

# Development of Health Literacy for Regular Hemodialysis Patients in Menoufia Governorate: A Cross-Sectional Study

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## Abstract

Health literacy (HL) is essential to access, comprehend, assess and use health data allowing patients to make better health and quality of life decisions. To assess the health literacy level of hemodialysis Egyptian patients, a cross-sectional study from March to September 2020 was conducted at 4 hemodialysis (HD) units on 439 patients. A translated questionnaire including demographic characteristics and health literacy components was conducted. This study adapted Nutbeam's model incorporating critical health literacy, interactive health literacy, and functional health literacy. Health literacy of hemodialysis patients was satisfactory among 35.5% of the studied patients. The average total score of health literacy questionnaire was  $(15.53 \pm 4.32)$  distributed as  $(2.90 \pm 1.26)$  for functional literacy,  $(3.10 \pm 1.26)$  for basic health knowledge,  $(1.65 \pm 1.21)$  for communicative literacy,  $(2.53 \pm 0.70)$  for interactive literacy,  $(1.75 \pm 1.30)$  for advanced health knowledge,  $(1.74 \pm 0.48)$  for critical literacy, and  $(1.83 \pm 0.93)$  for patient safety. It was found that poor health literacy was associated with low income (OR = 2.54, CI 95%: 1.66\_3.89,  $p < 0.001$ ), of increasing age (OR = 0.12 CI 95%: 0.07\_0.19,  $p < 0.001$ ), low education (OR = 1.08, CI 95%: 1.04\_1.11,  $p < 0.001$ ) and the patient did not undergo kidney transplant (OR = 4.19 CI 95%: 1.12\_15.62,  $p = 0.033$ ). There was a prevalent low health literacy among the studied regular hemodialysis patients which was affected by education, age and income and in turn it affected the adherence to treatment. Understanding the linkage between HL and self-care attitudes should enhance efforts to improve hemodialysis outcomes.

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## Keywords

Limited Health Literacy among Dialysis Patients, Knowledge among Hemodialysis Patients, Regular Hemodialysis

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## 1. Introduction

Dialysis has long been an important public health problem. Useful health outcomes and self-care abilities can be effectively achieved by raising the health literacy of hemodialysis patients.

Health literacy (HL) is essential to access, comprehend, assess and use health data allowing patients to make better decisions regarding their health and quality of life. Limited health literacy can hinder a patient's ability to interact with health services and social networks in the right way, negatively affecting their health outcomes [1].

Limited health literacy has been linked to low medication adherence, increased hospitalization, morbidity and mortality [2].

An appropriate HL enables renal patients to cope with a complex course of treatment with a heavy pill burden and required adherence to strong fluids and dietary restrictions. It can also be assumed that frequent and regular interactions with health systems and caregivers that are inherent in hemodialysis patient's treatment have the potential to enhance HL [3].

A validated Multidisciplinary Health Literacy Questionnaire (HLQ) has been used to assess several aspects related to a patient's interactivity with health systems and care delivery [4].

Based on our knowledge there is paucity of research about health literacy among hemodialysis Egyptian patients. This work aimed to assess the health literacy levels of hemodialysis Egyptian patients.

## 2. Methods

From March to September 2020, a cross-sectional study was performed at four Hemodialysis units at 4 different Egyptian districts. Adult patients who were receiving hemodialysis treatment for more than 3 months and who were able to communicate with their interlocutors were included in the study while those with a kidney transplant or were actively working for a living donor transplant, being diagnosed with dementia or mental impairment, had <12 months to live or were submitted to a course of renal palliative care were excluded.

A translated questionnaire (Appendix 1: English and Arabic forms) was adopted and it included questions about demographic characteristics and health literacy assessment:

- The demographic characteristics part included questions about patients' age, gender, education, income level and level of adherence to treatment.
- Assessment of health literacy: this study used the Nutbeam model and in-

corporated the three main divisions; critical, inter-active and functional health literacy. The health literacy has seven sub-structures: functional literacy (5 components), communicative literacy (4 components), interactive literacy (3 components), critical literacy (3 items), basic health knowledge (4 components), advanced health knowledge (5 components) and patient safety (2 components). The correct answer took one point while the incorrect answer took zero. The final score ranged from 0 - 26 with at least 80% correct answers were taken as satisfactory HL.

The questionnaire items passed through several steps 1: Arabic translation by two bilingual translators; 2: the translators and two healthcare professionals discuss the inconsistencies in the translations; 3: two new translators translated the Arabic version of the questionnaire back to the original language for validity confirmation; 4: reviewing the final translations followed by developing the pre-final version of the questionnaire; 5: a pilot study on ten patients of various ages and education were applied to assess the degree of response, comprehension and reactivity.

Two days' workshop training and health education was delivered to a team of primary care physicians, and nurses to improve the accuracy of the results including discussion of the aim of this study, detailed explanations and descriptions of methods, and the overall intended contents. The whole team was tested to avoid inter and intra-observer bias. The surveys were delivered by interviewers on an individual basis to enhance the quality and the consistency of the contents. The interview was performed in the first hour of hemodialysis to avoid any potential fluctuations in cognitive function as a consequence of the hemodialysis process. To avoid patient fatigue, these interviews were performed in an interlocking fashion over successive hemodialysis sessions.

In-depth group educational sessions were conducted on how to deal with the disease, proper medication handling and its potential side effects, with an explanation of appropriate management, and how to manage daily activities after the hemodialysis session. Expansion of these health education sessions in addition to laboratory testing to include many other patients was recommended by all included patients.

### 3. Sample Size

The number of patients to be selected was estimated using the following equation:  $n = (z^2 \times p \times q) / D^2$ . Since the actual prevalence of health literacy was unknown, so yes equaled no ( $p = q = 0.5$ ,  $D = 0.05$ ). Based on these assumptions, 377 patients were required. Accounting for a dropout of 15%, 445 patients were recruited. Out of 445 questionnaires distributed, 439 patients accepted to participate while 6 patients refused resulting in a response rate of 98.6%.

### 4. Statistical Analysis

Analysis of data were performed using SPSS version 22.0 (SPSS Inc., Chicago, IL,

USA). Data were presented as mean  $\pm$  SD or number and %. Kruskal-Wallis test was used for comparison of more than 2 groups with non-parametric information while Mann-Whitney test was applied to compare between two groups. Spearman correlation was applied. Logistic regression was applied to detect the predictors of health literacy. Linear regression analysis for using pathway analysis was applied for scores of health literacy and ages and education level of the patients. A *p*-value was considered significant if  $<0.05$ .

