

Self-Perceived Burden of Patients' Receiving Hemodialysis in Jordan: Association of Caregiver Burden and Sociodemographic Factors

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Abstract

This study aims at identifying, describing, and evaluating the relationship between patients' self-perceived burdens and their respective caregivers' burdens in terms of socio-demographic characteristics. A cross-sectional study, examining 142 pairs of patients and informal caregivers; participants were recruited from outpatient hemodialysis units. Along with recording socio-demographic characteristics, the Self-Perceived Burden Scale, the Oberst Caregiving Burden Scale, the Bakas Caregiving Outcomes Scale, and the Patient Health Questionnaire-9 were used for data collection.

Data analysis was performed using descriptive statistics, analyzing of variance, and the least significant difference. Most of the caregivers in this sample were sons of the patients (61.3%). Patients perceived themselves as a burden to caregivers, and that, in general, caregivers were moderately burdened and depressed. Further, traveling time to the patient's hemodialysis unit and economic and marital status significantly contributed to the burden among caregivers. The findings particularly highlight the importance of including both patients and caregivers in caregiver burden assessments.

Keywords

Caregiver Burden; Depression; Hemodialysis; Informal caregiver; Self-Perceived burden.

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1. Introduction

Over the past three decades, the caregiving burden has gained significant attention as an emerging health issue. This burden concerns the difficulties experienced when providing care for patients with chronic illnesses such as heart disease, Alzheimer's disease, and dialysis (Andreakou et al., 2016). Various characteristics, including socioeconomic status, education level, and age, have been linked to caregiver burden (Dye et al., 2018, Alnazly, 2016). Care recipients tend to perceive themselves as burdens, which increases their mortality rate, reduces their quality of life, and causes distress; this also affects clinical decisions concerning treatment methods and their acceptance (McPherson et al., 2010).

The treatment is burdensome to the patient since dialysis requires lifestyle change including diet, fluid restriction, travel to dialysis units weekly, and limited social activities, (Hoang, Green, & Bonner, 2018) Consequently, patients have shown perceiving themselves as burdens to caregivers (McPherson et al., 2010, Alnazly, 2020; Suri et al., 2011). Self-perceived burden (SPB) to the caregiver is defined as "empathic concern engendered from the impact on others of one's illness and care needs, resulting in guilt, distress, feelings of responsibility, and a diminished sense of self" (McPherson et al., 2010). Patients who perceive themselves as burdens are depressed and burdened, (Alnazly, 2020; Suri et al., 2011) decrease their quality of life (Suri et al., 2011), this also affects clinical decisions concerning treatment methods and their acceptance (McPherson et al., 2010).

Informal caregivers are individuals who provide unpaid care for a family member and assist with activities of daily living, tasks medical/nursing tasks, to allow patients to continue living at home. American Association of Retired Persons (AARP). Caregivers often experience guilt, grief, and worry, and socio-demographic variables are associated with caregivers' level of burden (Cook, Snellings & Cohen, 2018; Abu Kamel, 2015). However, caregiver distress is associated with employment status, socioeconomic status, being the patient's spouse, being younger than the patient, and the availability of personal or social support (Penning & Wu, 2015). Moreover, females tend to perform more intensive family caregiving tasks than males, causing significant implications for the health and quality of life of female caregivers (Sharma, Chakrabarti & Grover, 2016). Existing studies have mainly focused on key socio-demographic factors (Prevo et al., 2018). Thus, a comprehensive exploration of other possibly significant characteristics is needed. Caregivers require more attention, recognition, and support; therefore, understanding the socio-demographic factors that influence the positive and negative aspects of caregiver burdens is vital (Yakubu, 2018).

