

Quality of life, severity of burden and sleep disturbances among caregivers of people with dementia

Jakość życia, poczucie obciążenia oraz zaburzenia snu u opiekunów osób z demencją

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Abstract

Introduction: Aim of the study was to evaluate factors contributing to the quality of life (QoL) of caregivers of people with dementia. A number of previous studies have indicated different lower QoL predictors. However, the multidimensional approach was needed to assess aspects rarely taken into account: quality of sleep and individual resources such as locus of control. In our study, the QoL predictors were divided according to the traditional approach into subjective and objective factors.

Material and methods: Forty-eight caregivers of patients with dementia took part in the study. Caregivers responded to the Barthel Index (BI), Zarit Burden Interview (ZBI), General Quality of Life (QoL), Levenson Locus of Control Brief Scales (LOC-Brief) as well as the Hospital Anxiety and Depression Scale (HADS).

Results: The present study revealed a strong negative correlation between the quality of the caregiver's life and time spent on caring duties ($r = -0.68$). Also, the severity of depression symptoms ($r = -0.83$) presents a strong negative correlation with the quality of the caregiver's life, whereas the quality of sleep correlates moderately with life quality ($r = -0.47$). A strong positive relationship of the depression symptoms ($r = 0.75$) and caregiver's burden was found in the sample. The severity of the burden and depression symptoms significantly lower the caregiver's quality of life ($R^2 = 0.71$).

Conclusions: The findings suggest that more severe depression symptoms were the most important predictor of low QoL. Furthermore, sleep difficulties contributed to poorer QoL. Caregivers' burden did not predict QoL.

Key words: caregiver's burden, quality of life.

Introduction

Dementia is a broad category including chronic and progressive diseases caused by brain alterations

Streszczenie

Wstęp: Celem pracy była ocena zmiennych wpływających na jakość życia (*quality of life* – QoL) opiekunów osób z otępieniem. Wcześniejsze badania wskazują na różne predyktory niskiej QoL. Potrzebne jest jednak wielowymiarowe podejście, aby ocenić inne, rzadko brane pod uwagę czynniki: jakość snu oraz indywidualne zasoby, takie jak poczucie kontroli. W badaniu wykorzystano tradycyjny podział na subiektywne i obiektywne predyktory poczucia obciążenia.

Materiał i metody: W badaniu przekrojowym wzięło udział 48 opiekunów osób z otępieniem. Wykorzystano wskaźnik Barthela (BI), *Kwestionariusz poczucia obciążenia Zarita* (ZBI), ogólną jakość życia (QoL), *Krótką skalę umiejscowienia kontroli Levensona* (LOC-BRIEF) oraz *Szpitalną skalę lęku i depresji* (HADS).

Wyniki: Uzyskane wyniki wskazują na silny negatywny związek pomiędzy jakością życia opiekunów oraz czasem poświęcanym na obowiązki opiekuńcze ($r = -0.68$). Wykazano, że z jakością życia opiekunów silnie negatywnie ($r = -0.83$) koreluje nasilenie objawów depresji, podczas gdy jakość snu koreluje na średnim poziomie ($r = -0.47$). Zaobserwowano silny pozytywny związek między objawami depresji i poczuciem obciążenia w badanej grupie ($r = 0.75$). Nasilonie poczucie obciążenia i objawów depresyjnych znacząco obniża jakość życia opiekunów ($R^2 = 0.71$).

Wnioski: Nasilenie objawów depresyjnych było najważniejszym predyktorem QoL. Problemy ze snem przyczyniają się do niższego QoL. Poczucie obciążenia nie było predyktorem QoL.

Słowa kluczowe: poczucie obciążenia opiekunów, jakość życia.

affecting cognitive processes, behaviour, personality and daily living activities. Caregivers of people diagnosed with dementia are usually close relatives such as spouses or children. Family members who

are informal carers are vulnerable to experiencing more stress and feeling of burden (Freeman *et al.* 2010). Caregiver's burden is a complex phenomenon defined as a negative appraisal and perceived stress caused by taking care of an affected relative. The high level of perceiving burden may lead to worsening physical, psychological, emotional well-being, and physical health (Brodaty and Donkin 2009; Zarit *et al.* 1980).

