Predictors of the burden on family carers of patients on haemodialysis in Jordan

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Abstract

Background: Family caregivers of patients on haemodialysis can experience life changes and depression.

Aims: This study assessed the self-perceived burden on their family caregivers of haemodialysis patients in Jordan, and the caregivers' perceived burden of caregiving and depression. The predictors of caregiver outcomes were determined.

Methods: This cross-sectional study included 190 patients on haemodialysis and their caregivers in Jordan. Patients' self-perceived burden on their caregivers was assessed using the self-perceived burden scale. For caregivers, burden was assessed using the Oberst caregiving burden scale and Bakas caregiving outcomes scale – difficulty subscale. Caregivers' depression was assessed using the patient health questionnaire-9. Mean scores and standard deviations (SD) were calculated. Multiple regression analysis was done to determine the predictors of caregiver outcomes.

Results: Patients thought that they were a moderate to severe burden on their caregivers (mean score 36.31, SD 3.48). Caregivers perceived themselves as moderately burdened, and thought that their lives had changed for the worse because of caregiving (mean score 2.82, SD = 0.98). Caregivers were moderately depressed (mean score 1.80, SD 0.42). Multiple regression analysis showed that the perceived difficulty of caregiving tasks and patients' self-perceived burden predicted the caregiver outcomes. The difficulty of caregiver tasks explained 38% of the overall variance in the caregiver outcomes. Patient's self-perceived burden on their caregivers explained 16.4% of the variance.

Conclusion: Factors that affect the burden on caregivers of dialysis patients should be identified and interventions considered to support caregivers and reduce this burden.

Keywords: renal dialysis, caregiver, burden, depression, Jordan

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Introduction

In Jordan, the number of people with end-stage renal disease who receive dialysis in 2016 increased to 5130 *(1)*. Most of these people (5048, 98%) received haemodialysis and 2% received peritoneal dialysis *(1)*. However, the number of sessions a week varied between patients: 2% received treatment four times a week, 71% received treatment three times a week, 26% twice a week and 1% once a week, with the average duration of the treatment session being about four hours *(1)*. Therefore, family members, including spouses and children, or friends, usually provide care for people on dialysis, which can be a challenge *(2)*. Factors that can affect the burden on caregivers include patient characteristics and caregiver-related factors *(3)*.

Data on family caregivers for people with chronic kidney disease are not yet available in Jordan *(1)*. However, the prevalence of haemodialysis is increasing and family members often have to take over the responsibility of care for the person receiving dialysis. According to Jordanian culture and traditions, family members have a commitment to caring for the sick *(4)*.

Previous studies indicate that family caregivers can suffer from depression as a result of caregiving. A study in Turkey found that the burden on caregivers has a direct effect on the quality of the caregiving delivered *(5)*. The study further reported that emotional and psychological distress were common in caregiver spouses in relation to their cultural and traditional values. Other studies in Turkey reported that caregivers perceived that the burden of caring for people on haemodialysis was high *(6,7)*. A more recent study also found that most patients with kidney disease and their family caregivers were depressed *(8)*. Depression in people on dialysis was associated with their socioeconomic and marital status, while the socioeconomic status of caregivers was associated with caregivers' depression *(8)*.

Another study reported that the burden of caregiving was associated with the perceived difficulty of the tasks the caregiver was required to do and this burden strongly predicted caregiver depression *(9)*. However, a study in Saudi Arabia found that caring for people receiving haemodialysis was a subjective burden that contributed to depression, social isolation, financial constraints and declining physical health *(10)*. Furthermore, the demands associated with the provision of care for people on dialysis may result in caregivers making ineffective decisions that could adversely affect the way the caregiver manages the personal health needs of the person on dialysis *(5)*.

The family caregiver burden in primary care clinics is linked to psychological, socioeconomic, and physical consequences *(11,12)*. However, the quality of life of family caregivers of patients on haemodialysis tends to be neglected, although they are distressed emotionally, financially and psychologically *(13)*. The burden on caregivers of dialysis patients has been acknowledged in recent investigations in the Middle East *(4,10)*.