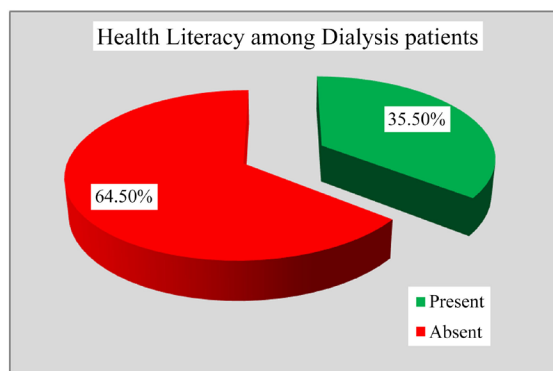
## 5. Results

Patients' characteristics were illustrated in **Table 1**, kidney disease is mainly distributed among males by 57.6%, those  $> 60$  years old by 40.8% and participants of low education by 85.6%. Primary care-giving was mainly by self or spouse (58.5%) followed by child or child spouse (35.1%). Kidney transplant was reported among 10.3% of the studied participants (**Table 1**).

Health literacy was satisfactory among 35.5% of hemodialysis patients while it was unsatisfactory among 64.5% of them (**Figure 1**).

**Table 1.** Patients' characteristics.

	N = 439	%
<b>Age (Y)</b>		
Mean $\pm$ SD/Range	55.76 $\pm$ 13.02/20 - 84	
<b>Age (Y)</b>		
$\leq 50$	131	29.8
$>50 - 60$	129	29.4
$>60$	179	40.8
<b>Sex</b>		
Male	253	57.6
Female	186	42.4
<b>Education Level</b>		
Illiterate or primary school	164	37.4
Preparatory school	38	8.7
Secondary school	174	39.6
College (and above)	63	14.4
<b>Income</b>		
Low	331	75.4
Moderate	108	24.6
<b>Primary Caregiver</b>		
Self or spouse	257	58.5
Child or child spouse	154	35.1
Parents or siblings	21	4.8
Others	7	1.6
<b>Kidney transplant</b>		
Yes	45	10.3
No	394	89.7



**Figure 1.** Health literacy among the studied participants.

The average total score of health literacy questionnaire was  $(15.53 \pm 4.32)$  out of 26 possible criteria and it was distributed as  $2.90 \pm 1.26$  for functional literacy,  $3.10 \pm 1.26$  for basic health knowledge,  $1.65 \pm 1.21$  for communicative literacy,  $2.53 \pm 0.70$  for interactive literacy,  $1.75 \pm 1.30$  for advanced health knowledge,  $1.74 \pm 0.48$  for critical literacy, and  $1.83 \pm 0.93$  for patient safety.

Among of these 7 sub-divisions, participants got high scores in basic functional literacy, health knowledge and interactive literacy but relatively low scores in advanced health knowledge, communicative literacy, critical literacy and patient satisfaction. Health literacy was high among young ages  $< 50$  years old ( $17.94 \pm 3.46$  vs.  $15.51 \pm 3.96$  and  $13.75 \pm 4.32$  for  $>50 - 60$  years old and  $>60$  years old respectively), males ( $16.25 \pm 4.30$  vs. females  $14.54 \pm 4.19$ ), moderate to high education ( $18.58 \pm 2.70$  vs.  $11.97 \pm 2.93$ , when self or spouse was responsible for primary care-giving ( $16.82 \pm 3.74$  vs. others  $13.71 \pm 4.46$ ) and those had kidney transplant ( $20.37 \pm 2.19$  vs. no transplant  $14.97 \pm 4.16$ ) ( $P < 0.001$ ). Health literacy was high among those with moderate income in comparison to low income ones ( $20.55 \pm 2.07$  vs.  $13.89 \pm 3.53$ ), also adherence to medication versus no adherence ( $17.72 \pm 3.20$  vs.  $12.91 \pm 4.02$ ) ( $P < 0.001$ ) (**Table 2**).

A binary logistic regression was processed to highlight the responsible factors like age, gender, education, type of caregiver, and if the patient underwent kidney transplant for the liability that participants may have poor health literacy. For knowledge, the logistic regression sample was statistically significant,  $\chi^2 = 311.27$ ,  $p < 0.001$ . The model explained 69.8% (Nagelkerke  $R^2$ ) of the variance in poor health literacy and correctly classified 84.3% of cases. It was found that poor health literacy was associated with low income (OR = 2.54, CI 95%: 1.66\_3.89,  $p < 0.001$ ), of increasing age (OR = 0.12 CI 95%: 0.07\_0.19,  $p < 0.001$ ), low education (OR = 1.08, CI 95%: 1.04\_1.11,  $p < 0.001$ ) and the patient did not undergo kidney transplant (OR = 4.19 CI 95%: 1.12\_15.62,  $p = 0.033$ ) (**Table 3**).

A significantly negative correlation was reported between age and the health literacy items ( $P < 0.05$ ) while a significantly positive correlation was reported with the educational level ( $P < 0.05$ ) (**Table 4**).

Age and education are strong predictors to health literacy items especially advanced health knowledge where age ( $\beta = -0.62$ , CI 95% ( $-0.75$ ) - ( $-0.48$ ) and education ( $\beta = 0.80$ , CI 95% 0.72\_0.88) (**Figure 2**).

