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Research Article

# The Relationship between Health-Related Quality of Life and Burden among Family Caregivers of Elderly Patients Undergoing Hemodialysis in Saudi Arabia

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## ABSTRACT

**Aim:** The aim of the study was to examine the relationship between health-related quality of life (HRQOL) and burden among family caregivers of elderly patients undergoing hemodialysis, in Saudi Arabia. **Methods:** Cross-sectional, descriptive, and correlational designs were used. A structured interviewing questionnaire was used to recruit 50 caregivers randomly. Pearson correlation was used to correlate between socio-demographic data, HRQOL, and burden degree. Ethical approval was assured. **Results:** A statistically significant negative association between the degree of burden and HRQOL among family caregivers was found. There was a significant positive association between burden degree and the caregivers' age, marital status, the duration of caregiving and care of recipient's age, physical function, physical health problems, and emotional problems. Meanwhile, there was a negative association between burden degree and level of education, general health perception, emotional well-being, vitality, and social functioning. **Conclusion:** When the nurses understand the relationship between burden of care experience among the caregivers and HRQOL that lead them to intervene effectively with a multi-disciplinary team to support caregivers for minimizing the level of burden and avoid burnout.

**Keywords:** Burden, Elderly patients, Family caregivers, Health-related quality of life, Hemodialysis

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## Introduction

Today, the world is facing the phenomenon of aging as a result of the increase in life expectancy over the next two decades, which is leading to an increase in the incidence of chronic diseases such end-stage renal disease (ESRD) among this aged group in both developed and developing countries, despite the development of medical modalities. Renal disease is a chronic illness and currently affects approximately 850 million people worldwide. One in ten adults has chronic kidney disease (CKD). The global burden of CKD is increasing and is proposed to turn the 5th most common cause of years of life missing globally by 2040. Many studies have shown that older age, diabetes mellitus, hypertension, cardiovascular disease, and higher body mass index (≥30 kg/$m^2$; BMI) are associated with CKD. In the World Kidney Day Report (2020), there is 10% of the population worldwide and is exaggerated by CKD, and each year millions die because they do not have access to accessible treatment.[1,2]

Moreover, 2 million people who takings management for kidney failure, the widely held is treated in only five countries– the United States, Japan, Germany, Brazil, and Italy. These five countries signify only 12% of the world population. Only 20% are cured in about 100 developing countries that make up over 50% of the world population.[3] More than 80% of all patients who obtain treatment for kidney failure are in prosperous countries with universal access to health care and great senior populations.[4]

In light of the United States Renal Data System (USRDS)-ESRD Database (2018) reported that the ESRD prevalence has risen over time, with steeper increases (4000/ million) among the older age groups (≥75).[5] Although the USRDS (USRDS, 2019) reported that the incidence rate was highest (1600/million/year) in the oldest group (≥75), ESRD prevalence was a little lower, due to greater mortality among the oldest ESRD patients.[6] In addition, ESRD is a major cause of the health income-expenditure where the costs of dialysis and transplantation around 2–3% of the annual health-care fund in high-income nations; most people with kidney failure have inadequate access to life-saving dialysis and renal transplantation. In the meantime, in Saudi Arabia, the estimated number of cases of kidney failure on hemodialysis was 10,203 patients, and also the number of cases of Saudi population aged >66 years was anticipated to rise up to 3.5 folds over the next 20 years. Probably, this will cause a rise in new cases in that the age group from 1198 in 2008 to 4109 in 2029. This would represent an increase in the incidence rate from 138 per million population (PMP) to 176 PMP (27.9%).[1,2] This variation in the incidence and prevalence rate between Kingdom of Saudi Arabia and the USA is due to decreased for diabetes in the USA, caused by ESRD, while it continues to increase in Saudi Arabia. In addition, to shift in age demographics and dynamics toward an older age and the increasing incidence of diabetes.[7,8]

As a consequence of ESRD, the patient is going on hemodialysis as a medical procedure that can support patients with this disease to increase quantity and quality of life (QOL). Although, there are several intrinsic risks associated with dialysis, which are more profound in patients at risk of complications, such as the elderly or those with other concurrent health conditions. These complications lead the patients to have a lot of restriction and also, they are at risk of developing other medical conditions, for example, amyloidosis where amyloid proteins produced in bone marrow build up in organs such as the kidneys, liver, and heart. This usually causes joint pain, stiffness, and swelling which may be difficult for some people to adjust to and completely disrupting their life and lead them to be totally dependent on the family caregivers for assessing them in essential activities of daily living such as bathing, transferring, eating, housekeeping, medications, and shopping for a long period of time when receiving treatment because they are the most significant closed relative to patients and the best caregiving source for patients as well as they are considered as a partner in the process of decision-making.[8-10]

