Relationship between Caregiver Health Literacy and Treatment Adherence of Patients with Advanced Chronic Kidney Disease Undergoing Hemodialysis: A Cross-sectional Dyadic Study

ABSTRACT

Background and Objectives: Hemodialysis reduces patients' ability to perform daily activities and makes them dependent on caregivers. Since the access to and understanding of health information by patients should be ensured by informal caregivers, caregivers' health literacy is of particular importance in treatment adherence. This study determined the relationship between caregivers' health literacy and hemodialysis patients' treatment adherence.

Materials and Methods: This descriptive correlational study was conducted on dyads of hemodialysis patients and their caregivers at all hemodialysis wards in Bushehr Province, Iran (2021) using the census method. Eligible patients and their caregivers were invited to participate (N=259). The data collection instruments were a demographic information form, the End-Stage Renal Disease Adherence Questionnaire, and the Health Literacy Instrument for Iranian Adults. The data were analyzed using SPSS19.0 via descriptive and analytical methods (univariate and multivariate linear regression). P<0.05 was considered statistically significant.

Results: In total, 78 and 181 of the caregivers were male and female, respectively, with the mean ±SD age of 58.53±12.63 years. Among the patients, 153 were male and the rest were female with the mean ±SD age of 43.47±11.97 years. The mean ±SD of caregivers' health literacy and treatment adherence was 3.42±0.81 and 1063.61±142.11, respectively. There was no significant correlation between caregivers' health literacy and patients' treatment adherence (P<0.89). However, there was a direct correlation between treatment adherence and caregivers' age (P<0.01). Moreover, there was a negative correlation between the number of hours of caregiving per day and the patients' treatment adherence (P<0.04).

Conclusion: Since caregivers' health literacy was not associated with patients' treatment adherence, if healthcare providers, provide appropriate information to informal caregivers even based on their health literacy, it may not be transferred well to their patients. Therefore, these results can be considered a warning for healthcare providers to pay attention to providing training in health promotion programs to both the patient and the caregiver.

Paper Type: Research Article

Keywords: Chronic kidney disease, Health literacy, Hemodialysis, Informal caregivers, Treatment adherence.

▶ **Citation:** Daneshmand S, Bagherzadeh R, Mohammadpour M, Heidari F, Vahedparast H. Relationship between Caregiver Health Literacy and Treatment Adherence of Patients with Advanced Chronic Kidney Disease Undergoing Hemodialysis: A Cross-sectional Dyadic Study. *Journal of Health Literacy*. Autumn 2023; 8(3): 43-54.

Sahar Daneshmand
MS of Nursing, Department of Nursing, Nursing and Midwifery Faculty, Bushehr University of Medical Sciences, Bushehr, Iran.

Razieh Bagherzadeh
PhD of Reproductive Health, Department of Midwifery, Nursing and Midwifery Faculty. Bushehr University of Medical Sciences. Bushehr, Iran.

Mehdi Mohammadpour
Nephrologist, Department of nephrology, Medical Faculty. Bushehr University of Medical Sciences. Bushehr, Iran.

Fatemeh Heidari
MS of Nursing, Department of Nursing, Nursing and Midwifery Faculty, Bushehr University of Medical Sciences, Bushehr, Iran.

Hakimeh Vahedparast
* PhD of Nursing, Department of Nursing, Nursing and Midwifery Faculty. Bushehr University of Medical Sciences, Bushehr. Iran. (Corresponding Author) : h.vahedparast@bpums.ac.ir

Received: 28 January 2023
Accepted: 05 May 2023
Doi: 10.22038/jhl.2023.70359.1384

Introduction

Chronic kidney disease (CKD) is a major problem and growing public health priority, associated with morbidity, mortality, and additional costs and imposing an increasing burden on the healthcare system and economy (1-3). More than 10% of the general population (over 800 million people) suffer from CKD (4), which is equal to the estimated prevalence of diabetes worldwide and more than 20 times the global prevalence of HIV (2, 5). CKD is more prevalent in low-and middle-income countries and accounts for about 80%of all CKD cases globally. Based on a 2021 study in Iran, about 8.4% of women and 9.3% of men develop CKD annually (6).