**Table 2.** Demographic characteristics and health literacy of hemodialysis patients (n = 439).

	Functional literacy	Basic health knowledge	Communicative literacy	Interactive literacy	Advanced health Knowledge	Critical Literacy	Patient safety	Total
<b>Age (Y)</b>								
≤50 (n = 131)	3.42 ± 1.08	3.34 ± 0.62	2.32 ± 1.16	2.74 ± 0.56	2.48 ± 1.06	1.70 ± 0.50	1.92 ± 0.26	17.94 ± 3.46
>50 - 60 (n = 129)	2.95 ± 1.16	3.11 ± 0.64	1.54 ± 1.12	2.52 ± 0.67	1.72 ± 1.36	1.79 ± 0.42	1.86 ± 0.36	15.51 ± 3.96
>60 (n = 179)	2.48 ± 1.30	2.93 ± 0.69	1.25 ± 1.12	2.40 ± 0.77	1.23 ± 1.18	1.72 ± 0.51	1.74 ± 0.46	13.77 ± 4.32
<b>P value</b>	<b>&lt;0.001*</b>	<b>&lt;0.001*</b>	<b>&lt;0.001*</b>	<b>&lt;0.001*</b>	<b>&lt;0.001*</b>	<b>0.251</b>	<b>&lt;0.001*</b>	<b>&lt;0.001*</b>
<b>Sex</b>								
Male (n = 253)	3.09 ± 1.23	3.13 ± 0.69	1.82 ± 1.21	2.56 ± 0.67	2.02 ± 1.34	1.77 ± 0.48	1.86 ± 0.35	16.26 ± 4.28
Female (n = 186)	2.64 ± 1.25	3.08 ± 0.66	1.43 ± 1.18	2.51 ± 0.72	1.38 ± 1.16	1.69 ± 0.49	1.79 ± 0.43	14.54 ± 4.19
<b>P value</b>	<b>&lt;0.001*</b>	<b>0.448</b>	<b>0.001*</b>	<b>0.456</b>	<b>&lt;0.001*</b>	<b>0.128</b>	<b>0.053</b>	<b>&lt;0.001*</b>
<b>Education Level</b>								
Low (n = 202)	1.90 ± 0.84	2.72 ± 0.60	0.83 ± 0.86	2.28 ± 0.80	0.82 ± 0.89	1.71 ± 0.48	1.68 ± 0.49	11.97 ± 2.93
Moderate to high (n = 237)	3.75 ± 0.86	3.43 ± 0.56	2.37 ± 1.0	2.75 ± 0.50	2.54 ± 1.06	1.75 ± 0.49	1.95 ± 0.20	18.56 ± 2.70
<b>P value</b>	<b>&lt;0.001*</b>	<b>&lt;0.001*</b>	<b>&lt;0.001*</b>	<b>&lt;0.001*</b>	<b>&lt;0.001*</b>	<b>0.373</b>	<b>&lt;0.001*</b>	<b>&lt;0.001*</b>
<b>Income</b>								
Low	2.45 ± 1.07	2.95 ± 0.66	1.26 ± 1.02	2.42 ± 0.75	1.32 ± 1.06	1.68 ± 0.48	1.77 ± 0.43	13.89 ± 3.53
Moderate +high	4.27 ± 0.66	3.58 ± 0.51	2.85 ± 0.96	2.88 ± 0.31	3.05 ± 1.10	1.89 ± 0.47	2.0 ± 0.0	20.55 ± 2.07
<b>P value</b>	<b>&lt;0.001*</b>	<b>&lt;0.001*</b>	<b>&lt;0.001*</b>	<b>&lt;0.001*</b>	<b>&lt;0.001*</b>	<b>0.373</b>	<b>&lt;0.001*</b>	<b>&lt;0.001*</b>
<b>Primary Caregiver</b>								
Self or spouse (n = 257)	3.21 ± 1.09	3.24 ± 0.64	1.90 ± 1.18	2.65 ± 0.57	2.19 ± 1.24	1.74 ± 0.48	1.88 ± 0.32	16.82 ± 3.72
Child or others (n = 182)	2.46 ± 1.34	2.92 ± 0.69	1.31 ± 1.18	2.37 ± 0.82	1.13 ± 1.14	1.73 ± 0.49	1.75 ± 0.45	13.71 ± 4.46
<b>P value</b>	<b>&lt;0.001*</b>	<b>&lt;0.001*</b>	<b>&lt;0.001*</b>	<b>&lt;0.001*</b>	<b>&lt;0.001*</b>	<b>0.884</b>	<b>0.001*</b>	<b>&lt;0.001*</b>
<b>Kidney transplant</b>								
Yes (n = 45)	4.08 ± 0.79	3.57 ± 0.46	2.91 ± 1.04	2.84 ± 0.36	3.08 ± 0.73	1.86 ± 0.45	2.0 ± 0.0	20.37 ± 2.19
No (n = 394)	2.76 ± 1.23	3.05 ± 0.68	1.51 ± 1.15	2.50 ± 0.72	1.60 ± 1.27	1.72 ± 0.49	1.81 ± 0.40	14.97 ± 4.16
<b>P value</b>	<b>&lt;0.001*</b>	<b>&lt;0.001*</b>	<b>&lt;0.001*</b>	<b>&lt;0.001*</b>	<b>&lt;0.001*</b>	<b>0.057</b>	<b>&lt;0.001*</b>	<b>&lt;0.001*</b>
<b>Adherence to treatment</b>								
<b>No (n = 200)</b>	2.21 ± 1.18	2.82 ± 0.65	1.04 ± 1.07	2.34 ± 0.80	0.99 ± 1.08	1.76 ± 0.46	1.72 ± 0.46	12.91 ± 4.02
<b>Yes (n = 239)</b>	3.48 ± 1.0	3.34 ± 0.61	2.16 ± 1.09	2.70 ± 0.54	2.38 ± 1.13	1.71 ± 0.50	1.92 ± 0.27	17.72 ± 3.20
<b>P value</b>	<b>&lt;0.001*</b>	<b>&lt;0.001*</b>	<b>&lt;0.001*</b>	<b>&lt;0.001*</b>	<b>&lt;0.001*</b>	<b>0.168</b>	<b>&lt;0.001*</b>	<b>&lt;0.001*</b>

\*: Significant.

**Table 3.** Predictors of limited health illiteracy among the studied patients.

	OR	95% CI		P value
		Lower	Upper	
Age	0.12	0.07	0.19	<0.001*
Sex (male)	1.73	0.89	3.37	0.105
Education level (high)	1.08	1.04	1.11	<0.001*
Income (high)	2.54	1.66	3.89	<0.001*
Caregiver (self)	1.31	0.74	2.33	0.346
Kidney transplant (yes)	4.19	1.12	15.62	0.033*

\*: significant (Reference).

