



## RESEARCH ARTICLE

# Functional health literacy and caregiving burden among family caregivers for patients with end-stage renal disease

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**Abstract**

Family caregivers of patients with end-stage renal disease (ESRD) experience significant caregiver-related burden, yet the contribution of their functional health literacy (FHL) to caregiving burden has not been elucidated. We investigated the magnitude of FHL and caregiving burden and their association in a descriptive, correlational cross-sectional study of family caregivers of Jordanian patients with ESRD (N = 88). The short versions of the FHL for Adults and the Zarit Burden Interview were used for assessment of caregivers. Demographic and clinical information of patients and their family caregivers were self-reported. Of family caregivers, 41% had limited FHL and 38% experienced high caregiver burden. FHL and history of comorbidity in family caregivers predicted caregiving burden independent of demographic and clinical factors. Consideration of FHL in support interventions for family caregivers may minimize some of the high perceived caregiving burden, but clinical trials of such interventions are needed to confirm this conclusion.

**KEYWORDS**

caregivers, end-stage renal disease, family, health literacy, Jordan

## 1 | INTRODUCTION

Patients with end-stage renal disease (ESRD) have complex care needs. Besides the complete failure of kidney function, patients usually have comorbidities that complicate their care. Among Jordanians with ESRD, 61% have hypertension, 42% have diabetes mellitus and 15% have cardiac disease (Ministry of Health, 2016). In addition, more than one-half (56%) develop malnutrition (Tayyem & Mrayyan, 2008) and the majority (78%) suffer from depressive symptoms (Khalil, Darawad, Al Gamal, Hamdan-Mansour, & Abed, 2012). Furthermore, complaints of tiredness, joint pain, sleep disturbances, anorexia, and fatigue are common among ESRD patients (Senanayake et al., 2017).

Almost all (98%) Jordanians with ESRD are on hemodialysis (Ministry of Health, 2016). The care of patients with ESRD demands regular and lengthy hemodialysis sessions, strict adherence

to a medication regimen and fluid and dietary restrictions, along with continuous surveillance for possible complications. Under these conditions, most patients with ESRD require the assistance of informal caregivers, usually family members, to manage their care.

Under the construct of social support, family caregivers play a substantial role in patients' lives (Khalil & Abed, 2014). Not only do they assist in meeting domestic needs, such as preparing meals, performing housework, doing laundry, providing transportation, and purchasing supplies, but they also help with more complicated tasks. These tasks include management of burdensome physical and psychological symptoms, medication administration, monitoring side effects and complications, navigating the healthcare system, interacting, and exchanging information with health care providers and making health care decisions (Eirini & Georgia, 2018). Fulfilling such tasks requires adequate health literacy.

Health literacy is defined as “the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health” (World Health Organization, 1998). Functional health literacy (FHL), the most basic type of health literacy, focuses on reading and writing skills which are necessary for effective functioning in health care settings (Nutbeam, 2008). Adequate FHL promotes one’s ability to exchange and comprehend information delivered via different communication methods (known as interactive health literacy) and also one’s ability to analyze and apply health information in different health contexts (known as critical health literacy; Nutbeam, 2008). In contrast, limited FHL creates considerable challenges even when trying to accomplish simple tasks, such as reading and understanding a consent form or a health education brochure (Baker, Williams, Parker, Gazmararian, & Nurs, 1999). It is also associated with poor understanding of oral instructions (Schillinger, Bindman, Wang, Stewart, & Piette, 2004), low disease knowledge (Yeh et al., 2018) and less use of more effective coping strategies, such as seeking information (Ellis, Mullan, Worsley, & Pai, 2012; Rahmani et al., 2019).

With limited FHL, family caregivers become vulnerable to a negative, burdensome caregiving experience. According to the Informal Caregiving Integrative Model, caregiving burden is perceived when caregivers sense an imbalance between what they possess in terms of resources, abilities, or skills and what their caregiving situation demands (Gérain & Zech, 2019). According to this model, negative beliefs about self, such as feeling incompetent, unconfident, or uncertain about one’s capabilities or self-efficacy increase feelings of burden and constrain one’s ability to cope effectively with caregiving demands or stressors (Gérain & Zech, 2019). Up to 52% of family caregivers of patients with chronic diseases, including ESRD, experience high caregiving burden (Jadhav, Dhavale, Dere, & Dadarwala, 2014) and limited FHL (Yuen, Knight, Ricciardelli, & Burney, 2018).

Though demonstrated in a few studies and in relation to other chronic diseases, such as diabetes mellitus (Gibson, 2012), the contribution of caregivers’ FHL to the caregiving burden of patients with ESRD has not been explored. As revealed in a review on health literacy in kidney disease care, attention was mostly given to patients’ health literacy and when caregivers’ health literacy was considered it was mostly investigated within the scope of patient’s outcomes (Dageforde & Cavanaugh, 2013). Further, the relationship of caregivers’ health literacy to caregiving burden was not confirmed in a systematic review on caregivers of adult patients secondary to scarcity of relevant studies (Yuen et al., 2018). Exploring the role of FHL as a determinant of caregiving burden is important especially with the high proportions of caregivers who suffer caregiving burden and also the growing evidence linking caregiving burden with caregivers’ and patients’ poor outcomes (e.g., low quality of life and increased use of health care services; Hooley, Butler, & Howlett, 2005; Jafari, Ebrahimi, Aghaei, & Khatony, 2018; Zarit, Todd, & Zarit, 1986). Therefore, the aim of the current study was to investigate, among family caregivers of Jordanian patients with ESRD, the magnitude of

FHL and caregiving burden, and their independent association. Results of the current study may inform interventions necessary to mitigate caregiving burden and its adverse effects on both caregivers and patients.

