

Evaluating the burden of caregivers of chronic hemodialysis patients

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Abstract

Background: Chronic kidney disease demands continuous care, which affects the patients' caregivers.

Objectives: to evaluate the burden of these caregivers and to identify possible demographic and other determinants of it.

Design: a cross-sectional study was conducted in the General Hospital of Argolis, in the Nursing Unit of Molaon as well as in two private clinics in Nafplio and Loutraki in Greece. The duration of the study was 3 months (December 2020-February 2021).

Participants: the sample consisted of 250 caregivers.

Measurements: a composite questionnaire was used, which included demographic information, care-related information and the Zarit Burden Interview.

Results: the mean time of caregiving was 30 months, 6 days/week and 8 hours/day. The caregivers' burden was not high enough. The highest score was recorded in the Personal Strain. Widows/widowers had higher score than single caregivers on Personal Strain ($p=0.013$) and on Deprived Relations ($p=0.013$). The number of caregiver's children and hours per day on care were positively associated with Personal Strain, Role Strain and Deprived Relations. Days per week on care were positively associated with Personal Strain and Deprived Relations and the duration of the disease was positively associated with Management of Care. According to a linear regression analysis performed, the score on Role strain, Relationship strain and Management of Care was positively associated with the score on Personal Strain ($p<0.001$).

Conclusions: the burden of persons who take care of chronic hemodialysis patients is not high enough and several demographic variables (eg. gender) and characteristics of the care (eg. days per week on care) affect it significantly.

Keywords

Chronic kidney disease, burden, caregivers, hemodialysis

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1. Introduction

Chronic kidney disease (CKD), also known as chronic renal failure (CRF), is the irreversible deterioration of renal function that gradually progresses to end stage renal disease (ESRD) (1). It is a challenging diagnosis for patients and their health care teams (2). It is also an increasing health problem worldwide and is associated with a number of clinical challenges and significant morbidity and mortality (3,4). The course of chronic renal failure is generally progressive (5) and detection is often delayed because of the insidious nature of kidney failure and symptoms experienced by patients (2). The prevalence of moderate and severe chronic kidney disease is usually below 5% in the general population, but this percentage is often higher in specific groups of patients such as those with type 2 diabetes (6). The global increase in this disease is mainly driven by the increase in the prevalence of diabetes mellitus, hypertension, obesity, and aging. But in some regions, other causes such as infection, herbal and environmental toxins are still common (7).

Kidney failure patients have two treatment options: transplantation (live and deceased donor kidneys) and dialysis (hemodialysis or peritoneal dialysis). Management of chronic renal failure aims at retarding progression of renal damage and treatment of complications related to renal dysfunction. Once end stage renal disease supervenes, renal replacement therapy in the form of chronic peritoneal or hemodialysis and transplantation is necessary (1). Chronic kidney disease not only compromises the physical health of patients but it also affects their psychological health, daily functioning, general wellbeing and social functioning (8). Physical symptoms, distress, sleep disturbances and depression are common among patients with chronic renal failure (9). Through the progress of treatment, they may experience dialysis-associated symptoms, immense psychological distress and depression (10). This may be caused by the influences of physical symptoms, including diet limitations, treatment-induced fatigue, limited physical activity and muscle cramps (11). In addition, patients with advanced chronic kidney disease have a high symptom burden, similar to that experienced by patients with Chronic Heart Failure, Chronic Obstructive Pulmonary Disease or cancer. Most commonly, patients report high rates of fatigue, dyspnea, insomnia, pain, anxiety, and depression. These symptoms are often unrecognized and undertreated and greatly affect patients' health-related quality of life (HRQL) (12). Consequently, chronic renal disease demands specific, continuous and varied care, which affects the health of family caregivers (13). Care in patients is mainly provided by their wives/husbands or by their adult children (14). Caregivers often live in the same house with the patients and help them in many daily activities, like transportation to dialysis centers, symptom management, mobility, dressing, cooking, shopping etc (15).