The burden on family caregivers of haemodialysis patients in Jordan is likely to be substantial because of the challenges that caregivers and patients face. However, the extent of the burden is not known. The aim of this study therefore was to investigate: (i) self-perceived burden of patients' receiving haemodialysis on their caregiver, (ii) the burden the caregivers themselves felt, (iii) depression in the caregivers and (iv) the predictors of caregiving burden and depression in caregivers.

Methods

Design, sampling, participants and procedures

This was a cross-sectional survey of people on haemodialysis and their family caregivers. A non-probability purposive sampling technique was used to select participants for this study. I approached the directors of four outpatient haemodialysis units in two large cities in Jordan before starting the study and explained its purpose. After receiving permission from the unit director, two volunteer nurses approached patients on dialysis who had family caregivers to enquire if they would be willing to participate in the study. The research staff approached 204 patients who had unpaid family caregivers. Out of the 204 patients, 199 (97.5%) agreed to participate paired with their caregivers. Of the 199 patients, five patients did not meet the inclusion criteria. Out of the194 eligible patients and their respective caregivers, four (2%) patients and their caregivers withdrew before the beginning of the data collection. Patients' inclusion criteria: were 21 years of age and older, were able to read and write, had been on haemodialysis for one year or more and had an unpaid family caregiver. The caregivers were required to meet the following inclusion criteria: were unpaid, were able to read and write, were 21 years or older, lived with or near the patient on dialysis and had been providing care for at least one year.

Data collection

This study was conducted from January 2017 to August 2017. The author met the participants at the outpatient haemodialysis units in two cities in Jordan. After explaining the purpose of the study, participants (patients and caregivers) gave written consent to participate. Patients' characteristics were recorded (age, sex, duration of dialysis) and they completed the self-perceived burden scale *(14)*. The family caregivers' characteristics were recorded (age, sex, education, employment, relation to patient, duration of caregiving and means of transport) and they completed the Oberst caregiving burden scales *(15)*, Bakas caregiving outcomes scales *(16)* and patient health questionnaire-9 *(17)*. Participants were provided with the researcher's phone number if they had any questions about the forms. A box was placed at each dialysis unit for the caregivers to drop off the completed forms.

Patients' self-perceived burden

Patients' self-perceived burden was assessed using the self-perceived burden scale *(14)*, which is a reliable and valid 10-item scale developed for people on haemodialysis to evaluate their feelings about being a burden on their caregivers. Each item was scored on a 5-point response scale, where 1 = none of the time, 2 = a little of the time, 3 = some of the time, 4 = most of the time and 5 = all of the time. A higher total score indicates a higher level of patients' self-perceived burden.

The scores ranged from 0 to 50. The level of subjective burden scoring was categorized as follows: < 19 = no to little burden, 20–29 = mild to moderate burden, 30–39 = moderate to severe burden and > 40 = very severe burden, as previously suggested *(2,18)*. The Cronbach alpha of the 10 items was 0.85 *(14)*; for this study, it was 0.77.

Caregivers' burden

Caregivers' burden was measured by the Oberst caregiving burden scale – difficulty subscale *(15)* and the Bakas caregiving outcomes scale *(16)*. The Oberst scale is a 15-item scale that was developed to assess caregivers' perception of the difficulty of the tasks associated with caregiving. All the items are judged based on the difficulty of each item (responses to the difficulty subscale were: 1 = not difficult, 2 = slightly difficult, 3 = moderately difficult, 4 = very difficult and 5 = extremely difficult). A higher score indicates the greater perceived difficulty associated with caregiving tasks. The Cronbach alpha for the 15 items is 0.94 for difficulties *(15)*; for this study, it was 0.80.

