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Being a caregiver as a determinant of quality of life and as a contributor to depressive symptoms

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A – Study Design, B – Data Collection, C – Statistical Analysis, D – Data Interpretation, E – Manuscript Preparation, F – Literature Search, G - Funds Collection

Summary Background. Taking care of elderly, ill and disabled people, as well as rearing children alone, involve a number of medical, psychological, economic and social problems.

Objectives. The aim of this study was to assess QoL and the severity of depressive symptoms in nonprofessional caregivers compared to non-caregivers.

Material and methods. The study involved 460 (100%) participants, including 335 (72.8%) women and 125 (27.2%) men. The individuals were divided into two groups of the same size: a study group of 230 (50%) caregivers and a control group of 230 (50%) non--caregivers. 35.2% (n = 81) of the caregivers were taking care of an adult family member (parent, husband, wife, sister or brother), and 64.8% (n = 149) were mothers rearing children alone, of whom 91 women (19.8% of the whole study sample) were unmarried. The instruments employed in this study were the World Health Organization Quality of Life-Bref (WHOQoL-Bref) questionnaire, the Beck Depression Inventory and a questionnaire of our own devising.

Results. The caregivers (p = 0.001) had lower general QoL — the non-caregivers (control group) scored 4 points more for general QoL, which was associated with a difference in the scores for the WHOQoL-Bref physical health domain. There were statistically significant differences in general QoL (p = 0.031) and in QoL scores in the physical health domain (p = 0.043) between the subgroups of caregivers. Conclusions. Estimating the extent of non-institutional care and concern for the quality of caregivers' lives will improve the physical and mental functioning of both caregivers and those under their care.

Regardless of the nature of care, state of health and family relationships, caregivers should receive support from healthcare professionals, the local community, authorities and volunteers.

Key words: caregivers, quality of life, depression, aged.

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Background

Looking after elderly, ill and disabled people, as well as rearing children alone, entail a number of medical, psychological, economic and social problems. Being a caregiver can involve feelings of fatigue, a decreased sense of meaning in life and a lower quality of life (QoL), and thus can constitute a heavy mental burden [1-4]. Single parenthood, disease and elderly relatives can require care from family members, which is challenging on personal, professional, health and social levels [2–6]. The need to alter social roles and the functioning of the family, being overloaded with care duties and combining care with gainful employment are all factors that can cause tiredness, stress and emotional exhaustion. These symptoms can also be seen in single parents, where they are associated with organisational, economic, behavioural and existential problems [7]. There is no reliable data on the number of people looking after family members at home. Estimates show that such care in Poland is provided by about 2 million people. The vast majority of caregivers are women [8]. Eurocare, the European Parliament and the Europe 2020 Strategy have drawn attention to the lack of support available to those who help others and who thus substantially relieve the healthcare system and reduce the cost of care [9, 10].

Kedra et al. and Xie et al., who examined the QoL of caregivers, have emphasised the emotions that accompany provision of care, including anxiety, uncertainty, exhaustion and helplessness. They claim that an overload of care-related duties has a negative effect on caregivers' own health status, family and social functioning, as well as on the psychological, spiritual and socio-economic aspects of life. The sense of responsibility for those under care, fear for their health and lives, a lack of spare time, social isolation and the financial burden particularly worsen the quality of caregivers' lives [11, 12]. Other authors have emphasised that caregivers often endure disorders, such as lack of good mood, concentration problems, problems sleeping and depressive symptoms. Caregivers can suffer from somatic complaints, backache, joint pain, headache and cardiovascular disease (for example, elevated blood pressure) [5, 12, 13]. Another disorder that caregivers are often afflicted with is depression caused by psychological factors, lack of social support, inability to cope with stress, somatic diseases, problems at work and in private life and financial distress [14-16].

Objectives

The aim of this study was to assess QoL and the severity of depressive symptoms in non-professional caregivers compared to non-caregivers.

The following hypotheses were formulated:

- H1: lower QoL and more severe depressive symptoms are more often observed in non-professional caregivers than in the control group;
- H2: severe depressive symptoms decrease QoL in both groups.



Family Medicine & Primary Care Review 2020; 22(1)

Material and methods

Study design

This was a cross-sectional retrospective study.

Setting

The study was carried out from January to March 2018. It involved 460 residents of the West Pomeranian Province, Poland. The study was approved by the Bioethical Committee of the Pomeranian Medical University in Szczecin (approval no. KB-0012/20/16).

