

## Investigation of the Caregivers' Quality of Life in Patients with Renal Failure

**Kyriaki Stavrou\* and Gülcan Garip**

*College of Health, Psychology and Social Care, University of Derby, UK*

**\*Corresponding Author:** Kyriaki Stavrou, Psychologist, College of Health, Psychology and Social Care, University of Derby, UK.

**Received:** January 16, 2023; **Published:** February 06, 2023

### Abstract

The care of patients with chronic renal failure is a specialized field in the field of health with significant peculiarities. The initial aim of the study is the investigation of the caregivers' quality of life in patients with renal failure, which arises both from the stress of the progression of the disease itself and from the burdens of care. The main variables of the research, the burden/fatigue of the caregivers and the general health index, are concepts that can be quantified, thanks to the special psychometric tools that have been developed for their measurement. The study was conducted from January 2022 until May 2022. The final sample of the present study is 100 caregivers of patients with renal failure. The need for permanent and continuous care requires on the part of the caregiver's daily engagement, the dedication of hours, neglect of personal needs or social activities and generally permanent changes in his life and daily life. Caregivers are at high risk of deteriorating quality of life due to their time and energy in providing care. The result of the correlation analysis confirms the research hypotheses that the health status of the caregivers is negatively affected by the burden and fatigue they receive from their work.

**Keywords:** *Renal Failure; Caregiver; Quality of Life; Burden*

### Abbreviations

MFI: Multidimensional Fatigue Inventory; ZBI: Zarit Burden Interview; SF: Short Form; SPSS: Statistical Package for the Social Sciences; QoL: Quality of Life

### Introduction

Patient care is defined as helping, which can take the form of aiding and abetting those in need [1]. Caregiving activities conjunction by family members to a patient are extensive, exerting a significant burden, particularly regarding the demands and duration of caregiving [2]. Family caregivers provide most of the patient's physical, emotional and social care needs throughout the care sequence without remuneration [3]. Also, caregiver burden has been used to identify the impact of caregiving on caregivers. Given., *et al.* [4] define this burden as a "multidimensional biopsychosocial response resulting from an imbalance of caregiving demands concerning caregivers' time, social roles, physical and emotional states, financial and health care resources".

Family caregivers may develop caregiver burden when the stress of caregiving exceeds the resources available to cope with the demands of caregiving [2]. As caregiving needs increase, family and caregivers are usually isolated from social activities [5,6], leading caregivers to various physical and psychological health problems. Hemodialysis is a life-long treatment for end-stage renal disease associated with physical and psychosocial challenges affecting the patients and the family members that care for them [7].

Caregivers assist patients at home with many activities of daily living, including transportation to dialysis centres, symptom management, mobility, dressing, and preparation of an appropriate renal diet [8]. Some studies have documented how family members' continuous caregiving of chronically ill patients negatively affects many aspects of caregivers' lives, including stress levels, family relationships, and social life [9].

### Aim of the Study

The initial aim of the study is the investigation of the caregivers' QoL in patients with renal failure, which arises both from the stress of the progression of the disease itself and from the burdens of care. To investigate the relationship between the burden and the general health of the caregiver and to test the research hypotheses, a quantitative methodology was chosen to be conducted. The use of the quantitative method for exploring concepts related to health has increased in recent years, mainly due to the development of special methodological and psychometric tools that allow a reliable and valid recording of the levels of a phenomenon for many participants and with less time.

Although many argue that the study of concepts such as the burden within the family caregiver is a complex phenomenon that the individual experiences and carries as his/her weight, therefore should be studied as such using qualitative methods (thematic analysis, interpretive phenomenological analysis); in this research, the purpose was not to investigate the caregiver's burden in-depth as an individual experience that each person experiences in his way. Instead, the focus of this research was to examine whether there can be a statistically significant and non-random relationship between the fatigue/burden experienced by the family caregiver and the general health, according to caregivers' estimates. The research was designed with the quantitative methodology to collect quantitative data and to investigate most effectively the systematic relationship between the burden/fatigue and the general health of caregivers. The main variables of the research, the burden/fatigue of the caregivers and the general health index, are concepts that can be quantified, thanks to the special psychometric tools that have been developed for their measurement. General health in the present study is mainly used as a dependent variable. In contrast, when taken as a factor affecting general health, the caregiver's burden and independent fatigue variables are considered dependent variables when it is concerning participants' demographics. Demographics also function as independent variables.

### 1<sup>st</sup> research hypothesis

The general health of the caregivers will be correlated negatively with the caregivers' burden due to the patient's care.

### 2<sup>nd</sup> research hypothesis

The general health of the caregivers will be correlated negatively with the caregivers' fatigue due to the patient's care.

### Methodology

This study design was between-subjects and cross-sectional with a questionnaire survey. Three primary measures were established: Questionnaire SF-36 Health Research, which measures the health status of a population, and the Zarit Burden Interview (ZBI-12) short form, which consists of 12 question items that assess the level at which the caregiver feels burdened by the patient's care and the Multidimensional Fatigue Inventory (MFI-20) which consists of 20 question - items and measures the level of the caregivers' fatigue. Dependent

variables were physical functioning, role limitations due to physical health, physical pain, general health, emotional well-being, social functioning, energy/fatigue and role limitations due to emotional problems. Independent variables were the gender, the age of the caregivers, the ZBI-12 and the MFI-20. The last two scales also played the role of the dependent variables in the case of bivariate analysis.