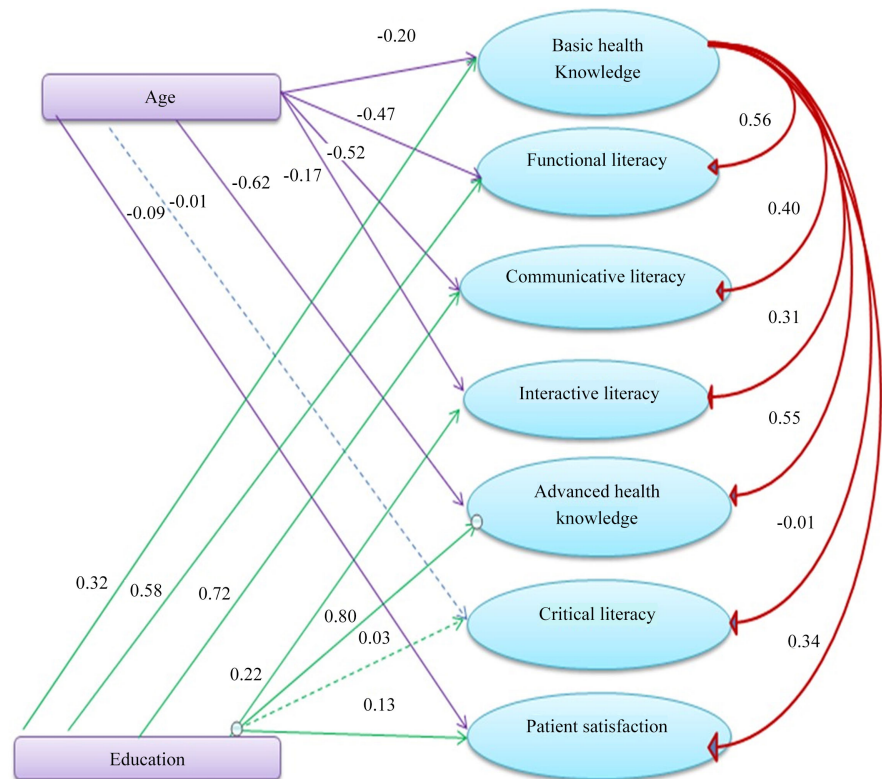
**Table 4.** Correlation between age and education level the patients and health literacy items.

	Age		Education	
	r	P value	r	P value
Q1	-0.298	<0.001*	0.369	<0.001*
Q2	-0.307	<0.001*	0.663	<0.001*
Q3	-0.176	<0.001*	0.367	<0.001*
Q4	-0.141	0.003*	0.335	<0.001*
Q5	-0.227	<0.001*	0.415	<0.001*
Q6	-0.247	<0.001*	0.519	<0.001*
Q7	-0.192	<0.001*	0.223	<0.001*
Q8	-0.010	0.838	0.052	0.279
Q9	-0.097	0.042	0.104	0.029
Q10	-0.295	<0.001*	0.461	<0.001*
Q11	-0.214	<0.001*	0.318	<0.001*
Q12	-0.310	<0.001*	0.530	<0.001*
Q13	-0.160	0.001*	0.282	<0.001*
Q14	-0.233	<0.001*	0.238	<0.001*
Q15	-0.048	<0.001*	0.171	<0.001*
Q16	-0.219	<0.001*	0.250	<0.001*
Q17	-0.336	<0.001*	0.454	<0.001*
Q18	-0.395	<0.001*	0.497	<0.001*
Q19	-0.065	0.174	0.077	0.109
Q20	-0.412	<0.001*	0.612	<0.001*
Q21	-0.128	<0.001*	0.295	<0.001*
Q22	0.057	0.233	-0.027	0.567
Q23	-0.083	0.081	0.148	0.002*
Q24	-0.126	0.008*	0.104	0.030*
Q25	-0.080	0.093	0.116	0.015
Q26	-0.200	<0.001*	0.337	<0.001*

\*significant

## 5. Discussion

Kidney disease was mainly reported among males (57.6%), those >60 years old (40.8%) and participants of low education (85.6%). Primary care-giving was mainly by self or spouse (58.5%) followed by a responsible child or child spouse (35.1%). Kidney transplant was reported among 10.3% of the studied participants. These results were supported by Qobadi *et al.*, [5] in Iran and Shih *et al.*, [6] in Chinese Taipei.



**Figure 2.** Path analysis of health literacy scores in relation to age and education level (n = 439).

Health literacy of the current hemodialysis patients was satisfactory among 35.5% while unsatisfactory among 64.5% of them. This finding agrees with Qobadi *et al.*, [5] in Iran who revealed that 65.2% his participants had considerable difficulty to understand and reading the information. On the contrary Green *et al.*, [7] in USA, demonstrated a low HL in 16% of his patients. Murali *et al.*, [8] in Australia, reported that limited HL ranges 8.4% - 49.6% in ESKD patients versus 16.3% - 63.3% in non-dialysis CKD patients. In the USA, Green *et al.*, [9] found low HL ranging from 7% to 37% at the participating units of dialysis while Cavanaugh *et al.*, [10] reported a Low HL up to 50%.

This wide difference in the reported percentage of HL may be due to the different instruments used to measure HL or it may be a result of increased frequency of hospitalizations of dialysis patients, times of exposure to medical preparation per week in addition to their participation in educational programs or receiving health materials and also their repeated contact with the responsible health team in contrast to the normal population or other patients.

The average total score of HL questionnaire was  $(15.53 \pm 4.32)$ . The participants got high scores in basic functional literacy, basic health knowledge and interactive literacy but relatively low scores in the advanced health knowledge, communicative literacy, critical literacy and patient's satisfaction. HL was high among young ages < 50 years old ( $17.94 \pm 3.46$ ) vs. ( $15.51 \pm 3.96$  and  $13.75 \pm 4.32$ ) for those aged > 50 - 60 years and > 60 years respectively, males ( $16.25 \pm$



4.30 vs. females  $14.54 \pm 4.19$ ), moderate to high education ( $18.58 \pm 2.70$  vs.  $11.97 \pm 2.93$ ), when self or spouse is responsible for primary care-giving ( $16.82 \pm 3.74$ ) vs. others ( $13.71 \pm 4.46$ ) and those have kidney transplant ( $20.37 \pm 2.19$ ) vs. no transplant ( $14.97 \pm 4.16$ ). All of these results agree with Shih *et al.*, [6] in Chinese Taipei.

Health literacy was low among those with low income patients. These results agree with Cavanaugh *et al.*, [11] in the USA and Grubbs *et al.*, [12] in San Francisco who reported that lower income among participants, lower health literacy compared to higher health literacy. Grubbs *et al.*, [12] found that HL scores were significantly lower among those > 65 years old and with incomes less than \$30,000 annually. Lee *et al.*, [13] in the USA found that about 30% of adults were found to have low (inadequate or marginal) health literacy with lower household income. Lastrucci *et al.*, [14] in Italy reported similar results (OR 2.03, 95% CI: 1.28 - 3.21). In contrast, Mollakhaili, *et al.*, [15] in Iran found that monthly income and education were not meaningfully related.

