



DETERMINANTS OF BURDEN AND QUALITY OF LIFE IN CAREGIVERS OF DIALYSIS PATIENTS IN A DESCRIPTIVE CROSS SECTIONAL STUDY

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OBJECTIVES

Hemodialysis causes many restrictions on patients in various aspects of their life but affect caregivers also. Specifically, the ESRD and its treatment include a series of dramatic changes in the lifestyle of the family (Levy et al, 2004; Steinglass et al, 1982). These families have to cover a period of reorganization and readjustment, where roles and rules changes (Olsen, 1970).

As a result of this reorganization is that family carers are experiencing a particularly intense stress (presence of intense physical, emotional, psychological problems and social exclusion) which leads to impaired quality of life.

During the past decades, research focused on assessing the quality of life of chronic disease patients but data on burden and quality of life of caregivers of dialysis patients are scarce. It is important to assess the quality of life and the burden of caregivers, because these parameters can result in physical and mental disturbances. This is important for the caregiver but also for the patient because it can lead to impaired quality of care.

The purpose of this study was to describe characteristics of hemodialysis patients' caregivers, to assess their burden and QoL and to investigate any association with factors connected with caregivers, patients and hemodialysis modality.

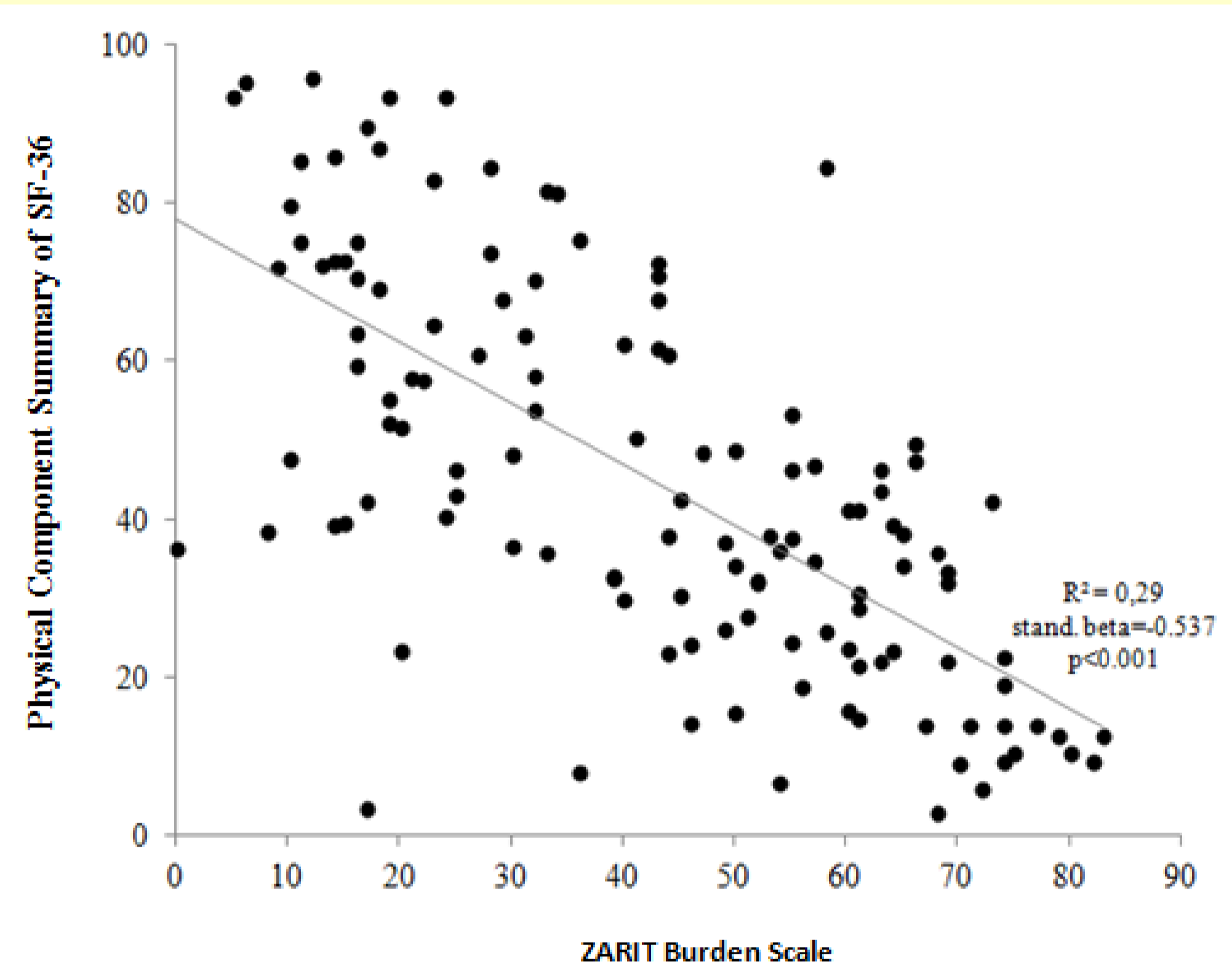
METHODS

158 questionnaires were initially distributed and finally 135 of them were completed. 23 caregivers refused to answer due to time restrictions.

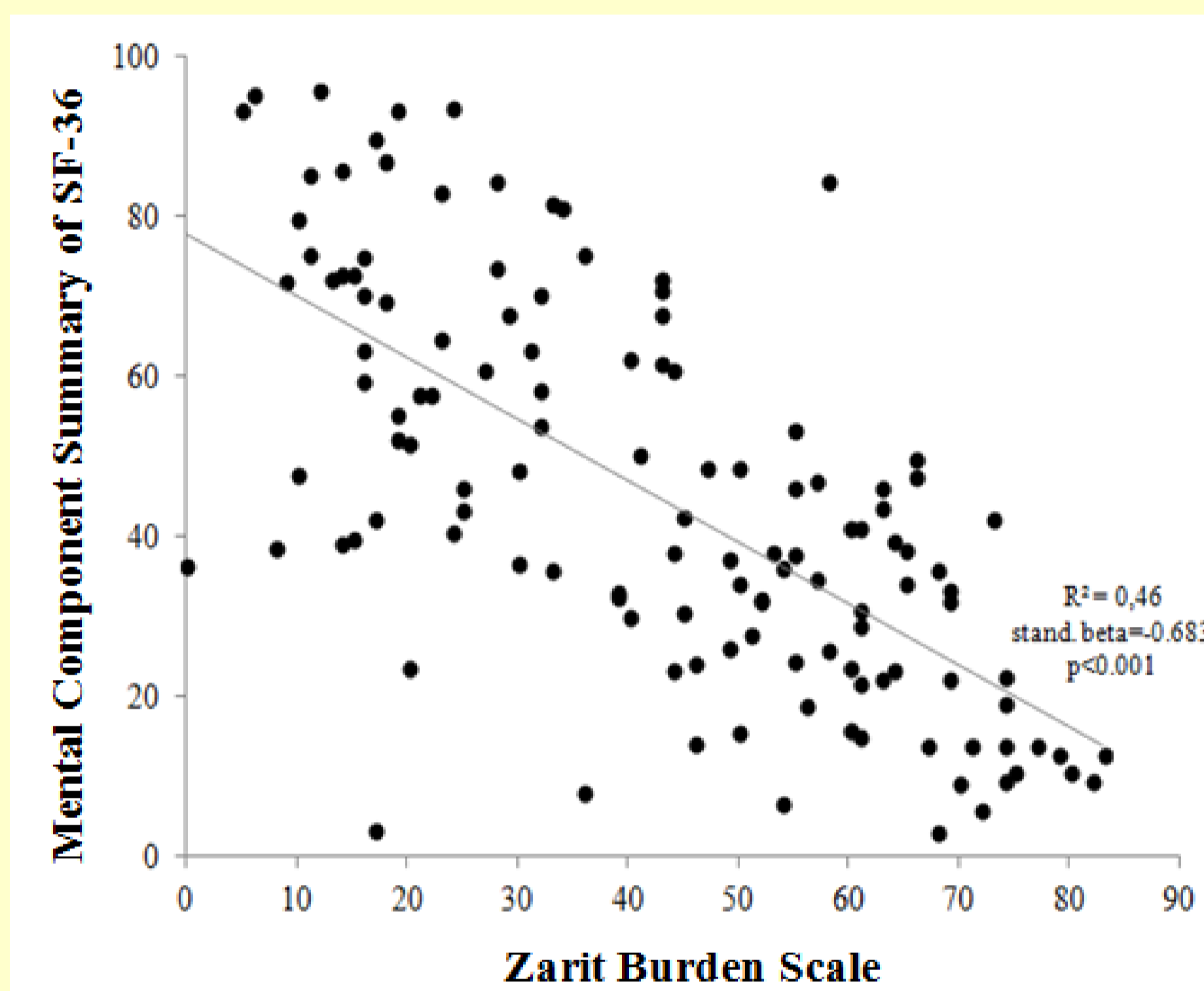
133 questionnaires were completed, having at least 50% of the questions answered (at least 18 questions). The other 2 had <50% of questions answered and were excluded from the analysis. The missing response from the 133 questionnaires, account for 2.5% of all cells (119 missing responses from a total of 4752). Due to their small number, they were replaced (imputation procedure) with the prevailing values / answers (modes) per question.