The data collection of the present study was gathered using a structured and self-completed questionnaire by the participants. Precisely, the questionnaire distributed for completion consists of the following parts: In the first part of the questionnaire, there was a sheet of the caregivers' characteristics; study participants completed a form designed for this study to gather information on their gender and age. The MFI-2032 Multidimensional Fatigue Questionnaire is a questionnaire of 20 questions - items designed to evaluate fatigue through five factors. Specifically, evaluates the following factors: "general fatigue", "body fatigue", "reduced activity", "reduced motivation" and "mental fatigue". Participants are graded for each test sentence based on whether they say its content characterizes them. The ratings they can receive per sentence range from 1 to 5 points. Inverted sentences are also used in the test; they are evaluated in reverse order by the degree of agreement or disagreement. The inverted sentences are 2, 5, 9, 10, 13, 14, 16, 17, 18 and 19, which are converted to 1 = 5, 2 = 4, 3 = 3, 4 = 2, 5 = 1 respectively. The points of each participant are added up to calculate the total value that indicates fatigue and can take values from 20 - 100.

The SF-36 Health status is a self-completing questionnaire consisting of 36 questions and is used to measure the health status of a population [10]. It is aimed at healthy and sick people over 14 [11]. The questions are summarized in 8 dimensions: physical functionality, physical role, physical pain, general health, vitality, social functionality, emotional role, and mental health [12]. For each variable, the data are scored, summed and converted on a scale ranging from 0 to 100 [13], with the lowest scores indicating a worse QoL in this dimension.

The fourth part of the questionnaire consists of the general caregiver evaluation questionnaire Zarit Burden Interview (ZBI-12). This questionnaire consists of 22 question-items that assess the level at which the caregiver feels burdened by the patient's care and is also structured in 4 subscales: a) role intensity, b) personal tension, c) deprivation of relationships; and d) care management. The emotional intensity sub-scale is referred to in questions 8, 9, 10, 14, 15, 16, 17 and 18. The role intensity is referred to in questions 1, 4, 5, 6, 7, 13 and 19. Relationship deprivation is mentioned in questions 2, 3, 11 and 12, and finally, the care management subscale is mentioned in questions 20 and 21. The questions are answered on five-point Likert scales. The minimum score that can be collected is 0 points, and the maximum is 88 points. In the current study, we have used the short form of the scale, which uses only 12 items for participants to answer the questionnaire. The short form of the ZBI-12 consists of two sections, personal and role strain. Each question - item is answered on a five-point Likert scale from 0 to 4 (0 = never to 4 = almost always). Higher values indicate a higher level of burden. The score is calculated by summing all the items, range 0 - 48.

The study population were caregivers of patients of people with chronic renal failure. Accessibility/Eligibility criteria for inclusion in the present study were: The caregivers should be the primary caregivers of the patient over the age of 18 and understand the English language to complete the questionnaire. The study was conducted from January 2022 until May 2022. The final sample of the present study is 100 caregivers of patients with renal failure (45 male and 55 females, 61 are 30 - 40 years old, 32 are 40 - 50 years old, and 7 are more than 50 years old). The sample of 100 caregivers is considered sufficient to achieve 80% power at the level of statistical significance of 0.05 for detecting a difference of 0.52 \* standard deviation for comparison of equal-sized subgroups in bilateral parametric control. The power calculation was performed with the program G \* Power 3.1.9.2.

The questionnaires were uploaded online, so family caregivers of people with chronic renal failure belonging to the healthy population and then the caregivers completed the questionnaires. Before handing out the questionnaires, the researcher explained to the caregivers the purpose of the research, assuring the participants that the data would be used strictly and only for specific research purposes. During the completion of the questionnaires, the researcher was at the disposal of the caregivers, helping and explaining to them the points they

did not understand. The SPSS22.0 statistical software was used in this study to conduct the statistical analysis. Descriptive and inferential statistics were used (Pearson index, t-test, Anova, Manova).

## Results

The initial aim of the study is the investigation of the caregivers' QoL in patients with renal failure, which arises both from the stress of the progression of the disease itself and from the burdens of care.

Cronbach's alpha index was used to investigate the reliability of the questionnaire. The index values were satisfactory ( $> 0.7$ ) except for one dimension. The cause of this is probably the small number of questions. Table 1 shows the scores of the index.

|   | Cronbach's alpha | N  |
|---|------------------|----|
| <b>S.F. - 36</b>                            |                  |    |
| Physical functioning                        | 0,946            | 10 |
| Role limitations due to physical health     | 0,807            | 4  |
| Physical pain                               | 0,878            | 2  |
| General health                              | 0,839            | 6  |
| Total physical health                       | 0,944            | 22 |
| Emotional well-being                        | 0,762            | 3  |
| Social functioning                          | 0,455            | 2  |
| Energy/fatigue                              | 0,815            | 4  |
| Role limitations due to emotional problems  | 0,828            | 5  |
| Total mental health                         | 0,877            | 14 |
| Zarit Caregiver Burden Interview (ZBI-12)   | 0,784            | 12 |
| Multidimensional Fatigue Inventory (MFI-20) | 0,803            | 20 |

**Table 1:** Cronbach's alpha index.

Table 2 shows the scores of the S.F.-36 scale dimensions.

|  | Minimum | Maximum | M     | SD    |
|--|---------|---------|-------|-------|
| Physical functioning                       | 0       | 100     | 64,86 | 30,03 |
| Role limitations due to physical health    | 0       | 100     | 64,50 | 37,64 |
| Physical pain                              | 10      | 100     | 66,30 | 25,19 |
| General health                             | 4,17    | 91,67   | 41,21 | 19,63 |
| Total physical health                      | 6,59    | 97,73   | 58,42 | 24,04 |
| Emotional well-being                       | 0       | 100     | 71,00 | 36,29 |
| Social functioning                         | 37,5    | 100     | 69,00 | 20,68 |
| Energy/fatigue                             | 5       | 100     | 46,33 | 19,41 |
| Role limitations due to emotional problems | 12      | 100     | 62,76 | 17,67 |
| Total mental health                        | 21,79   | 100     | 60,73 | 18,12 |

**Table 2:** Health quality, SF36 scale.

Note: M = Mean, SD = Standard Deviation.