HL score was ( $17.72 \pm 3.20$ ) for those adherent to medication (54.4%) versus non-adherent (45.6%) ( $12.91 \pm 4.02$ ). This result agrees with Cavanaugh *et al.*, [11], Noureldin *et al.*, [16] and Collins *et al.*, [17] in the USA who reported also that prevalence of no adherence to medication in ESRD ranged from 22% to 74%. In Australia, Ghimire *et al.*, [18] found non-adherence among over 50% of the dialysis patients. Low HL and hence low adherence is a direct cause of high mortality, increased utilization of health resources and poor quality of life of dialysis patients. Green *et al.*, [7] patients with a low HL cannot read medication labels, medication instructions, and health brochures or better communicate and understand the health care staff which leads to taking inappropriate medications, discontinuing the prescribed diet, and selecting inappropriate treatment option.

The present finding revealed that low HL was significantly linked to the low educational level (OR = 1.08, CI 95%: 1.04 - 1.11), increasing age (OR = 0.12 CI 95%: 0.07 - 0.19), and with kidney transplant (OR = 4.19 CI 95%: 1.12 - 15.62). Paasche-Orlow *et al.*, [19] in the USA reported high literacy among young ages (OR = 15.9) comparing to low literacy among old ages (OR = 37.9). Murali *et al.*, [8] in Australia found that as age increased, there was “less capability to actively manage the health” (OR = 1.43). On the contrary Cavanaugh *et al.*, [11] in the USA revealed no significant association between age, gender and race of the participants and HL.

Education is a strong predictor to health literacy items especially advanced health knowledge ( $\beta = 0.62$ , CI 95% 0.72 - 0.88). Paasche-Orlow *et al.*, [19] in USA, Lastrucci *et al.*, [14] in Italy and Murali *et al.*, [8] in Australia reported that the lower the educational level, the lower the rate of literacy (OR 2.59, 95% CI: 1.66 - 4.02), in contrast Escobedo *et al.*, [20] in the USA reported that assessment of educational level alone is not predictive of health literacy; (18%) of participants had a high school or college education yet scored as having a limited health literacy.

Bains *et al.*, [21] in the USA and Qobadi *et al.*, [5] in Iran reported that low

HL is a predictor of kidney knowledge. Lower disease-specific knowledge due to low literacy causes difficulty in understanding or reading disease specific medical information and management and low ability to communicate with medical staff.

Health literacy helps communication between patients, their caregivers, and health care providers to enhance the transmission, better understanding and useful application of information for successful health decision-making. In all patients whatever their conditions, a lower level of HL leads to less knowledge of one's health status, less participation in self-care especially when cognitive impairment is high in patients on dialysis and hence repeated hospitalization and death [22]. A broad understanding of these relationships will facilitate the development of targeted interventions to enhance health literacy, quality of care, and outcomes in renal patients. Designing appropriate educational interventions during the initial stages of CKD to prevent ESRD, increase the burden of renal failure and manage disease is essential.

## **6. Strengths and Limitations**

The present work was carried out on Egyptian dialysis patients, thus generalization of the findings cannot necessary be achieved to all kidney patients in the world. Also, all data were self-reported with no gold standard for health literacy assessment, so this is a point of debate [23]. A post-test to assess HL post-health education was needed. But this work is the first to assess and investigate health literacy in a representative sample of patients on dialysis in Egypt. As noted 98.60% of the patients responded to the study which is so acceptable. This work included 439 participants providing statistically high power with consequently less Type 2 errors probability [24].

## **7. Conclusion**

There was a prevalent low health literacy among the studied regular hemodialysis patients which was affected by education, age and income and in turn it affects the adherence to treatment. Understanding the linkage between HL and self-care attitudes should enhance efforts to improve hemodialysis outcomes.

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## **Author Contribution**

All persons who meet authorship criteria are listed as authors, and all authors certify that they have participated sufficiently in this work. Said Sayed Ahmed Khamis, Muhammad Abdul Mabood Khalil and Mahmoud Mohammed Emara have the role of getting the idea and final revision, Zeinab A. Kasemy had the role of performing the statistical analysis, writing the methodology and results sections, final revision and publishing, Marwa Salah Ahmed Elnashar had the

role of collecting the needed data and writing of the introduction and discussion.

### Data Availability

All required data are included in the manuscript.

### Declarations

#### Ethics Approval and Consent to Participate

This study was approved by the Committee for Medical Research Ethics at our Faculty of Medicine with ID: 191219INTM57.

#### Informed Consent

This study was obtained from all participants after explaining the main purpose of the research work. Consent for publication: The authors provide consent to publish.

#### Disclaimer

The authors are solely responsible for all contents.

#### Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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### Appendix 1. Health literacy in hemodialysis patients.

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#### Functional literacy:

1. Which of the following statements is INCORRECT for patients who are receiving dialysis treatment?
  - A. They should consume a high-protein diet.
  - B. It is normal for their stool and urine to appear red.
  - C. They should consume plenty of red meat, which is rich in iron.
  - D. They should check their skin regularly for lesions or signs of infection.
2. Which of the following is NOT a purpose of dialysis?
  - A. To remove excess bodily fluid.
  - B. To filter out metabolic waste from the blood.
  - C. To improve the function of the GI system.
  - D. To balance the body's electrolytes.
3. Which of the following statements regarding artificial blood vessel (Port-A) or arteriovenous fistula care is TRUE?
  - A. The patient can touch it or check with a stethoscope—it is functioning normally if it is silent.
  - B. The patient's blood pressure can be measured on the arm with the fistula.
  - C. A warm compress should be applied to the site of the fistula to induce blood circulation on the day of dialysis.
  - D. Redness at the site is normal and is no cause for concern.
4. Which of the following is a CORRECT way to control blood pressure?
  - A. Have a regular lifestyle and eat a low-sodium diet.
  - B. Stay up late working.
  - C. Smoking tobacco and drinking.
  - D. The patient can adjust their dosage of medication depending on their current blood pressure.
5. Which of the following is NOT true for patients with uremia?
  - A. They can consume a high protein diet including foods like fish, pork, egg and milk.
  - B. They should not be concerned to find red spots in their stool.
  - C. They are advised to consume a high-iron diet rich in red meat.
  - D. They should regularly check their skin for abrasions and lesions.