The Bakas scale is a 15-item questionnaire that measures life changes in family caregivers. The items address changes in social function, subjective well-being and physical health as a result of caring for a family member. The items were scored on a 7-point scale with the responses ranging from: 1 = change for the worse to 7 = change for the better, and 4 = no change. A score of more than 4 indicates that the caregiver perceives his/her life has changed for the better; a score less than 4 indicates that life has changed for the worse *(16)*. The Cronbach alpha for the revised 15-item scale is 0.90 *(16)*; for this study, it was 0.88.

Caregiver's depressive symptoms

Depressive symptoms were measured using the patient health questionnaire – 9 *(17)*. This questionnaire is a 9-item scale that measures depressive symptoms in the past two weeks. The items are scored on a 4-point scale (0 = not at all (on no days), 1 = several days, 2 = more than half of the days and 3 = nearly every day). The total score ranges from 0 to 27 and a higher score indicates that the caregiver is more depressed. The severity index of depression score is categorized as follows: mild (5–9), mod-

erate (*10–14*), moderate to severe (*15–19*) and severe (*20*). The Cronbach alpha for PHQ-9 is 0.88 *(17)*; it was 0.80 for this study.

All the questionnaires were translated from English into Arabic in accordance with proposed guidelines for adaptation of health-related quality of life measures *(19)*. A pilot study was conducted on 12 patients and caregivers using the translated questionnaires to evaluate the feasibility of the scales. Participants indicated that there were unclear items in four questionnaires. The scales were reviewed by experts to ensure the appropriateness of the content and the items were rephrased in Arabic. A second pilot study was conducted on 10 different patients and caregivers. There was a marked improvement in the caregivers' understanding of the items as reflected by a decline in requests for clarifications of the meaning of statements and by the data analysis of the scale. The time to complete all the questionnaires, which was also estimated during the pilot studies, ranged between 20 and 30 minutes.

Data analyses

Descriptive statistics (mean and standard deviation (SD) and percentage) were calculated to describe the sociodemographic characteristics of patients and caregivers. Mean (SD) scores on questionnaires were calculated. Multiple regression analyses were also done to predict caregiving outcomes (perceived life changes) as a function of caregivers' burden using patients' self-perceived burden, difficulty of caregiving tasks and depressive symptom scores. The difficulty of caregiving tasks, self-perceived burden and depressive symptoms were used as dependent and independent variables since they are strong predictors of caregiving outcomes. Multiple regression analysis was done to assess the associations between perceived life changes, task difficulty, patients' self-perceived burden and caregiver depression.

A *P*-value less than 0.05 was considered statistically significant. Data were analysed using *SPSS*, version 21.0.

Ethical considerations

The study was approved by the internal review boards of the participating hospitals, and all participating patients and caregivers gave their informed consent. Participants were informed that they could withdraw from the study at any time for any reason and their names were kept confidential.

Results

The study included 190 people on dialysis and their caregivers. Their sociodemographic characteristics are shown in Table 1. The mean ages of the patients and caregivers were 63.62 (SD 8.79) years and 42.44 (SD 11.18) years respectively. Almost two thirds (65%) of the patients were male as were just over half (54%) of the caregivers.

The mean (SD) scores of the patients and caregivers on the questionnaires are given in Table 2. The mean score of patients on the patient self-perceived burden questionnaire was 36.31 (SD 3.48), indicating that the patients felt they were a moderate burden on their caregivers. Fourteen (7.4%) patients were mildly burdened, 135 (71%) were moderately burdened, 38 (20.0%) were moderately to severely burdened and 3 (1.6%) were very severely burdened.

The mean score on caregivers' perception of the difficulty of caregiving tasks was 3.01 (SD 0.31), indicating that caregivers felt moderately burdened by their caregiving. The mean score on the change to their life perceived by the caregivers was 2.82 (SD 0.98), which means that, overall, caregivers perceived their lives had changed for the worse. The mean score of caregivers on the depressive symptom scale was 1.80 (SD 0.42) and 71% of caregivers were moderately depressed.