Caregivers frequently report having a poor quality of life (QoL) and mood disorders such as depression. Moreover, carers often suffer from cardiovascular diseases and report general health impairment (Molyneux *et al.* 2008; Serrano-Aguilar *et al.* 2006). Furthermore, high prevalence of sleep disturbances among carers (Byun *et al.* 2016; Gehrman *et al.* 2018; Song *et al.* 2021) has been reported in previous studies. Also, the literature suggests that approximately two-thirds of carers declare disrupted sleep patterns as a consequence of depression. Moreover, it is very often linked to changes in the day/night functioning of the care recipient such as uncontrolled nocturnal awakening and increased activity at night (Creese *et al.* 2008). Sleep disorders may constitute an important source of objective caregiver burden (McCurry *et al.* 2007; McKibbin *et al.* 2005). Additionally, other consequences of providing care for residents with dementia, such as depression and tiredness, can also decrease the quality of caregiver's sleep (Cross *et al.* 2018).

In response to all categories of the negative consequences of caregiver burden, there have been identified predictors of experiencing caregiver burden. Feeling stressed depends on a variety of factors including socio-economic status, the relationship between carer and care-recipient, the severity of the disease (physical health and cognitive disorders), and psychological resources (Carretero *et al.* 2009; Eppers *et al.* 2008; Schulz and Martire 2004). The actual level of cognitive functioning is also a significant determinant of the degree of burden experienced by caregivers, due to a lack of or minimized independence in daily living activities in individuals with dementia (Kang *et al.* 2014). Furthermore, the psychological resources should be taken into account in the development of the caregiver's burden. Locus of control was found to be an important factor related to subjective caregivers' stress intensity. Carers with an internal locus of control believing in exercising control of life events are likely to feel less burden (Bruvik *et al.* 2013a). In the current study, predictors were divided into two categories: objective and subjective factors contributing to

the caregiver burden. The objective burden is defined as the observable cost of caregiving and as opposed to the subjective burden is the caregiver's appraisal of the current difficulties resulting from all aspects of caring. The subjective and objective division is according to the traditional approach to caregiver's studies (Hughes *et al.* 2014).

Summarizing findings from previous studies, there is a knowledge gap in the multidimensional approach to caregivers' burden and their declared quality of life. We aimed to verify the relationship between objectively measured impairment in daily functioning among people with dementia and consequently their lesser autonomy. We combined it with the caregiver's psychological resources such as internal locus of control and less frequently verified consequences of carers' duties such as sleep disorders.

Hence, we hypothesized that:

H1: The quality of life of caregivers having a more external locus of control while experiencing a more severe burden will be lower, and the intensity of anxiety and depression symptoms will be higher, compared to caregivers characterized by a more internal locus of control.

H2: Participants who look after less self-standing individuals with dementia will experience a lower quality of life and more unendurable anxiety and depression symptoms in comparison to caregivers who look after more self-sufficient individuals with dementia. Furthermore, there will be an interaction between subjective burden and the locus of control.

H3: The subjective predictors such as the amount of burden, locus of control, and severity of depression symptoms will account for the quality of the caregiver's life.

H4: The objective predictors such as the functional statuses of the individuals with dementia, time devoted to the caring duties, and the quality of sleep will account for the variability in caregiver's life quality.

H5: The severity of the depression symptoms and the quality of sleep will account for the quality of life of the caregivers. Also, there will be an interaction between the quality of sleep and the severity of the depression symptoms.

Material and methods

Participants and procedure

To examine the role of caregivers' psychological dispositions and attempting to measure their burden, we conducted a study using the survey-based methodology. We collected data from October 2018 to April 2019. Caregivers were

recruited in non-profit organizations in Gdańsk supporting caregivers, in the hospital in Bydgoszcz and in The Greater Poland Alzheimer's Association. Of the 75 surveys collected, 27 with missing data were eliminated. The final analytic sample comprised 48 caregivers providing day-to-day care of older adults, diagnosed with dementia according to ICD-10 criteria (valid in Poland). The study protocol was approved by the Ethics Committee at the Institute of Psychology at the University of Gdańsk. Participation in the study was voluntary.