Participants

The study involved 460 (100%) participants, including 335 (72.8%) women and 125 (27.2%) men. Their mean age was 43.09 ± 19.74 . The individuals were divided into two groups of the same size: a study group of 230 (50%) caregivers and a control group of 230 (50%) non-caregivers. 35.2% (n = 81) of the caregivers were taking care of an adult family member (parent, husband, wife, sister or brother), and 64.8% (n = 149) were mothers rearing children alone, of whom 91 women (19.8% of the whole study sample) were unmarried (Table 1).

The sole inclusion criterion was consent to take part in the study. The questionnaires were completed voluntarily and anonymously.

Data sources

The instruments employed in this study were the World Health Organization Quality of Life-Bref (WHOQoL-Bref) questionnaire, the Beck Depression Inventory and a questionnaire of our own devising.

The WHOQoL-Bref instrument measures QoL in the following broad domains: physical health, psychological health, social relationships and environment. The questionnaire comprises 26 items, rated on a five-point Likert scale (from 1 to 5 points), including two global items concerning QoL and health, respectively, and 24 items relating to the four domains. A maximum of 20 points can be obtained in each domain. The domain scores

are scaled in a positive direction, so that higher scores denote higher QoL, except in the case of questions 3, 4 and 26, which are scaled in a negative direction.

The severity of depressive symptoms was assessed using the Beck Depression Inventory, whose possible score ranges from 0 to 63 points. A score of 0–11 points denotes a lack of depressive symptoms, a score of 12–26 points indicates mild depressive symptoms, 27–49 points suggests moderate depressive symptoms, and 50–63 points refers to severe depressive symptoms.

Our own questionnaire included questions concerning socio-demographic data and caregiving. It provided information that was used to classify respondents as caregivers (the study group) or non-caregivers (the control group).

Statistical methods

Statistical analysis was performed using IBM SPSS Statistics 25. The Shapiro–Wilk test was applied to verify the normality of quantitative variable distribution. The non-parametric Mann–Whitney U-test was used to compare differences between two independent groups, the Z-test was used to check for a significant percent difference, and the Kruskal–Wallis H-test was employed to compare more than two groups. Comparison of the groups in terms of qualitative variables was performed using Pearson's chi-square test. Spearman's (rho) rank correlation coefficient for data, with non-parametric distribution, was used to measure the strength and direction of the association between two ranked variables. Statistical significance was set as p < 0.05.

Single gaps in responses were left uncompleted; when comparing the groups in terms of socio-demographic data, in some cases the sum of data in the table was not the same (n = 460).

Results

Hypothesis 1

Lower QoL and more severe depressive symptoms are observed in the group of non-professional caregivers.

The caregivers (p = 0.001) had lower general QoL: non-caregivers (control group) scored 4 points more for general QoL, which was associated with a difference in the scores for the WHOQoL-Bref physical health domain (Table 2).

Table 1. Socio-demographic data						
Variable		Total sample n = 460	Caregivers n = 230	Control group n = 230	Chi²; Z*	
Sex n (%)	women men	335 (72.8) 125 (27.2)	184 (80.0) 46 (20.0)	151 (65.7) 79 (34.3)	11.890 0.001	
Age, M (SD)		43.09 (19.74)	45.98 (12.62)	44.53 (22.17)	1.288 0.198	
Marital status n (%)	single married separated divorced widowed	143 (31.1) 181 (39.3) 15 (3.3) 66 (14.3) 55 (12.0)	35 (15.2) 113 (49.2) 12 (5.2) 49 (21.3) 21 (9.1)	108 (46.9) 68 (29.6) 3 (1.3) 17 (7.4) 34 (14.8)	52.442 < 0.001	
Place of residence n (%)	≥ 200 000 100 000–199 999 50 000–99 999 20 000–49 999 10 000–19 999 5 000–1 000 rural areas	135 (29.3) 35 (7.6) 59 (12.8) 40 (8.7) 53 (11.5) 89 (19.4) 49 (10.7)	62 (26.9) 12 (5.2) 42 (18.3) 23 (10.0) 32 (13.9) 43 (18.7) 16 (7.0)	73 (31.7) 23 (10.0) 17 (7.4) 17 (7.4) 21 (9.1) 46 (20.1) 33 (14.3)	24.626 < 0.001	
Education n (%)	primary vocational secondary tertiary	39 (8.5) 100 (21.7) 246 (53.5) 75 (16.3)	17 (7.4) 52 (22.6) 121 (52.6) 40 (17.4)	22 (9.6) 48 (20.9) 125 (54.3) 35 (15.2)	1.200 p = 0.753	