## 2 | METHODS

### 2.1 | Design, sample, and setting

This was a descriptive correlational cross-sectional study. Family caregivers and patients were recruited at hemodialysis units in different hospitals in Jordan. For inclusion in the current study, both members of the dyad needed to be adults (i.e., older than 18 years), and not diagnosed with cognitive or mental disorders. Patients had to be on hemodialysis, secondary to ESRD, for a period not less than 3 months and free from physical conditions requiring hospital admission. With regard to family caregivers, they needed to be primary caregivers who were able to write, read, and speak Arabic fluently.

### 2.2 | Ethical considerations and data collection

The current study conformed to the principles outlined in the Declaration of Helsinki. Institutional ethical approval was obtained before data collection. The nursing supervisor in the dialysis unit of each hospital was contacted first to explain the purpose of the current study and data collection process, and to introduce the researcher to potential participants. Patients were asked to determine their primary family caregivers. Both members of the dyad were invited to participate in the study if both met the inclusion criteria. The purpose of the study, confidentiality of collected data and rights of participants were explained. Enrolled family caregivers and patients signed a consent form and filled out study questionnaires separately during patients’ hemodialysis sessions and were asked to not discuss their answers with each other. Data were collected between November 2018 and March 2019.

### 2.3 | Measures

#### 2.3.1 | Functional health literacy

FHL of family caregivers was assessed using the Arabic version (Fadda, Kanj, Kabakian-Khasholian, & Johannes Schulz, 2018) of the short Test of FHL for Adults (S-TOFHLA; Baker et al., 1999). The S-TOFHLA is a reading comprehension, 7-minute time-limited test that examines basic reading skills necessary for effective functioning in a health context (Baker et al., 1999). It is composed of 36 cloze-type items (i.e., text with embedded answers) for two health-related passages. Per the S-TOFHLA guideline, participants should not be informed about the time frame for the test, but should be requested to submit their answers, if not already submitted, no later than

7 minutes after the beginning of the test. Each correct answer on the S-TOFHLA is scored with one point while each incorrect answer (or no answer) gets 0 points, for a total possible score of 36. Cut off scores of the S-TOFHLA are then used to categorize participants into three levels; inadequate FHL (total score: 0–16), marginal FHL (total score: 17–22), and adequate FHL (total score: 23–36). Inadequate and marginal FHL levels can be collapsed to low or limited FHL (Garcia, Espinoza, Lichtenstein, & Hazuda, 2013). The validity of the S-TOFHLA, including the Arabic version, was previously demonstrated (Fadda et al., 2018). Cronbach's  $\alpha$  of the S-TOFHLA in the current study was .89.

### 2.3.2 | Caregiving burden

Caregiving burden as perceived by family caregivers was assessed using the Arabic version of the short Zarit Burden Interview (S-ZBI), a self-administered questionnaire (Bachner, 2013). The S-ZBI is composed of 12 items (Bedard et al., 2001). Each item is scored on a 5-point Likert scale ranging from 0 (*never*) to 4 (*nearly always*). The total score of the S-ZBI is calculated by summing the scores of the 12 items and can range between zero and 48; higher total scores indicate greater perceived caregiving burden (Bedard et al., 2001). The published cut off score of 17 differentiates between higher and lower levels of burden (Bedard et al., 2001). The psychometric properties of the S-ZBI were demonstrated among caregivers of patients with different health conditions (Higginson, Gao, Jackson, Murray, & Harding, 2010). Cronbach's  $\alpha$  of the S-ZBI in the current study was .84.

### 2.3.3 | Demographic and clinical variables

Data on demographic and clinical variables of both patients and their family caregivers were collected via self-report. This included information on age, gender, marital status, highest educational level, current employment condition, monthly income, and history of comorbidities (i.e., hypertension and diabetes; yes, no). Patients also stated their years on hemodialysis and frequency of their hemodialysis sessions per week. Family caregivers reported their kinship to patients and duration of caregiving.

## 2.4 | Statistical analysis

Data entry and analyses were accomplished using SPSS software version 21. Accuracy of data entry and assumptions of tests were verified before analysis. Descriptive statistics (mean [M], median [Md], frequency, percent, standard deviation [SD], range) were performed to report demographic and clinical characteristics of all participants. Based on the published cut off scores of S-TOFHLA and S-ZBI, the magnitudes of FHL and caregiving burden among family caregivers were reported as percentile values and 95% confidence

interval (CI). To examine the relationship of caregiving burden to demographic and clinical variables and FHL, we used Spearman's rho correlation for age and duration of both caregiving and hemodialysis, the Kruskal-Wallis test for caregiver kinship to patient (adult children, spouse, others) and the Mann-Whitney *U* test for gender, marital status (married, not married), history of comorbidity (yes, no), employment (working, not working), income (high, low), education level ( $\leq$ high school,  $>$ high school) and FHL level (adequate, limited). To determine the unique contribution of FHL to caregiving burden, we conducted a multiple hierarchical linear regression model with two blocks (first block: demographic and clinical characteristics; second block: FHL level). In the multivariable regression model, caregiving burden was treated as a continuous variable and FHL as a categorical variable (adequate, limited). Demographic and clinical variables in the regression model were those shown relevant in prior research and theory (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014; Gérain & Zech, 2019). Effect sizes associated with correlation coefficients for predictors in the regression model were reported. The *p* value was set at  $<.05$  for all analyses.