Hemodialysis is the most common form of kidney replacement therapy in the world (7). However, about 9-13% of patients undergoing dialysis die within one year. The mortality rate among hemodialysis patients is 6.3-8.2 times higher than the general population. The most common factors affecting the survival of these patients are pre-dialysis care, inadequate dialysis, and non-adherence (1). The term treatment adherence refers to all patient behaviors (diet, fluid restriction, disease follow-up, participating in hemodialysis sessions, and receiving medication) that are in line with the recommendations provided by healthcare providers (3). Adhering to dietary recommendations, fluid restriction, and prescribed medication, and attending hemodialysis sessions are necessary for optimal and effective treatment of CKD (8) and could play an important role in improving patients' health level (1). However, non-adherence to treatment recommendations is common among hemodialysis patients and is reported at 25-86% (9). Nalouh et al. (2017) showed that only 24% and31% of hemodialysis patients followed the diet and fluid restrictions, respectively, and 44.6% had moderate to poor adherence to treatment recommendations (8).

Hemodialysis treatment changes the performance of CKD patients, which subsequently affects treatment adherence because their daily activity level is disturbed and patients' ability to perform daily activities decreases. Therefore, it makes them dependent on caregivers (10). Therefore, these patients need adequate support from others, especially family caregivers who are directly involved in their care (11). The required care is mostly provided by informal caregivers (12). Informal caregivers are those who are most involved in taking care of patients and helping them during the treatment period and are often the patient's family members (12). They have a positive effect on the adaptation of their patients and play a crucial role in managing various aspects of patient care (12, 13). Informal caregivers are considered as the main member of the care system (12). Depending on the diagnosis and disease severity, they are involved in providing direct care (14). Caregivers actually fill service gaps in the health and governance system, and hence, the involvement of informal caregivers significantly affects the health-related quality of life (HRQOL) of CKD patients (15).

The results of Surendran et al.'s study showed that caregivers play an important role in providing palliative care and are involved in providing various services and caring support to hemodialysis patients (15). Informal caregivers are often responsible for self-management support activities such as accessing and understanding health information, communicating with healthcare providers, coordinating support services, and participating in decision-making and problem-solving. In such cases, caregiver health literacy is of particular importance (13).

Health literacy is defined as cognitive and social skills that determine individuals' motivation and ability to access, understand, and use information

in a way that promotes and maintains health (16). Based on the conceptual framework of dyadic health behavior change model, patients and informal caregivers constantly interact with each other, and this interaction is influenced by various factors. The informal caregiver's health literacy might be an influencing factor on patients' adherence to treatment regimens (17). Jafari et al. (2018) found a significant relationship between caregivers' health literacy and the behavior of women with multiple sclerosis (18). The results of Levin et al.'s (2014) study showed that caregivers' health literacy is only related to one domain of self-care behavior index in heart failure patients (19). However, Høeg et al. (2021) did not find a relationship between caregiver health literacy and cancer patients' anxiety (20). Yuen et al. (2018) argued that the existing studies are more focused on the health literacy of parents of sick children and its consequences for children (14). Høeg et al. (2021) stated that few studies have been conducted on the relationship between caregivers' health literacy and relevant outcomes for the recipient (20). Having knowledge of the relationship between informal caregivers' health literacy and the treatment adherence of hemodialysis patients can help identify ways to support these patients' treatment adherence through the caregiver and contribute to interventional research on family caregivers.

Considering the limited relevant studies and the contradictions in the existing evidence, this study was conducted to determine the relationship between caregivers' health literacy and treatment adherence of hemodialysis patients.

Materials & Method

Study design & Participants

This cross-sectional and correlational study was conducted in 2021. The population included hemodialysis patient and caregiver dyads in all hemodialysis centers of Bushehr Province, Iran. Given the sample size based on the regression analysis formula, which requires selecting 10 to 30 participants per predictor variable (n =10–30k), 15 participants were selected for each predictor variable. Since there was just one main predictor variable, all the main demographic variables were also included in the set of potential predictors. Approximately, 225 participants were eventually considered with a maximum of 15 predictor variables. As it was not clear how many patients and caregivers meet the inclusion criteria, the participants were selected using the census method based on these criteria. Questionnaires were administered to all the eligible patients and caregivers and, finally, 259 patient-caregiver dyads were included.

The inclusion criteria for patients were providing informed consent to participation, at least six months having passed since the start of hemodialysis treatment, being over 18 years old, and having the ability to perform self-care behaviors. Patients who temporarily required hemodialysis (poisoning, acute renal failure, and guests) and those whose dyad did not agree to participate in the study were excluded. The inclusion criteria for informal caregivers were providing informed consent to participation, being over 18 years old, the patient having introduced them as the main caregiver, the caregiver considering themselves as the patient's main caregiver, living in the same house as the patient, having a history of at least six months of patient care, not receiving money for providing care, and being able to read and write.

Data Collection Tools

The data collection tools included a demographic information form (age, sex, income, number of children, etc.), the End-Stage Renal Disease

Adherence Questionnaire, and the Health Literacy Instrument for Iranian Adults (HELIA).