Multiple regression analyses

Table 3 shows the predictors of the caregiver's perceived life changes. Caregivers' perception of the difficulty of their tasks was a statistically significant predictor of caregiver life changes ($R = 0.62$, $P < 0.001$). In addition, R^2 was 0.38, indicating that caregiver's perception of the difficulty of the caregiving tasks was the most significant predictor, explaining 38.0% of the variance of the life changes perceived by caregivers as a result of caregiving.

Patients' self-perceived burden was also significantly associated with life changes for the caregiver ($R = 0.40$, $P = 0.002$). Furthermore, R^2 was 0.164, indicating that the patients' self-perceived burden explained 16.4% of the variance of the life changes perceived by caregivers as a result of caregiving. However, depression in caregivers was not significantly associated with caregivers' life changes.

Table 4 shows four factors of caregivers' perceived task difficulty that predicted the caregiving outcome. Medical or nursing treatments ($P < 0.001$) and providing transportation ($P = 0.04$) were significant predictors of negative caregiver outcomes; an increase in the medical or nursing treatments and providing transportation decreased caregiving outcomes indicated a life change for the worse. However, assistance with personal care ($P < 0.001$) and structuring/planning activities ($P = 0.02$) were associated with positive caregiver outcomes: an increase in the assistance with personal care and structuring/planning activities increased the caregiving outcomes, indicating a life change for the better.

Table 5 presents three factors of patients' self-perceived burden on their caregiver that predicted the caregiving outcomes. The patient's worry that the caregiver was overextending him/herself in providing care was a predictor of negative caregiver outcomes ($P = 0.02$); the greater the patients' worry about caregivers' overextending themselves in helping, the greater the decrease in caregiving outcomes, indicating a life change for the worse. However, patient's belief that they made things hard for their caregiver and that they were a burden of their caregiver were a predictor of positive caregiving outcomes ($P = 0.01$), indicting a life change for the better for the caregiver.

Table 1 Demographic characteristics of the patients (*n* = 190) and caregivers (*n* = 190)

Patient characteristics	Value
Patient age (years), mean (SD)	63.62 (8.79)
Patient sex, no. (%)	
Male	124 (65)
Female	66 (35)
Years on haemodialysis, mean (SD)	4.99 (2.98)
Caregiver characteristics	
Caregiver age (years), mean (SD)	42.44 (11.18)
Caregiver sex, no. (%)	
Male	103 (54)
Female	87 (46)
Duration of caregiving (years), mean (SD)	4.30 (2.65)
Travelling time for one round trip (hours), mean (SD)	68.18 (17.58)
Means of transport, no. (%)	
Private car	67 (35)
Taxi	22 (12)
Public transport	59 (31)
Carpool	42 (22)
Caregiver's education, no. (%)	
High school and below	66 (35)
Community college	48 (25)
University/graduate school	76 (40)
Caregiver's employment, no. (%)	
Yes	73 (38)
No	117 (62)
Caregiver's relation to patient, no. (%)	
Spouse	62 (33)
Son	72 (38)
Daughter	52 (29)

SD: standard deviation.

Table 2 Descriptive statistics of the patient and caregiver burden

Variable	Mean scores (SD)
Patient's self-perceived burden	36.31 (3.48)
Caregiving burden	
Caregiver's perceived tasks difficulties	3.01 (0.31)
Perceived life changes in family caregivers	2.82 (0.98)
Depressive symptoms	1.80 (0.42)
	No. (%)
Severity of patients' perceived burden (n = 190)	
Mild	14 (7.4)
Moderate	135 (71.0)
Moderate to severe	38 (20.0)
Very severe	3 (1.6)

SD: standard deviation.