Respectively for the Zarit questionnaire, 133 forms were completed having answers at least 50% of the questions (had answered at least 11 questions) and the remaining 2 were <50%, so these were excluded from the analysis. The missing answers from the 133 questionnaires amounted to 1.1% of total cells (38 missing responses in all 2838). These in the same manner, was replaced (imputation procedure) with prevailing values / responses (modes) per question.

The final sample of this study was 133 ESRD patients' caregivers. 65 patients (48.9%), dialyzed in two public hospitals, while the remaining 68 (51.1%) patients were dialyzed in a private HD center. Inclusion criteria in the study were that caregivers should have the main responsibility and the basic care of the patient or at least most of it, from the first day the patient's inclusion in the HD therapy, caregivers were not salaried, can communicate in the Greek language (the questionnaires were in Greek language), during the time the study was not present the patient because of the possible influence on the caregiver, the patient is in chronic dialysis schedule.



Linear correlation of Zarit Burden Scale with physical component of SF-36 Quality of Life in the 133 caregivers



Linear correlation of Zarit Burden Scale with Mental Component Summary of SF-36 (R²=0.46, stand beta=0.683, p<0.001)

Multiple Linear Regression analysis of Zarit Burden Scale and demographic characteristics of 133 caregivers with QoL scale SF-36

Predictive Factors	Quality of Life - SF36			
	Physical Component		Mental Component	
	stand. beta	p-value	stand. beta	p-value
Caregivers' demographics				
Sex	-0,033	0,671	-0,025	0,724
Age	0,033	0,762	0,144	0,154
Family status	-0,042	0,688	-0,088	0,368
Education	0,316	<0,001	0,205	0,010
Income	-0,036	0,654	0,017	0,821
Comorbidity	-0,247	0,006	-0,209	0,013
Distance from Dialysis Unit	-0,118	0,277	-0,035	0,732
Staying in the same house with patient	0,080	0,424	0,005	0,961
Relationship with patient	-0,023	0,846	-0,057	0,596
Patients' demographics				
Hospital	-0,075	0,387	0,068	0,402
Age (years)	0,064	0,491	0,073	0,401
Co morbidity (n of diseases)	-0,075	0,596	-0,103	0,434
Duration of dialysis (months)	0,119	0,278	-0,024	0,811
Zarit Burden scale				
Total Burden score	-0,440	0,004	-0,503	<0,001
	adjusted R ²		0,40	
			0,49	

Sex (1:men, 2:women), age (1:29-35, 2:36-50, 3:51-65, 4:>65), family condition (1:married, 2:unmarried, 3:divorced, 4:widow, education status (1:no education, 2:elementary, 3:high school, 4:lyceum, 5:University), Income (1:<800 euro, 2:800-1500, 3:1501-2500, 4:>2500), Co morbidity (1:no disease, 2: one, 3: two or more) Distance from Dialysis Unit (1:<15 Km, 2:16-30, 3:31-50, 4:>50), Same house with patient (1:no, 2:yes), Relation with patient: (1:spouse, 2:child, 3:brother/sister) and Dialysis Unit (1:NHS, 2:Private). *p-value<0,05 **p-value<0,001

RESULTS

The majority of caregivers were women (55.6%, n=74), aged over 65 years (47%, n=62) and were spouses of the patient 64.4% (n=85). The mean score of total burden experienced was 42.4±21.6 (p<0,001). The parameters with the greatest impact on burden were the personal strain and the strain of the role. The most affected subscales of quality of life were Emotional Role 34.9±40.3, General Health 42.3±22.8 and Physical Role 43.3±44.5. Also was found positive correlation of Zarit Burden Interview scale with the Physical Component Summary of SF-36 (R²=0.29, stand Beta=0.537, p<0.001) and the Mental Component Summary of SF-36 (R²=0.46, stand beta=0.683, p<0.001). Factors associated with perceived burden and health related quality of life are the caregiver's age, caregiver's educational level, distance from dialysis unit, residence in the same house with patient, caregiver's income, private or public dialysis unit and dialysis duration.