Few studies have explored the socio-demographic characteristics of caregivers of patients receiving

hemodialysis in Jordan. Research on caregivers' burden in Jordan showed that sociodemographic were factors that related to caregivers' burdens and recommended that health care professional should be acquainted with these differences and continually assess and plans patient's needs (Alnazly, 2016). A qualitative study, which studied the burden of caregivers of patients receiving hemodialysis in Jordan showed that older caregivers above the age of 65 were experiencing physical and psychosocial stress and recommended that special attention should be directed towards caregivers. Such as including policies in the health care system to provide community support and counselling (Alnazly & Samara, 2014). However, the contribution and impact of informal caregivers to hemodialysis patients had not been surveyed at the regional or country-level, although most chronic patients and older people receive care at home which saves money on the health care system.

The present study aims at identifying, describing, and evaluating, in terms of sociodemographic characteristics, the relationship between the self-perceived burden of Jordanian patients receiving hemodialysis and the burden of their respective informal caregivers. Understanding caregivers' sociodemographic characteristics could highlight the differing effects of caring on caregivers with various backgrounds. Further, such understanding is essential for developing evidence-based interventions for minimizing perceived burdens.

2. Methods

2.1 Subjects and Methods

This study is a cross-sectional design. Patients and their informal caregivers were the main participants recruited from outpatient haemodialysis units in three urban communities in Jordan. A nurse from the research team approached the patients who usually had the same caregivers presented in the haemodialysis unit. The nurse approached a total of 155 patients who agreed to participate but only 142 (90) showed up to the first meeting with their caregivers. Two nurses from each dialysis unit recruited patients who had unpaid informal caregivers. The inclusion criteria for patients were: (1) receiving hemodialysis for at least one year, (2) aged over 21 years, (3) able to read and answer the questionnaire. The inclusion criteria for caregivers were: (1) able to read and answer the questionnaire; (2) willing to participate; (3) caregiving for at least one year. Exclusion criteria were paid caregivers friends and neighbors' caregivers.

The questionnaires used were the sociodemographic characteristics, Self-Perceived Burden Scale (SPBS), the Oberst Caregiving Burden Scale-Difficulty subscale (OCBSD), the Bakas Caregiving Outcomes Scale (BCOS), and the Patient Health Questionnaire-9 (PHQ-9).

To obtain sociodemographic data, the author developed custom questionnaires. For caregivers,

the author obtained age, gender, marital status, employment status, relation to the patient, years of caregiving, caregiving living arrangement (distance from caregiver's and patient's residences), and travel time to the dialysis unit. For patients, information obtained included age, gender, and years receiving hemodialysis.

2.2 Instruments

The SPBS is a 10-item scale that measures three dimensions of burden, "body burden," "emotional burden," "economic burden". The scale is a five-point response scale (1 = "none of the time," 5 = "all of the time") that evaluates the degree to which hemodialysis patients feel they are a burden to their caregivers. An overall score ranging from 10 no burden to 50 maximum burden with higher scores indicate greater perceived burden. The original scale had a Cronbach's alpha of 0.93 (Cousineau et al., 2003) for this study, it was 0.88.

The OCBS-D is a 15-item, five-point response scale that measures caregivers' stress levels, emotional health, and physical well-being. The OCBS-D contains 15 items, which are measured using a five-point Likert scale (1 = "not difficult"; 5 = "extremely difficult"). The 15 item total scores were summed up to obtain a score between 15-75 and the higher scores representing a greater perceived burden (Bakas et al., 2004). The Cronbach's alpha for was 0.90 (Jessup et al., 2015); for this study, it was 0.82.

The BCOS assesses self-perceived changes in caregivers' lives due to caregiving tasks among caregivers of patients with stroke. The BCOS measures 'social functioning,' 'subjective well-being,' and 'somatic health.' These three life-change domains represent Lazarus' (1991) conceptualization of adaptation outcomes. The instrument is a valid and reliable 15-item, seven-point response scale (1 = "change for the worst," 4 = "no change," 7 = 'change for the best). Meaning scores below 4 indicate worsened perception, while scores over 4 indicate improved perception with total scores range from 15 to 105 (Bakas, Champion, Perkins, Farran, & Williams, 2006). Among caregivers of stroke survivors, Cronbach's alpha was 0.90 (Jessup et al., 2015); for this study, it was 0.80.