Table 3 Multiple regression analysis of the associations between life changes in family caregivers, perceived task difficulty, perceived burden and caregiver depression

Variable	Unstandardized B	Unstandardized SE	Standardized B	R	R^2	Adjusted R^2	*P*-value
Caregiver's perceived task difficulty [a]	−0.160	0.046	0.151	0.621	0.380	0.29	< 0.001
Patient's self-perceived burden on caregiver [b]	−0.072	0.038	−0.100	0.405	0.164	0.108	0.002
Caregiver depression [c]	−0.038	0.067	−0.044	0.125	0.016	0.002	0.453

B: beta coefficient, SE: standard error,

[a]*Dependent variables: caregiving outcomes and patient's self-perceived burden.*

[b]*Dependent variables: caregiving outcomes and caregiver's perceived task difficulty.*

[c]*Dependent variables: caregiving outcomes, caregiver's perceived task difficulty and patient's self-perceived burden.*

Table 4 Association between factors of caregiver's perception of the difficulty of tasks and caregiving outcomes: regression analysis

Perceived task difficulty	Unstandardized coefficients		Standardized coefficient	*t*	*P*-value
	B	SE	B		
Constant	3.55	0.35		10.17	< 0.001
Medical or nursing treatments	−0.11	0.04	−0.25	−2.92	< 0.001
Assistance with personal care	0.11	0.03	0.33	3.71	< 0.001
Providing transportation	−0.06	0.03	−0.18	−2.13	0.04
Structuring/planning activities	0.07	0.03	0.19	2.33	0.02

B: beta coefficient, SE: standard error.

P < 0.05 was considered statistically significant.

Discussion

This study investigated patients' self-perceived burden on their caregiver, caregivers' burden, caregiver depression and the predictors of caregiving outcomes (e.g. social function, subjective well-being and health as a result of providing care for a family member). The results of this study are in line with previous studies that found that patients perceived their burden on caregivers to be moderate to severe, caregivers perceived their burden of caregiving to be moderate and caregivers were mildly depressed *(2,3)*.

The multiple regression analysis showed that the tasks perceived to be difficult by the caregiver – providing medical or nursing treatment and transportation – were significant independent predictors of worse caregiving outcomes. These results indicate the importance of assessing both patients' and caregivers' understanding and knowledge of patients receiving haemodialysis, and assessing patients' and caregivers' need for transportation to the dialysis units and physician appointments. The other tasks perceived to be difficult – assistance with personal care and structuring/planning activities – were significant predictors of positive caregiver outcomes over time (life change for the better). This positive finding in the caregiver outcomes indicates a decrease in the caregiver burden which will enable the caregiver to continue providing care for their family member. The caregiving task-related factors explained 38.0% of the overall variance in the caregiving outcomes, while patient's self-perceived burden explained 16.4% of the variance in the caregiving outcomes.

Notably, the greater the patient's belief that his/her caregiver was overextending him/herself in providing care, the more the caregiving outcomes were negative. However, the patient's belief that he/she made things hard for the caregiver and that he/she was a burden on the caregiver predicted more positive caregiving outcomes. These findings reflect the influence of the patients' self-perceived burden on the caregiving outcomes. Assessing patients' sense of perceived burden and improving the caregiving outcomes by identifying patients' and caregivers' roles and relationship is beneficial in the assessment process for future intervention. However, in a qualitative study on end of life patients, the patients' self-perceived burden main themes were: "concern for others", the physical, social and emotional burden patients feel they impose on caregivers, and "implications for self", reflecting patients' thoughts and feelings about being a burden to others resulting in patients' burden and distress *(20)*. The results of the present study highlight that patients' self-perceived burden and caregivers' burden are interrelated and of concern since the burden is as a result of chronic illness and its treatment.

Although caregivers in the current study were moderately depressed, depression symptoms in caregivers were not a significant predictor of patients'

Table 5 Association between factors of patient's self-perceived burden on their caregiver and caregiving outcomes: regression analysis

Patient's self-perceived burden	Unstandardized coefficients		Standardized coefficients	t	P-value
	B	SE	B		
Constant	2.40	0.36		6.65	< 0.001
Worry that my caregiver is overextending him/herself in helping me	−0.06	0.03	−0.20	−2.30	0.02
Think that I make things hard for my caregiver	0.08	0.03	0.21	2.79	0.01
Feel that I am a burden on my caregiver	0.11	0.04	0.21	2.74	0.01

B: beta coefficient, SE: standard error.