The overall impact of physical, psychological, social, and financial demands of caregiving has been termed *caregiver burden*. It can be further differentiated into *objective burden* (events and activities associated with negative caregiving experience, practical consequences of physical and behavioral

changes of the care receiver) and *subjective burden* (emotional reactions, such as worry, anxiety, frustration and fatigue) (16). Caregivers face several health problems and psychological disorders are the health problems that are most mentioned (13). Depression is common and associated with conflict between caregiving responsibilities and work, poor caregiver health and fears about the future outcomes of relatives for whom they provide care (17). There are also negative effects in family relationships, in social life and in family income (18, 19). Several factors positively or negatively affect caregivers' physical health, such as age, gender, socioeconomic status, patient's behavioral problems, and level of informal social support (20).

Various demographic characteristics of the caregivers and the patients, as well as characteristics of the care have been found to be associated with the caregivers' burden (in several chronic diseases and especially in chronic kidney disease). Gender has been examined in many studies and female caregivers-who usually provide more immediate care-experience higher levels of burden and depression (21). In addition, male caregivers of persons with end stage renal disease often experience negative outcomes (17). Concerning the educational level, less educated caregivers report higher levels of depression (22). With regard to the relationship to the patient, family caregivers are emotionally involved with their care recipients and perceive a higher level of stress than non-family caregivers (23). Moreover, caregiving is more difficult for spouses than for adult children, because they are more likely to suffer from age-associated chronic illness. On the other hand, adult children are more likely than spouses to have alternative roles and social activities outside the home that might function as a buffer against severe and long-lasting caregiving stress (22). Caregivers who live in the same home with the patients are more likely to experience higher levels of stress than those who stay in another house (24). Furthermore, the patient's physical and behavioral health is often used as a measure of the caregiver's burden (25). However, other researchers argue that the caregiver's subjective burden has greater impact than patient's health status (26).

The aim of this study was to evaluate the burden of caregivers of chronic hemodialysis patients and to identify possible demographic and other determinants of it. Although caregivers' burden has been examined in many studies, the investigation of caregiver's burden in chronic kidney disease is a relatively neglected area of research. According to the authors' knowledge, this is one of the few studies investigating this field in Greece. According to the literature review, we hypothesized that:

- There are differences in the caregivers' burden based on their gender, marital status and educational level (hypothesis 1).
- Caregivers' age and number of their children are correlated with their burden (hypothesis 2).
- Time on care is correlated with caregivers' burden (hypothesis 3).
- The duration of the Chronic Kidney Failure is associated with caregivers' burden (hypothesis 4).

2. Method

2.1. Design

A cross-sectional study was conducted with a sample of 250 caregivers of chronic hemodialysis patients in the General Hospital of Argolis, in the Nursing Unit of Molaon as well as in two private clinics in Nafplio and Loutraki. The duration of the study was 3 months (December 2020-February 2021). The selection of the sample held by random sampling of the caregivers of the patients who came in the above settings.

The participants were selected based on the following eligibility criteria: 1) male-female caregivers with sufficient ability to understand and respond to the questionnaire; 2) ability to speak-understand the Greek language; 3) persons wishing to participate voluntarily in the research. Caregivers who did not wish to participate voluntarily in the research and those who were unable to respond to the questions were excluded from the study.

A composite questionnaire was used. The first part included sociodemographic data and information about the relationship of the caregiver with the patient. The second part consisted of The Zarit Burden Interview.

Caregivers were informed in detail about the purpose of the study, were given an information sheet, signed the consent form and were included into the study.