HELIA was used to measure caregivers' health literacy. It was developed by Montazeri et al. for Iranian adults. The validity of this questionnaire has been confirmed by using face and construct validity. The Cronbach's alpha of the subscales in the relevant constructs was acceptable (0.72-0.89) and the scale reliability was confirmed. This 33-item scale consists of 5 subscales: access (6 items) (α = 0.86), reading skill (4 items) (α = 0.72), understanding (7 items) (α = 0.86), appraisal (4 items) (α = 0.77), and decision-making and application of health information (12 items) (α = 0.89). The subscale of reading skills and access are scored on a 5-point Likert scale ranging from 1 to 5 (1= completely difficult, 5 = completely easy). Other subscales are scored on a five-point Likert scale ranging from 1 to 5 (always = 5, most of the time = 4, sometimes = 3, seldom = 2, and never = 1). A higher score reflects a higher level of health literacy (21).

Kim's End-Stage Renal Disease Adherence Questionnaire (ESRD-AQ) was used to evaluate treatment adherence(22). The steps of translation and cultural adaptation were performed by Rafiei et al. The 46-item ESRD-AQ consists of 5 main sections, including general information (5 items), hemodialysis attendance (14 items), medication adherence (9 items), fluid restriction (10 items), and dietary recommendations (8 items). Only 6 items (14, 17, 18, 26, 31, 46) measuring treatment adherence were used for analysis, and the other items were only for descriptive purposes. The scoring scale was different for these 6 items. Items 14, 17, 18, 26, 31, and 46 were scored as 0, 50, 100, 200, 300; 0, 50, 100, 150, 200; 0, 25, 50, 75, 100; 0, 50, 100, 150, 200; 0, 50, 100, 150, 200; and 0, 50, 100, 150, 200, respectively. The minimum and maximum scores of the scale are 0 and 1200, respectively. Higher scores indicate better treatment adherence. The mean value of the content validity of the Iranian version was 0.98 for the scale, which was favorable. The scale reliability was calculated as 0.85 using the test-retest method (23).

Data Collection Process

After obtaining the approval of the Ethics Committee of the Bushehr University of Medical Sciences (IR.BPUMS.REC.1399.048), hemodialysis patients and their informal caregivers were selected based on the inclusion criteria. After introducing themselves to the patients and their caregivers and explaining the research objectives, the researchers administered the questionnaires after obtaining their consent and emphasizing that their information would be kept confidential and anonymous. ESRD-AQ was completed by the researcher while the patients were waiting to be connected to the machine or during hemodialysis. HELIA was completed by the informal caregivers while the patients were undergoing hemodialysis.

Data analysis

The data were analyzed using SPSS 19.0 via descriptive and inferential statistical tests. Univariate linear regression was used to determine the relationship between demographic variables and treatment adherence, and also the relationship between caregivers' health literacy and treatment adherence. To simultaneously determine the role of variables in predicting adherence to treatment, multivariate linear regression was used with the inter method, at the significance level of < 0.05. To control possible confounding variables, some of them were mentioned in the inclusion criteria while designing the study, and some were included in the demographic profile form.

Results

In total, 259 patient-caregiver dyads participated. Among the caregivers, 78 were male and 181 were female with a mean ±SD age of 58.53 ± 12.63 years. Moreover, 153 of the patients were male and the rest were female, with a mean ±SD age of 43.47 ± 11.97 years. The mean ±SD duration of care was 49.17 ± 34.52 months, and the mean ±SD number of hours of caregiving per day was 12.76 ± 8.97 hours. Tables 1 and 2 present the other demographic information.

Table 1. Frequency distribution of demographic variables of informal caregivers

Variable (number of analyzed cases)	Variable level	Frequency*/	% /SD**
Number of people living with the patient		3.38*	1.72**
Duration of kidney failure/month		48.61*	48.89**
Caregiver's educational level (259)	Illiterate	19	7.3
	Elementary school	51	19.7
	High school, no degree	39	15.1
	Diploma	71	27.4
	Associate degree	28	10.8
	Bachelor's degree and higher	51	19.7
Caregiver's employment status (258)	Unemployed	42	16.3
	Housewife	122	47.3
	Employed	31	12.0
	Worker	11	4.3
	Self-employed	31	12.0
	Retired	21	8.2
Type of relationship between caregiver and patient (259)	Spouse	110	42.5
	Brother/sister	14	5.4
	child	111	42.9
	Others (friends or other relatives)	24	9.2
Caregiver's income adequacy (259)	Adequate	18	6.9
	Somewhat adequate	135	52.1
	Inadequate	106	40.9
Receiving training on therapeutic-care regimen by caregiver (259)	Yes	214	82.6
	No	45	17.4
Getting help for caregiving (259)	Yes	145	56.0
	No	114	44.0

The mean ±SD caregivers' health literacy and treatment adherence was 3.42 ± 0.81 and 1063.61 ± 142.11, respectively (Table 3). The results showed no significant correlation between caregivers' health literacy and patients' treatment adherence ($P<0.89$) (Table 4). However, statistically significant correlations were found between treatment adherence and caregiver's age ($P < 0.01$) and the number of hours of caregiving per day ($P < 0.04$) (Table 5).