## 3 | RESULTS

### 3.1 | Demographic and clinical characteristics

Family caregivers ( $N = 88$ ) were distributed among adult children (38%), spouses (36%), and others (26%). The age of family caregivers ranged between 18 and 73 years ( $M = 40.8$ ,  $SD = 14.2$ ). Close to three-quarters of family caregivers were females (73%). Duration of caregiving ranged between 0.33 and 18 years ( $M = 3.9$ ;  $SD = 3.5$ ). Caregivers provided care to patients ( $N = 88$ ) who were nearly equally distributed between females (52%) and males (48%) and their age ranged between 18 and 85 years ( $M = 54.9$ ;  $SD = 16.6$ ). Most patients underwent three hemodialysis sessions per week (84%). Years on hemodialysis ranged between 0.42 and 24 ( $M = 4.5$  years;  $SD = 4.6$ ). Detailed description of family caregivers and patients is provided in Table 1.

### 3.2 | Magnitude of FHL and caregiving burden

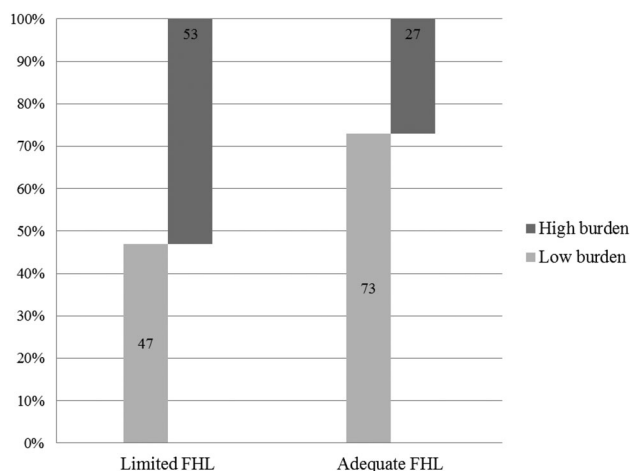
Health literacy, as measured by the S-TOFHLA, ranged between 1 and 36 ( $M = 23.8$ ;  $SD = 10.4$ ). Only 59% of family caregivers had adequate FHL levels (S-TOFHLA scores between 23 and 36) while 41% (95% CI: [31–52%]) had limited FHL (6% marginal FHL levels [S-TOFHLA scores between 17 and 22], 35% inadequate FHL levels [S-TOFHLA scores between 0 and 16]). Caregiving burden, as measured by the S-ZBI, ranged between 1 and 39 with a mean score of 14.4 ( $SD = 8.9$ ). More than one-third (38%, 95% CI: [27–49%]) of family caregivers experienced high caregiving burden (S-ZBI score  $\geq 17$ ). When the cross-tabulated, proportion of family caregivers with high burden was two times higher in family caregivers with limited FHL (53%) than their counterpart caregivers with adequate FHL (27%; Figure 1).

**TABLE 1** Characteristics of family caregivers and patients

Characteristic	Family caregivers (N = 88) n (%)	Patients (N = 88) n (%)
<b>Gender</b>		
Female	64 (73)	46 (52)
Male	24 (27)	42 (48)
<b>Marital status</b>		
Married	55 (63)	62 (71)
Not married	33 (37)	26 (29)
<b>Education</b>		
≤High school	63 (72)	68 (77)
More than high school	25 (28)	20 (23)
<b>Employment</b>		
Working	16 (18)	9 (10)
Not working	72 (82)	79 (90)
<b>Income per month</b>		
Low (≤500 JOD)	73 (83)	75 (85)
High (>500 JOD)	15 (17)	12 (14)
<b>History of comorbidity</b>		
Yes	21 (24)	76 (86)
No	67 (76)	12 (14)
<b>Kinship to patients</b>		
Adult children	33 (38)	
Spouses	32 (36)	
Others	23 (26)	

### 3.3 | Correlates of caregiving burden

By Spearman's rho correlation, there was a small, but significant, positive relationship of caregivers' age to caregiving burden ( $r = .25$ ;  $p = .02$ ). There was no significant relationship of caregiving burden



**FIGURE 1** Proportions of family caregivers with high and low caregiving burden according to their functional health literacy level (N = 88). FHL, functional health literacy

with patients' age ( $r = -.15$ ;  $p = .15$ ), duration of both caregiving ( $r = .21$ ;  $p = .06$ ), or hemodialysis ( $r = .15$ ;  $p = .17$ ). With regard to caregivers' kinship to patients, the Kruskal-Wallis test revealed no statistically significant difference ( $\chi^2 [2, 88] = 4.1$ ;  $p = .13$ ) across the three groups of family caregivers in caregiving burden (adult children [ $n = 33$ ]; Md = 11.0, spouses [ $n = 32$ ]; Md = 15.0, others [ $n = 23$ ]; Md = 17.0). By Mann-Whitney  $U$  test, a significant relationship was observed between caregiving burden and both FHL (limited: Md = 17; adequate: Md = 11;  $U = 661.5$ ;  $Z = -2.33$ ;  $p = .02$ ,  $n = 88$ ) and history of comorbidity in caregivers (yes: Md = 21; no: Md = 11;  $U = 378.0$ ;  $Z = -3.19$ ;  $p = .001$ ,  $n = 88$ ). The remaining categorical variables were not significantly related to caregiving burden in bivariate analyses (Table 2).