Instruments

We used an authorial questionnaire to ascertain some basic demographic information and to collect data on how many hours are allotted for taking care of individuals with dementia. Moreover, a question on how many years the caregivers had been fulfilling their duties was included. We also asked about the affinity between care providers and the patients with dementia. Unlike many previously conducted studies, we intended to investigate the role of the caregiver's quality of sleep.

Barthel Index

The functional status was measured with the 10-item Barthel Index (BI) to assess individuals with dementia' limitations in various daily activities, including bathing, feeding, toilet use, ascending and descending stairs, dressing, bladder control, moving from a wheelchair to bed and returning, and walking on a flat surface. The total BI score ranges from 0 to 100, with higher scores indicating less need for support. The satisfactory reliability and usefulness of the BI have been proven in numerous studies (Mahoney and Barthel 1965).

Zarit Burden Interview

The Zarit Burden Interview (ZBI) is a commonly used questionnaire enabling self-assessment of the burden caused by performing daily duties as a caregiver. The original ZBI contains 22 items rated on a five-point Likert scale (0 = *not at all*, 4 = *extremely*). In the present study we used the Polish adaptation of the ZBI (unpublished manuscript). The ZBI adapted to Polish sociocultural conditions also included 22 questions with a five-point Likert scale. The Cronbach's α obtained in the Polish sample ranged from 0.87 to 0.93, suggesting satisfactory reliability of the scale.

General Quality of Life

Ten questions assessing the subjective quality of life, rated on a nine-point Likert scale (1 = *very dissatisfied*, 9 = *very satisfied*). Questions were taken from the WHOQOL Brief scale (Skevington *et al.* 2004). The scales have shown good validity and reliability in previous research (Atroszko *et al.* 2015; Atroszko *et al.* 2018).

Levenson Locus of Control Brief Scales (LOC-Brief)

Seven questions assessing to what extent one's locus of control (powerful others factor) is internal versus external. The higher the score is, the more internal is one's locus of control. A six-point Likert scale was used (1 = *totally disagree*, 6 = *entirely agree*). The LOC has presented satisfactory utility and good reliability in previous research (Atroszko 2015).

Hospital Anxiety and Depression Scale

A commonly used measure allowing one to determine the intensity of anxiety and depression symptoms one is suffering from. The Hospital Anxiety and Depression Scale (HADS) includes sixteen items rated on a four-point Likert scale (0 = *rarely*, 3 = *very often*). In the present study, we used the modified version, adapted to Polish sociocultural requirements (Majkovicz 1994).

Firstly, the data were tested against normality. Then, the data were checked to ensure completeness of the cases and eliminate missing data. Next, descriptive statistics were performed for the given sample (Stanley 2021). In order to verify the above stated hypothesis, regression models were applied. Hypotheses 1, 2 and 5 required a multiple regression model with an interaction effect, between the subjective burden measured with ZBI and caregiver's locus of control. Testing hypotheses 3 and 4 required running separate multiple regression models. All of the presented statistical analyses were performed using the R software environment for statistical computing and graphics (RStudio, Open Source & Professional Software for Data Science Teams – RStudio, n.d.; The Comprehensive R Archive Network, n.d.).

Results

Analysed sample

In the analysed sample, 64% of the patients with dementia were diagnosed with Alzheimer's disease and 8% with Parkinson's disease.

The remaining 28% of the diagnoses were several other types of dementia. Caregivers in the present study were a mean of (M) 54.62 years old (SD = 14.55). Daily time devoted to providing care was M = 12.05 (SD = 7.41) hours. Caregivers in the analysed sample have been taking care of their relatives for over four years (M = 4.52, SD = 2.66). In answer to the question: How do you rate the quality of your sleep from 0 to 10 (0 indicates excellent quality of sleep whereas 10 indicates poor sleep), the score was M = 6.62 (SD = 2.54) The remaining characteristics of the caregivers are presented in Table 1.