Table 2. Frequency distribution of demographic variables of hemodialysis patients

Variable (number of analyzed cases)	Variable level	Frequency	Percentage
Marital status (259)	Single	65	25.1
	Married	194	74.9
Educational level (259)	Illiterate	96	37.2
	Elementary school	61	23.6
	High school, no degree	40	15.5
	Diploma	32	12.4
	Associate degree	13	5
	Bachelor's degree and higher	16	6.2
Employment status (258)	Unemployed	79	30.5
	Housewife	85	32.8
	Employed	10	3.9
	Worker	21	8.1
	Self-employed	4	1.5
	Retired	60	23.2
Income adequacy (258)	Adequate	35	13.6
	Somewhat adequate	110	42.6
	Inadequate	113	43.8
Insurance type (254)	Health services	103	40.6
	Social security	133	52.4
	Armed Forces	18	7.1
Receiving training on therapeutic-care regimen (259)	Yes	245	94.6
	No	14	5.4

Table 3. Mean and standard deviation of health literacy of informal caregivers and treatment adherence of hemodialysis patients

Variable		Mean (median)	SD
Caregiver health literacy (score range 1-5)	Access	3.47	0.99
	Reading	3.42	1.14
	Comprehension	3.80	0.91
	Evaluation	3.42	1.06
	Decision-making	3.96	0.79
	Total health literacy	3.63	0.81
Range of score that can be obtained for patient's treatment dherence (0-1200)		1063.61	142.11
Range of score that can be obtained for caregiver health literacy (1-5)			

Table 4. Univariate regression between demographic variables and health literacy based on treatment adherence of hemodialysis patients

Variable	Treatment adherence	
	Standardized coefficient	Significance level
Caregiver's age	0.049	<.001
Caregiver's gender	0.010	0.055
Caregiver's marital status (being married)	0.014	0.059
Caregiver's educational level	0.019	0.083
Caregiver's employment status	0.051	0.020
Type of relationship between caregiver and patient	0.009	0.528
Caregiver's income adequacy	0.001	0.991
Receive training on therapeutic-care regimen by caregiver	0.004	0.335
Getting help for caregiving	0.001	0.896
Duration of care/month	0.003	0.413
Care hours per day	0.022	0.016
Patient's age	0.008	0.147
Patient's gender	0.002	0.482
Patient's marital status	0.001	0.868
Patient's educational level	0.021	0.362
Patient's occupation	0.012	0.678
Patient's income adequacy	0.010	0.176
Number of people living with the patient	0.003	0.373
Access	0.080	0.203
Reading	-0.024	0.698
Comprehension	-0.062	0.322
Evaluation	-0.069	0.266
Decision-making	-0.001	0.986
Total health literacy	-0.009	0.892

Table 5. Regression coefficients of predictor variable of treatment adherence among patients

Predictor variable		Model 1				
		Unstandardized regression coefficient (B)	Standard regression coefficient (Beta)	(P-value)	0.95% confidence interval	
					Lower limit	Upper limit
y-intercept		102.180		.000	98.242	186.11
Caregiver's age		2.013	.169	.017	.354	3.665
Care hours per day		-2.934	-.185	.004	-4.938	-.935
Caregiver's employment status (unemployed reference)	Housewife	30.586	.107	.230	-19.436	80.505
	Employed	-12.961	-.030	.703	-79.884	53.958
	Worker	-75.957	-.103	.124	-172.98	21.066
	Self-employed	-8.231	-.019	.804	-73.35	56.887
	Retired	30.586	.107	.230	-19.43	80.598
Coefficient of determination		.101				
F		4.023				
P-value		<.001				

Discussion

This study determined the relationship between caregivers' health literacy and treatment adherence of patients undergoing hemodialysis. There was no relationship between caregivers' health literacy and patients' treatment adherence. However, there was a direct correlation between the caregivers' age and the patients' treatment adherence. Moreover, a negative correlation was found between the number of hours of caregiving per day and treatment adherence.