P < 0.05 was considered statistically significant.

self-perceived burden or caregivers' perceived burden. This finding contradicts the hypothesis that higher rates of depression symptoms would be a predictor of caregiver burden *(8,9)*. The present study had a cross-sectional design and therefore conclusions cannot be drawn on causation. However, the results confirm that caregivers were depressed and needed management to minimize depression.

This study has some limitations. As a cross-sectional study, cause and effect cannot be determined. The selection of patients and caregivers did not include haemodialysis units in the northern or southern parts of the country and did not include patients who had paid caregivers, which might cause a bias that could influence the caregiving outcomes. The results cannot therefore be generalized to all caregivers of patients receiving haemodialysis in Jordan, and future research should include a wider and more representative sample. The use of a non-probability sampling technique is also a limiting factor for the generalizability of the findings beyond the study sample.

Patients and any family member providing care should be included in patient assessment and decisions about treatment. The assessment should include caregivers' social function, subjective well-being and physical health. Such practice may help haemodialysis units to establish and implement interventions that reduce caregiver and patient burden.

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Facteurs prédictifs de la charge pour les aidants familiaux de patients sous hémodialyse en Jordanie

Résumé

Contexte : Les aidants familiaux de patients sous hémodialyse peuvent être confrontés à des changements de vie et à la dépression.

Objectifs : La présente étude visait à évaluer la charge pour les aidants familiaux telle que perçue par les patients sous hémodialyse en Jordanie, ainsi que la charge perçue par les aidants eux-mêmes par rapport aux soins et à la dépression. Elle a permis de déterminer les facteurs prédictifs de l'impact pour les aidants.

Méthodes : Cette étude transversale comprenait 190 patients sous hémodialyse et leurs aidants en Jordanie. La charge pour les aidants familiaux telle que perçue par les patients a été évaluée à l'aide de l'échelle d'auto-perception de la charge. Concernant les aidants, l'évaluation a été réalisée à l'aide de l'échelle d'Oberst, qui évalue la charge pour les aidants, et de l'échelle de Bakas, qui mesure l'impact pour les aidants, à travers la sous-échelle des difficultés. La dépression chez les aidants a été évaluée à l'aide du questionnaire de santé des patients à 9 items. Les scores moyens et les écarts-types (ET) ont été calculés. L'analyse de régression multiple a été réalisée afin de déterminer les facteurs prédictifs de l'impact pour les aidants.

Résultats : Les patients estimaient représenter une charge modérée à sévère pour leurs aidants (score moyen : 36,31 ; ET : 3,48). Les aidants percevaient quant à eux la charge comme modérée et estimaient que leur vie avait empiré du fait de leur rôle d'aidant (score moyen : 2,82, ET : 0,98). Les aidants étaient modérément déprimés (score moyen : 1,80 ; ET : 0,42). L'analyse de régression multiple a montré que la difficulté perçue relativement aux tâches liées à la prise en charge et la charge perçue par les patients eux-mêmes étaient des facteurs prédictifs de l'impact pour les aidants. La difficulté des tâches liées à la prise en charge expliquait 38 % de la variance globale dans la mesure de l'impact pour les aidants. La charge pour les aidants telle que perçue par leurs patients expliquait 16,4 % de la variance.

Conclusion : Les facteurs influant sur la charge pour les aidants de patients sous dialyse devraient être identifiés, et des mesures devraient être envisagées afin de fournir un appui aux aidants et de réduire cette charge.

العوامل الـمُنبئة بالعبء الذي يتحمله أفراد الأسرة الذين يقدمون الرعاية لمرضى غسيل الكلى في الأردن

إيمان خميس النزلي

الخلاصة

الخلفية: قد يتسبب تقديم أفراد الأسرة الرعاية لمريض غسيل الكلى في تغيير حياتهم وإصابتهم بالاكتئاب.