### 3.4 | Independent predictors of caregiving burden

The first step of the hierarchical regression analysis included demographic and clinical variables (duration of caregiving and caregivers' age, income, employment condition, kinship to the patient, and history of comorbidity) while the second step included FHL level. Analyses indicated no violation of the assumptions of normality, linearity, homoscedasticity, and multicollinearity, as revealed by inspecting the normal probability plot [P-P] of the regression standardized residual, the scatterplot and tolerance and VIF values. Effect sizes associated with correlation coefficients for predictors in the regression model are summarized in Table 3. The first step in the regression model explained 14% of the variance in caregiving burden ( $p = .004$ ). After entry of FHL level at step two, the total variance explained by the model as a whole was 18%,  $F(6, 81) = 3.47$ ,  $p = .002$ . FHL explained an additional 4% of the variance in caregiving burden,  $R^2$  change = .04,  $F$  change (1, 80) = 4.35,  $p = .04$ . In the final model, caregiver's history of comorbidity ( $\beta = -.39$ ;  $p < .001$ ) and FHL level ( $\beta = -.21$ ;  $p = .04$ ) were statistically significant (Table 4).

## 4 | DISCUSSION

In the current study, we demonstrated two main points. First, more than one-third of family caregivers of Jordanian patients with ESRD had limited FHL and experienced high caregiving burden, and second, caregivers' limited FHL aggravated caregiving burden independent of other demographic and clinical characteristics. This study took a further step by identifying the unique contribution of caregivers' FHL to caregiving burden within the context of ESRD.

Family caregiving burden and poor outcomes are thought to be components of a vicious cycle (Jafari et al., 2018). Driven by feelings of commitment toward their ill loved one and their desire for competence, family caregivers often sacrifice several essentials, such as comfort, sleep, socialization and finances (Salehitali et al., 2018; Alnazly & Samara, 2014; Oyegbile & Brysiewicz, 2017). This sacrifice is linked with high burden among caregivers as manifested by worsening of their psychological and physical well-being, social life,

**TABLE 2** Results of the Mann–Whitney *U* test for the differences in the mean ranks of caregiving burden according to demographic and clinical variables (*N* = 88)

Characteristic	Caregiver				Patient			
	M (SD)	Md	<i>U</i>	<i>p</i>	M (SD)	Md	<i>U</i>	<i>p</i>
Gender			646.5	.25			761.0	.09
Male	12.5 (8.5)	11.5			16.1 (9.7)	16.0		
Female	15.2 (8.9)	13.0			12.9 (7.8)	11.0		
Marital status			803.0	.37			680.5	.25
Married	14.9 (8.6)	13.0			13.7 (8.9)	11.5		
Not married	13.7 (9.3)	11.0			16.2 (8.7)	14.0		
Education			679.0	.32			579.0	.31
≤High school	15.2 (9.0)	12.0			14.0 (9.0)	12.0		
>High school	12.7 (8.4)	11.0			16.0 (8.6)	14.5		
Employment			419.0	.09			272.5	.25
Working	11.3 (9.2)	9.5			13.1 (12.5)	7.0		
Not working	15.2 (8.7)	13.0			14.6 (8.5)	12.0		
Income per month			389.0	.09			370.0	.17
Low	15.3 (8.9)	13.0			14.1 (9.0)	12.0		
High	11.1 (8.0)	10.0			16.8 (7.8)	18.0		
History of comorbidity			378.0	.001			363.5	.26
Yes	20.4 (9.7)	21.0			14.0 (8.8)	12.0		
No	12.6 (7.7)	11.0			17.3 (9.2)	15.5		
Frequency of HD sessions							458.0	.49
Two sessions/week					13.4 (10.0)	10.5		
Three sessions/week					14.6 (8.7)	12.5		
FHL level			661.5	.02				
Limited	17.2 (9.4)	17.0						
Adequate	12.6 (8.0)	11.0						

Abbreviations: FHL, functional health literacy; HD, hemodialysis; M (SD), mean (standard deviation); Md, median.

financial status and quality of life (Jafari et al., 2018; Oyegbile & Brysiewicz, 2017; Salehitali et al., 2018). Secondary to higher burden, caregivers' abilities to continue supporting their ill family member decline, which in turn adversely affects patients' health, as can be seen through increased rates of patients' hospitalizations and emergency department visits as well as reports of high depression and anxiety and poor quality of life (Adelman et al., 2014; Kuzuya et al., 2011). The deterioration in care recipients' and caregivers' lives causes further burden among family caregivers. To break the vicious cycle of caregiving burden and poor outcomes, determinants of caregiving burden have to be identified.

According to our results, family caregivers with limited FHL had a burden score that is on average 4.6 points higher than that of family caregivers with adequate FHL. In the adjusted model adequate FHL was associated with nearly two points less burden on the ZBI. FHL explained a small but significant additional 4% of the variance in caregiving burden even when the effects of other relevant demographic and clinical variables were statistically controlled. Although the associations among some variables were significant, the effect sizes were small and the clinical significance of our findings must be considered. These findings indicate that health literacy plays a small,

but meaningful role in caregiver burden, particularly when viewed in a multivariate context. Our findings also indicate the other variables beyond demographic, clinical and health literacy variables should be explored to complete the picture of caregiver burden. Our findings are consistent with those of others, adding to the existing literature.