Chi² – a measure of the strength of an association in Pearson's chi-square test; Z – a measure of the strength of an association in the Mann-Whitney U-test; p – level of significance caregivers – single gaps in responses were left uncompleted; when comparing the groups in terms of sociodemographic data, in some cases the sum of data in the table was not the same (n = 460).

Table 2. QoL of caregiver and non-caregiver groups, as determined by the WHOQoL-Bref							
	Caregivers and control group altogether n = 460		Caregivers n = 230	Control group n = 230	Z	p	
	Min–Max	M ± SD	M ± SD	M ± SD			
General QoL	44–100	82.09 ± 13.03	80.10 ± 12.15	84.08 ± 13.59	-3.343	0.001	
Physical health	8–35	23.49 ± 4.96	21.61 ± 3.91	25.37 ± 5.18	-7.815	< 0.001	
Psychological health domain	9–30	20.51 ± 3.89	20.84 ± 3.50	20.17 ± 4.21	1.615	0.106	
Social relationships domain	3–15	10.65 ± 2.32	10.60 ± 2.28	10.70 ± 2.36	-0.609	0.543	
Environment domain	11–40	27.44 ± 4.90	27.04 ± 5.01	27.83 ± 4.76	-1.708	0.088	

Table 3. Comparison of the severity of depressive symptoms as determined by the Beck Depression Inventory and QoL determined by the WHOQoL-Bref between single mothers and caregivers of ill and disabled people

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	Mothers rearing their children alone n = 91	Other caregivers n = 139	Z	p		
	M ± SD	M ± SD				
Depressive symptoms	11.88 ± 9.36	11.49 ± 9.40	-0.543	0.587		
General QoL	78.87 ± 11.97	85.33 ± 16.21	-2.161	0.031		
Physical health domain	20.79 ± 3.40	22.13 ± 4.16	-2.028	0.043		
Psychological health domain	20.69 ± 3.59	20.91 ± 3.46	-0.376	0.707		
Social relationships domain	10.62 ± 2.34	10.57 ± 2.24	-0.094	0.925		
Environment domain	26.59 ± 5.17	27.31 ± 4.92	-1.139	0.255		

Table 4. Correlations between severity of depressive symptoms determined by the Beck Depression Inventory and QoL determined by the WHOQoL-Bref

Beck Depression Inventory	General QoL	QoL domains according to the WHOQoL-Bref					
		Physical health	Psychological health	Social relationships	Environment		
Total, n = 460	-0.712***	-0.536***	-0.621***	-0.536***	-0.594***		
Caregivers, n = 230	-0.682***	-0.530***	-0.601***	-0.523***	-0.566***		
Control group, n = 230	-0.743***	-0.611***	-0.658***	-0.548***	-0.618***		

^{***} p < 0.001.

Table 5. Analysis of correlations between the age and QoL of caregivers and non-caregivers							
Age		QoL domains					
		General	Physical health	Psychological health	Social relationships	Environment	
Caregivers	rho	-0.098	-0.009	-0.109	-0.132	-0.106	
	p	0.139	0.888	0.100	0.045	0.110	
Control group	rho	-0.137	-0.197	-0.055	-0.081	-0.137	
	р	0.038	0.003	0.410	0.225	0.039	

rho: Spearman's correlation coefficient; p – level of significance.

Being a caregiver had no effect on the severity of depressive symptoms (Z = 1.268, p = 2.205). The number of individuals with mild or moderate depressive symptoms in the study group and in the control group were similar (Chi²(2) = 0.024, p = 0.988).

We checked whether the fact of rearing children alone in the group of caregivers contributed to QoL and the severity of depressive symptoms (Table 3).

There were statistically significant differences in general QoL (p=0.031) and in QoL scores in the physical health domain (p=0.043) between the subgroups of caregivers. Single mothers assessed their QoL as lower.