The results revealed no significant correlation between the caregivers' health literacy and patients' treatment adherence, which was in line with the results of Belice et al. (2020) and Rak et al. (2016) (24, 25). However, our results were not consistent with studies by Levin et al. (2014) on heart failure patients and their caregivers (19), Rahman's study (2014) on hospitalized elderly patient-caregiver dyads (26), Jafari et al.'s (2018) on MS patients and their caregivers (18), and Ramezannia et al.'s (2020) on breast cancer patients and their caregivers (27). The results of these studies showed a significant correlation between caregivers' health literacy and treatment adherence, health behaviors, and health outcomes (18, 19, 26, 27). Inconsistency in the results could be due to diversity in research instruments and patients' type of disease. Levin et al. outcomes related to caregivers' health literacy were consistent only in one domain with this study and inconsistent in two domains (19), the reason for which could be the used caregiver health literacy research tool. In the mentioned study, the Newest Vital Sign was employed, which measures numerical skills and reading comprehension and determines patients at risk of low health literacy (28). Rahman(2014) assessed caregiver health literacy using the Newest Vital Sign and rapid estimate of adult literacy in medicine considering strict criteria (26). Caregivers' health literacy was considered adequate if they had sufficient health literacy in both tests. However, the present study assessed caregivers' health literacy using HELIA, which measures reading skills, access, understanding, appraisal, and decision-making and use of health information (28). Difference in the used instrument could make it difficult to compare the findings.

Ramezannia et al. and Jafari et al. assessed health literacy more strictly using TOFHLA (18, 26). This instrument measures the ability to read and pronounce words correctly and determine the health literacy level (18, 27) Moreover, TOFHLA provides functional and relatively tangible assessment of health literacy (29). However, HELIA is considered a general health literacy scale due to its items and is not specific to diseases such as CKD and its problems, but measures cases such as "I take care of my health in all situations" or "I fasten my seat belt while driving"(21). Difference in the type of disease of patients receiving care was another reason for inconsistent results; for instance, in the study by Jafari et al., the patients had MS (28). In this disease, there are different options for the type of treatment, type of medicine, attending physician, etc. Therefore, the caregivers' health literacy could be of special importance, and thus, caregivers always seek to update their health information to choose the most appropriate treatment and care option for patients. Choosing the right treatment and care option could improve patients' treatment adherence (28). However, the type of treatment and medication is limited for hemodialysis patients (7). The results of studies show that having health literacy alone may not be enough to improve health outcomes (30, 31). Hayden et al. (2018) noted that health literacy alone may not be sufficient to influence self-management behaviors to control diabetes

(30), but how caregivers convey their knowledge and acceptance of their recommendations by patients are elements that could affect caregivers' health literacy outcomes for patients. Having sufficient health literacy and transferring the knowledge to patients are two separate points, i.e., caregivers may have a high level of health literacy, but may not be able to transfer it to recipients.

This finding could be justified by the cultural aspects of our research population. This study was carried out in Bushehr Province, which has a relatively traditional context from socioeconomic and cultural perspectives. Despite the recent socioeconomic and cultural changes made in Bushehr and the whole country, it seems that traditional institutions still dominate this city and its subordinate counties. In such conditions (patriarchy, considering men as breadwinners, and women's low socioeconomic participation), men are more likely to be the main decision-makers in the family (32). Such an attitude among men and women may cause female caregivers not to convey their knowledge to patients, and male patients may not follow the advice of their caregivers, who are mostly their wives and daughters, and only rely on their own or medical caregivers' health literacy. Moreover, taking care of patients undergoing hemodialysis, such as dietary adherence and fluid restriction, is mainly provided at home, and spouses play a significant role in obliging patients to follow the treatment (33). Based on the health belief model, apart from perceived susceptibility and severity, guidance for action is also important for creating correct behaviors. This guidance may be achieved through patients' self-study and receiving training from formal and informal caregivers. In the studied population, which is still largely patriarchal(35), women as informal caregivers consider themselves obligated only to provide services such as accompanying patients to receive dialysis, preparing food, etc., and do not consider transferring their knowledge to patients as a part of their duties. Therefore, more accurate results could be obtained by examining patients' health literacy through treatment adherence and conducting qualitative studies on the role of caregivers in providing care, how care is provided, and how caregivers use their health literacy to improve patients' condition.

The results showed a positive correlation between caregivers' age and treatment adherence. In a review of the literature, the researchers did not find any study that assessed the relationship between informal caregivers' age and treatment adherence. When people live with various stresses in the environment or perceive high levels of risk for a long period of time, their resilience is stimulated to help them adapt to the situation. As a result, their resilience increases over time (34). It seems that with increasing age, informal caregivers' resilience increases, as well as their experience in providing care, which improves treatment adherence in the patients.