Table 1. Demographic characteristics of the sample

	Frequency	Percentage %
Gender		
Man	93	37.2
Woman	157	62.8
Level of education		
Elementary school	61	24.4
Secondary school	37	14.8
High school	106	42.4
University	38	15.2
Msc, Phd	8	3.2
Job		
Civil servant	36	14.4
Private employee	54	21.6
Freelancer	48	19.2
Unemployed	49	19.6
Pensioner	63	25.2
Marital Status		
Single	50	20
Married	183	73.2
Separated/divorced	6	2.4
Widow/er	11	4.4
Having children		
Yes	188	75.2
No	62	24.8
Number of children		
0	62	24.8
1 child	66	26.4
2 children	46	18.4
3 children	75	30.0
Economic status		
Good	104	41.6
Medium	123	49.2
Bad	23	9.2

2.2. Participants

According to the eligibility criteria, 380 caregivers were selected to participate in the study and 250 of them accepted (response rate: 66%). Non-participation was mainly due to time constraints. There were 93 men (37.2%) and 157 women (62.8%) (%). The mean age of the participants was 52.5 years ($M = 52.55, SD = 15.53, Min = 18, Max = 83, Range = 65$). The demographic characteristics of the sample are presented in table 1.

2.3. Measures

2.3.1. Demographic Information

Participants reported their gender, age, marital status, level of education and job. They also reported the number of their children and their relationship with the patients (spouse, son, daughter etc).

2.3.2. The Zarit Burden Interview

It is a popular caregiver self-report measure, which consists of 22 items (27). It is a revised version of the original 29-item questionnaire. These items reflect the sentiments of the individuals who care old persons. Each item on the interview is a statement which the caregiver is asked to endorse using a 5-point scale. Response options range from 0 (Never) to 4 (Nearly Always). The total score is calculated by summing the scores of the items and ranges from 0 to 88. Higher scores reflect greater levels of caregivers' burden. Caregivers' burden consists of four dimensions, which include: role strain, personal strain, relationship deprivation and care management.

The factor structure of the Zarit Burden Interview is somewhat unclear. A number of researchers have suggested different models, but the most frequently mentioned is the two-factor model, addressing personal strain and role strain (28).

The Greek version of the Interview consists of four factors:

1. **Personal strain** (9 items), eg. "do you feel strained when you are around your relative?"
2. **Role strain** (7 items) eg. "do you feel angry when you are around your relative?"
3. **Deprived relations** (4 items) eg. "do you feel that you don't have as much privacy as you would like because of your relative?"
4. **Management of care** (2 items) eg. "do you feel that you should be doing more for your relative?"

This Interview has been translated in several languages (eg. Greek, Chinese, French, Japanese, German, Hebrew, Spanish, Korean, Hindi, Portuguese etc), demonstrating good psychometric properties. In this study the Greek version of the scale (29) was used and Cronbach's α was 0.92. With regard to the subscales, Cronbach's α was 0.80 for "personal strain", 0.82 for "role strain", 0.83 for "deprived relations" και 0.59 for "management of care".

2.4. Data analysis

The statistical program SPSS 26.0 was used for the analysis of data and the statistical significance level (p -value) was set to 5%. To examine the normality of continuous variables, the Kolmogorov-Smirnov test was used. The analysis included at first the descriptive statistics. Pearson's correlation coefficient

was used for the investigation of linear correlation among quantitative variables. Statistically significant differences in certain variables between two groups or more than two groups were checked by t-test for independent samples and ANOVA test, correspondingly. Multiple comparisons in ANOVA were performed by means of Bonferroni correction. Moreover, a hierarchical multiple linear regression analysis was performed, with Personal strain score as the dependent variable.

2.5. Ethics

An approval was sought from the hospitals' Research and Ethics Committee, which was granted. A signed informed consent was obtained from all research participants. All caregivers took part on voluntary basis and were not remunerated for their participation. They were given assurance of anonymity and confidentiality of the information provided and were informed that they could stop completing the questionnaire at any time if they wished. They were also assured that the collected data would be used only for the purpose of the study, and that their decision to withdraw would not compromise the standards of the care provided.

3. Results

The mean duration of the chronic kidney disease was ten years ($M=9.64$, $SD=9.25$, $Min=1$, $Max=15$, $Range=44$). The mean time of caregiving was 30 months ($M=30.75$, $SD=37.59$, $Min=1$, $Max=140$, $Range=139$), 6 days per week ($M=5.60$, $SD=2.03$, $Min=1$, $Max=7$, $Range=6$) and 8 hours per day ($M=7.76$, $SD=7.57$, $Min=1$, $Max=24$, $Range=23$). Several other characteristics of the caregiver and the care are presented in table 2.