On the other hand, when the caregivers carried all responsibilities to take care of the patients for a long period of time with load and at they did not have time for caring of themselves that lead them more exposed to a lot of challenges and feeling of burden.[11] In addition, the burden of care for caregivers of hemodialysis patients was significantly higher than that for caregivers of non-dialysis patients. For the caregivers of hemodialysis at disease outcomes individuals' ideas, life experiences, personality, and expectations about the disease outcomes.[12,13] In the mean-time, caregivers can expose to burden and then followed by burnout as a state of emotional and physical exhaustion if they stay for a prolonged period of stress and frustration which affect negatively on the QOL. In addition, health-related QOL (HRQoL) brings up to the cognitive of the influence of the disease and its management on the individual's health and social dimensions.[14-16]

Moreover, several studies showed that the QOL of the family caregivers of hemodialysis patients was lower than the general population of the same age and sex. In addition, the younger family caregivers who were looking after elderly patients on the dialysis with lower QOL had an experience of the higher burden of care, lower HRQoL and a higher risk of stress, depression, anxiety, lack of confidence, fatigue, social isolation, frustration, lack of independence, and financial, and communication constraint of the care.[16-21]

To provide the health-care providers by evidence data-based toward the relationship between the HRQoL and the levels of burden among family caregivers of the elderly undergoing hemodialysis in Saudi Arabia, a careful assessment and constant reassurance of the family caregivers are essential intervention to avoid any threats that can lead to burden and decrease QOL among the caregivers. Hence, the geriatrics nurse can assist the family caregivers to live healthy, to provide better care for their beloved ones, and to minimize the burden of caregiving among family caregivers of hemodialysis elderly patients.

## Aim of the study

The aim was to examine the relationship between HRQoL and burden among family caregivers of the elderly patients undergoing hemodialysis, in Saudi Arabia.

### Research questions

1. What are the levels of QOL according to the degree of burden among the family caregivers in the study sample?
2. What are the highest dimensions of burden among the family caregivers in the study sample?
3. Is there an association between socio-demographic characteristics and degree of burden among family caregivers of elderly patients undergoing hemodialysis?
4. Is there an association between HRQoL and degree of burden among family caregivers of elderly patients undergoing hemodialysis?

## Material and Methods

### Research design

Cross-sectional, descriptive, correlational, and comparative designs were used between January 2019 and March 2019.

### Research setting

The researchers contacted the family caregivers in the waiting area of the hemodialysis unit, Riyadh, Saudi Arabia. This hemodialysis unit is providing the medical services to all patients regularly attending the in-patient hemodialysis. The family caregivers were selected randomly from the patients' names list as a sampling frame and then follow-up to them at home to collect the data through the cell phone.

### Study sample

A probability simple random sampling was used to recruit the study sample. Eligible family caregivers are the participants who have 20 years and above; both genders, welling to participate in the study, and who are caring for their elderly undergoing hemodialysis, while the other family caregivers of patients under 60 years old were excluded from the study sample. According to the National Guard Health Affairs data from the previous year's population, the number of family caregivers of the elderly undergoing hemodialysis had taken treatment in King Abdul-Aziz Medical City (KAMC). Using sample size calculator Raosoft, in power analysis of α 0.05, power 90, and medium effect size of 0.2, and using the correlation test, considering the confidence level 95% and confidence interval 5%. The recommended sample size is (50) family caregivers of the elderly undergoing hemodialysis.

### Data collection

A structured interviewing questionnaire is composed of three tools that answered within 20–25 min. All the instruments are valid and reliable for data collection. Meanwhile, the Zarit Burden Interview (ZBI) tool was translated into Arabic and any modifications were carried out accordingly. A group of experts had tested the content validity.

### Instruments

Socio-demographic characteristics of the family caregiver and care recipients included age, gender, marital status, levels of education, the relationship of the caregivers to care, recipients, family income sufficiency, and duration of caregiving/year.

### Zarit caregiver burden interview (ZBI)

It is an assessment tool for evaluating caregiver burden. This tool consists of 22 items rated on a 5-point Likert scale that ranges from 0= "never" to 4= "nearly always". The sum score of ZBI items is ranging from 0 to 88. The highest score indicates to severe burden degree. The levels of burden were categorized into no burden (0–20) mild/moderate burden (21–60), severe burden (61–88). The ZBI items are focused on four dimensions of burden which included the caregiver's physical health, psychological well-being, financial status, social life, and the relationship between caregiver and patient distresses. The Cronbach's alpha for the ZBI was 0.921. The ZBI tool had good item-total ($r = 0.395$) and item-correlation (mean $r = 0.365$). It was found that the Arabic version of the ZBI had high reliability where the Cronbach's alpha value for the ZBI items was 0.86.[22,23]