The findings showed a negative relationship between the number of hours of caregiving per day and treatment adherence. Hoang et al. (2020) found that increasing the number of hours of caregiving per day was directly correlated with care burden (35). In the present study, the caregivers and patients lived together, and the mean number of hours of caregiving was determined with a general question, and the outcome was more than 12 hours per day. This could be among the limitations of the present study because those who take care of patients at home and live with them may consider the time they spend on routine tasks as patient care hours. Furthermore, patients with less treatment adherence cause more time to be

spent on their care. It is suggested that patient care hours be determined based on accurate tools by separating care hours from caregivers' daily activities.

Strengths and limitations of the study: This study had certain strengths and limitations. The main strength was that this was the first study on caregivers' health literacy and treatment adherence of patients undergoing hemodialysis which focused on dyads (patient/caregiver) in Iran. Hence, it contributes to the body of knowledge about the role of informal caregivers, especially in the case of hemodialysis patients in Iranian society. However, treatment adherence was measured only by using a self-report questionnaire. More accurate data could be obtained in future studies using more accurate criteria and standard evaluation methods such as bioimpedance, biochemical tests, and dialysis adequacy. Moreover, the census sampling method was used, which limited the generalization of the results to the whole population and similar populations. Since the study was conducted in an environment with geographical limitations and specific sociocultural characteristics, the results should be generalized to other societies and cultures with caution.

Conclusion

Due to the lack of correlation between caregivers' health literacy and patients' treatment adherence, if health service-providers educate caregivers even based on their health literacy, it may not be transferred well to their patients. Since patients' adherence without their participation and self-care activities does not bring desirable results, they should participate in any activity programs and services to promote their health behaviors, so that they can be empowered to make informed decisions about their health-related behaviors.

The results of our study also provide implications for healthcare providers to improve treatment adherence in hemodialysis patients. The findings provide a warning for health service-providers not to be limited in providing training only to informal caregivers based on their health literacy and pay attention to the presence of the patient and the caregiver in the provision of training for health promotion programs. Conducting qualitative studies on the role of caregivers' health literacy in promoting patients' treatment adherence could reveal the dimensions of the problem.

Acknowledgments: The authors would like to thank the officials at hemodialysis centers as well as patients and their caregivers who cooperated with us in conducting this research.

This paper was approved by Ethics Committee of Bushehr University of Medical Sciences with reference number IR.BPUMS.REC.1399.048. Study objectives description, voluntarily and confidentiality participation were considered. Written consent forms were taken from of the participants.

Availability of data and materials: The anonymized datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Conflict of interest: The authors have no conflict of interest to declare.

Consent for publication: Not applicable

Ethical consideration: This study was conducted after obtaining a permit from the committee of research and ethics of Bushehr University of Medical Sciences (IR.BPUMS.REC.1399.048). Study objectives description, confidentiality participation and completing the consent form were considered. Furthermore, the study was performed in line with the principles of the Declaration of Helsinki.

Funding: This research received grant from funding agencies in the public, commercial,

or not-for-profit sectors

Authors' contributions: HV, RB and MM designed the study. Data collection: SD and FH. Data analysis: RB. HV and SD drafted the manuscript and R.B prepared tables. HV and RB read, edited for scientific accuracy. All authors read and approved the final manuscript.

References

. Beerappa H, Chandrababu R. Adherence to dietary and fluid restrictions among patients undergoing hemodialysis: An observational study. Clinical Epidemiology and Global Health. 2019;7(1):127-30. https://doi.org/10.1016/j.cegh.2018.05.003

2. Bello AK, Okpechi IG, Osman MA, Cho Y, Htay H, Jha V, et al. Epidemiology of haemodialysis outcomes. Nature Reviews Nephrology. 2022;18(6):378-95. https://doi.org/10.1038/s41581-022-00542-7 PMid:35194215 PMCid:PMC8862002

3. Sultan BO, Fouad AM, Zaki HM. Adherence to hemodialysis and medical regimens among patients with end-stage renal disease during COVID-19 pandemic: a cross-sectional study. BMC nephrology. 2022;23(1):1-9. https://doi.org/10.1186/s12882-022-02756-0 PMid:35397516 PMCid:PMC8994066

4. Kovesdy CP. Epidemiology of chronic kidney disease: an update 2022. Kidney International Supplements. 2022;12(1):7-11. https://doi.org/10.1016/j.kisu.2021.11.003 PMid:35529086 PMCid:PMC9073222