Correlation of Zarit Burden Scale & QoL SF-36 score of the 133 caregivers with their and patients' demographic characteristics.

	Zarit Burden Scale		Quality of Life - SF36	
	Total Burden Score	Physical Component	Mental Component	
	r-Pearson			
Caregivers Characteristics				
Sex	0,116	-0,106	-0,063	
Age	0,189*	-0,166	-0,285*	
Family condition	-0,086	0,001	-0,030	
Education	-0,231*	0,342**	0,435**	
Income	-0,169	0,213*	0,194*	
Co-morbidity	0,101	-0,211*	-0,349**	
Distance from Dialysis unit	0,697**	-0,449**	-0,429**	
Staying in the same house with patient	0,167	-0,109	-0,042	
Relationship with patient	-0,066	-0,023	-0,011	
Χαρακτηριστικά ασθενών				
Hospital	-0,372**	0,090	0,257**	
Age (years)	0,193*	-0,124	-0,228*	
Co morbidity (number of major diseases)	0,835**	-0,620**	-0,495**	
Duration of HD (months)	0,695**	-0,489**	-0,314**	

Sex (1:men, 2:women), age (1:29-35, 2:36-50, 3:51-65, 4:>65), family condition (1:married, 2:unmarried, 3:divorced, 4:widow, education status (1:no education, 2:elementary, 3:high school, 4:lyceum, 5:University), Income (1:<800 euro, 2:800-1500, 3:1501-2500, 4:>2500), Co morbidity (1:no disease, 2: one, 3: two or more) Distance from Dialysis Unit (1:<15 Km, 2:16-30, 3:31-50, 4:>50), Same house with patient (1:no, 2:yes), Relation with patient: (1:spouse, 2:child, 3:brother/sister) and Dialysis Unit (1:NHS, 2:Private). *p-value<0,05 **p-value<0,001

Statistical analysis of caregivers' demographic factors affecting indicators of Quality of Life

	Quality of Life - SF36			
	Physical Component		Mental Component	
	Mean	SD	Mean	SD
Sex				
Men	51,4	27,1	47,7	25,3
Women	48,1	27,0	43,4	24,3
Age, years				
29-35	62,9	16,6	49,4	16,5
36-50	63,0	28,4	35,7	28,2
51-65	50,4	26,1	47,0	24,1
>65	42,9	26,1	41,7	23,2
Family condition				
Married	48,8	27,2	45,1	25,2
Unmarried	66,3	21,8	35,5	24,2
Divorced	38,2	14,2	35,5	15,9
Widow/widower	46,2	30,2	46,2	25,7
Education				
No education	25,5	17,1	26,5	17,7
Elementary	40,4	25,4	40,6	23,2
High school	46,9	23,5	48,01	23,5
Lyceum	65,2	24,8	56,5	23,6
University	66,7	20,4	62,6	28,1
Caregiver's income				
<800 euro	42,8	26,2	40,5	24,8
800-1500	56,0	24,9	60,06	21,9
1501-2500	66,6	23,9	58,1	28,9
>2500	41,0	40,1	52,8	30,8
Co morbidity				
No co morbidity	60,2	26,1	51,1	25,2
1	51,7	27,8	48,01	42,7
2+	38,2	22,6	39,0	21,3
Dialysis Unit Distance				
<15 Km	64,7	22,6	60,4	25,1
16-30	53,3	30,1	48,01	49,7
31-50	40,6	18,4	35,5	16,9
>50	33,2	23,1	30,9	20,8
Staying in the same house with patient				
No	51,5	27,1	63,7	50,4
Yes	48,9	27,1	44,2	24,4
Relationship with patient				
Spouse	49,3	28,3	45,7	25,4
Child	52,4	26,3	67,0	47,7
Brother/Sister/Nephew	47,0	22,7	42,9	23,4

CONCLUSIONS

Caregivers of hemodialysis patients present moderate to severe burden and deduction of quality of life. Therefore the review and the re-design of a national social policy concerning to end renal stage dialysis patients and informal family caregivers, it is imperative to rated as a high priority issue.