### HRQoL

It is a tool to assess how health impacts an individual's ability to function and his/her perceived well-being in physical, mental, and social domains of life. It is comprised 36 items that assess eight health concepts: Physical functioning, role limitations caused by physical health problems, role limitations caused by emotional problems, social functioning, emotional well-being, vitality (energy/fatigue), bodily pain, and general health perceptions. The Cronbach's alpha value for each subscale the intra-class correlation coefficient for the test-retest reliability of the score of the English was physical functioning (0.90), role limitations physical health (0.76), role limitation emotional health (0.74), energy/fatigue (0.61), emotional well-being (0.79), social functioning (0.60), bodily pain (0.73), and general health perception (0.68). The intra-class correlation coefficient for the test re-test reliability of the score in the Arabic version is physical functioning (0.88), role limitations physical health (0.80), role limitation emotional health (0.70), energy/fatigue (0.82), emotional well-being (0.84), social functioning (0.79), bodily pain (0.80), and general health perception (0.57).[24] Total score of the overall QOL items was categorized into worse QOL (0–3) and better QOL (4-5). Meanwhile, summation of each subscale was done separately according to rating score of each scale.

## Translation

In the current study, these tools were adapted and translated from English to the Arabic language and translated back to English by a group of experts in the geriatric nursing field College of Nursing, Cairo and Menoufia University, Egypt, as external reviewers for checking the consistency after back translation to English. The required modification was done accordingly.

## Pilot study

The questionnaire was piloted among five family caregivers of the elderly undergoing hemodialysis to assess the clarity and feasibility of the questionnaires and also to determine the time frame that will be required to fulfill the questionnaire. The necessary modification was done accordingly.

## Ethical considerations

The research proposal was approved by the Institutional Review Board (IRB). All participants were fully informed regarding the purpose of the study, expectations of participation and clarified that no potential risks associated with this participation and they have the right to withdrawal from the research without penalty. Privacy and confidentiality were completely protected; no personal information was collected.

## Statistics

Data entry and analysis were performed using SPSS for windows version 22. The responses in the completed questionnaires were coded and entered into a data template. Descriptive statistical analysis as frequencies or percentages means, figures, and graph chart was used for describing data. Pearson correlation coefficient (r) was employed to address the correlation between HRQoL and levels of burden among family caregivers of elderly undergoing hemodialysis. The statistical significance level was $P < 0.05$.

## Results

### Socio-demographic characteristics

Table 1 shows the socio-demographic characteristics of family caregivers and care recipients in the study sample. The results displayed that the study sample participants were (50) family caregivers who are responsible to provide care to their elderly patients who are undergoing hemodialysis. Moreover, the mean age of the family caregivers was (39.12 ± 7.08); meanwhile, the mean age of the care recipients was 69.40 ± 6.11. More than two-thirds of family caregivers were females and about one-third was males. However, the majority of the care recipients were males 78% and 22% were females. Half of the study sample was married and

**Table 1:** Socio-demographic characteristics of family caregivers and care recipients in the study sample

| Variables | Family caregivers | | Care recipients | |
|---|---|---|---|---|
| | *n* (%) | M±SD | *n* (%) | M±SD |
| Age/Year | | | | |
| >20–39 | 16 (32.0) | 39.12±7.08 | 0 (0.0) | 69.40±6.11 |
| >40–59 | 34 (68.0) | | 0 (0.0) | |
| >60–74 | 0 (0.0) | | 33 (66.0) | |
| >75+ | 0 (0.0) | | 17 (34.0) | |
| Gender | | | | |
| Female | 36 (72.0) | | 11 (22.0) | |
| Male | 14 (28.0) | | 39 (78.0) | |
| Marital status | | | | |
| Single | 11 (22.0) | | | |
| Married | 25 (50.0) | | | |
| Widowed | 14 (28.0) | | | |
| Levels of education | | | | |
| No formal education | 17 (34.0) | | | |
| Primary/Middle schools | 13 (26.0) | | | |
| Secondary school/diploma | 16 (32.0) | | | |
| University | 4 (8.0) | | | |
| The relationship of the family caregivers to care recipients | | | | |
| Spouse | 4 (8.0) | | | |
| Daughter | 30 (60.0) | | | |
| Son | 16 (32.0) | | | |
| Family income sufficiency | | | | |
| Sufficient | 44 (88.0) | | | |
| Insufficient | 6 (12.0) | | | |
| Duration of caregiving/Year | | | | |
| More than 5 years | 27 (54.0) | | | |
| Less than 5 years | 23 (46.0) | | | |

28% was widowed. Only (32%) of caregivers had completed secondary school/diploma, while (34%) not have formal education and 8% had completed a university. Sixty percent of the caregivers who giving care to the care recipients were their daughters, while 32% was their sons and only 8% was their spouse. In addition, this result displayed the majority of the study sample (88%) had family income sufficiency, and more than half of the family caregivers (54%) were providing care to their elderly patients for more than 5 years.