الأهداف: هدفت هذه الدراسة إلى تقييم العبء المدرك ذاتيا لدى أفراد الأسرة من مقدمي الرعاية لمرضى غسيل الكلى في الأردن، وكذلك العبء المُدرك الواقع على عاتق مقدمي الرعاية جرّاء تقديم الرعاية والإصابة بالاكتئاب. كما حددت الدراسة العوامل الـمُنبئة بالمخرجات الخاصة بمقدم الرعاية.

طرق البحث: تضمنت هذه الدراسة المقطعية 190 مريضا يقومون بغسيل الكلى بالإضافة إلى مقدمي الرعاية لهم في الأردن. وقيمت الدراسة العبء الذي يدرك المرضى بأنفسهم وقوعه على عاتق مقدمي الرعاية، وذلك باستخدام مقياس العبء المدرك ذاتيا. وبالنسبة لمقدمي الرعاية، فقد قيمت الدراسة العبء باستخدام مقياس "أوبيرست" للعبء الناجم عن تقديم الرعاية ومقياس "باكاس" لمخرجات تقديم الرعاية – والمقياس الفرعي للصعوبة. وقُيِّمت إصابة مقدمي الرعاية بالاكتئاب باستخدام استبيان صحة المرضى9-. واحْتُسب كل من متوسط الدرجات والانحراف المعياري. وأُجري تحليل انحدار متعدد المتغيرات لتحديد العوامل المُنبئة بمخرجات مقدمي الرعاية.

النتائج: اعتقد المرضى بأنهم يمثلون لمن يقدمون الرعاية لهم عبئا يتراوح بين المتوسط والشديد (متوسط الدرجة 36.31، بانحراف معياري 3.48). بينما رأى مقدمو الرعاية أن العبء الملقى عليهم متوسط في شدته، كما اعتقدوا أن حياتهم تغيرت للأسوأ بسبب تقديم الرعاية (متوسط الدرجة 2.82، بانحراف معياري = 0.98). وتعرض مقدمو الرعاية لاكتئاب من النوع المتوسط الشدة (متوسط الدرجة 1.80، بانحراف معياري = 0.42). وأظهر تحليل الانحدار المتعدد المتغيرات أن الصعوبة الملحوظة على مهام تقديم الرعاية والعبء المدرك ذاتيا من جانب المرضى يُنبئان بمخرجات مقدمي الرعاية. وفسّرت صعوبة مهام تقديم الرعاية 38% من الفرق الإجمالي في مخرجات مقدمي الرعاية. وفسر إدراك المرضى ذاتيا للعبء الواقع على من يقدمون لهم الرعاية 16.4% من ذلك الفرق.

الاستنتاج: ينبغي تحديد العوامل المؤثرة على العبء الذي ينوء به مقدمو الرعاية لمرضى غسيل الكلى، والنظر في تصميم تدخلات لدعم مقدمي الرعاية من أجل الحد من ذلك العبء.