In table 2 it can be seen that the level of the physical functioning (M = 64.86, SD = 30.03), the role limitations due to physical health (M = 64.50, SD = 37.64), the physical pain (M = 66.30, SD = 25.19), the total physical health (M = 58.42, SD = 24.04), the emotional well-being (M = 71.0, SD = 36.29), the social functioning (M = 69.00, SD = 20.68), the role limitations due to emotional problems (M = 62.76, SD = 17.67) and the total mental health (M = 60.73, SD = 18.12) of the caregivers is above average. Furthermore, the level of the general health (M = 41.21, SD = 19.63) and the energy/fatigue (M = 46.33, SD = 19.41) of the caregivers is below average.

Table 3 shows the score of the Zarit Caregiver Burden Interview.

| Minimum | Maximum | M     | SD   |
|---------|---------|-------|------|
| 13,00   | 41,00   | 28,84 | 6,11 |

**Table 3:** Zarit caregiver burden interview (ZBI-12).

Note: M = Mean, SD = Standard Deviation.

In table 3, the level of the caregiver burden (M = 28.84, SD = 6.11) is above average.

Table 4 shows the score of the MFI-20 scales.

| Minimum | Maximum | M     | SD   |
|---------|---------|-------|------|
| 43,00   | 95,00   | 70,20 | 8,67 |

**Table 4:** Multidimensional fatigue inventory - MFI-20.

Note: M = Mean, SD = Standard Deviation.

In table 4, the level of caregiver fatigue (M = 70.20, SD = 8.67) is above average.

In table 5, we have tested the effect of the gender and the age of the caregivers, and the Zarit Caregiver Burden Interview (ZBI-12) and the Multidimensional Fatigue Inventory (MFI-20) on their health status, physical functioning, the role limitations due to physical health, the physical pain, the general health, the emotional well-being, the social functioning, the fatigue and the role limitations due to emotional problems.

| Effect                                      |                    | Value | F                  | Hypothesis Df | Error Df | P    |
|---|--------------------|-------|--------------------|---------------|----------|------|
| Intercept                                   | Pillai's Trace     | ,444  | 8,488 <sup>b</sup> | 8             | 85       | ,000 |
|   | Wilks' Lambda      | ,556  | 8,488 <sup>b</sup> | 8             | 85       | ,000 |
|   | Hotelling's Trace  | ,799  | 8,488 <sup>b</sup> | 8             | 85       | ,000 |
|   | Roy's Largest Root | ,799  | 8,488 <sup>b</sup> | 8             | 85       | ,000 |
| Zarit Caregiver Burden Interview (ZBI-12)   | Pillai's Trace     | ,152  | 1,909 <sup>b</sup> | 8             | 85       | ,069 |
|   | Wilks' Lambda      | ,848  | 1,909 <sup>b</sup> | 8             | 85       | ,069 |
|   | Hotelling's Trace  | ,180  | 1,909 <sup>b</sup> | 8             | 85       | ,069 |
|   | Roy's Largest Root | ,180  | 1,909 <sup>b</sup> | 8             | 85       | ,069 |
| Multidimensional Fatigue Inventory (MFI-20) | Pillai's Trace     | ,025  | ,272 <sup>b</sup>  | 8             | 85       | ,973 |
|   | Wilks' Lambda      | ,975  | ,272 <sup>b</sup>  | 8             | 85       | ,973 |
|   | Hotelling's Trace  | ,026  | ,272 <sup>b</sup>  | 8             | 85       | ,973 |
|   | Roy's Largest Root | ,026  | ,272 <sup>b</sup>  | 8             | 85       | ,973 |

|              |                    |      |                    |    |     |      |
|--------------|--------------------|------|--------------------|----|-----|------|
| Gender       | Pillai's Trace     | ,089 | 1,042 <sup>b</sup> | 8  | 85  | ,412 |
|              | Wilks' Lambda      | ,911 | 1,042 <sup>b</sup> | 8  | 85  | ,412 |
|              | Hotelling's Trace  | ,098 | 1,042 <sup>b</sup> | 8  | 85  | ,412 |
|              | Roy's Largest Root | ,098 | 1,042 <sup>b</sup> | 8  | 85  | ,412 |
| Age          | Pillai's Trace     | ,399 | 2,677              | 16 | 172 | ,001 |
|              | Wilks' Lambda      | ,635 | 2,709 <sup>b</sup> | 16 | 170 | ,001 |
|              | Hotelling's Trace  | ,522 | 2,740              | 16 | 168 | ,001 |
|              | Roy's Largest Root | ,384 | 4,127 <sup>c</sup> | 8  | 86  | ,000 |
| Gender * Age | Pillai's Trace     | ,094 | ,529               | 16 | 172 | ,929 |
|              | Wilks' Lambda      | ,908 | ,525 <sup>b</sup>  | 16 | 170 | ,932 |
|              | Hotelling's Trace  | ,099 | ,520               | 16 | 168 | ,934 |
|              | Roy's Largest Root | ,068 | ,731 <sup>c</sup>  | 8  | 86  | ,664 |

Table 5: Manova (I).