#### Basic Health Knowledge:

6. Why do you need to control the intake of calcium, potassium and phosphorous?
  - A. Excessive intake can cause accumulation of these minerals in the body.
  - B. Uremia can decrease the density of bones, so it is important to replenish the body's stores of calcium.
  - C. These minerals are not important for human health.
  - D. The body cannot excrete these minerals normally due to decreased renal function.

14. What should you do when you receive treatment advice from non-medical sources?
  - A. Try it immediately.
  - B. Ask my nephrologist about it.
  - C. Ask other patients about it.
  - D. Ask my relatives about it.
15. What should you do when you have a GI problem?
  - A. Go to the hospital immediately and make sure to tell them that you're on dialysis.
  - B. Go to the hospital, but there is no need to mention that you're on dialysis.
  - C. Go to the hospital and only describe the GI problem.
  - D. Go to the pharmacy and buy OTC medication.
16. When receiving dialysis treatment, which of the following statements is TRUE?
  - A. When I feel better, I can decide to reduce the frequency of dialysis treatment on my own without my doctor's approval.
  - B. I should postpone all medication regimens until dialysis treatment finishes.
  - C. I should discuss any medications I'm taking with my nephrologist.
  - D. Feeling nauseated after dialysis is a normal symptom, and I do not need to tell the doctor.

#### Advanced health knowledge:

17. Which of the following is NOT a common complication in dialysis patients?
  - A. High blood pressure.
  - B. Cardiovascular disease.
  - C. Stroke.
  - D. Kidney stones.
18. Which of the following therapies can treat EndStage Renal Disease (ESRD)?
  - A. Traditional Chinese medicine and acupuncture.
  - B. Kidney transplantation.
  - C. Cocktail therapy.
  - D. Medication.
19. Which of the following statements about dialysis is FALSE?
  - A. Hemodialysis uses an artificial filter machine (artificial kidney) to filter excess fluid and waste products from the blood stream.
  - B. Peritoneal dialysis uses the patient's peritoneum (located in the abdomen) as a membrane across which excess fluids and waste products are exchanged from the blood.
  - C. Patients receiving hemodialysis need to visit a dialysis center 2 - 3 times a week to receive treatment.
  - D. Hemodialysis is more effective and has fewer complications than peritoneal dialysis.

**Continued**

7. Which type of food should you AVOID when receiving dialysis?
- Starfruit
  - Tofu
  - Fresh meat such as fish, duck, or chicken
  - Foods low in phosphorous and potassium
8. Which of the following is the medical reason for monitoring fluid intake?
- There is calcium and potassium in water, which should be avoided.
  - Drinking enough water can help the kidneys get rid of excess waste.
  - Water can cause edema inside the body due to decreased kidney function and urinary output.
  - Drinking too much water causes frequent bathroom visits.
9. Which of the following statements regarding fluid consumption is CORRECT for patients receiving dialysis?
- Measure out the daily fluid allowance and put it in bottles to be consumed throughout the day.
  - It is fine to consume water-rich foods such as noodles, curry, and hotpot.
  - Fruit should be replaced with fresh juice.
  - The patient should eat more processed and heavily seasoned foods.
20. Which of the following statements about kidney transplant is CORRECT?
- I can only receive a kidney from blood relatives.
  - As long as someone is willing to donate their kidney, I don't need to wait and can proceed with transplantation immediately.
  - The condition of the donor and recipient must match in order for a transplantation to proceed.
  - Once the donor is willing to donate, there is no checkup needed.
21. Which of the following is an APPROPRIATE precaution when taking oral?
- Before a dialysis session, I should stop taking all hypertensive medications.
  - When I feel better, I can stop taking the oral medication.
  - I don't need to take my medication on a regular schedule. I only need to take it when I have elevated blood pressure.
  - Dialysis will remove the medication from my system, so I need to take oral medications again after the dialysis.

**Communication literacy:**

10. What should you do when you are uncertain about medical advice or a prescribed treatment regimen?
- Doctors are very intelligent and knowledgeable, so it's normal that I don't understand and I shouldn't ask for clarification.
  - It concerns my health; I have to find out the answer.
  - I should ask my friends who have had similar problems.
  - It's just a minor issue, so I don't need to bother the doctor about it.

11. What should you do when you are uncertain about your prescribed medication?

- I will not take any medication before asking my nephrologist.
- I will take it first and monitor my condition.
- These medications are normally safe, so it is okay to take them.
- I need to take it because my doctor says it is necessary.

12. What should you do with your lab results?

- Lab results are too complicated, so I don't need to understand the results as long as the doctor sees it.
- I don't need to ask about my results because the doctors will tell me themselves.
- I will ask about my results even if I don't understand everything.
- Lab results are not important, so I won't ask about them.

**Critical literacy**

22. If your dry weight is 50 kg, which of the following is NORMAL weight gain?

- 0 - 1 kg
- 2 - 3 kg
- 4 - 5 kg
- 5 - 6 kg

23. If the doctor tells you that you can gain 2 kg after two dialysis treatments, your urine output is about 200 cc, and you experience natural water loss of about 500 cc, what is your ideal amount of water intake per day?

- 700 cc
- 1700 cc
- 2700 cc
- 3700 cc

24. Which of the following statements about self-care is CORRECT for patients receiving dialysis?

- Patients should have a regular exercise schedule of at least 30 minutes 3 times a week.
- I can consume traditional Chinese herbs to help with my disease.
- I should use low-sodium salt when cooking.
- Drinking a cup of wine can help with sleeping.

**Patient safety literacy :**

25. Which of the following statements regarding fall prevention is TRUE?

- After a dialysis treatment, even if I am feeling dizzy and nauseated I can get off the bed without assistance.
- I should gradually get off of the bed or change positions, and I can stand up only after I am able to sit up without experiencing dizziness.
- Feeling dizzy is a normal and does not require extra precautions.
- To prevent foot injuries, I can wear shoes that are larger than my regular size.