Among family caregivers of patients with type two diabetes, Gibson (2012) also found a significant independent relationship of caregivers' FHL to caregiving burden. In bivariate analyses, Barutcu (2019) demonstrated weak to moderate, negative relationships of caregiving burden to health literacy in terms of information access, understanding, appraisal, and application. In other bivariate analyses, Ishida, Matsuoka, Nakatsugawa, Saka, and Tsuchihashi-Makaya (2017) also found that FHL of heart failure patients and their family caregivers were significantly associated with caregiving burden. In their multiple linear regression model, however, they found that only patients' (not caregivers') FHL, and family caregivers' other types of health literacy (i.e., interactive and critical health literacy) were independent predictors of caregiving burden. To what degree Ishida's findings apply to ours is unknown as we did not collect information on patients' FHL nor did we assess family caregivers' interactive and critical health literacy. In general, health literacy at a

**TABLE 3** Effect sizes associated with correlation coefficients for predictors in the regression model (N = 88)

Predictors	Age, caregiver	Income, caregiver	Employment, caregiver	Kinship to patient	Comorbidity, caregiver	Duration of caregiving
Age, caregiver	-					
Income, caregiver	0.02 <sup>a</sup>	-				
Employment, caregiver	0.06 <sup>a</sup>	0.18 <sup>b</sup>	-			
Kinship to patient	0.27 <sup>c,*</sup>	0.21 <sup>d</sup>	0.32 <sup>d,*</sup>	-		
Comorbidity, caregiver	0.35 <sup>b,*</sup>	0.04 <sup>b</sup>	0.20 <sup>b</sup>	0.30 <sup>d,*</sup>	-	
Duration of caregiving	0.04 <sup>e</sup>	0.15 <sup>a</sup>	0.05 <sup>a</sup>	0.003 <sup>c</sup>	0.07 <sup>a</sup>	-

Note: Analysis tests by:

<sup>a</sup>Mann-Whitney *U* test.

<sup>b</sup> $\chi^2$  Test for independence, phi coefficient.

<sup>c</sup>Kruskal-Wallis test.

<sup>d</sup> $\chi^2$  Test for independence, Cramer's *V*.

<sup>e</sup>Spearman's rho. Cohen effect size for group comparisons: small,  $d = 0.2$ ; medium,  $d = 0.5$ ; large,  $d = 0.8$ . Cohen effect size for correlation: small,  $r = .10-.29$ ; medium,  $r = .30-.49$ ; large,  $r = .50-1.0$ .

\* $p < .05$ .

patient-caregiver dyad level and its relationship to caregiving burden, caregiver role in terms of mastery, strain and captivity and also health outcomes within the context of ESRD are unexplored research areas and merit further in-depth investigations.

Gaining and processing relevant information is the main vehicle by which family caregivers can support their ill loved one's needs. According to empirical evidence, limited FHL negatively affects an individual's motivation and capacity to seek, comprehend and act on health information. For example, Kim and Utz (2018) demonstrated that FHL operated as an independent indicator of preference for seeking health information among chronically ill patients. In addition, those with limited FHL accessed health information from fewer resources and were more likely to use television but not printed media or health organization documents as their main source of health information (Yoshida, Iwasa, Kumagai, Suzuki, & Yoshida, 2014).

Oliffe et al. (2019) found that in comparison to patients with adequate FHL their counterparts with limited FHL were less likely to give correct answers to questions indicating an understanding of medication labels and were more likely to make errors while demonstrating medication administration. Limited FHL was also a strong indicator of poor processing of oral communication. Schillinger et al. (2004) found a worse evaluation of clarity of physicians' communication and poorer explanations of health conditions and care processes among patients with limited FHL. Moreover, limited FHL was found to be independently related to patients' low perceived control over self-care and organization of care (van der Heide, Heijmans, Schuit, Uiters, & Rademakers, 2015). Though such consequences of limited FHL were largely investigated among populations of chronically ill patients, there is no reason to believe that they do not apply to family caregivers.

**TABLE 4** Two-step multiple hierarchical regression analysis to predict caregiving burden

Variable	Model I ( $F [6, 81] = 3.47; p = .004$ )			Model II ( $F [7, 80] = 3.72; p = .002$ )		
	<i>B</i> (std. error)	$\beta$	<i>p</i>	<i>B</i> (std. error)	$\beta$	<i>p</i>
Age, caregiver	0.08 (0.07)	.13	.26	0.06 (0.07)	.10	.39
Income, caregiver	-2.3 (2.5)	-.10	.35	-1.9 (2.4)	-.09	.42
Employment, caregiver	2.3 (2.4)	.10	.33	2.2 (2.3)	.09	.36
Kinship to patient	0.03 (2.1)	.001	.99	0.07 (2.0)	.004	.97
History of comorbidity, caregiver	-8.4 (2.2)	-.41	<.001	-8.0 (2.2)	-.39	<.001
Duration of caregiving	0.34 (0.26)	.13	.19	0.25 (0.26)	.10	.34
Functional health literacy, caregiver				-1.95 (0.94)	-.21	.04
Adjusted $R^2$	.14			.18		

Note: Reference groups of categorical variables: income, low; employment, working; kinship to patient, spouse; history of comorbidity, yes, functional health literacy, limited.