Table 2 displays the means, standard deviations and values of the correlation between variables used in the present study. The association between the number of hours caregivers allocate for their duties and the BI score is moderate and negative. Evidently, the less self-sufficient patients with dementia are, the higher the number of hours the caregiver must allot for care. The values of correlation coefficients suggest a very weak positive relationship between the number of hours devoted to care and subjective burden and a weak negative relationship between burden and the Barthel score. A strong negative association between burden and quality of life suggests the lower quality among caregivers experiencing a more severe burden. As demonstrated in Table 2, the locus of control is not significantly correlated with any other variable analysed in the present study. A strong positive relationship between burden and the anxiety and depression symptoms indicates that the more severe the burden is, the more intense are the symptoms. On the other hand, the strong negative correlation between anxiety and depression symptoms and the quality of life implies the evident exacerbation of the quality of life quality as anxiety and depression intensify. Additionally, a moderate negative correlation between the quality of sleep and the quality of life was revealed in the present study. Table 3 presents the data on the caregivers' sleep quality in the given sample.

Consistently with our anticipations and with previous research, the more severe the burden, the lower is the quality of the caregiver's life and the more intense are the anxiety and depression symptoms. Yet, hypotheses 1 and 2 were not confirmed, as neither the locus of control nor the BI was found to significantly predict the quality of life. Additionally, the interaction between predictors was insignificant. The model presented in Table 4 accounts for approximately 67% of the variability in the dependent variable attributed to the predictors.

Table 1. Characteristics of the caregivers in the given sample (N = 48)

Characteristic	n (%)
Sex (female)	40 (83)
Education level	
Secondary school	3 (6)
High school	20 (41)
Bachelor's degree	6 (12)
Master's degree	19 (39)
Marital status	
Single	6 (12)
Married	30 (62)
Cohabitation	2 (4)
Widow/widower	3 (6)
Divorced	7 (14)
Place of residence	
Rural area	10 (20)
A town with a population of fewer than 50,000 residents	7 (14)
A town with a population of fewer than 100,000 residents	7 (14)
With a population less than 250,000 residents	10 (20)
City with a population of more than 250,000 residents	14 (29)
Employment	
Unemployed, still in the course of studying	1 (2)
Unemployed	10 (20)
Working full-time	20 (41)
Annuity	1 (2)
Retirement	16 (33)
Economic status	
Very good	1 (2)
Good	16 (33)
Fair	21 (43)
Poor	8 (16)
Extremely poor	2 (4)
Affinity with the caregiver	
Wife/husband	9 (18)
Grandmother/grandfather	24 (50)
Mother/father	8 (16)
Sibling	1 (2)
Aunt/uncle	1 (2)
Mother-in-law/father-in-law	5 (10)
Main caregiver (yes)	25 (50)
Health condition	
Very good	1 (2)
Good	15 (31)
Fair	22 (45)
Poor	22 (20)

Table 2. Means, standard deviations, and correlations with confidence intervals of all the variables in the study

Variable	M	SD	1	2	3	4	5	6
1. Time devoted to care (in hours)	12.04	7.41						
2. BI	44.06	33.32	-0.31* [-0.54, -0.03]					
3. ZBI	70.15	16.86	0.08 [-0.21, 0.36]	-0.16 [-0.42, 0.13]				
4. QoL	47.69	12.92	-0.14 [-0.41, 0.15]	0.13 [-0.16, 0.40]	-0.68** [-0.81, -0.49]			
5. LOC	21.98	4.09	0.01 [-0.27, 0.30]	-0.16 [-0.43, 0.13]	0.18 [-0.11, 0.44]	0.00 [-0.28, 0.28]		
6. HADS	24.58	9.89	0.04 [-0.25, 0.32]	-0.23 [-0.48, 0.06]	0.75** [0.59, 0.85]	-0.83** [-0.90, -0.72]	0.08 [-0.21, 0.36]	
7. Quality of sleep	6.62	2.54	0.15 [-0.14, 0.41]	-0.15 [-0.41, 0.15]	0.26 [-0.03, 0.50]	-0.47** [-0.66, -0.21]	0.04 [-0.25, 0.32]	0.54** [0.30, 0.71]

M and SD are used to represent mean and standard deviation, respectively. Values in square brackets indicate the 95% confidence interval for each correlation. * $p < 0.05$, ** $p < 0.01$