## Continued

13. What should you do if you feel uncomfortable or unwell after taking a prescribed medication?
- A. I should contact my nephrologist immediately or go to the ER if I can't reach my nephrologist.
- B. I'm probably just overthinking things and there's no need to worry.
- C. I should stop taking the medication immediately, but there's no need to inform the doctor.
- D. I should continue taking the medication because the doctor says I can't just stop whenever I want.

## Interactive literacy:

26. Which of the following statements about infection prevention in dialysis patients is CORRECT?
- A. Before dialysis, I can wash the site with soapy water or clean water.
- B. After installation of an artificial blood vessel, I should keep the wound clean.
- C. I should only wash my body with a wet cloth to avoid excess water on the wound.
- D. When there is redness or signs of swelling around the wound, I should go to the hospital immediately. If there is bleeding, I should not apply pressure to the wound.

## Appendix 1. استبيان عن تنمية المعرفة الصحية لمرضى الغسيل الكلوي

## المعرفة العلمية :

## المعرفة التفاعلية:

## 14. ماذا يجب أن تفعل عندما تتلقى نصيحة علاجية من مصادر غير طبية؟

- أ. أجربها علي الفور. ب. أسأل أخصائي الكلى عن ذلك
- ج. اسأل المرضى الآخرين عن ذلك. د. أسأل أقاربي حول هذا الموضوع

## 15. ماذا يجب أن تفعل عندما يكون لديك مشكلة في الجهاز الهضمي؟

- أ. أذهب إلي المستشفى علي الفور والتأكد من أخبارهم أنك تقوم بعمل غسيل الكلى .
- ب. أذهب إلي المستشفى، لكن لا داعي لذكر أنك تقوم بغسيل الكلى .
- ج. الذهاب إلي المستشفى ووصف فقط مشكلة الجهاز الهضمي .
- د. الذهاب إلي الصيدلية وشراء الأدوية اللاوصفية

## 16. عندما تتلقى علاج غسيل الكلى، أي من العبارات التالية صحيحة ؟

- أ. عندما أشعر بالتحسن، يمكنني أن أقرر تقليل تواتر علاج غسيل الكلى لوحدي دون موافقة طبيبي .
- ب. يجب علي تأجيل جميع أنظمة الدواء حتى ينتهي علاج غسيل الكلى .
- ج. يجب أن أناقش أي أدوية أتناولها مع أخصائي أمراض الكلى .
- د. الشعور بالغثيان بعد الغسيل الكلوي هو أحد الأعراض الطبيعية، ولست بحاجة إلي إخبار الطبيب

## المعرفة الصحية المتقدمة:

## 17. أي مما يلي ليس شائع المضاعفات في مرضي غسيل الكلى؟

- أ. ارتفاع ضغط الدم. ب. مرض القلب والأوعية الدموية ج. السكتة الدماغية د. حصي الكلى

## 18. أي من العلاجات التالية يمكن علاج المرحلة النهائية لمرض الكلى ؟

- أ. الطب الصيني التقليدي والوخز بالإبر. ب. زرع الكلى .
- ج. مزيج من العلاج. د. الدواء

## 1- أي من العبارات التالية غير صحيح للمرضى الذين يتلقون علاج غسيل الكلى؟

- أ. ينبغي عليهم أن يتناولوا نظاما غذائيا عالي البروتين. ب. من الطبيعي أن يظهر البراز والبول بلون احمر.
- ج. ينبغي عليهم أن يستهلكوا الكثير من اللحوم الحمراء الغنية بالحديد.
- د. ينبغي عليهم فحص جلدهم بانتظام لمعرفة الآفات أو علامات العدوى

## 2- أي مما يلي ليس الغرض منه غسيل الكلى؟

- أ. إزالة السوائل الزائدة من الجسم . ب. تصفية النفايات الأيضية من الدم.
- ج. تحسين وظيفة الجهاز الهضمي . د. تحقيق توازن الشوارد في الجسد

## 3- أي من العبارات التالية يعد صحيحا يتعلق بالأوعية الاصطناعية أو رعاية الناسور الشرياني الوريدي؟

- أ. يمكن للمريض لمسها أو التحقق منها من خلال سماعه الطبيب إنها تعمل بشكل طبيعي إذا كانت خالية من الحركة (صامتة) .
- ب. يمكن قياس ضغط دم المريض علي الذراع عند الناسور.
- ج. ينبغي الضغط علي نحو بسيط علي مكان الناسور للحث علي الدورة الدموية في اي يوم عند القيام بغسيل الكلى.
- د. إن الإحمرار في المكان يكون أمرا طبيعيا وليس مدعاة للقلق

## 4. أي مما يلي يعد طريقة صحيحة للتحكم في ضغط الدم؟

- أ. ينبغي أن يكون لديك أسلوب حياة منتظم والقيام بتناول النظام الغذائي ذات الصوديوم المنخفض. ب. البقاء حتى وقت متأخر في العمل
- ج. تدخين التبغ والكحوليات. د. يمكن للمريض ضبط جرعة الدواء حسب ضغط الدم الحالي

## 5. أي مما يلي صحيح بالنسبة للمرض الذين يعانون من تبلون الدم؟

- أ. يمكنهم تناول نظام غذائي عالي البروتين يشمل أطعمة مثل السمك ولحم الخنزير والبيض والحليب.
- ب. يجب ألا يبدوا إهتماما بإيجاد بقع حمراء في البراز.
- ج. ينصح بتناول نظام غذائي عالي الحديد غني باللحوم الحمراء.



د. يجب عليهم فحص جلدهم بانتظام بحثاً عن التآكل و الآفات

#### المعرفة الصحية الأساسية :

6. لماذا تحتاج للسيطرة على تناول الكالسيوم ، البوتاسيوم و

الفوسفور؟ أ.

أ. يمكن للإفراط في تناول الطعام أن يسبب تراكم هذه المعادن في

الجسم.

ب. يمكن لتلوث الدم أن يقلل من كثافة العظام ،لذلك من المهم تجديد مخزون الجسم من الكالسيوم.

ج. هذه المعادن ليست مهمة لصحة الإنسان.

د. لا يستطيع الجسم إفراز هذه المعادن عادة بسبب انخفاض وظائف الكلى

7- أي نوع من الطعام يجب أن تتجنبه عندما تقوم بعمل غسيل الكلى؟

أ. فاكهة النجمة . ب. فول الصويا.

ج. لحم طازج مثل السمك أو البط أو الدجاج. د. الأطعمة منخفضة ب. طالما أن شخصاً ما علي استعداد للتبرع بكليته، فلست بحاجة إلي الانتظار ويمكنني إجراء عملية الزرع فوراً .