Table 5 shows the multivariate analysis of variance with dependent variables: physical functioning, role limitations due to physical health, physical pain, general health, emotional well-being, social functioning, energy/fatigue and role limitations to emotional problems. Independent variables were the gender and the age of the caregivers, and as covariates, we used the ZBI-12 and the MFI-20. The ZBI-12 (at a 10% significant level) and the caregivers' age (1%) were statistically significant variables.

In table 6, we have tested the effect of the gender and the age of the caregivers, the ZBI-12 and the MFI-20, on their health status, total physical health, and total mental health.

| Effect                                      |                    | Value | F                   | Hypothesis Df | Error Df | P    |
|---|--------------------|-------|---------------------|---------------|----------|------|
| Intercept                                   | Pillai's Trace     | ,371  | 26,870 <sup>b</sup> | 2             | 91       | ,000 |
|   | Wilks' Lambda      | ,629  | 26,870 <sup>b</sup> | 2             | 91       | ,000 |
|   | Hotelling's Trace  | ,591  | 26,870 <sup>b</sup> | 2             | 91       | ,000 |
|   | Roy's Largest Root | ,591  | 26,870 <sup>b</sup> | 2             | 91       | ,000 |
| Zarit Caregiver Burden Interview (ZBI-12)   | Pillai's Trace     | ,057  | 2,750 <sup>b</sup>  | 2             | 91       | ,069 |
|   | Wilks' Lambda      | ,943  | 2,750 <sup>b</sup>  | 2             | 91       | ,069 |
|   | Hotelling's Trace  | ,060  | 2,750 <sup>b</sup>  | 2             | 91       | ,069 |
|   | Roy's Largest Root | ,060  | 2,750 <sup>b</sup>  | 2             | 91       | ,069 |
| Multidimensional Fatigue Inventory (MFI-20) | Pillai's Trace     | ,009  | ,421 <sup>b</sup>   | 2             | 91       | ,658 |
|   | Wilks' Lambda      | ,991  | ,421 <sup>b</sup>   | 2             | 91       | ,658 |
|   | Hotelling's Trace  | ,009  | ,421 <sup>b</sup>   | 2             | 91       | ,658 |
|   | Roy's Largest Root | ,009  | ,421 <sup>b</sup>   | 2             | 91       | ,658 |
| Gender                                      | Pillai's Trace     | ,064  | 3,104 <sup>b</sup>  | 2             | 91       | ,050 |
|   | Wilks' Lambda      | ,936  | 3,104 <sup>b</sup>  | 2             | 91       | ,050 |
|   | Hotelling's Trace  | ,068  | 3,104 <sup>b</sup>  | 2             | 91       | ,050 |
|   | Roy's Largest Root | ,068  | 3,104 <sup>b</sup>  | 2             | 91       | ,050 |

|              |                    |      |                    |   |     |      |
|--------------|--------------------|------|--------------------|---|-----|------|
| Age          | Pillai's Trace     | ,171 | 4,296              | 4 | 184 | ,002 |
|              | Wilks' Lambda      | ,829 | 4,467 <sup>b</sup> | 4 | 182 | ,002 |
|              | Hotelling's Trace  | ,206 | 4,635              | 4 | 180 | ,001 |
|              | Roy's Largest Root | ,206 | 9,472 <sup>c</sup> | 2 | 92  | ,000 |
| Gender * Age | Pillai's Trace     | ,006 | ,128               | 4 | 184 | ,972 |
|              | Wilks' Lambda      | ,994 | ,127 <sup>b</sup>  | 4 | 182 | ,973 |
|              | Hotelling's Trace  | ,006 | ,125               | 4 | 180 | ,973 |
|              | Roy's Largest Root | ,005 | ,241 <sup>c</sup>  | 2 | 92  | ,787 |

Table 6: Manova (II).

Table 6 shows the multivariate analysis of variance with dependent variables the total physical and mental health. Independent variables were the gender and the age of the caregivers, and as covariates, we used the ZBI-12 and the MFI-20. Statistically significant variables were the caregivers' burden (at 10% significant level) and the caregivers' age (at 1%), and gender (at 5%). In the following tables, we conduct bivariate tests, Pearson index, t-test and Anova to investigate how the independent variables affect the health status of the caregivers.

In table 7, the differences between male and female caregivers are presented regarding the QoL, the Sf-36, the ZBI-12 and the MFI -20 caregivers of renal failure patients.