Descriptive statistics for the Zarit Burden Interview 21 are presented in table 3.

With regard to the characteristics of the caregiver and the care, caregiver's health problems, sharing the care with other persons and caregiver's information /counseling about the disease didn't significantly affect the score on the Zarit Burden Interview.

On the contrary, the marital status of the caregiver significantly affected the score on Personal Strain [$F(3,240)=3.69$, $p=0.013$, $\eta^2=0.044$] and on Deprived Relations [$F(3,240)=2.65$, $p=0.013$, $\eta^2=0.032$]. Widows/widowers participants had significant higher score than single caregivers (see table 4).

The number of caregiver's children and hours per day on care were positively associated with Personal Strain, Role Strain and Deprived Relations. In addition, days per week on care were positively associated with Personal Strain and Deprived Relations and the duration of the CKD was positively associated with Management of Care. Significant intercorrelations were also recorded between the Zarit Burden Interview subscales (table 5).

Following the above findings, a hierarchical linear regression analysis was performed. Demographic characteristics (age, gender, having children, number of children), characteristics of the caregiver and the care (days per week on care, hours per day on care) and Role Strain, Deprived relations and Management of care score were classified as predictor variables in

block 1,2 and 3, respectively and score in Personal Strain was the resulting variable. The blocks were included in the model independently by stage. No evidence of multicollinearity among the variables was suggested producing tolerance levels over 0.1 and VIF (Variance Inflation Factor) values under 10. In addition, no evidence of outliers or influential points was suggested upon the examination of Mahalanobis and Cook distance, Centered Leverage Value and Dffits and DfBetas. The results of the hierarchical regression analysis are presented in Table 6.

The results of the above illustrated that the score on Role strain, Relationship strain and Management of Care was positively associated with the score on Personal Strain and this relationship was statistically significant ($p<0.001$). The proportion of variance in Personal strain score accounting for by all independent variables was equal to 0.752 (75.2%). The best predictor variable of Personal Strain score in the model was Score on Relationship Strain followed by Role Strain and Management of Care.

Table 2. Characteristics of the caregiver and the care

	Frequency	Percentage %
Relationship to the patient		
Husband	40	16
Wife	60	24
Son	53	21.2
Daughter	36	14.4
Grandson	1	0.4
Granddaughter	4	1.6
Brother	14	5.6
Sister	11	4.4
Nephew	3	1.2
Niece	6	2.4
Daughter in law	15	6.0
Son in law	5	2.0
Professional caregiver	2	0.8
Caregiver's residence in relation to the patient		
In the same house with the patient	160	64.0
In a house next door	46	18.4
In the same neighborhood	16	6.4
In another city / village	28	11.2
Caregiver's health problems		
Yes	54	21.6
No	196	78.4
Other persons in the home of the patient		
Yes	153	61.2
No	97	38.8
Sharing the care with other persons		
Yes	141	56.4
No	109	43.6
Caregiver's information / counseling about the disease		
Yes	150	60.0
No	100	40.0

Table 3. Descriptive Statistics for the Zarit Burden Interview

	Mean	SD	MIN	MAX	Range
The Zarit Burden Interview					
Total score	25.20	15.52	0	76	76
Personal strain	11.95	61.60	0	33	33
Role strain	6.30	5.24	0	24	24
Deprived relations	4.54	3.86	0	14	14
Management of care	2.55	1.82	0	8	8

Table 4. Descriptive statistics and differences between the demographic categories and the Zarit Burden Interview subscales