The PHQ-9 is a nine-item, four-point response scale (0 = "not at all," 1 = "Several days," 2 = "more than half the days," 3 = "nearly every day") for measuring depressive symptoms over the previous two weeks. The PHQ-9 severity index scores are calculated by summing the nine items and are categorized into four levels of depression: "no depression" (0-4), "mildly depressed" (5-9), "moderately depressed" (10-14), "moderately severe" (15-19), and "severely depressed" (20-27). The reliability of the PHQ-9 ranges from 0.86 to 0.89 (Kroenke et al., 2001), and the Cronbach's alpha for this study was 0.78.

The three scales (SPBS, OCBS-D, BCOS, and PHQ-9) were translated from English into Arabic as recommended by Guillemin et al (1993). The instruments were piloted with a group of 11 caregivers of patients receiving haemodialysis and 11 of patients receiving haemodialysis. Participants' results who took part in the pilot study were excluded from the study. The pilot study was conducted to determine the degree of agreement among examiners. The Cronbach's alpha internal consistency results were: SPBS = 0.89, OCBS-D = 0.80 BCOS = 0.78, and PHQ-9 = 0.80.

2.3 Data Collection

The researcher explained the purpose of the study and the questionnaires to the participating caregivers and patients. Patients completed the SPBS, while caregivers completed the OCBS, BCOS, and PHQ-9. Both groups provided sociodemographic data. The nurses and the author were available to answer any questions, they also checked out the questionnaires at the time the participants handed them back to avoid exclusion of any participant responses. The data was collected between June 2019 and January 2020.

2.4 Ethics statement

This study accords with the Code of Ethics of the World Medical Association (Declaration of Helsinki, 2013), and permission was obtained from each participating hemodialysis unit to conduct the study. All participants provided informed consent, and all information regarding the participants and the data collected remained confidential.

2.5 Statistical Analysis

Descriptive statistical analysis was conducted, using mean differences and standard deviations (SDs) to obtain an overview of the participants' sociodemographic characteristics and SPBS, OCBS, BCOS, and PHQ-9 scores. The variables included in the analysis were: travel time to dialysis unit, caregiver economic status, caregiver relation to the patient, caregiver living arrangement, caregiver employment status, and caregiver marital status.

Analyses of variance (ANOVAs) were used to determine whether the demographic variables outcomes and depression; the statistical significance of the mean differences was determined using an ANOVA, at $p < 0.05$. The least significant differences (LSD) between three means were also computed to facilitate a pairwise comparison of the means. The statistical tests were performed using the Statistical Package for Social Sciences (SPSS) software, version 20 (SPSS, Chicago, IL, USA).

3. Results

This study's sample incorporated 142 pairs of patients and informal caregivers. The patients' minimum and maximum ages were 40 and 75 years, respectively; the average age was 63.78 years ($SD = 7.42$). Most participants were males (61.3%, $n = 87$). The caregivers' mean age was 44.84 years ($SD = 11.27$), and their experience ranged from one to eight years. In addition, most caregivers were males (59%, $n = 84$). Regarding the familial relationship between patients and their caregivers, (23.9%, $n = 34$) were daughters or daughters-in-law, (45.1%, $n = 64$) were sons, and (31%, $n = 44$) were spouses.

Table 1 shows that the means of SPBS, OCBSD, and BCOS were 3.63 ($SD = 0.35$), 2.74 ($SD = 0.27$), 3.18 ($SD = 0.36$) respectively. Concerning the recoded PHQ-9, category three (scores of 10–14, moderately depressed) represented almost 59.9% of the total sample caregivers, while category four (scores of 15–19, moderately severe) represented 35.2%.