In order to verify hypothesis 3, how the subjective predictors account for the quality of life of the caregivers, we performed regression analysis including quality of life as the dependent variable. The model fits the data reasonably well, with the R^2 equal to 0.71. It means that more than 71% of the quality of the caregiver's life is explained by the subjective predictors incorporated into the regression model. However, only the severity of depression symptoms was found to be a significant predictor ($\beta = -0.94^{**}$) (Table 5). The multiple regression model conducted to test hypothesis 4 presents a rather a poor fit to the data, explaining about 23% of the variability in life quality among caregivers accounted for by the objective predictors. Importantly, the quality of sleep proves to be a highly relevant predictor. As we stated in hypothesis 5, the lower the quality of sleep, the worse is the quality of life. The results of linear regression with an interaction effect suggest that both quality of sleep and the severity of depression symptoms hinder the quality of life. However, only the severity of depression symptoms proved to be a significant predictor ($\beta = -2.30^{**}$). The interaction effect is insignificant ($p = 0.00$). The model with two predictors explains about 70% of caregiver's quality of life ($R^2 = 0.667$).

Discussion

Despite the number of previous scientific reports indicating that the quality of life of caregivers of people with dementia has decreased,

Table 3. Sleep disruptions and disturbances in the analysed sample (N = 48)

	n (%)
Morning fatigue (tired after sleeping)	26 (54)
Falling asleep with no regular pattern	21 (43)
Sleeping time with no regular pattern	19 (39)
Falling asleep lasting longer than 30 min	19 (39)
Poor quality of sleep	27 (56)
Sleeping less than 6 hours per day	24 (50)
Excessive daytime sleepiness	24 (50)
Naps during the day	11 (22)
Waking up with no regular pattern	7 (14)
Anxiety dreams	13 (27)
Previous episodes of sleep disorders	5 (10)
Light sleep	18 (37)
Waking up early in the morning	14 (29)
Difficulty staying asleep at night	18 (37)
Sleeping more than 10 hours per day	0 (0)

Table 4. Regression results using quality of life as a dependent variable

Predictor	b	b 95% CI [LL, UL]	sr ²	sr ² 95% CI [LL, UL]	Fit
ZBI	-2.61***	[-7.35, 2.14]	0.01	[-0.03, 0.05]	
BI	-0.82	[-5.73, 4.09]	0.00	[-0.01, 0.01]	
LOC	0.87	[-1.08, 2.83]	0.01	[-0.02, 0.04]	
HADS	-0.45***	[-1.90, 1.00]	0.00	[-0.02, 0.02]	
LOC*ZBI	-0.03	[-0.10, 0.04]	0.01	[-0.02, 0.03]	

 $R^2 = 0.669^{**}$

A significant *b*-weight indicates the semi-partial correlation is also significant. *b* represents unstandardized regression weights. *sr*² represents the semi-partial correlation squared. LL and UL indicate the lower and upper limits of a confidence interval, respectively.

p* < 0.05, *p* < 0.01

Table 5. A regression model with subjective life quality predictors

Predictor	b	b 95% CI [LL, UL]	sr ²	sr ² 95% CI [LL, UL]	Fit
ZBI	-0.12	[-0.31, 0.07]	0.01	[-0.02, 0.04]	
LOC	0.28	[-0.25, 0.80]	0.01	[-0.02, 0.03]	
HADS	-0.94**	[-1.27, -0.62]	0.23	[0.07, 0.39]	

 $R^2 = 0.710^{**}$

A significant *b*-weight indicates the semi-partial correlation is also significant. *b* represents unstandardized regression weights. *sr*² represents the semi-partial correlation squared. LL and UL indicate the lower and upper limits of a confidence interval, respectively.

p* < 0.05, *p* < 0.01

according to our knowledge, there is no report on factors influencing the quality of life of caregivers including sleep difficulties and psychological resources at once. This study was designed to assess the associations between caregivers' quality of life. Moreover, the traditional approach to caregiver's related variables divided into subjective and objective variables (Modi *et al.* 2020) was analysed. The objective factors were functional abilities and daily independence of people with dementia, time devoted to care, and caregiver's sleep patterns. The subjective predictors included selected aspects demanding the caregiver's individual appraisal of the current situation such as the feeling of burden, declarative severity of depressive symptoms, and locus of control (Fig. 1).