Though the main focus of the current study was on FHL, it should be highlighted that caregiver's history of comorbidity was another independent predictor of caregiving burden in our analysis. In the adjusted models, reporting no comorbidities was associated with nearly four points lower burden on the ZBI. Other investigators as well demonstrated a significant independent relationship of family caregivers' self-perceived health to caregiving burden (Affinito & Louie, 2018). In a qualitative study, family caregivers attributed forgetting to take their medications and postponing their medical appointments to their mental and physical involvement with their patients (Alnazly & Samara, 2014). They also reported worries about their high blood pressure and uncontrolled blood sugar (Alnazly & Samara, 2014). The fact that our model as a whole explained a relatively small variance in caregiving burden may suggest that other variables could play a more important role in explaining caregiving burden in family caregivers of Jordanian patients with ESRD. Other investigators demonstrated that quality of the relationship of between caregivers and patients (e.g., closeness, conflict, inequity) in addition to caregiver-care recipient dyads' psychological condition (e.g., anxiety, depression) as well as actual and perceived social support have an impact on perceived caregiving burden (Adelman et al., 2014; Shakya, 2017; Tough, Brinkhof, Siegrist, & Fekete, 2017).

Based on our 95% CIs of both FHL and caregiving burden, it could be estimated that around one-third to one-half of family caregivers of Jordanian patients with ESRD have limited FHL and one-quarter to one-half experience a burdensome caregiving experience. Jordan has no national census on family caregivers' numbers and attributes, nor does it have a national policy for supporting their needs. In addition, studies of family caregivers of Jordanian patients indicated that caregivers were often not acknowledged by formal health care providers and were not prepared to handle caregiving tasks (Alnazly, 2018; Salehitali et al., 2018). The lack of formal attention to family caregivers contradicts what Jordanian society expects from family caregivers. Based on social and religious norms, Jordanians have to show and demonstrate interest, patience and caring when a family member gets ill. In addition, Jordanians believe that taking care of their ill loved family member is one way to please God. Voicing burden is, on the other hand, unacceptable and considered taboo. Therefore, giving more attention to family caregivers' needs or attributes, including FHL, may minimize family caregivers' perception of burden from a social perspective.

There are limitations of the current study that have to be acknowledged. These include the cross-sectional design, which limits our ability to establish a causal relationship of FHL to caregiving burden. Other limitations are the convenience sampling method, which limits the generalization of results, and also the possibility that eligible family caregivers with low literacy may have declined participation in the current study because of embarrassment. Moreover, individuals with low literacy often do not engage the health care system unless absolutely necessary, limiting their accessibility to researchers. The impact of social desirability on family caregivers' report of burden is also possible. Confounders that were not

controlled for in the current study may involve the patient's health literacy and its interaction with that of family caregivers.

## 5 | CONCLUSION

Family caregivers are partners in patient care and should not be left alone to struggle with high caregiving demands. To decrease caregiving burden and to improve outcomes of caregivers and patients, our results suggest giving more attention to caregivers' FHL. There is a need, for example, to emphasize the importance of measuring FHL of caregivers, in addition to that of care recipients, in clinical settings, especially with the reported difficulty of health care providers to estimate it (Dickens, Lambert, Cromwell, & Piano, 2013). Oral and written health information has to be delivered in a way that considers needs of people with limited FHL, such as following the recommended strategies for clear communication (e.g., avoiding jargon, using teach-back technique and visual aids, focusing on main points; Kripalani & Weiss, 2006) and ensuring appropriateness of written material in terms of readability, graphs and layout. Incorporating family caregivers with low FHL in advisory committees for designing and evaluating relevant health education programs may be helpful to meet caregivers' information needs.

## CONFLICT OF INTERESTS

The authors declare that there are no conflict of interests.

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## REFERENCES

- Adelman, R. D., Tmanova, L. L., Delgado, D., Dion, S., & Lachs, M. S. (2014). Caregiver burden: A clinical review. *JAMA - Journal of the American Medical Association*, 311(10), 1052–1059. <https://doi.org/10.1001/jama.2014.304>
- Affinito, J., & Louie, K. (2018). Positive coping and self-assessed levels of health and burden in unpaid caregivers of patients with end stage renal disease receiving hemodialysis therapy. *Nephrology Nursing Journal*, 45(4), 373–379. <http://www.ncbi.nlm.nih.gov/pubmed/30303647>
- Alnazly, E. K. (2018). The impact of an educational intervention in caregiving outcomes in Jordanian caregivers of patients receiving hemodialysis: A single group pre-and-post test. *International Journal of Nursing Sciences*, 5(2), 144–150. <https://doi.org/10.1016/j.ijnss.2018.03.007>
- 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*, 2(1), 118. <https://doi.org/10.4172/2375-4273.1000118>
- Bachner, Y. G. (2013). Preliminary assessment of the psychometric properties of the abridged Arabic version of the Zarit Burden Interview among caregivers of cancer patients. *European Journal of Oncology Nursing*, 17, 657–660. <https://doi.org/10.1016/j.ejon.2013.06.005>