|   | Gender |       |        |       | Levene's Test | T-Test | T      | Df     | P    |
|---|--------|-------|--------|-------|---------------|--------|--------|--------|------|
|   | Male   |       | Female |       |               |        |        |        |      |
|   | M      | Sd    | M      | Sd    |               |        |        |        |      |
| Physical functioning                        | 75,67  | 26,60 | 56,02  | 29,99 | 2,858         | ,094   | -3,427 | 98     | ,001 |
| Role limitations due to physical health     | 73,89  | 34,52 | 56,82  | 38,63 | 2,640         | ,107   | -2,305 | 98     | ,023 |
| Physical pain                               | 74,72  | 25,20 | 59,41  | 23,19 | ,059          | ,808   | -3,159 | 98     | ,002 |
| General health                              | 44,63  | 20,27 | 38,41  | 18,82 | ,260          | ,611   | -1,588 | 98     | ,115 |
| Total physical health                       | 66,69  | 22,36 | 51,66  | 23,42 | ,252          | ,617   | -3,258 | 98     | ,002 |
| Emotional well-being                        | 75,56  | 37,20 | 67,27  | 35,42 | ,538          | ,465   | -1,137 | 98     | ,258 |
| Social functioning                          | 73,89  | 21,29 | 65,00  | 19,45 | ,703          | ,404   | -2,178 | 98     | ,032 |
| Energy/fatigue                              | 50,41  | 21,07 | 43,00  | 17,44 | 2,731         | ,102   | -1,924 | 98     | ,057 |
| Role limitations due to emotional problems  | 64,27  | 19,55 | 61,53  | 16,05 | 1,367         | ,245   | -,770  | 98     | ,443 |
| Total mental health                         | 64,13  | 20,23 | 57,95  | 15,85 | 4,075         | ,046   | -1,672 | 82,385 | ,098 |
| Zarit Caregiver Burden Interview (ZBI-12)   | 29,69  | 6,45  | 28,15  | 5,77  | 1,291         | ,259   | -1,261 | 98     | ,210 |
| Multidimensional Fatigue Inventory (MFI-20) | 69,87  | 10,36 | 70,47  | 7,10  | 6,406         | ,013   | ,334   | 75,273 | ,740 |

Table 7: Differences between male and female caregivers.

Note: M = Mean, S.D. = Standard Deviation, Levene's test was Used to Test the Equality of the Variances.

Table 7 shows that male caregivers in comparison with female caregivers exhibit higher level of physical functioning ( $M_M = 75.67, SD_M = 25.20$  vs  $M_F = 56.02, SD_F = 29.99$ ), role limitations due to physical health ( $M_M = 73.89, SD_M = 34.52$  vs  $M_F = 56.82, SD_F = 38.63$ ), Physical pain ( $M_M = 74.72, SD_M = 25.20$  vs  $M_F = 59.41, SD_F = 23.19$ ) (higher values of physical pain exhibit higher health level status), total physical health ( $M_M = 66.69, SD_M = 22.36$  vs  $M_F = 51.66, SD_F = 23.42$ ) and social functioning ( $M_M = 73.89, SD_M = 21.29$  vs  $M_F = 65.00, SD_F = 19.45$ ) ( $p < .05$ ).

In table 8, the differences among the age groups of the caregivers are presented regarding QoL, Sf-36, ZBI-12 and MFI-20 of caregivers of patients with renal failure.

|   | Age     |       |         |       |       |       | F2, 97) | p    | F      | P    |
|---|---------|-------|---------|-------|-------|-------|---------|------|--------|------|
|   | 30 - 40 |       | 40 - 50 |       | 50+   |       |         |      |        |      |
|   | M       | SD    | M       | SD    | M     | SD    |         |      |        |      |
| Physical functioning                        | 73,46   | 26,14 | 57,03   | 29,07 | 25,71 | 28,49 | 1,112   | ,333 | 11,576 | ,000 |
| Role limitations due to physical health     | 68,03   | 37,40 | 60,94   | 37,53 | 50,00 | 40,82 | ,220    | ,803 | ,930   | ,398 |
| Physical pain                               | 71,43   | 22,14 | 61,33   | 27,80 | 44,29 | 24,69 | 1,072   | ,346 | 4,927  | ,009 |
| General health                              | 46,45   | 19,98 | 32,68   | 16,94 | 34,52 | 12,89 | 2,273   | ,108 | 6,182  | ,003 |
| Total physical health                       | 64,85   | 21,66 | 51,47   | 24,06 | 34,22 | 22,24 | 1,140   | ,324 | 8,073  | ,001 |
| Emotional well-being                        | 71,04   | 37,75 | 70,83   | 33,60 | 71,43 | 40,50 | ,172    | ,843 | ,001   | ,999 |
| Social functioning                          | 72,54   | 20,89 | 63,67   | 19,41 | 62,50 | 20,41 | ,527    | ,592 | 2,366  | ,099 |
| Energy/fatigue                              | 49,23   | 18,59 | 43,75   | 19,43 | 32,86 | 21,96 | ,061    | ,941 | 2,744  | ,069 |
| Role limitations due to emotional problems  | 64,59   | 17,02 | 60,00   | 18,60 | 59,43 | 19,52 | ,194    | ,824 | ,839   | ,435 |
| Total mental health                         | 62,73   | 18,00 | 58,20   | 18,19 | 54,85 | 18,85 | ,225    | ,799 | 1,052  | ,353 |
| Zarit Caregiver Burden Interview (ZBI-12)   | 28,21   | 6,05  | 29,75   | 6,50  | 30,14 | 4,56  | ,743    | ,478 | ,833   | ,438 |
| Multidimensional Fatigue Inventory (MFI-20) | 69,57   | 7,94  | 71,37   | 10,31 | 70,29 | 7,06  | 1,242   | ,293 | ,448   | ,640 |

**Table 8:** Differences among the age groups of the caregivers.

Note: M = Mean, S.D. = Standard Deviation, Levene's Test was Used to Test the Equality of the Variances.