Table 1 Patient Self-Perceived Burden, Informal Caregiver Burden and depression of Hemodialysis Patients

Measures of Caregiver Burden		Mean \pm SD or n (%)
Patient burden	Self-perceived burden	3.63 \pm .35
Caregiving burden	OCBS*-Difficulty	2.74 \pm .27
	BCOS*	3.18 \pm .36
Depression	PHQ-9	
	Minimal (1-4)	0 (0.0%)
	Mild (5-9)	4(3.5)
	Moderate (10-14)	85 (59.9%)
	Moderately severe (15-19)	50 (35.2%)
	Severe (20-27)	3(2.1%)

* BCOS.: Bakas Caregiving Outcomes Scale, OCBSD: Oberst Caregiving Outcomes Scale Difficulty subscale;

Table 2 presents the means and standard deviations for patients' SPBS scores based on travel time to the dialysis unit, and caregivers' economic status, relation to the patient, living arrangement, employment status, and marital status. ANOVAs were conducted to test whether these differences were statistically significant.

Table 3 illustrates that the means of travelled time to the dialysis unit ($F(2) = 4.764$, $p < 0.010$), caregiver economic status ($F(2) = 5.892$, $p < 0.004$), and caregiver marital status ($F(2) = 3.988$, $p < 0.048$) significantly differed according to the SPBS scores. To complement

the ANOVAs, LSD post-hoc tests were conducted to allow comparisons of the patients' self-perceived burden in terms of each category of travel time, caregiver economic status, and caregiver marital status.

Table 3 shows clear differences between patients who travelled for less than 60 minutes, 60–90 minutes, and more than 90 minutes. Patients who travelled for less than 60 minutes had the least self-perceived burden. The statistic of the economic status illustrates the main differences in these outcomes between the categories of comfortable, just enough, and not sufficient caregiver economic statuses. The data indicates that caregivers with comfortable economic status had a lower self-perceived burden.

Table 3 ANOVAs on patients' SPBS

Variables	SPBS				
Demographic characteristics	Type III Sum of Squares	df	Mean Square	F	p
Travel time to dialysis unit (round trip)	46.180	2	23.090	4.76	.010
Economic status	57.113	2	28.557	5.89	.004
Relation to the patient	2.796	2	1.398	.29	.750
Living arrangement	4.183	2	2.092	.43	.650
Employment status	.018	1	.018	.01	.952
Marital status	19.328	1	19.328	3.99	.048
Error	634.899	131	4.847		
Corrected total	779.831	141			

*SPBS: Self-Perceived Burden Scale

Table 2 shows the means and standard deviations for OCBSD scores based on travel time to the dialysis unit and caregivers' economic status, relation to the patient, living arrangement, employment status, and marital status. Table 2 shows apparent differences in the means of the OCBSD scores across the various categories relating to the above-mentioned variables, the results presented in Table 4 indicate that these differences were not statistically significant.

Table 4 ANOVAs on patients' OCBS-D

Variables	OCBS-D				
Demographic characteristics	Type III Sum of Squares	df	Mean Square	F	p
Travel time to dialysis unit (round trip)	6.29	2	3.15	0.24	0.790
Economic status	74.16	2	37.08	2.78	0.070
Relation to the patient	33.38	2	16.69	1.25	0.290
Living arrangement	30.43	2	15.22	1.14	0.320
Employment status	16.36	1	16.36	1.23	0.270
Marital status	0.08	1	0.08	0.01	0.940
Error	1748.66	131	13.35		
Corrected total	1896.46	141			
Corrected total	1896.46	141			

*OCBS-D: Oberst Caring Burden Scale-Difficulty subscale

The caregiving outcomes were investigated using a presentation of the associated means and standard deviations, along with an ANOVA. Table 2 presents the means and standard deviations for BCOS scores based on travel time to the dialysis unit and caregivers' economic status, relation to the patient, living arrangement, employment status, and marital status. These descriptive statistics presented in Table 2 illustrate observable differences in the means of BCOS scores based on the above-mentioned variables. To determine whether these differences were statistically significant, an ANOVA was conducted.