	The Zarit Burden Interview subscales							
	Personal strain	p	Role strain	p	Deprived relations	p	Management of care	p
Gender								
Man	11.18	NS	5.63	NS	4.24	NS	2.39	NS
Woman	12.41		6.70		4.73		2.64	
Marital status								
Single	10.80	0.013	5.38	NS	4.00	0.049	2.32	NS
Married	11.82		6.33		4.48		2.53	
Separated/divorced	16.00		7.50		5.67		3.50	
Widow/er	16.90		9.27		7.45		3.27	
Level of education								
Elementary school	11.79	NS	11.95	NS	4.54	NS	2.52	NS
Secondary school	14.51		5.51		5.46		2.47	
High school	11.12		7.84		4.15		2.41	
University	11.76		6.06		4.50		2.95	
Msc, Phd	13.50		6.37		5.63		2.88	
Having Children								
Yes	12.16	NS	6.45	NS	4.71	NS	2.53	NS
No	11.28		5.82		4.03		2.59	

Note: NS= No significant

Table 5. Correlations and intercorrelations for the Zarit Burden Interview subscales

	The Zarit Burden Interview subscales			
	Personal strain	Role strain	Deprivedrelations	Management of care
Age	.093	.079	.089	-.082
Number of children	.166*	.162*	.151*	.058
Months on care	-.086	-.053	-.095	.026
Days per week on care	.145*	.101	.142*	.065
Hours per day on care	.132*	.128*	.189**	.019
Duration of the CKD	.43	.044	.008	.165**
Personal strain	1			
Role strain	.798**	1		
Deprived relations	.791**	.808**	1	
Management of care	.493**	.374**	.333**	1

Note: * Correlation is significant at the p<.005 level (2-tailed). ** Correlation is significant at the p<.001 level (2-tailed).

Table 6. Hierarchical linear regression with Personal strain score as the dependent variable

Predictor	Unstandardized Coefficients		Standardized Coefficients	t	Sig.	95,0% Confidence Interval for B	
	B	Std. Error	Beta			Lower Bound	Upper Bound
	(Constant)	1.184	1.368				.865
Age	.029	.019	.059	1.501	.135	-.009	.067
Gender men** versus women	.559	.548	.039	1.019	.310	-.523	1.640
Having children yes*** versus no	-1.864	2.179	-.034	-.855	.394	-6.163	2.436
Number of children	.156	.301	.020	.517	.606	-.438	.750
Days per week on care	.034	.050	.026	.691	.490	-.064	.133
Hours per day on care	.001	.034	.001	.025	.980	-.066	.067
Role strain	.521	.086	.402	6.057	<.001	.351	.690
Relationship strain	.688	.111	.401	6.168	<.001	.468	.908
Management of care	.750	.155	.195	4.840	<.001	.444	1.056

Note: **Reference category, *** Number of observations = 250; R-squared = .764; Adjusted R-square = .752

4. Discussion

This study aimed to assess the burden of caregivers of chronic hemodialysis patients in a convenience sample in Greece. The literature review suggested that this burden is a global public health concern and caregivers face several health problems and psychological disorders (13), thus highlighting the importance of the present study. The main results indicated that caregivers' burden is not high enough and the highest score-proportionally-was recorded in the Personal Strain dimension. This may be attributed to the long mean duration (10 years) of the chronic kidney disease, which possibly means that the patients and caregivers have successfully developed their own adaptation strategies to the requirements of the disease. Most of the caregivers in the study were family members, particularly a spouse or the patient's children who usually lived with the patient. This result is consistent with that found in other studies (30).

With regard to the rest characteristics of the caregiver and the care, caregiver's health problems, sharing the care with other persons and caregiver's information /counseling about the disease didn't significantly affect the score on the Zarit Burden Interview. This result is somehow unexpected and needs further elaboration in future studies. It can possibly be explained by the satisfactory adaptation of the caregivers to the requirements of the disease, too. Other studies (24) have established that caregivers who live in the same home with the patients are more likely to experience higher levels of stress than those who stay in another house. However, this finding was not supported in this study. This may be due to the Greek cultural context and the consequent fact that the large proportion (64%) of the caregivers in this study lived in the same home with the patients.