In table 8, they are statistically significant differences among the age groups of the caregivers in the case of physical functioning, physical pain, general health and total physical health ( $p < .05$ ). To investigate which age groups are statistically significant differences, the Bonferroni post hoc test was performed (Table 3, Appendix). Also, the Bonferroni correction was used to calculate the new significant level,  $\alpha^* = \alpha/3 = 0.05/3 = 0.017$ . In the case of physical pain, they were no statistically significant differences  $p > .0017$ . Furthermore, caregivers 30 - 40 years old, compared to caregivers over 50, exhibited a higher level of Physical functioning ( $p = .000$ ) and total physical health ( $p = .003$ ). Moreover, caregivers of 30 - 40 years old, compared to caregivers of 40 - 50, exhibited a higher level of General health ( $p = .003$ ).

Table 9 presents the correlations among the QoL, the S.F.-36, the ZBI-12 and the MFI-20 of caregivers of patients with renal failure.

In table 9 it can be seen that there is a statistical significant negative correlation between the caregivers Burden and the Role limitations due to physical health ( $r = -.273, p < .01$ ), the total physical health ( $r = -.206, p < .05$ ), the emotional well-being ( $r = -.485, p < .01$ ), the social functioning ( $r = -.198, p < .05$ ), the energy/fatigue ( $r = -.278, p < .05$ ), the role limitations due to emotional problems ( $r = -.289, p < .01$ ) and the total mental health ( $r = -.425, p < .01$ ). Also, there is a statistical significant negative correlation between the caregivers fatigue and the role limitations due to physical health ( $r = -.311, p < .01$ ), the total physical health ( $r = -.239, p < .05$ ), the emotional well-being ( $r = -.441, p < .01$ ), the social functioning ( $r = -.229, p < .05$ ), the energy/fatigue ( $r = -.294, p < .05$ ), the role limitations due to emotional problems ( $r = -.278, p < .01$ ) and the total mental health ( $r = -.412, p < .01$ ).



|   | Physical functioning | Role limitations due to physical health | Physical pain | General health | Total physical health | Emotional well-being | Social functioning | Energy/fatigue | Role limitations due to emotional problems | Total mental health | Zarit Caregiver Burden Interview (ZBI-12) |
|---|----------------------|---|---------------|----------------|-----------------------|----------------------|--------------------|----------------|--|---------------------|---|
| Physical functioning                        | 1                    |   |               |                |                       |                      |                    |                |  |                     |   |
| Role limitations due to physical health     | ,591**               | 1                                       |               |                |                       |                      |                    |                |  |                     |   |
| Physical pain                               | ,705**               | ,498**                                  | 1             |                |                       |                      |                    |                |  |                     |   |
| General health                              | ,655**               | ,422**                                  | ,588**        | 1              |                       |                      |                    |                |  |                     |   |
| Total physical health                       | ,948**               | ,760**                                  | ,770**        | ,773**         | 1                     |                      |                    |                |  |                     |   |
| Emotional well-being                        | ,390**               | ,650**                                  | ,335**        | ,410**         | ,531**                | 1                    |                    |                |  |                     |   |
| Social functioning                          | ,463**               | ,579**                                  | ,556**        | ,554**         | ,605**                | ,613**               | 1                  |                |  |                     |   |
| Energy/fatigue                              | ,608**               | ,466**                                  | ,624**        | ,599**         | ,673**                | ,469**               | ,564**             | 1              |  |                     |   |
| Role limitations due to emotional problems  | ,269**               | ,334**                                  | ,365**        | ,514**         | ,400**                | ,321**               | ,568**             | ,697**         | 1  |                     |   |
| Total mental health                         | ,523**               | ,633**                                  | ,552**        | ,628**         | ,672**                | ,785**               | ,797**             | ,841**         | ,792**                                     | 1                   |   |
| Zarit Caregiver Burden Interview (ZBI-12)   | -,135                | -,273**                                 | -,145         | -,155          | -,206*                | -,485**              | -,198*             | -,278**        | -,289**                                    | -,425**             | 1   |
| Multidimensional Fatigue Inventory (MFI-20) | -,172                | -,311**                                 | -,182         | -,149          | -,239*                | -,441**              | -,229*             | -,294**        | -,278**                                    | -,412**             | ,794**                                    |

**Table 9:** Correlation.

\*\*  $p < .01$ , \*  $p < .05$ .

## Discussion

Research on the burden of care has focused primarily on the effect of family and informal caregiving on psychiatric patients transitioning from institutions to homes. Older studies generally do not examine caregivers' physical or mental health outcomes [14]. However, in recent years researchers have accumulated a growing body of evidence for caregivers, particularly those who care for a chronically ill family member [15,16], arguing that there are psychological and natural consequences. Exposure to stress has been linked to various physical and psychological problems [17]. Recent research assists the connection between physical and psychological health, that suggests that mental health affects the physical health of caregivers [18,19]. Knight and Losada point out that psychological burden is associated with adverse physical outcomes for caregivers, including low immunity and higher levels of stress hormones [19]. Knight and Losada [19] argue that carers caring for people with dementia significantly impact their mental health. Butler's research has argued a high correlation between caregiver burden and depression. He reports high caregiver burden and depression, including isolation, task knowledge, job difficulty, and family support. There does not appear to be a strong association between demographic variables (including age, gender, education and employment) and caregiver burden or the presence of depression [16]. In

current study, the state of the disease must be investigated and analyzed in all aspects of social life, especially the daily life of people living together and under the weight of the disease. Chronic renal failure is a significant health problem worldwide associated with increased morbidity and mortality and significantly impacts patients' quality of life. As a chronic disease, it has a decisive effect on patients' QoL and creates adverse effects at the individual, family and social levels.