The results presented in Table 5 illustrate statistical significance at the .05 alpha level regarding the effects of travel time to the dialysis unit ($F(2) = 4.59, p < 0.01$) and caregiver relation to the patient ($F(2) = 12.92, p < 0.01$). The LSD post-hoc test was conducted to test comparisons of BCOS means on each pair of possible responses relating to the travel category and caregiver relationship type. The differences among caregivers who travelled for less than 60 minutes, for 60–90 minutes, and more than 90 minutes, respectively. Those who travelled for less than 60 minutes were less burdened. There were also differences between daughter/daughter-in-law caregivers and son and spouse caregivers, suggesting that daughter/daughter-in-law caregivers have a lower caregiving burden.

Table 5 ANOVAs on patients' BCOS

Variables	BCOS				
Demographic characteristics	Type III Sum of Squares	df	Mean Square	F	p
Travel time to dialysis unit (round trip)	173.60	2	86.80	4.59	0.010*
Economic status	49.56	2	24.78	1.31	0.270
Relation to the patient	489.17	2	244.58	12.92	0.000*
Living arrangement	85.34	2	42.67	2.25	0.11
Employment status	40.50	1	40.50	2.14	0.150
Marital status	0.00	1	0.00	0.00	1.000
Error	2479.43	131	18.93		
Corrected total	3526.62	141			
Corrected total	3526.62	141			

BCOS: Bakas Caregiving Outcomes Scale

4. Discussion

This study was conducted to identify, describe, and evaluate, in terms of sociodemographic characteristics, the relationship between the self-perceived burden of hemodialysis patients and their informal caregivers' burden. The findings indicate that most caregivers in this study were males. This observation is not situated within broader Jordanian literature on caregivers where caregiving tasks were mainly performed by women (Abu Kamel, 2015; Al-Jauissy, 2010). The increase of male caregivers may be related to the sample selection or to the nature of a variety of complex skills that patients need.

Patients on average reported a moderate level of self-perceived burden and caregivers on average reported moderate burden and depression. Travel duration to the dialysis unit and caregivers' economic and marital status significantly contributed to the caregivers' burden. Caregivers of patients' receiving hemodialysis perceived burdens when addressing patients' personal and medical needs. Caregivers accompany patients to the dialysis unit, prepare and monitor patients' diets, ensure that they take their medications regularly, and provide emotional support (Zhang et al., 2016).

The current study found that patients perceived themselves as burdens on caregivers. The sociodemographic characteristics that were associated with patients' self-perceptions in this regard, included travel time to the dialysis unit and caregivers' economic and marital status. The fewer the travel time to the dialysis unit and the more comfortable the economic status, the less patients perceived themselves to be burdened.

Patients perceived themselves more of a burden to single than married caregivers. However, Suri et al. (2011) found sociodemographic characteristics are unrelated to caregiver burden. These findings could be useful for preparing an effective intervention program to address the burden of single caregivers. In determining the sociodemographic factors that affect caregiver burden, caregivers' lives worsen as a result of caregiving responsibilities, with travel times and caregiver-patient relations affecting significant changes in caregivers' lives. Daughters and daughters-in-law showed the lowest level of changes; this finding contradicts that of Subhashini and Indira (2016), who reported that women suffer more negative caregiving consequences than men.

Future research on caregiver burden on familial relationships particularly daughters and daughters-in-law versus sons and spouses is recommended. Patients who have end-stage renal disease and who are receiving hemodialysis commonly have other ongoing chronic conditions, resulting in poor health, morbidity, and psychological problems (Zhang et al., 2016). Caring for chronically ill family members can also be depressing for caregivers (Hoang, 2019). Consistent with Zhang et al. (2016), the current study concluded that caregivers are moderately depressed but unrelated to measured variables; however, informal caregiver burden and depression are complex issues. Performing caregiving for loved ones is very difficult; providing a framework for supportive care for informal caregivers could help minimize caregivers' burden.