Hypothesis 1 was not confirmed as the external locus of control was not found to significantly account for severity of caregiver's burden. Based on previous studies, we assumed that the feeling of burden and quality of life also depend on subjective psychological resources, such as locus of control, but the result from the current study is not consistent with other reports (Möller-Leimkühler and Wiesheu 2012; Zampieri and Pedroso de Souza 2011). It can be explained by the fact that the LOC-Brief questionnaire used

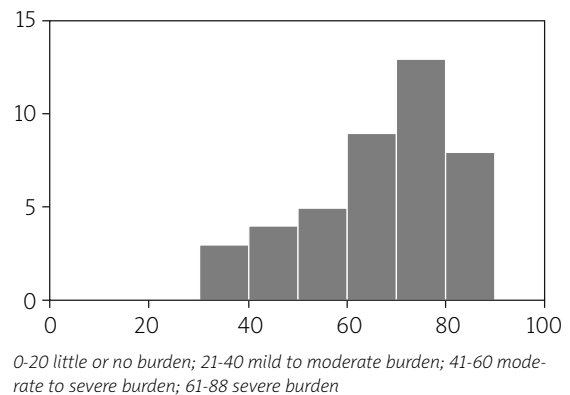


Fig. 1. The histogram of the caregivers burden in the analyzed sample.

in the current study based on Levenson's concept consists of two factors: Internal Control and Powerful Others. Generally, a person believing that most life events happen as a result of their own characteristics and actions is classified as having an internal locus of control (Levenson 1974, 1981). However, people declaring their belief in control by powerful others may also perceive most life events as purposeful actions simultaneously. Therefore, based on Levenson's theory, caregivers demonstrating the external orientation may be cognitively different from

people believing in an unpredictable world. Perceiving life occasions under one's control might be related to the requirements of cooperation with medical staff in providing the care. Paradoxically, according to Contador *et al.* (2015), external locus of control is associated with a can-do attitude, and the initiative to visit dementia centres dedicated to support people with dementia. This willingness to seek professional help and support services may contribute to lowering caregiver burden. Nevertheless, further research is needed to deepen the knowledge on locus of control and other psychological resources.

The obtained results also did not support hypothesis 2. Patients' autonomy is not related to caregivers' low quality of life and the intensity of depression and anxiety symptoms. Furthermore, we did not observe any significant interaction between subjective burden and the locus of control. This is not in line with our assumptions and results of previous studies (Bruvik *et al.* 2013b; Kim *et al.* 2012). However, according to Lazarus and Folkman and consistently with the basic stress model, objective events do not induce stress automatically. The rise in stress depends on one's event appraisal as stressful or not (Folkman 2013; Lazarus and Folkman 1984). This outcome points to the importance of subjective perspective equally with objective factors (e.g. sleep duration or material status) contributing to caregivers' burden. From this point of view the classical division into subjective and objective variables is not clear and sufficient, because every factor classified as objective may be mediated by other elements such as internal personal resources, social support or financial factors. As a result, the individual situation of the caregiver is the combination of interdependence between personal resources and situational factors. This leads us to the conclusions, applicable in designing future research. It would be valuable to take into account possible mediators and create holistic models.

Hypothesis 3 was only been partially confirmed. Consistently with our expectations, lower quality of life was associated with more severe depression symptoms and caregiver's subjective burden. Depression was the most significant factor contributing to the caregiver's quality of life. This result is in line with findings from reports assessing QoL in patients with neurodegenerative disorders (Kudlicka *et al.* 2014). Supposedly, depression is an overall powerful predictor of QoL, not specific for caregivers of people with dementia, because comparable effects are observed in other samples and contexts,