### Dimensions of burden and degree of burden

Figure 1 presents dimensions of burden among the family caregivers in the study sample. The results illustrated those family caregivers who are always exposed to psychological and social distress, those are the ones who perceived severe degree of burden (30% and 29%), respectively, compared to the degree of burden of the family caregivers who never exposed to psychological and social distress; followed by the caregivers who are always exposed to physical and finance distress, those are the ones who perceived severe degree of burden (20% and 16%), respectively, compared to the degree of burden of the family caregivers who never exposed to physical and finance distress.

### Association between the degree of burden and socio-demographic characteristics

Table 2 pointed out the association between the degree of burden and socio-demographic characteristics of the family caregivers and care recipient. The results revealed that the family caregivers' age (>40–60 years) who are the ones perceived severe degree of a burden compared to the family caregivers' age (>20–39 years). There was a significant correlation between the degree of burden and the caregivers' age (r = 0.280, *P* = 0.049). In addition, the degree of severe burden was high among the family caregivers who deliver care to the old-old group compare to the young-old group. There was a significant correlation between the degree of burden and the care recipients' age (r = 0.394, *P* = 0.005). Furthermore, the finding presented there is no correlation between the degree of burden and both family caregivers' gender and care recipients' gender. There was a no significant correlation between the degree of burden and the caregivers' gender and care recipients' gender (r = 0.236, *P* = 0.099; r = −0.028, *P* = 0.848), respectively. Regarding the marital status, the results exposed that the single caregivers who the ones are perceived severe degree of a burden compared to married and widowed caregivers. There was a significant correlation between the degree of burden and the marital status of the caregivers (r = 0.419, *P* = 0.002). Moreover, the caregivers who had no formal education perceived a severe degree of a burden compared to those who had a university education. There was a significant negative correlation between the degree of burden and caregivers' education (r = −0.320, *P* = 0.023). In addition, the results exhibited caregivers who giving care more than 5 years perceived severe degree of a burden compared to those who give a care <5 years. There was a significant positive correlation between the degree of burden and the duration of caregiving (r = 0.446, *P* = 0.001). Moreover, there is no significant relation between the degree of burden and the relationship of the caregivers to care recipients as well as family income (r = 0.255, *P* = 0.073; r = 0.248, *P* = 0.082), respectively.

### Association between HRQoL and degree of burden

Table 3 exhibited the association between HRQoL and degree of burden among the family caregivers of elderly patients undergoing hemodialysis. The result declared

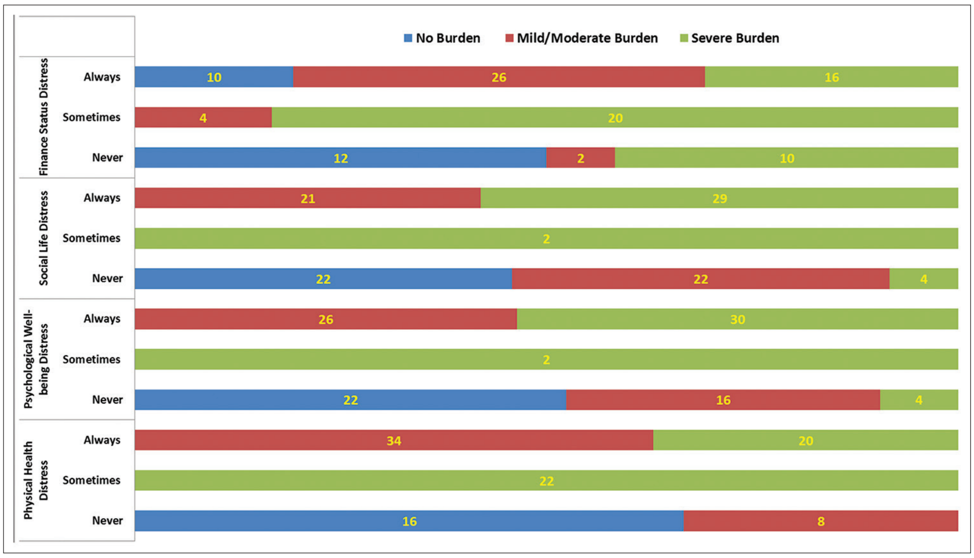

**Figure 1:** Percentage distribution of the degree and dimensions of burden among the family caregivers in the study sample