In general, females perform caregiving roles; largely as a result of societal and cultural norms and females' ability to perform caregiving tasks and can cope with caregiving stressors (Sharma et al., 2016, Subhashini & Indira, 2016). In this study, male caregivers outnumbered their female counterparts. In terms of hemodialysis caregiving tasks; male caregivers may have a unique ability regarding accomplishing caregiving tasks. The gender gaps in the caregiving burden observed may be due to gender differences regarding perceptions of caregiving. In Jordan, 67% of caregivers are males (Alnazly, 2016), and the experiences of males as informal caregivers for patients receiving hemodialysis have not been as thoroughly examined as those of females. Thus; further research is recommended to bridge this gap in the literature.

Informal income and caregiver-patient relationship have previously been reported to contribute to caregiver burden (Zhang et al., 2016). In particular, low economic status has been found to affect families' ability to afford caregivers. Therefore, children, spouses, or other relatives must perform this role (Zhang et al., 2016).

These findings correspond with those of the current study, were all caregivers were either children

or spouses of the patients. In addition, over half of the caregivers were unemployed, and over half described the family income as insufficient (only 7% were financially comfortable).

The economic-status-related burden of caregivers is worrisome; the caregivers were either retired or close to retirement, (27% were aged 60 or older) and consequently were facing or would soon face financial burdens. These results accord with the findings of the American Association of Retired Persons (2015) study regarding the effects of financial status on informal caregivers' burden.

Informal relationships were negatively impacted by caregiving, and daughters and daughters-in-law were the least burdened among caregivers. Although women are perceived as the main caregivers in most societies, maybe in Jordanian society being a daughter or daughter-in-law does not obligate an individual to be a caregiver. Currently, there are no indicators of the reasons for this, but it is worth investigating for education, caregiving-experience, employment-status, coping-strategy, and social-support-related reasons.

5. Strength and Limitation

This study's strength was the validated tools that were used to measure patient self-perceived burden, caregivers' burden and depression. There are some limitations, firstly. the patient and caregivers' health status were underrepresented such as patient and caregivers' comorbidities, physical and mental health status, level of independence. Such measurements in caregiver studies are important to report since they might affect patients' and caregivers' outcomes. These misreported measures may be potential confounders. Secondly, the study design was cross-sectional, which does not induce good causality between variables and the utilization of a small sample which limits the generalizability of this result.

6. Implications for practice and future research

Caregivers and patients both experienced burdens, which is concerning. Awareness among health-care professionals' regarding the sociodemographic characteristics that influence caregiving burden is essential for supporting informal caregivers' needs and providing timely and appropriate public services to caregivers. Health-care systems and health insurance should provide a database that caregivers can use to find relevant assistive services from the health-care systems and non-profit organizations.

Involving both caregivers and patients in assessments and interventions may lessen patients' feeling of being a burden to their caregivers, as well as reduce caregivers' sentiments of depression and being burdened.

Based on the findings, the author recommends qualitative research that includes both informal caregivers and patients in qualitative study designs for a deeper understanding of the self-perceived burden on the burden of care. A longitudinal study is needed to examine the burden of care change with time about caregiver burden and sociodemographic characteristics.

Conclusion

The overall results revealed that patients perceived themselves as a burden to their caregivers, and caregivers are moderately burdened and depressed. The demographics variables, economic status, traveling time to hemodialysis units, and being single are contributing factors to patients' self-perceived burden and informal caregivers' burden. Daughter/daughter-in-law caregivers have a lower caregiving burden. Moreover, by identifying the sociodemographic factors that contribute to informal caregivers' burden, the presented information that health-care providers, advanced practice nurses, and policymakers should consider when caring for chronically ill patients and when designing direct community resources to prevent burden among informal caregivers.