References

1. Al-Qaisi S, Asaad M. Non-communicable disease directorate, National Registry of End Stage Renal Disease. Annual report 2016. Amman: Ministry of Health; 2016 (https://www.moh.gov.jo/Echobusv3.0/SystemAssets/debff26b-c6df-4244-b7f6-4244cdf58733.pdf, accessed 28 January 2019).
2. Geng D, Ou R, Miao X, Zhao L, Wei Q, Chen X, Liang Y, et al. Patients' self perceived burden, caregivers burden and quality of life for amyotrophic lateral sclerosis patients: a cross-sectional study. J Clin Nurs. 2017;26(19–20):3188–99. https://doi.org/10.1111/jocn.13667
3. Bhattacharjee M, Vairale J, Gawali K, Dalal PM. Factors affecting burden on caregivers of stroke survivors: population-based study in Mumbai (India). Ann Indian Acad Neurol. 2012;15(2):113–9. https://doi.org/10.4103/0972-2327.94994
4. Alnazly EK. Burden and coping strategies among Jordanian caregivers of patients undergoing hemodialysis. Hemodial Int. 2016;20(1):84–93. https://doi.org/10.1111/hdi.12318
5. Kilic H F, Kaptanogullari KA. A bicommunal study: burden of caregivers of hemodialysis patients. Int J Caring Sci. 2017;10(3):1382–90.
6. Gulpak M, Kocaoz S. The care burden and the affecting factors of individuals receiving hemodialysis treatment. TAF Prev Med Bull. 2014;13(2):99–108. https://doi.org/10.5455/pmb.1-1359391140
7. Mollaoglu M., Kayataş M, Yurugen B. Effects on caregiver burden of education related to home care in patients undergoing hemodialysis. Hemodial Int. 2013;17(3):413–20. https://doi.org/10.1111/hdi.12018.
8. Hawamdeh S, Almari AM, Almutari AS, Dator WLT. Determinants and prevalence of depression in patients with chronic renal disease, and their caregivers. Int J Nephrol Renovasc Dis. 2017;10:183–9. http://doi.org/10.2147/IJNRD.S139652.
9. Govina O, Vlachou E, Kavga-Papaglou A, Kalemikerakis I, Papageorgiou D, Fasoi G, et al. Exploring the factors influencing time and difficulty of tasks provided by family caregivers of patients with advanced cancer in Greece. Health Scien J. 2014;8(4) 438–51.
10. Bayoumi MM. Subjective burden on family carers of hemodialysis patients. Open J Neph. 2014;4(2):79–85. http://doi.org/10.4236/ojneph.2014.42011
11. Alshammari SA, Alzahrani AA, Alabduljabbar KA, Aldaghri AA, Alhusainy YA, Khan MA, et al. The burden perceived by informal caregivers of the elderly in Saudi Arabia. J Fam Comm Med. 2017;24(3):145–50. https://doi.org/10.4103/jfcm.JFCM_117_16
12. Saleh E, Gomaa Z, Al-Jamal R, El-Hadidy MA, Aboul-Ezz Y. Psychosocial burden on informal caregivers of patients with bipolar mood disorders. Middle East Curr Psychiatry. 2013;20:216–22. https://doi.org/10.1097/01.XME.0000433783.67281.55

13. Ghane G, Farahani MA, Seyedfatemi N, Haghani H. The effect of supportive educative program on the quality of life in family caregivers of hemodialysis patients. J Edu Health Promot. 2017;6(80):1–12. https://doi.org/10.4103/jehp.jehp_78_16

14. Cousineau N, McDowell I, Hotz S, Herbert P. Measuring chronic patients' feeling of being a burden to their caregivers: development and preliminary validation of a scale. Med Care. 2003;41(1):110–8. https://doi.org/10.1097/00005650-200301000-00013

15. Bakas T, Austin JK, Jessup SL, Williams LS, Oberst, MM. Time and difficulty of tasks provided by family caregivers of stroke survivors. J Neuroscience Nurs. 2004;36(2);95–106. https://doi.org/10.1097/01376517-200404000-00007

16. Bakas T, Champion V, Perkins SM, Farran C, Williams L. Psychometric testing of the revised 15 item Bakas caregiving outcomes scale. Nurs Res. 2006;55(5):346–55. https://doi.org/10.1097/00006199-200609000-00007

17. Kroenke K, Spitzer R, Spitzer RL. The PHQ-9: validity of a brief depression severity measure. J Gen Int Med. 2001;16(9):606–13. https://doi.org/10.1046/j.1525-1497.2001.016009606.x

18. Xu S-Y, Xian Z-I, Huang A, Yu T-g. Self-perceived burden among elderly patients with chronic obstructive pulmonary disease. Chinese J Nurs. 2011;46:914–16.

19. Guillemin F, Bombardier C, Beaton D. Cross cultural adaptation of health-related quality of life measures: Literature review and proposed guidelines. J Clin Epidemiol. 1993;46(12):1417–32. https://doi.org/10.1016/0895-4356(93)90142-n

20. McPherson CJ, Wilson KG, Murray MA. Feeling like a burden: exploring the perspectives of patients at the end of life. Soc Sci Med. 2007;64(2):417–27. https://doi.org/10.1016/j.socscimed.2006.09.013