inter alia in nephrology and multiple sclerosis research (Fruewald *et al.* 2001; Ibrahim and El Salamony 2008). Nevertheless, depression may be considered as a potential consequence of a severe caregiver's burden, which has been demonstrated in a number of studies (Epstein-Lubow *et al.* 2008; Gaugler *et al.* 2010). According to Clair, Fitzpatrick and La Gory (Clair *et al.* 1995), feeling of burden and depression have other correlates. The burden is primarily related to acute stressors, whereas depression, as a subjective factor, is the final result. Researchers (Pinquart and Sörensen 2003) in their meta-analysis found that depression among dementia caregivers is more frequent than among caregivers of nondemented (physically) impaired patients. Also, depression among carers is strongly related to cognitive impairments and behaviour changes – typical difficulties observed in people with dementia. However, our results showed no relationship between activities of daily living and caregiver burden, regardless of disrupted activities of daily living, severe cognitive difficulties of individuals with dementia or stage of the illness. Hypothesis 4 was partially confirmed.

Hypotheses 4 and 5 were not confirmed. Only the poor quality of sleep proved to significantly lower the quality of caregivers' life. In line with our results, sleep deprivation and disturbances have been proved to hinder one's well-being in numerous previous studies (Gao *et al.* 2019). Other objective predictors included in our study, such as the level of independence of the individual diagnosed with dementia or the time devoted to care, did not significantly account for explaining the caregiver's quality of life's quality. Possibly, as we suggested before, the individual assessment of life situations accounts for the most variability in caregivers' quality of life, not the objective indicators measured in the present study. We suppose that coping strategies play a crucial role as mediator between quality of life and objective predictors (Wang *et al.* 2020). Consistently with this finding, the subjective burden seems to be the most important predictor of distress experienced by families of the mentally ill (Kaplan *et al.* 1987). Our study revealed a positive correlation between sleep quality, higher caregiver's burden, and lower QoL. Multiple explanations might be considered as mechanisms of this relationship. First of all, there is an objective lack of sleep caused by supporting care recipients at night during their awakenings and their insomnia (Bliwise 2004). Secondly, caregivers may be stressed and sleep under the constant pressure of potential

calling for help. Consequently, poor quality of sleep leads to negative effects (Brummett *et al.* 2005), which account for more severe depression symptoms.

Summing up, the caregiver burden is a complex and heterogeneous phenomenon. Even when the declared level of burden is not very high, it may explicitly worsen the quality of life as a result of poor sleep quality and depression.

Implications of the study

Our study indicates the most important caregiver's support areas, thus allowing for a better understanding of the mechanisms behind family members' lower QoL. Considering the important role of depression in decreasing caregiver's life quality, accurate psychological and psychiatric interventions should be implemented. The previous studies showed that the undertaken therapeutic actions among carers proved successful, resulting in reduced depression symptoms, lower anxiety levels, and higher sleep quality. The previous findings proved the effectiveness of different sorts of interventions: cognitive and behavioural therapy, psychoeducation and stress management, mindfulness, and multicomponent-based therapy in reducing negative psychological distress (Cheng *et al.* 2020; Pinquart and Sörensen 2003).

Limitation of the study

The study has a number of limitations and it needs to be taken into account during the interpretation of the outcomes. Firstly, there is possible sample bias due to the fact that some of the participants were recruited from Polish associations helping people with dementia and their caregivers. The members of such associations may receive more social support and be more educated. Furthermore, participation in the study was optional and volunteers may be more involved in the caring process. In addition, this research employed a small sample of caregivers and further studies are necessary to validate the results in larger groups. A larger sample would enable more advanced statistical analysis to be carried out, including structural modelling. Moreover, the LoC-Brief questionnaire has been widely used in personality psychology, but to our knowledge, this is the first attempt to employ this method in a study on caregivers. There is a need for future research on the usage of the LoC-Brief in caregiver's quality of life studies. Taking into account that the most important factor contributing to caregiver's low quality

of life was depression, it would be valuable to implement as a complementary objective measurement of mental disorders' psychiatric assessment. Additionally, including other possible caregiver's psychological resources and more caregiver-specific related variables should be considered in further caregivers' QoL projects.

The most important finding from this research is the crucial role of depression in lowering the caregiver's quality of life. Moreover, quality of sleep also seems to be an important factor contributing to lower QoL. At the same time, time devoted to care and activities of daily living did not prove to significantly predict the quality of life.

Disclosure

The authors declare no conflict of interest.

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