- Baker, D. W., Williams, M. V., Parker, R. M., Gazmararian, J. A., & Nurss, J. (1999). Development of a brief test to measure functional health literacy. *Patient Education and Counseling*, 38(1), 33–42. [https://doi.org/10.1016/S0738-3991\(98\)00116-5](https://doi.org/10.1016/S0738-3991(98)00116-5)
- Barutcu, C. D. (2019). Relationship between caregiver health literacy and caregiver burden. *Puerto Rico Health Sciences Journal*, 38(3), 163–169.
- Bedard, M., Molloy, D. W., Squire, L., Dubois, S., Lever, J. A., & O'Donnell, M. (2001). The Zarit Burden Interview: A new short version and screening version. *Gerontologist*, 41(5), 652–657. <https://doi.org/10.1016/j.jclinepi.2009.06.014>
- Dageforde, L. A., & Cavanaugh, K. L. (2013). Health literacy: emerging evidence and applications in kidney disease care. *Advances in Chronic Kidney Disease*, 20(4), 311–319. <https://doi.org/10.1053/j.ackd.2013.04.005>
- Dickens, C., Lambert, B. L., Cromwell, T., & Piano, M. R. (2013). Nurse overestimation of patients' health literacy. *Journal of Health Communication*, 18(Suppl. 1), 62–69. <https://doi.org/10.1080/10810730.2013.825670>
- Eirini, G., & Georgia, G. (2018). Caregivers of patients on haemodialysis. In M. Mollaoglu (Ed.), *Caregiving and Home Care* (pp. 75–84). London, England: InTechOpen. <https://doi.org/10.5772/intechopen.72400>
- Ellis, J., Mullan, J., Worsley, A., & Pai, N. (2012). The role of health literacy and social networks in arthritis patients' health information-seeking behavior: A qualitative study. *International Journal of Family Medicine*, 2012, 1–6. <https://doi.org/10.1155/2012/397039>
- Fadda, M., Kanj, M., Kabakian-Khasholian, T., & Johannes Schulz, P. (2018). Validation of three Arabic health literacy assessment tools in Lebanon. *Health Promotion International*, 33(2), 261–267. <https://doi.org/10.1093/heapro/daw079>
- García, C. H., Espinoza, S. E., Lichtenstein, M., & Hazuda, H. P. (2013). Health literacy associations between hispanic elderly patients and their caregivers. *Journal of Health Communication*, 18, 256–272. <https://doi.org/10.1080/10810730.2013.829135>
- Gibson, J. (2012). Correlation of health literacy to the stress level of informal caregivers for people with type 2 diabetes. (Doctoral dissertation). Available from ProQuest Dissertations and Theses database.
- Gérain, P., & Zech, E. (2019). Informal caregiver burnout? Development of a theoretical framework to understand the impact of caregiving. *Frontiers in Psychology*, 10, 1748. <https://doi.org/10.3389/fpsyg.2019.01748>
- Higginson, I. J., Gao, W., Jackson, D., Murray, J., & Harding, R. (2010). Short-form Zarit Caregiver Burden Interviews were valid in advanced conditions. *Journal of Clinical Epidemiology*, 63(5), 535–542. <https://doi.org/10.1016/j.jclinepi.2009.06.014>
- Hooley, P. J., Butler, G., & Howlett, J. G. (2005). The relationship of quality of life, depression, and caregiver burden in outpatients with congestive heart failure. *Congestive Heart Failure*, 11(6), 303–310. <https://doi.org/10.1111/j.1527-5299.2005.03620.x>
- Ishida, H., Matsuoka, S., Nakatsugawa, E., Saka, M., & Tsuchihashi-Makaya, T. -M. (2017). Health literacy of heart failure patients and their caregivers is independently associated with caregiver burden. *Circulation*, 136, A16251.
- Jadhav, B., Dhavale, H., Dere, S., & Dadarwala, D. (2014). Psychiatric morbidity, quality of life and caregiver burden in patients undergoing hemodialysis. *Medical Journal of Dr. D.Y. Patil University*, 7(6), 722. <https://doi.org/10.4103/0975-2870.144858>
- Jafari, H., Ebrahimi, A., Aghaei, A., & Khatony, A. (2018). The relationship between care burden and quality of life in caregivers of hemodialysis patients. *BMC Nephrology*, 19(1), 321. <https://doi.org/10.1186/s12882-018-1120-1>
- Khalil, A. A., & Abed, M. A. (2014). Perceived social support is a partial mediator of the relationship between depressive symptoms and quality of life in patients receiving hemodialysis. *Archives of Psychiatric Nursing*, 28(2), 114–118. <https://doi.org/10.1016/j.apnu.2013.11.007>
- Khalil, A. A., Darawad, M., Al Gamal, E., Hamdan-Mansour, A. M., & Abed, M. A. (2012). Predictors of dietary and fluid non-adherence in Jordanian patients with end-stage renal disease receiving haemodialysis: A cross-sectional study. *Journal of Clinical Nursing*, 22(1–2), 127–136. <https://doi.org/10.1111/j.1365-2702.2012.04117.x>
- Kim, S. H., & Utz, S. (2018). Association of health literacy with health information-seeking preference in older people: A correlational, descriptive study. *Nursing Health & Science*, 20(3), 355–360. <https://doi.org/10.1111/nhs.12413>
- Kripalani, S., & Weiss, B. D. (2006). Teaching about health literacy and clear communication. *Journal of General Internal Medicine*, 21(8), 888–890. <https://doi.org/10.1111/j.1525-1497.2006.00543.x>
- Kuzuya, M., Enoki, H., Hasegawa, J., Izawa, S., Hirakawa, Y., Shimokata, H., & Akihisa, I. (2011). Impact of caregiver Burden on adverse health outcomes in community-dwelling dependent older care recipients. *American Journal of Geriatric Psychiatry*, 19(4), 382–391. <https://doi.org/10.1097/JGP.0b013e3181e9b98d>
- Ministry of Health. (2016). *National Registry of End Stage Renal Disease, 2016 report*. Retrieved from <http://www.moh.gov.jo/Echobusv3.0/SystemAssets/5dc890f3-d08e-45a9-8adb-e82d99974bda.pdf>
- Nutbeam, D. (2008). The evolving concept of health literacy. *Social Science and Medicine*, 67(12), 2072–2078. <https://doi.org/10.1016/j.socscimed.2008.09.050>
- Oliffe, M., Thompson, E., Johnston, J., Freeman, D., Bagga, H., & Wong, P. K. K. (2019). Assessing the readability and patient comprehension of rheumatology medicine information sheets: A cross-sectional Health Literacy Study. *BMJ Open*, 9(2), 024582. <https://doi.org/10.1136/bmjopen-2018-024582>
- Oyegbile, Y. O., & Brysiewicz, P. (2017). Exploring caregiver burden experienced by family caregivers of patients with end-stage renal disease in Nigeria. *International Journal of Africa Nursing Sciences*, 7, 136–143. <https://doi.org/10.1016/j.ijans.2017.11.005>
- Rahmani, F., Ranjbar, F., Hosseinzadeh, M., Razavi, S. S., Dickens, G. L., & Vahidi, M. (2019). Coping strategies of family caregivers of patients with schizophrenia in Iran: A cross-sectional survey. *International Journal of Nursing Sciences*, 6(2), 148–153. <https://doi.org/10.1016/j.ijnss.2019.03.006>
- Salehitali, S., Ahmadi, F., Hasanpour Dehkordi, A., Noorian, K., Fereidooni-Moghadam, M., & Zarea, K. (2018). Progressive exhaustion: A qualitative study on the experiences of Iranian family caregivers regarding patients undergoing hemodialysis. *International Journal of Nursing Sciences*, 5(2), 193–200. <https://doi.org/10.1016/j.ijnss.2018.01.005>
- Schillinger, D., Bindman, A., Wang, F., Stewart, A., & Piette, J. (2004). Functional health literacy and the quality of physician-patient communication among diabetes patients. *Patient Education and Counseling*, 52(3), 315–323. [https://doi.org/10.1016/S0738-3991\(03\)00107-1](https://doi.org/10.1016/S0738-3991(03)00107-1)
- Senanayake, S., Gunawardena, N., Paliwardana, P., Bandara, P., Haniffa, R., Karunaratna, R., & Kumara, P. (2017). Symptom burden in chronic kidney disease: A population based cross sectional study. *BMC Nephrology*, 18(1), 228. <https://doi.org/10.1186/s12882-017-0638-y>
- Shakya, D. (2017). Burden and depression among caregivers of hemodialysis patients. *Palliative Medicine & Care: Open Access*, 4(1), 1–6. <https://doi.org/10.15226/2374-8362/4/1/00131>
- Tayyem, R. F., & Mrayyan, M. T. (2008). Assessing the prevalence of malnutrition in chronic kidney disease patients in Jordan. *Journal of Renal Nutrition*, 18(2), 202–209. <https://doi.org/10.1053/j.jrn.2007.10.001>
- Tough, H., Brinkhof, M. W., Siegrist, J., & Fekete, C. (2017). Subjective caregiver burden and caregiver satisfaction: The role of partner relationship quality and reciprocity. *Archives of Physical Medicine and Rehabilitation*, 98(10), 2042–2051. <https://doi.org/10.1016/j.apmr.2017.02.009>