**Table 2:** Association between socio-demographic characteristics of the family caregivers and care recipients with degree of burden in the study sample

| **Socio-demographic characteristics** | **Degree of burden** | | | |
|---|---|---|---|---|
| | **No burden *n* (%)** | **Mild/Moderate burden *n* (%)** | **Severe burden *n* (%)** | ***P* value (r)** |
| | **11 (22%)** | **21 (42%)** | **18 (36%)** | |
| Caregiver's age/Year | | | | |
| >20–39 | 10 (20.0) | 16 (32.0) | 10 (20.0) | 0.049* (0.280) |
| >40–60 | 1 (2.0) | 5 (10.0) | 8 (16.0) | |
| Caregiver's gender | | | | |
| Female | 7 (14) | 12 (24) | 17 (34) | 0.099 (0.236) |
| Male | 4 (8) | 9 (18) | 1 (2) | |
| Marital status | | | | |
| Single | 3 (6.0) | 7 (14) | 15 (30) | 0.002** (0.419) |
| Married | 2 (4) | 8 (16) | 1 (2) | |
| Widowed | 6 (12.0) | 6 (12) | 2 (4) | |
| Levels of education | | | | |
| No formal education | 1(2) | 7(14) | 9(18) | 0.023* (−0.320) |
| Primary/Middle school | 2(4) | 7(14) | 4(8) | |
| Secondary school | 7(14) | 6(12) | 3(6) | |
| University | 1(2) | 1(2) | 2(4) | |
| The relationship of the caregivers to care recipients | | | | |
| Spouse | 2 (4.0) | 1 (2.0) | 1 (2.0) | 0.073 (0.255) |
| Daughter | 5 (10.0) | 11 (22.0) | 14 (28.0) | |
| Son | 4 (8.0) | 9 (18.0) | 3 (6.0) | |
| Family income sufficiency | | | | |
| Sufficient | 0 (0.0) | 2 (4) | 4 (8) | 0.082 (0.248) |
| Insufficient | 11 (22) | 19 (38) | 14 (28) | |
| Duration of caregiving/ Year | | | | |
| More than 5 years | 3 (6) | 8 (16) | 16 (32) | 0.001** (0.446) |
| Less than 5 years | 8 (16) | 13 (26) | 2 (4) | |
| Age of the care recipient (Year) | | | | |
| Young-old (60–74) | 10 (20.0) | 16 (32.0) | 7 (14.0) | 0.005** (0.394) |
| Old-old (75–84) | 1 (2.0) | 5 (10.0) | 11 (22.0) | |
| Gender of the care recipient | | | | |
| Female | 7 (14.0) | 15 (30.0) | 12 (24.0) | 0.848 (0.028) |
| Male | 4 (8.0) | 6 (12.0) | 6 (12.0) | |

*$P<0.05$, **$P<0.001$

that there was a significant negative correlation between the degree of burden and overall QOL of the caregivers, where the caregivers who had worse QOL, those are the ones perceived severe burden compared to those who had no burden ($r = -0.465$, $P = 0.001$). Moreover, the results identified a significant negative correlation between the degree of burden and general health perception, where the caregivers who had poor general health perception, those are perceived severe degrees of a burden compared to those who had good general health perception ($r= -0.277$, $P = 0.051$). Furthermore, there is a significant correlation between the degree of burden and physical function as well as physical health problems, whereas the caregivers who had limitation a lot in their physical function and also had physical health problems, those are the ones who perceived severe degree of a burden compared to those who had no physical function limitation at all and who had no physical health problems ($r = 0.383$, $P = 0.006$; $r = 0.286$, $P = 0.044$), respectively.

In this regard, the study findings showed a statistically significant correlation between the degree of burden and bodily pain as well as vitality. The results revealed that caregivers had severe bodily pain and poor vitality, those are the ones who perceived a severe degree of a burden compared to those who had no/mild bodily pain and poor vitality ($r = 0.479$, $P = 0.000$; $r = -0.832$, $P = 0.000$), respectively. On the other hands, there is a statistically significant correlation between the degree of burden and emotional well-being as well as emotional health problems, where the result indicated that the caregivers did not have emotional well-being all the time and also who had emotional health problems, those who are perceived severe degree of a burden compared to those who had emotional well-being and also who had no emotional health problems ($r = -0.438$, $P = 0.001$; $r = 0.369$, $P = 0.008$), respectively. In addition, there is a statistically significant correlation between the degree of burden and social functioning; wherever the results indicated that the caregivers do not interfere social activities at all, those who are perceived severe degree of a burden compared to those who are extremely interfere social activities problems ($r = 0.515$, $P = 0.000$).