On the other hand, some research suggests that caregivers' care can bring about positive psychological and physical outcomes [20,21]. Stressors, especially work and social relationships, interact strongly with well-being indicators. Caregiver well-being and health are influenced by several factors, including demographic characteristics, levels of caregiving-related stress, and the quality of resources available to help caregivers cope with stress [22]. The combination of caregiver tasks and stress can lead to compromised health among caregivers [16]. Caregiver research identifies the potential adverse effects of stress on caregivers' psychological and physical health. Saldaña, *et al.* [23] report that caregivers experience poor psychological and physical health due to stress resulting from isolation and reduced available support.

Casado, *et al.* [24] linked patient behavioural problems with adverse effects on caregivers' well-being, including psychological and emotional distress, increased caregiver burden, and general physical health problems. However, the relationship between caregiver and care recipient well-being is not well established, especially in countries with more family-based care structures [25].

Caregiving is a chronic stressful experience accompanied by high uncertainty about the future, loss of control over the caregiver's life, and the possibility of the patient's death, also affecting work and family relationships [26]. Due to the multiple roles played, the caregiver must balance the role of caregiver and their obligations for work and other family responsibilities [27].

Chronic renal failure, in this research, affects the psychological well-being of patients and their social and financial well-being. According to the literature, the main factors that affect the QoL of hemodialysis patients are the problems arising from the severity of the disease, various socio-demographic factors (age, gender), financial problems, depression, mental disorders or failure compliance with treatment guidelines, the support provided by the family and social environment, sleep disorders and insufficient information.

Objective stressors in caregivers caring for a hemodialysis patient are associated with physical, psychiatric, and cognitive impairments experienced by the hemodialysis patient [28,29]. This leads to psychosocial stress and harmful health-related behaviours, which trigger physiological responses and risk developing secondary health problems that undermine the ability to care [26,30]. Studies have shown that caregivers who report stress experience cardiovascular problems, lower immunity, higher concentrations of stress hormones, and a higher estimated risk of stroke [26,31,32]. Because of their frailties, elderly caregiver spouses who report stress have a 63% higher 4-year mortality rate than age-matched non-caregivers, as shown in the Caregiver Health Effects Study [33]. Caregiver stress is also associated with sleep disturbances, fatigue, and neglect of one's health [34]. The highest stress level was reported among those in poorer health and exhibiting a more intense level of caregiving. The prevalence of emotional distress leading to depression and anxiety-related symptoms ranges from 18 - 47%. Those experiencing emotional distress reported higher burden [34,35].

The emotional disturbances of the caregivers come not only from the care but also from the daily contact with the sufferer [36]. These disorders are more common in women than men [37]. Any emotional disturbance has significant consequences on the QoL among caregivers and the quality of care for the patient. A study comparing caregivers of hemopurified patients and those with kidney transplants had higher emotional disturbances and poor sleep quality than caregivers of transplant patients [38].

Since caregiving is time-consuming, it can lead to social isolation and loss of personal time [34]. Mental health and social functioning are the most negatively affected domains with the highest perceived burden significantly associated with a lower quality of life. Caregivers have also reported feeling restricted and socially isolated as they have no time for social interactions [7].

## Conclusion

The statistical analysis conducted above resulted in the level of physical functioning, the role limitations due to physical health, the physical pain, the total physical health, the emotional well-being, the social functioning, the role limitations due to emotional problems, and the total mental health of the caregivers was moderate. Furthermore, the level of general health and the energy/fatigue of the caregivers was below average. In addition, the caregiver's burden and fatigue level were above average. Additionally, inferential statistics showed that male caregivers, in comparison with female caregivers, exhibited a higher level of physical functioning, role limitations due to physical health, Physical pain (higher values of physical pain exhibit higher health level status), and total physical health and social functioning. Furthermore, caregivers 30-40 years old, compared to caregivers over 50, exhibited a higher level of physical functioning and total physical health. Moreover, caregivers of 30 - 40 years old, compared to caregivers of 40-50, exhibited a higher level of general health. The correlation analysis resulted in a statistically significant negative correlation between the caregivers' burden/fatigue with the role limitations due to physical health, total physical health, emotional well-being, social functioning, energy/fatigue, and role limitations due to emotional problems and the total mental health. The result of the correlation analysis confirms the research hypotheses that the health status of the caregivers is negatively affected by the burden and the fatigue they receive from their work.

## Bibliography

1. Brown R Michael and Stephanie L Brown. "Informal caregiving: A reappraisal of effects on caregivers". *Social Issues and Policy Review* 8.1 (2014): 74-102.
2. Northouse Laurel L., et al. "The impact of caregiving on the psychological well-being of family caregivers and cancer patients". *Seminars in Oncology Nursing* 28.4. (2012).
3. Collins Lauren G and Kristine Swartz. "Caregiver care". *American Family Physician* 83.11 (2011): 1309-1317.
4. Given Charles W., et al. "Predictors of pain and fatigue in the year following diagnosis among elderly cancer patients". *Journal of Pain and Symptom Management* 21.6 (2001): 456-466.
5. Bauer Jan Michael and Alfonso Sousa-Poza. "Impacts of informal caregiving on caregiver employment, health, and family". *Journal of population Ageing* 8.3 (2015): 113-145.
6. Crespo Carla., et al. "Family routines and rituals in the context of chronic conditions: A review". *International Journal of Psychology* 48.5 (2013): 729-746.
7. Low Joseph., et al. "The impact of end-stage kidney disease (ESKD) on close persons: a literature review". *NDT Plus* 1.2 (2008): 67-79.
8. Einollahi Behzad., et al. "Burden among care-givers of kidney transplant recipients and its associated factors". *Saudi Journal of Kidney Diseases and Transplantation* 20.1 (2009): 30.
9. Stenberg Una., et al. "Review of the literature on the effects of caring for a patient with cancer". *Psycho-Oncology* 19.10 (2010): 1013-1025.
10. Brazier John E., et al. "Validating the SF-36 health survey questionnaire: new outcome measure for primary care". *British Medical Journal* 305.6846 (1992): 160-164.
11. Lins Liliane and Fernando Martins Carvalho. "SF-36 total score as a single measure of health-related quality of life: Scoping review". *SAGE Open Medicine* 4 (2016): 2050312116671725.