5. Jafari Y, Tehrani H, Esmaily H, Shariati M, Vahedian-shahroodi M. Family-centred empowerment program for health literacy and self-efficacy in family caregivers of patients with multiple sclerosis. Scandinavian journal of caring sciences. 2020;34(4):956-63 https://doi.org/10.1111/scs.12803 PMid:31985862

6. Moazzeni SS, Arani RH, Hasheminia M, Tohidi M, Azizi F, Hadaegh F. High incidence of chronic kidney disease among Iranian diabetic adults: using CKD-EPI and MDRD equations for estimated glomerular filtration rate. Diabetes & Metabolism Journal. 2021;45(5):684-97. https://doi.org/10.4093/dmj.2020.0109 PMid:33715338 PMCid:PMC8497933

7. Eirini G, Georgia G. Caregivers of patients on haemodialysis. Caregiving and home care. 2018;14:75. https://doi.org/10.5772/intechopen.72400

8. Naalweh KS, Barakat MA, Sweileh MW, Al-Jabi SW, Sweileh WM, Zyoud SeH. Treatment adherence and perception in patients on maintenance hemodialysis: a cross-sectional study from Palestine. BMC nephrology. 2017;18(1):1-9. https://doi.org/10.1186/s12882-017-0598-2 PMid:28558719 PMCid:PMC5450383

9. Naderifar M, Tafreshi MZ, Ilkhani M, Akbarizadeh MR, Ghaljaei F. Correlation between quality of life and adherence to treatment in hemodialysis patients. Journal of Renal Injury Prevention. 2018;8(1):22-7. https://doi.org/10.15171/jrip.2019.05

10. Zakiyeh A, Mostafa R, Reza BH, Akram S, Leila J, Azadeh K. The effects of foot reflexology on the level of depression in patients under hemodialysis. Journal of Nursing Education (JNE). 2017;5(6):31-38. https://doi.org/10.21859/jne-05065

11. Farahani MA, Ghane G, Sydfatemi N, Hagani H. Effect of educational program on the burden of family caregivers of hemodialysis patients. Evidence Based Care. 2016;6(1):7-17. https://doi.org/10.15412/J.JCCNC.04010401

12. Khiyali Z, Khani M. survey of Caregiver Burden and its related factors in Caregiver of hemodialysis patients referring to Shahid Mohammadi Hospital in Bandar Abbas. Nursing Journal of the vulnerable. 2018; 5(16): 35-44

13. Yuen EY, Knight T, Ricciardelli LA, Burney S. Health literacy of caregivers of adult care recipients: A systematic scoping review. Health & Social Care in the Community. 2018;26(2):e191-e206. https://doi.org/10.1111/hsc.12368 PMid:27426731

14. Yuen E, Knight T, Dodson S, Chirgwin J, Busija L, Ricciardelli LA, et al. Measuring cancer caregiver health literacy: Validation of the Health Literacy of Caregivers Scale-Cancer (HLCS-C) in an Australian population. Health & social care in the community. 2018;26(3):330-44. https://doi.org/10.1111/hsc.12524 PMid:29210140

15. Surendran P, Venugopal V, Dongre A, Paninjukunnath R. Perceived challenges faced by family caregivers of chronic kidney disease patients and suggested solutions: a qualitative study. Int J Med Sci Public Health. 2018;7(6). https://doi.org/10.5455/ijmsph.2018.0307819032018

16. Moshavvegh S, Goodarzi N, Emamipour S, Sepah Mansour M. Development of a health model in patients with type 2 diabetes based on psychological toughness, health literacy, self-efficacy and health beliefs mediated by self-management behaviors and social support. Journal of Research in Behavioural Sciences. 2021;19(1):24-34. https://doi.org/10.52547/rbs.19.1.24

17. Trivedi R, Slightam C, Fan VS, Rosland A-M, Nelson K, Timko C, et al. A couples' based self-management program for heart failure: results of a feasibility study. Frontiers in public health. 2016;4:171. https://doi.org/10.3389/fpubh.2016.00171 PMid:27626029 PMCid:PMC5004799

18. Jafari Y, Vahedian-Shahroodi M, Tehrani H, Esmaily H, Haresabadi M, Shariati M. The relationship between caregivers' health literacy and the behavior of women with Multiple Sclerosis. The Iranian Journal of Obstetrics, Gynecology and Infertility. 2018;21(7):64-71.