**Table 3:** Association between health-related quality of life and degree of burden among family caregivers of elderly undergoing hemodialysis

| **Health-related quality of life domains** | **Degree of burden** | | | |
|---|---|---|---|---|
| | **No burden** ***n* (%)** | **Mild/Moderate burden** ***n* (%)** | **Severe burden** ***n* (%)** | ***P* value (r)** |
| | **11 (22%)** | **21 (42%)** | **18 (36%)** | |
| Overall QoL | | | | |
| Better | 7 (14.0) | 3 (6.0) | 2 (4.0) | 0.001** (−0.465) |
| Worse | 4 (8.0) | 18 (36.0) | 16 (32.0) | |
| General health perception | | | | |
| Good | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0.051* (−0.277) |
| Fair | 1 (2.0) | 0 (0.0) | 7 (14.0) | |
| Poor | 10(20) | 21 (42.0) | 11 (22.0) | |
| Physical function | | | | |
| Yes, limited a lot | 2 (4.0) | 7 (14.0) | 11 (22.0) | 0.006** (0.383) |
| Yes, limited a little | 2 (4.0) | 7 (14.0) | 4 (8.0) | |
| No, limited at all | 7 (14.0) | 7 (14.0) | 3 (6.0) | |
| Physical health problems | | | | |
| Yes | 6 (12.0) | 15 (30.0) | 16 (32.0) | 0.044* (0.286) |
| No | 5 (10.0) | 6 (12.0) | 2 (4.0) | |
| Bodily pain | | | | |
| Severe pain | 3 (6.0) | 8 (16.0) | 16 (32.0) | 0.000** (0.479) |
| Mild pain | 3 (6.0) | 10 (20.0) | 1 (2.0) | |
| No pain | 5 (10.0) | 3 (6.0) | 1 (2.0) | |
| Emotional well-being | | | | |
| All the time | 6 (12.0) | 4 (8.0) | 2 (4.0) | 0.001** (−0.438) |
| Good bit of the time | 2 (4.0) | 8 (16.0) | 1 (2.0) | |
| None of the time | 3 (6.0) | 9 (18.0) | 15 (30.0) | |
| Social functioning | | | | |
| Extremely interfere social activities | 3 (6.0) | 7 (14.0) | 15 (30.0) | 0.000** (0.515) |
| Moderate interfere social activities | 3 (6.0) | 12 (24.0) | 3 (6.0) | |
| Not at all interfere social activities | 5 (10.0) | 2 (4.0) | 0 (0.0) | |
| Energy/fatigue (Vitality) | | | | |
| Good | 11 (22.0) 0 | 0 (0.0) | 0 (0.0) | 0.000** (−0.832) |
| Fair | (0.0) | 13 (26.0) | 5 (10.0) | |
| Poor | 0 (0.0) | 8 (16.0) | 13 (26.0) | |
| Emotional problems | | | | |
| Yes | 6 (12.0) | 17 (24.0) | 17 (24.0) | 0.008** (0.369) |
| No | 5 (10.0) | 4 (8.0) | 1 (2.0) | |

*$P<0.05$, **$P<0.001$. QOL: Quality of life

## Discussion

When the family caregivers provide support to their elderly patients undergoing hemodialysis that can make the difference in the successful achievement of the plan of treatment and support of the elderly patients from different human life aspects either "physical, social, financial, or emotional" for the feeling of well-being and improving their QOL. Although the family caregivers of the elderly patients undergoing hemodialysis are acquired more information and skills during the home care services to their patients, but still they are exposed to the subjective burden experience from different dimensions where the degree of burden is increased particularly with caring of the elderly patients because they are required more attention and care. Therefore, this study is aimed to examine how the degree of burden is affecting their quality of life (QOL) when they are giving care to their patients.

In reference to the relationship between the degree of burden and socio-demographic data, the results of the present study exhibited that there was a statistically significant correlation between the degree of burden and caregiver's age as well as care recipient's age, caregivers' marital status, level of education, and the duration of caregiving. Meanwhile, the results of the current study showed that there is no correlation between the degree of burden and both gender of the family caregivers and care recipients, the relationship of caregivers to care recipients, and family income. This results supported by Bayoumi (2014); Haleh *et al*., (2018); and Cantekin *et al*., (2016) who reported that the burden on family caregivers is important predicator which may be influenced with increased age of the caregivers, patients' age, level of education, and length of dialysis duration for hemodialysis patients.[21,25,26] Moreover, they showed that the caregiver burden increases if the caregivers are the patient's spouse. In contrast, Sedigheh *et al*. (2019) who stated that there was no significant relationship between the caring burden and age of the caregivers ($P = 0.35$, $r = 0.06$) caregivers' marital status ($P = 0.94$), levels of education, sex, race, average caring hours ($P = 0.86$, $r = 0.011$), and income level of the caregivers ($P = 0.07$, $r = -0.012$).[27] In addition, they revealed that there was no significant correlation between the caring burden score and the number of dialysis sessions and also the relationship with patients ($P = 0.09$).