12. Yfantopoulos J. "Measuring quality of life and the European health model". *Archives of Hellenic Medicine* 24.1 (2007): 6-18.
13. Jenkinson Crispin., et al. "Short form 36 (SF36) health survey questionnaire: normative data for adults of working age". *British Medical Journal* 306.6890 (1993): 1437-1440.
14. Raveis Victoria H., et al. "Psychological impact of caregiving on the caregiver: A critical review of research methodologies". (1990).
15. Pinquart Martin and Silvia Sörensen. "Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis". *Psychology and Aging* 18.2 (2003): 250.
16. Butler Sandra S., et al. "Depression and caregiver burden among rural elder caregivers". *Journal of Gerontological Social Work* 46.1 (2005): 47-63.
17. Chiriboga David A., et al. "The stress of caregivers". *Journal of Applied Social Sciences* (1990).
18. Savundranayagam, Marie Y., et al. "A dimensional analysis of caregiver burden among spouses and adult children". *The Gerontologist* 51.3 (2011): 321-331.
19. Knight Bob G and Andres Losada. "Family caregiving for cognitively or physically frail older adults: Theory, research, and practice". *Handbook of the Psychology of Aging* (2011): 353-365.
20. Foley KL., et al. "Self-gain and self-loss among African American and White caregivers". *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences* 57.1 (2002): S14-S22.
21. Brown Stephanie L., et al. "Caregiving behavior is associated with decreased mortality risk". *Psychological Science* 20.4 (2009): 488-494.
22. Byrd Joshua., et al. "Differences in caregiving: Does residence matter?". *Journal of Applied Gerontology* 30.4 (2011): 407-421.
23. Salda Delia H., et al. "When is caregiving a burden? Listening to Mexican American women". *Hispanic Journal of Behavioral Sciences* 21.3 (1999): 283-301.
24. Casado Banghwa Lee., et al. "Unmet needs for home and community-based services among frail older Americans and their caregivers". *Journal of Aging and Health* 23.3 (2011): 529-553.
25. Isaac Vivian., et al. "Caregiver burden and quality of life of older persons with stroke: A community hospital study in South India". *Journal of Applied Gerontology* 30.5 (2011): 643-654.
26. Schulz Richard and Paula R Sherwood. "Physical and mental health effects of family caregiving". *Journal of Social Work Education* 44.3 (2008): 105-113.
27. Reinhard Susan C and Lynn Friss Feinberg. "The escalating complexity of family caregiving: Meeting the challenge". *Family Caregiving in the New Normal* (2015): 291-303.
28. Ziegert Kristina. "Everyday life among next of kin of haemodialysis patients". Diss. Dept. of Medicine and Care, Linköping University (2005).
29. Jadhav Bindoo S., et al. "Psychiatric morbidity, quality of life and caregiver burden in patients undergoing hemodialysis". *Medical Journal of Dr. DY Patil University* 7.6 (2014): 722.

30. Antonaki E., *et al.* "Burden and quality of life of caregivers of chronic haemodialysis patients in Heraklion, Crete". *Elliniko Periodiko tis Nosileutikis Epistimis* 11.3 (2018): 33-47.
31. Beinart Naomi., *et al.* "Caregiver burden and psychoeducational interventions in Alzheimer's disease: a review". *Dementia and Geriatric Cognitive Disorders Extra* 2.1 (2012): 638-648.
32. Haley William E., *et al.* "Caregiving strain and estimated risk for stroke and coronary heart disease among spouse caregivers: differential effects by race and sex". *Stroke* 41.2 (2010): 331-336.
33. Schulz Richard and Scott R Beach. "Caregiving as a risk factor for mortality: the Caregiver Health Effects Study". *The Journal of the American Medical Association* 282.23 (1999): 2215-2219.
34. White Yvonne and Brin FS Grenyer. "The biopsychosocial impact of end-stage renal disease: the experience of dialysis patients and their partners". *Journal of Advanced Nursing* 30.6 (1999): 1312-1320.
35. Parks Susan Mockus and Karen D Novielli. "A practical guide to caring for caregivers". *American Family Physician* 62.12 (2000): 2613-2620.
36. Aldrich N. "CDC seeks to protect health of family caregivers". *National Association of Chronic Disease (CDC)* (2011).
37. Hébert Réjean., *et al.* "Reliability, validity and reference values of the Zarit Burden Interview for assessing informal caregivers of community-dwelling older persons with dementia". *Canadian Journal on Aging/La Revue Canadienne du Vieillessement* 19.4 (2000): 494-507.
38. Avşar U., *et al.* "Caregiver burden, anxiety, depression, and sleep quality differences in caregivers of hemodialysis patients compared with renal transplant patients". *Transplantation Proceedings* 47.5 (2015): 1388-1391.

**Volume 12 Issue 3 March 2023**

**©All rights reserved by Kyriaki Stavrou and Gülcan Garip .**