care setting (home vs. nursing home). As we hypothesized, caregivers who provided care at home reported higher levels of subjective caregiver burden in comparison to caregivers who decided to place their parents in a nursing home. One possible explanation is that providing care at home is associated with more stressful situations. Caregivers often report struggling with the behavioral and psychological symptoms of dementia (BPSD) that include agitation, wandering, sleep disruption, disinhibition, irritability, and aggression [29]. In addition, caregivers who provide care at home have more responsibilities, such as feeding or bathing, than caregivers who choose

to institutionalize a care recipient. Therefore, the overall feeling of subjective burden can be higher. Some studies, however, demonstrated that placing a care-recipient in a nursing home does not significantly decrease the burden [30]. Perhaps such a solution is a source of additional stress because placing a care-recipient in a long-term care facility can be associated with a variety of feelings such as a sense of guilt. Further research is necessary to understand these discrepancies but the inconsistencies in the findings also emphasize how complex caregiver burden can be.

Although there were no significant differences in caregivers' levels of depression, both groups indicated a mild mood disturbance meaning that their scores were not considered normal, nor were they high enough to indicate clinical depression. These findings support previous research that found that caregivers report higher levels of depression [31] in comparison to the general population. This provides important information that can be used in the design of interventions to decrease depression among caregivers. Depression is a very serious condition and can negatively impact quality of care. Moreover, depressed caregivers are more likely to suffer from coexisting anxiety disorders, substance abuse or dependence issues, and are at risk for chronic health conditions [32]. Given the potential harm of depression, it is of growing importance for healthcare providers to learn more about recognizing the early symptoms of depression among caregivers and offer them resources before their symptoms worsen over time.

It is worth noting that even caregivers who choose to place their parent in a nursing home may have higher levels of depressive symptoms. This is consistent with previous findings which also demonstrated depressive symptoms and anxiety were not resolved after placing a care-recipient in a nursing home [33]. Some studies demonstrated that caregivers report higher levels of depression and loneliness during the care-recipients' first 3 years of institutionalization than non-caregivers [34]. Unfortunately, healthcare professionals often assume that if a care-recipient is taken care of in a nursing home, the caregiver's symptoms of burden and depression diminish. Our findings demonstrate that caregivers who choose to place a parent in a nursing home should also be screened for depression and provided with information about support.

The current study also provides insight into caregivers' plans of continuing to provide care. When asked if participants had ever considered placing a parent in a nursing home, the majority of caregivers declared that they would not take this option into account. Previous studies demonstrated that this is a common finding among Polish caregivers. One study demonstrated that caregivers believed that an admission to a nursing home would cause a quicker deterioration of the care-recipient's physical and mental health [35]. This draws attention to how important the commitment to caring for a parent is for Polish caregivers. Future studies should address the factors that influence a caregiver's decision to place a parent in a nursing home.

There are several restrictions of this study that should be noted. Firstly, the findings of this study could be limited by the fact that the sample size consisted of individuals who resided

in Poland, which limits the ability to generalize the results of this study to a broader population of caregivers. Secondly, we could not compare gender differences in the prevalence of depression and caregiver burden because the majority of participants were female. However, this is consistent with previous studies as, across the world, women are the predominant providers of informal care for older adults. Finally, our sample was relatively small and included caregivers from a wide range of ages (34–77 years old). Additional studies are necessary to compare younger vs. older caregivers.

To conclude, this study contributes to the literature of caregiving by comparing 2 groups of caregivers. We found that caregivers who provided care at home experienced higher levels of burden than caregivers who chose institutionalization. The study emphasizes the need for intervention to help caregivers cope with the strains of providing care and to decrease levels of depression.

Declaration of conflicting interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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