Furthermore, the present study was illustrated that the majority of the caregivers had a high percent of the burden of care experience that ranged from mild/moderate to severe burden. This result is supported by Bayoumi,(2014); Haleh *et al.* (2018) studies showed that the burden of caregivers was experiencing high levels of care burden that was ranged from 33% to 37%, while moderate/intermediate was ranged from 43% to 53%.[21,25] Moreover, Cantekin *et al.*, 2016; and Purlusory *et al.* (2011) who stated that the percentage of the caregivers with high levels of burden was high (33.3%) among the HD patients, while the burden score was low (16.7%) among peritoneal dialysis (PD) patients. In addition, it proposed that caregivers' burden with PD patients was ranged from low to medium level of burden.[26,28]

The present study illustrated that the highest percentages of severe burden degree were presented among caregivers who are always exposed to psychological and social life distress, they are perceived the highest degree of burden more than the caregivers who are always exposed to a physical and finances distress. This result comes on the same line with Arechabala *et al.*, (2011), and Shakya *et al.* (2017) stated that caregivers of HD patients had depressive symptoms and fatigue. In addition, there was a statistically significant positive association ($r = 0.43$, $P < 0.001$) between self-perceived burden and the presence of depressive symptoms in patients.[29,30]

At the same time, caregivers who are burden with caregiving to their HD patients that lead to changes in lifestyle, which result in depression, worry, decrease physical health, social isolation, and financial distress for the caregiver. Furthermore, this results supported by Purlusory *et al.*, (2011); Arechabala *et al.*, (2011); and Shakya *et al.*, (2017) who mentioned that the significant predictor for caregiving by older caregivers lead to poor physical health, depression, and even increased mortality, while younger caregivers had juggle work, their own family responsibilities, and expenses involving their social lives. In addition, middle-aged caregivers typically worry about missed workdays, disturbances at work, taking leaves of absence, and reduced productivity.[28-30]

Regarding the QOL and degree of burden, the current study projected that an increase in the burden of care experience was associated with decreased the QOL. This finding comes in agreement with Bayoumi, (2014); Haleh *et al.*, (2018); Cantekin *et al.*, (2016); and Sedigheh *et al.* (2019), reported that there was an inverse relationship between caring burden score and QOL score ($P < 0.001$). In addition, the results of the current study exhibited a statistically significant correlation between the burden of care and all the QOL domains that included general health perception, physical function, physical health problems, bodily pain, social functioning, energy/fatigue (vitality), and emotional problems.[21,25-27]

This result is supported by Cantekin *et al.*, (2016); Mashayekhi *et al.*, (2015); Ghane *et al.*, (2015) stated that the caregivers are giving care to their HD patients, they suffer from physical and psychological complications during the care of the patient and experience anxiety, fatigue, social isolation, stress, and exhaustion. These factors have a direct influence on their QOL. In addition, the QOL of the hemodialysis patients' caregivers is affected physically, mentally, and vitality.[13,26,31] In addition, Talebi *et al.* (2016) reported that increased caregivers burden can concession the physical and mental health of the caregiver; subsequently, they may experience high levels of the physical burden, which disturbs their QOL. Moreover, the family caregivers of chronic patients exposed to problems such as emotional stress and illness that have adverse effects on their social activities' participation, and their family and work lives are disrupted.[8]

## Conclusion

Comprehensive assessment of the family caregivers is one of the main nursing roles toward the caring of the elderly patients on hemodialysis to address their needs and provide guidance with constant reassurance for all decisions regarding their elderly care for minimizing the burden of care.

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## References

1. Centers for Disease Control and Prevention. National Diabetes Statistics Report. Atlanta, GA: Centers for Disease Control and Prevention, US Department of Health and Human Services; 2018.
2. Saudi Center for Organ Transplantation. Dialysis in the Kingdom of Saudi Arabia. Saudi J Kidney Dis Transpl. 2018;29:1012-20.
3. Couser WG, Remuzzi G, Mendis S, Tonelli M. The contribution of chronic kidney disease to the global burden of major non-communicable diseases. Kidney Int 2011;80:1258-70.