19. Levin JB, Peterson PN, Dolansky MA, Boxer RS. Health literacy and heart failure management in patient-caregiver dyads. Journal of Cardiac Failure. 2014;20(10):755-61 https://doi.org/10.1016/j.cardfail.2014.07.009 PMid:25072623
20. Høeg BL, Frederiksen MH, Andersen EAW, Saltbæk L, Friberg AS, Karlsen RV, et al. Is the health literacy of informal caregivers associated with the psychological outcomes of breast cancer survivors? Journal of Cancer Survivorship. 2021;15(5):729-37. https://doi.org/10.1007/s11764-020-00964-x PMid:33169190
21. Montazeri A, Tavousi M, Rakhshani F, Jahangiri K, et al. Health Literacy for Iranian Adults (HELIA): Development and Psychometric Properties. PAYESH. 2014;13(5):589-600.
22. Kim Y, Evangelista LS. Relationship between illness perceptions, treatment adherence, and clinical outcomes in patients on maintenance hemodialysis. Nephrology nursing journal: journal of the American Nephrology Nurses' Association. 2010;37(3):271.
23. Rafiee Vardanjani L, Parvin N, Mahmoodi Shan GR, Molaie E, Shariati A, Hasheminia MA. Adherence to hemodialysis treatment and some related factors in hemodialysis patients admitted in Shahrekord Hajar hospital. Journal of Clinical Nursing and Midwifery. 2014;2(4):17-25.
24. Belice PJ, Mosnaim G, Galant S, Kim Y, Shin H-W, Pires-Barracosa N, et al. The impact of caregiver health literacy on healthcare outcomes for low income minority children with asthma. Journal of Asthma. 2020;57(12):1316-22. https://doi.org/10.1080/02770903.2019.1648507 PMid:31340703
25. Rak EC, Hooper SR, Belsante MJ, Burnett O, Layton B, Tauer D, et al. Caregiver word reading literacy and health outcomes among children treated in a pediatric nephrology practice. Clinical kidney journal. 2016;9(3):510-5. https://doi.org/10.1093/ckj/sfw015 PMid:27274841 PMCid:PMC4886911
26. Rahman TTA. Health literacy: prevalence among elderly care givers and its impact on the frequency of elderly hospitalization and elderly health related quality of life. Advances in Aging Research. 2014;3(05):380. https://doi.org/10.4236/aar.2014.35048
27. Ramezannia P, Vahedian Shahroudi M, Tehrani H, Esmaili H. Relationship between the Behavior of Patients with Tuberculosis and the Health Literacy of Mashhad Caregivers. Journal of Advanced Biomedical Sciences. 2020;10(4):2926-35.
28. Samadbeik M, Garavand S, Sohrabi Zadeh M, Koshki N, Mohammadi Z. Health Literacy Instruments for Computer-Based Applications: A Review Article. Journal of Health and Biomedical Informatics. 2015;2(3):195-203.
29. Tavousi M, Ebadi M, Fattahi E, Jahangiry L, Hashemi A, Hashemiparast M, et al. Health literacy measures: A systematic review of the literature. Payesh (Health Monitor). 2015;14(4):485-96.
30. Hayden S. An Analysis of Factors Which Affect Self-Management in Language-Diverse Patients with Type 2 Diabetes. Doctorate of Nursing Practice (DNP), Health Sciences & Nursing Belmont University, 2018.
31. Kugbey N, Meyer-Weitz A, Asante KO. Access to health information, health literacy and health-related quality of life among women living with breast cancer: Depression and anxiety as mediators. Patient education and counseling. 2019;102(7):1357-63. https://doi.org/10.1016/j.pec.2019.02.014 PMid:30772116
32. Ahmadi S, Hamidpoor K, Sedaghat H, Karami F. Violence against Women: The Rule of Patriarchal Ideology and the Hegemony of Male Domination (Case study: Women in Bushehr. Women in Development & Politics. 2021;19(4):545-72.
33. Salehitali S, Ahmadi F, Dehkordi AH, Noorian K, Fereidooni-Moghadam M, Zarea K. Progressive exhaustion: A qualitative study on the experiences of Iranian family caregivers regarding patients undergoing hemodialysis. International Journal of Nursing Sciences. 2018;5(2):193-200. https://doi.org/10.1016/j.ijnss.2018.01.005 PMid:31406824 PMCid:PMC6626230
34. Liew EWK, Low EMJ, Ho GLL. Perceived risk, fear of Covid-19, and resilience on mental health among Malaysian emerging adults during the Covid-19 pandemic. IJRICE, 2021; 5(2). https://doi.org/10.24036/00456za0002
35. Hoang VL, Green T, Bonner A. Informal caregivers of people undergoing haemodialysis: Associations between activities and burden. Journal of Renal Care. 2019;45(3):151-8. https://doi.org/10.1111/jorc.12280 PMid:31297973