Relationship between QoL and the severity of depressive symptoms

Hypothesis 2

Severe depressive symptoms decrease QoL in both groups. The severity of depressive symptoms in the study group was significantly related to every QoL domain (Table 3). Significant relationships were also observed between the study and the control groups (p < 0.001). The results of the Beck Depression

Inventory were strongly negatively correlated with the general QoL score and the QoL scores in particular domains — the more severe the depressive symptoms, the lower the QoL (Table 4).

The relation of QoL and severity of depressive symptoms with socio-demographic data

Marital status did not have an effect on either general QoL (H(4) = 4.508, p = 4320) or on QoL in the particular domains (p > 0.05). The analysis of depressive symptoms with regard to marital status showed that there was no difference between the study and the control groups. In the group of caregivers, the severity of depressive symptoms was the same for single, married, divorced and widowed participants (H(4) = 4.057, p = 0.398).

In the group of caregivers, there was a weak negative correlation between caregivers' age and their QoL in the social relationships domain (p=0.045). In the control group, there was a weak but significant negative correlation between age and QoL in the physical health (p=0.003) and environment (p=0.039) domains (Table 5).

Discussion

The results allow us to conclude that caregiving imposes a substantial psychological burden on caregivers and affects their QoL [9, 17]. Good physical and mental health of caregivers, as well as a high QoL, translate into good quality of care and, consequently, the wellbeing of those under their care [4, 18–21].

Our results verified the hypothesis that the role of a caregiver is associated with lower QoL, though only in the somatic sphere. We observed significant differences in the general QoL between both groups. Janowicz and Grabowska-Fudała et al., who studied those caring for chronically ill and untreatable family members, reported that the caregivers had lower QoL [9, 10]. Golińska and Bizan drew attention to impairments in physical, mental and social life realms. According to these authors, caregiver burden leads to a decline in health status, depression, the disruption of family life, impoverished social life and worse financial standing [5]. Nursing tasks, such as maintaining hygiene, changing the position of patients and helping them dress, eat and move all entail the necessity of heavy lifting and put a significant load on the spine. If caregivers do not know the principles of ergonomics in nursing, health consequences seem inevitable. Families of patients in need of care have to devote their lives to looking after them. As a result, they forgo rest and travel, limit cultural and social activities and often ignore their own health problems. Sleep deprivation, chronic stress, fear for the person under care and loss of energy can all disturb mental functions [22]. An important factor in the provision of care is age: the older the caregiver, the greater the psychological and physical burden. We observed that among caregivers, QoL in the social relationships domain decreased with the caregiver's age. Similarly, in the control group, QoL in the physical health and environment domains decreased with age. This trend has been confirmed by a social diagnosis based on a study of factors that determine the wellbeing of people in Poland [19]. A study of Dutch seniors [23] also suggested a connection between lower QoL and older age.

The study group mainly consisted of female caregivers (184, 80%), which resulted from the fact that some social roles (housekeeping, care of family members, etc.) are traditionally ascribed to women. Janowicz, Krawczyk-Wasielewska et al. and many other authors have also noted that caregiving men are outnumbered by caregiving women [6, 8, 9, 11, 24].

In our investigation, caregiving did not increase the risk of depressive symptoms. In the study group, symptoms of depression were independent of caregiving, including when marital status was considered. Moderate depressive symptoms were observed in 8.9% of the participants.

In a study conducted in the USA, Coon and Evans demonstrated that caregivers were at risk of depression [16]. A similar relationship was also indicated by Mausbach et al. [25]. In a Chinese study, lower QoL was accompanied by severe depressive symptoms among those taking care of elderly, ill and disabled people [12]. Our analysis has shown that the severity of depressive symptoms is closely associated with QoL in all domains. A similar conclusion has been drawn by Humańska and Kędziora-Kornatowska, as well as by Neumann and Byrne [26, 27].

Conclusions

Estimating the extent of non-institutional care and concern for the quality of caregivers' lives will improve the physical and mental functioning of both caregivers and those under their care. Regardless of the nature of care, state of health and family relationships, caregivers should receive support from healthcare professionals, the local community, authorities and volunteers. It would be reasonable to develop standards that would identify the problems of people who take care of ill and disabled family members and to implement these in community-based care.

Recommendation

Since the number of people over 75 years of age who require constant care is growing, it seems reasonable to implement State subsidy programmes for non-professional caregivers.

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Family Medicine & Primary Care Review 2020; 22(1)

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Tables: 5 Figures: 0 References: 27

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