4. Jha V, Garcia-Garcia G, Iseki K, Li Z, Naicker S, Plattner B, *et al*. Chronic kidney disease: Global dimension and perspectives. Lancet 2013;382:260-72.
5. Saran R, Robinson B, Abbott KC, Agodoa LY, Bragg-Gresham J, Balkrishnan R, *et al*. US renal data system 2018 annual data report: Epidemiology of kidney disease in the United States. Am J Kidney Dis 2019;73 Suppl 1:A7-8.
6. United States Renal Data System. 2019 USRDS Annual Data Report: Epidemiology of Kidney Disease in the United States. Bethesda, MD: National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases; 2019.
7. Al-Jumaih A, Al-Onazi K, Binsalih S, Hejaili F, Al-Sayyari A. A study of quality of life and its determinants among hemodialysis patients using the KDQOL-SF instrument in one center in Saudi Arabia. Arab J Nephrol Transplant 2011;4:125-30.
8. Talebi M, Lakeh NM, Rezasoltani P, Leili EK, Shamsizadeh M. Caregiver burden in caregivers of renal failure patients under hemodialysis. J Holist Nurs Midwifery 2016;26:59-68.
9. Nikmanesh Z, Shahinfar M. The role of caregiver burden in quality of life and perception of patients with chronic kidney failure on hemodialysis. Ann Mil Health Sci Res 2016;14:e11465.
10. Rabiei L, Eslami A, Abedi H, Masoudi R, Sharifirad GR. Caring in an atmosphere of uncertainty: Perspectives and experiences of caregivers of peoples undergoing hemodialysis in Iran. Scand J Caring Sci 2016;30:594-601.
11. Marijean B. Assessment of caregiver burden in families of persons with multiple sclerosis. J Neurosci Nurs 2008;40:25-31.
12. Shah HB, Atif I, Rashid F, Babar MW, Arshad F, Qamar W, *et al*. Assessment of caregiver burden of patients receiving dialysis treatment in Rawalpindi. J Pak Med Assoc 2017;67:1498-501.
13. Mashayekhi F, Pilevarzadeh M, Rafati F. The assessment of caregiver burden in caregivers of hemodialysis patients. Mater Sociomed 2015;27:333-6.
14. Mashayekhi F, Mohammadi-Sardo M, Soltaninejad M. Relations between depressive symptoms and quality of life with caregivers' burden in hemodialysis patients. Int J Adv Res Biol Sci 2015;2:225-33.
15. Reza S, Saeid P, Mousa A. The effect of a family-based training program on the care burden of family caregivers of patients undergoing hemodialysis. Iran J Nurs Midwifery Res 2019;24:144-50.
16. Al-Shehhi M, El-Soud FA. Factors affecting quality of life in patients with end stage renal disease on hemodialysis, Ras Al Khaimah-United Arab Emirates. J Health Med Nurs 2016;26:2422-19.
17. Sajadi SA, Ebadi A. Quality of life among family caregivers of patients on hemodialysis and its relevant factors: A systematic review. Int J Community Based Nurs Midwifery 2017;5:206.
18. Leiknes I, Lien UT, Severinsson E. The relationship between caregiver burden, demographic variables, and the clinical characteristics of patients with Parkinson's disease-a systematic review of studies using various caregiver burden instruments. Open J Nurs 2015;5:855-77.
19. Gerasimoula K, Lefkothea L, Maria L, Victoria A, Paraskevi T, Maria P. Quality of life in hemodialysis patients. Mater Sociomed 2015;27:305-9.
20. Jadhav BS, Dhavale HS, Dere SS, Dadarwala DD. Psychiatric morbidity, quality of life and caregiver burden in patients undergoing hemodialysis. Med J Dr DY Patil Univ 2014;7:722-7.
21. Bayoumi MM. Subjective burden and family careers of hemodialysis patients. Open J Nephrol 2014;4:79-85.
22. Zarit SH, Todd PA, Zarit JM. Subjective burden of husbands and wives as caregivers: A longitudinal study. Gerontologist 1986;26:260-6.
23. Seng BK, Luo N, Ng WY, Lim J, Chionh H, Goh J, *et al*. Validity and reliability of the zarit burden interview in assessing caregiving burden. Ann Acad Med Singapore 2010;39:758-63.
24. Coons S, Draugalis J, Hays R, Albdulmohsin S. Reliability of an Arabic version of the RAND-36 health survey and its equivalence to the US-English version. Med Care 1998;36:428-32.
25. Haleh J, Azita E, Abbas A, Alireza K. The relationship between care burden and quality of life in caregivers of hemodialysis patients. BMC Nephrol 2018;19:321.
26. Cantekin I, Kavurmaci M, Tan M. An analysis of caregiver burden of patients with hemodialysisand peritoneal dialysis. Hemodial Int 2016;20:94-7.
27. Sedigheh F, Saba F, Azam M, Maryam E, Mohsen S, Mahin M. Caring burden and quality of life of family caregivers in patients undergoing hemodialysis: A descriptive-analytic study. Int J Community Based Nurs Midwifery 2019;7:88-96.
28. Pürlüsoy G, Sunay DS, Engezer T, YalçIntas A. Care burden in caregivers of dialysis patients and depression. Türk Aile Hek Derg 2011;15:17-23.
29. Arechabala MC, Catoni MI, Palma E, Barrios S. Depression and self-perceived burden of care by hemodialysis patients and their caregivers. Rev Panam Salud Pública 2011;30:74-9.
30. Shakya D, Tuladhar J, Poudel S. Burden and depression among caregivers of hemodialysis patients. Palliat Med Care 2017;4:1-6.
31. Ghane G, Farahani MA, Fatemi NS, Haghani H. Effect of educational program on the "quality of life" of family caregivers of patients undergoing hemodialysis. J Client Cent Nurs Care 2015;1:167-76.