Concerning the demographic characteristics, only the marital status of the caregiver significantly affected the score on the Zarit Burden Interview. More specifically, it effected the score on Personal Strain and on Deprived Relations and widows/widowers participants had significant higher score than single caregivers. It was also established that one's educational level played a crucial role as a significant determinant of burden in several other relevant studies (22) and less educated caregivers report higher levels of depression. In contrast to these findings, in this study no significant differences were observed in the caregivers' burden related to their level of education.

Gender has been examined in many studies and female caregivers-who usually provide more immediate care-experience higher levels of burden and depression (21). In addition, male caregivers of persons with end stage renal disease often experience negative outcomes (17). In this study, caregivers' gender and their rest demographic characteristics did not significantly affect their burden. Consequently, hypothesis 1 was only partially confirmed. However, it must be noted that these studies examine the burden of caregivers who care patients with other diseases. The incompatibility of these findings may be attributed to differences in the cultural context and in the characteristics of the patients and caregivers' sample.

The association between age and burden is still unclear in bibliography and contradictory results have been proposed

by researchers. In this study, caregivers' age didn't significantly correlate with their experienced burden. On the other hand, the number of caregiver's children was positively associated with Personal Strain, Role Strain and Deprived Relations. That is, hypothesis 2 was partially confirmed, too. It is noteworthy that the latter variable (caregivers' children) has not examined in previous studies (neither in chronic kidney disease nor in other diseases).

On the contrast, hypothesis 3 was fully confirmed and the hours per day on care were positively associated with Personal Strain, Role Strain and Deprived Relations and days per week on care were positively associated with Personal Strain and Deprived Relations.

In addition, the duration of the chronic kidney disease was positively associated with Management of Care, thus confirming hypothesis 4. It is an expected and logical result. However, when interpreting it, one should have in mind the above-mentioned main result that caregivers' burden is not high enough in CKD. In conclusion, although these caregivers don't experience high burden in general, the duration of the disease is a significant predictor of their burden.

The results of the hierarchical linear regression indicated that the main determinants of Personal Strain were Relationship Strain, followed by Role Strain and Management of Care.

The fundamental advantages of this study include the originality of the topic examined for the Greek population and the fact that the hypotheses examined provide evidence and information about the burden of caregivers of chronic hemodialysis patients that can be used by health and mental health practitioners. Furthermore, the prevalence of caregivers' burden in modern times demonstrates its importance in everyday clinical practice.

As for the research limitations, it must be highlighted that this is a cross-sectional study, in which it is not possible to examine causal relations. Moreover, the prerequisite that the respondents submit a written consent and/or the completion of the questionnaire before the patient's examination may have affected the answers provided. In addition, the questionnaires were completed in the hospitals during the dialysis procedure and the caregivers possibly exaggerated their burden due to their emotional distress.

Future research is suggested, so that further investigation and clarification of the study's results to be possible. Conducting a longitudinal study would be beneficial, with the scope to overcome the limitations of a cross-sectional study. Various variables that presented not significant influence on the caregivers' burden in this study (like caregiver's health problems, sharing the care with other persons and caregiver's information /counseling about the disease) could be further examined. Surveys could also focus on caregivers with particular needs and characteristics, e.g. on old caregivers, on those who suffer from other chronic diseases or present high comorbidity etc. Finally, researchers could examine the quality of caregivers-patient relationship as a predictor of the caregiver's experienced burden.

Implications for clinical practice and Conclusion

The burden of caregivers of chronic hemodialysis patients is a global public health concern and caregivers face several health problems and psychological disorders. According to this

study, their burden is not high enough and the Personal Strain seems to be the most affected dimension. Notwithstanding the limitations discussed above, the results of the research are useful enough as to make suggestions for convenient management of the burden experienced by the caregivers of chronic hemodialysis patients. The healthcare professionals will be able to evaluate the caregivers' problems, to recognize the vulnerable groups of them (having in mind the variables that raise their burden) and to refer them to other professionals (eg. psychologists). In this way, they will see their patients' caregivers within a biopsychosocial perspective and they will provide them with qualitative healthcare services.

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