Declaration of conflicting interest

The authors declares no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

The authors contribution:

Study conception and design: EN, OMK; data collection: EN, MAA; analysis and interpretation of results: EN, OMK, AMA; draft manuscript preparation: AMA, MAA. All authors reviewed the results and approved the final version of the manuscript.

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Table 2 Mean and standard deviations for SPBS, OCBS, and BCOS.

Variables	Category	n	SPBS		OCBS-D		BCOS	
			Mean	SD	Mean	SD	Mean	SD
Travel time to dialysis unit (round trip)	<60 minutes	73	37.03	2.44	45.31	3.88	45.34	4.86
	60–90 minutes	65	36.62	2.13	44.96	3.47	42.88	4.84
	>90 minutes	4	33.25	1.26	44.50	3.32	41.25	5.32
	Total	142	36.73	2.35	45.13	3.67	44.10	5.00
Economic status	Comfortable	10	38.60	2.41	43.70	4.24	44.70	4.72
	Just enough	53	37.02	2.19	45.91	3.65	43.81	5.12
	Not sufficient	79	36.30	2.33	44.80	3.55	44.22	5.01
	Total	142	36.73	2.35	45.13	3.67	44.10	5.00
Relation to the patient	Daughter/daughter-in-law	34	36.91	2.02	46.03	2.94	45.09	3.69
	Son	56	36.71	2.44	45.11	3.24	46.21	5.17
	Spouse	52	36.63	2.49	44.58	4.41	41.17	4.16
	Total	142	36.73	2.35	45.13	3.67	44.10	5.00
Living arrangement	Live with patient	75	36.93	2.18	45.24	3.96	43.76	4.40
	Live within 50 m of patient	51	36.55	2.51	44.80	3.49	44.59	5.69
	Live over 50 m from patient	16	36.38	2.68	45.69	2.80	44.13	5.50
	Total	142	36.73	2.35	45.13	3.67	44.10	5.00
Employment status	Employed	62	36.87	2.46	45.05	3.28	45.66	5.26
	Unemployed	80	36.63	2.27	45.20	3.96	42.89	4.46
	Total	142	36.73	2.35	45.13	3.67	44.10	5.00
Marital status	Single	35	37.49	1.92	45.69	3.52	44.86	4.22
	Married	107	36.49	2.44	44.95	3.71	43.85	5.22
	Total	142	36.73	2.35	45.13	3.67	44.10	5.00

References

- Al Jauissy, M. S. (2010). Health care needs of Jordanian caregivers of patients with cancer receiving chemotherapy on an outpatient basis. *EMHJ-Eastern Mediterranean Health Journal*, 16 (10), 1091-1097, 2010.
- Alnazly, E. (2016). Coping strategies and socio-demographic characteristics among Jordanian caregivers of patients receiving hemodialysis. *Saudi Journal of Kidney Diseases and Transplantation*, 27(1), 101.
- Alnazly, E. (2020). Predictors of the burden on family carers of patients on haemodialysis in Jordan. *Eastern Mediterranean Health Journal*, 26(5).
- Alnazly, E. K., & Samara, N. A. (2014). The burdens on caregivers of patients above 65 years old receiving hemodialysis: A qualitative study. *Health Care: Current Reviews*, 1-5.
- American Association of Retired Persons. Caregiving in the U.S. National Alliance for Caregiving. 2015. Retrieved from <https://www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-united-states-2015-report-revised.pdf>.
- Andreakou, M. I., Papadopoulos, A. A., Panagiotakos, D. B., & Niakas, D. (2016). Assessment of health-related quality of life for caregivers of Alzheimer's disease patients. *International journal of*