- van der Heide, I., Heijmans, M., Schuit, A. J., Ueters, E., & Rademakers, J. (2015). Functional, interactive and critical health literacy: Varying relationships with control over care and number of GP visits. *Patient Education and Counseling*, 98(8), 998–1004. <https://doi.org/10.1016/j.pec.2015.04.006>
- World Health Organization. (1998). *Health Promotion Glossary*. Retrieved from [https://www.who.int/healthpromotion/about/HPR\\_Glossary\\_1998.pdf](https://www.who.int/healthpromotion/about/HPR_Glossary_1998.pdf)
- Yeh, J. Z., Wei, C. J., Weng, S. F., Tsai, C. Y., Shih, J. H., Shih, C. L., & Chiu, C. H. (2018). Disease-specific health literacy, disease knowledge, and adherence behavior among patients with type 2 diabetes in Taiwan. *BMC Public Health*, 18(1), 1062. <https://doi.org/10.1186/s12889-018-5972-x>
- Yoshida, Y., Iwasa, H., Kumagai, S., Suzuki, T., & Yoshida, H. (2014). Limited functional health literacy, health information sources, and health behavior among community-dwelling older adults in Japan. <https://doi.org/10.1155/2014/952908>
- Yuen, E. Y. N., Knight, T., Ricciardelli, L. A., & Burney, S. (2018). Health literacy of caregivers of adult care recipients: A systematic scoping review. *Health and Social Care in the Community*, 26(2), e191–e206. <https://doi.org/10.1111/hsc.12368>
- Zarit, S. H., Todd, P. A., & Zarit, J. M. (1986). Subjective burden of husbands and wives as caregivers: A longitudinal study. *Gerontologist*, 26(3), 260–266. <https://doi.org/10.1093/geront/26.3.260>

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