- Alzheimer's disease, 2016.
- Bakas, T., Austin, J. K., Jessup, S. L., Williams, L. S., & Oberst, M. T. (2004). Time and difficulty of tasks provided by family caregivers of stroke survivors. *Journal of Neuroscience Nursing*, 36(2), 95.
- Bakas, T., Champion, V., Perkins, S. M., Farran, C. J., & Williams, L. S. (2006). Psychometric testing of the revised 15-item Bakas Caregiving Outcomes Scale. *Nursing research*, 55(5), 346-355.
- Beaton, D. E., Bombardier, C., Guillemin, F., & Ferraz, M. B. (1993). Guidelines for the process of cross-cultural adaptation of Vocci MC, Fontes CMB, Abbade LPF. literature review and proposed guidelines. *J Clin Epidemiol*, 46(12), 1417-32.
- Cook, S. K., Snellings, L., & Cohen, S. A. (2018). Socioeconomic and demographic factors modify observed relationship between caregiving intensity and three dimensions of quality of life in informal adult children caregivers. *Health and quality of life outcomes*, 16(1), 1-12.
- Cousineau, N., McDowell, I., Hotz, S., & Hébert, P. (2003). Measuring chronic patients' feelings of being a burden to their caregivers: development and preliminary validation of a scale. *Medical care*, 110-118.
- Dye, C., Willoughby, D., Aybar-Damali, B., Grady, C., Oran, R., & Knudson, A. (2018). Improving chronic disease self-management by older home health patients through community health coaching. *International journal of environmental research and public health*, 15(4), 660.
- Hoang, V. L., Green, T., & Bonner, A. (2018). Informal caregivers' experiences of caring for people receiving dialysis: A mixed methods systematic review. *Journal of Renal Care*, 44(2), 82-95.
- Jessup, N. M., Bakas, T., McLennon, S. M., & Weaver, M. T. (2015). Are there gender, racial or relationship differences in caregiver task difficulty, depressive symptoms and life changes among stroke family caregivers?. *Brain injury*, 29(1), 17-24.
- Kamel, A. M. A. (2016). Who are the elder's caregivers in Jordan: A cross-sectional study. *Journal of Nursing Education and Practice*, 6(3), 116.
- Kroenke, K., Spitzer, R. L., & Williams, J. B. (2001). The PHQ-9: validity of a brief depression severity measure. *Journal of general internal medicine*, 16(9), 606-613.
- Lazarus, R. S. (1991). *Emotion and Adaptation*. New York (Oxford University Press) 1991.
- McPherson, C. J., Wilson, K. G., Chyurlia, L., & Leclerc, C. (2010). The balance of give and take in caregiver-partner relationships: An examination of self-perceived burden, relationship equity, and quality of life from the perspective of care recipients following stroke. *Rehabilitation Psychology*, 55(2), 194.
- Penning, M. J., & Wu, Z. (2016). Caregiver stress and mental health: Impact of caregiving relationship and gender. *The gerontologist*, 56(6), 1102-1113.
- Prevo, L., Hajema, K., Linssen, E., Kremers, S., Crutzen, R., & Schneider, F. (2018). Population characteristics and needs of informal caregivers associated with the risk of perceiving a high burden: a cross-sectional study. *INQUIRY: The Journal of Health Care Organization, Provision, and Financing*, 55, 0046958018775570.
- Sharma, N., Chakrabarti, S., & Grover, S. (2016). Gender differences in caregiving among family-caregivers of people with mental illnesses. *World journal of psychiatry*, 6(1), 7.
- Subhashini, N., & Indira, A. (2016). Assess the burden among caregivers of patients undergoing haemodialysis in tertiary care hospital, Nellore. *Int J Applied Res*, 2(4), 559-561.
- Suri, R. S., Larive, B., Garg, A. X., Hall, Y. N., Pierratos, A., Chertow, G. M., ... & FHN Study Group. (2011). Burden on caregivers as perceived by hemodialysis patients in the Frequent Hemodialysis Network (FHN) trials. *Nephrology Dialysis Transplantation*, 26(7), 2316-2322.
- Yakubu, Y. A., & Schutte, D. W. (2018). Caregiver attributes and socio-demographic determinants of caregiving burden in selected low-income communities in cape town, South Africa. *Journal of Compassionate Health Care*, 5(1), 1-10.

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