8- أي مما يلي هو السبب الطبي لمراقبة كمية السوائل؟

أ. هناك الكالسيوم والبوتاسيوم في الماء ، والتي ينبغي تجنبها.

ب. قد يساعد شرب كمية كافية من الماء الكلى علي التخلص من النفايات الزائدة.

ج. يمكن أن يسبب الماء تورم داخل الجسم بسبب انخفاض وظائف الكلى والإخراج البولي.

د. يسبب شرب الكثير من الماء زيارات متكررة للحمام

9- أي من العبارات التالية بخصوص استهلاك السوائل هو صحيح

للمرضى الذين يقومون بغسيل الكلى؟

أ. قم بقياس بديل السوائل اليومية ووضعها في زجاجات ليتم استهلاكها علي مدار اليوم.

ب. من الأفضل أن تتناول الأطعمة الغنية بالمياه مثل المكرونة والكاربي والأطباق الساخنة.

ج. يجب استبدال الفاكهة بعصير طازج . د. يجب علي المريض تناول المزيد من الأطعمة المصنعة والمتبلّة بكثرة

10- ماذا يجب عليك أن تفعله عندما تكون غير متأكد من المشورة

الطبية أو النظام العلاج المصروف ؟

أ. الأطباء ماهرون للغاية ولديهم دراية، لذلك من الطبيعي ألا أفهم ولا ينبغي أن أطلب التوضيح .

ب. إن الأمر يتعلق بصحتي، ولا بد من معرفة الجواب.

ج. يجب أن أسأل أصدقائي الذين لديهم مشاكل مماثلة.

د. إنها مجرد مشكلة بسيطة، لذلك لست بحاجة إلي إزعاج الطبيب حيال ذلك

11. ماذا يجب أن تفعله عندما تكون غير متأكد من الأدوية

الموصوفة؟

أ. لن أتناول أي دواء قبل أن أسأل أخصائي الكلى .

19. أي من العبارات التالية خاطئة حول غسيل الكلى ؟

أ. يستخدم في غسيل الكلى آلة تصفية اصطناعية ( الكلى الاصطناعية ) لتصفية السوائل الزائدة ومنتجات النفايات من مجرى الدم .

ب. يستخدم عندي مرضي غسيل الكلى الغشاء البريتوني (الموجود في البطن ) كغشاء

يتم عبره تبادل السوائل الزائدة ومنتجات النفايات من الدم .

ج. يحتاج المرضى الذين يتلقون غسيل الكلى إلي زيارة غسيل الكلى 2-3 مرات في

الأسبوع لتلقي العلاج .

د. غسيل الكلى هو أكثر فاعلية ولها مضاعفات أقل من غسيل الكلى البريتوني

20. أي من العبارات التالية عن زرع الكلى هي صحيحة؟

أ. لا يمكنني تلقي زرع الكلى سوي من أقارب الدم .

ب. طالما أن شخصاً ما علي استعداد للتبرع بكليته، فلست بحاجة إلي الانتظار ويمكنني إجراء عملية الزرع فوراً .

ج. يجب أن تتطابق حالة المتبرع والمتلقي حتى تتم عملية الزرع .

د. بمجرد أن يكون المانح مستعداً للتبرع، لن تكون هناك حاجة إلي الفحص

21. أي مما يلي يعد احتياطات مناسبة عند تناولها عن طريق الفم؟

أ. قبل جلسة غسيل الكلى ، يجب أن أتوقف عن تناول جميع الأدوية التي تسبب ارتفاع ضغط الدم .

ب. عندما أشعر بتحسن ، أستطيع التوقف عن تناول الدواء عن طريق الفم .

ج. لا أحتاج إلي تناول الدواء علي جدول منتظم ، أحتاج فقط إلي تناوله عندما يكون لدي ضغط مرتفع .

د. غسيل الكلى سوف يزيل الدواء من نظامي ،لذلك أنا بحاجة إلي تناول الأدوية عن طريق الفم مرة أخرى بعد غسيل الكلى

#### المعرفة الهامة :

22. إذا كان وزنك الجاف 50 كجم ، أي مما يلي هو زيادة الوزن الطبيعي ؟

أ. 0- 1 كجم . ب. 2-3 كجم. ج. 4-5 كجم . د. 5-6 كجم

23. إذا أخبرك الطبيب أنه يمكنك الحصول علي 2 كجم بعد علاجين لغسيل الكلى ،

ويبلغ إخراج البول حوالي 200 سم ، وتعاني من فقد الماء الطبيعي حوالي 500 سم مكعب ، ما هي الكمية المثالية من استهلاك المياه يوميا ؟

أ. 700 سم مكعب . ب. 1700 سم مكعب ج. 2700 سم مكعب . د. 3700 سم مكعب

24. أي من العبارات التالية حول الرعاية الذاتية صحيحة للمرضى الذين يتلقون

غسيل الكلى ؟

أ. يجب أن يكون لدي المريض جدول منتظم لمدة 30 دقيقة علي الأقل 3 مرات في الأسبوع .

ب. يمكنني تناول الأعشاب الصينية التقليدية للمساعدة في مرضي .

ج. يجب أن استخدم الملح قليل الصوديوم عند الطهي . د. شرب كوب من النبيذ يمكن أن يساعد في النوم

ب. سوف أتناولها أولاً وأراقب حالتني .

ج. هذه الأدوية آمنة عادة، لذلك لا بأس من تناولها.

د. أحتاج إلى تناولها لأن طبيبي وصفها بأنها ضرورية

معرفة سلامة المرضى :

25. أي من العبارات التالية المتعلقة بمنع السقوط هي صحيحة ؟

12. ماذا يجب أن تفعله مع نتائج المختبر الخاص بك؟ أ. بعد علاج غسيل الكلي ، حتى لو شعرت بالدوار والغثيان ، يمكنني النزول من السرير دون مساعدة .

أ. نتائج المختبر معقدة للغاية ، لذلك لست بحاجة إلى فهم النتائج طالما رأي الطبيب ذلك. ب. يجب أن اخرج تدريجياً من السرير ولا يمكنني الوقوف إلا بعد أن أتمكن من الجلوس دون الشعور بالدوار .

ب. لست بحاجة إلى السؤال عن نتائجي لأن الأطباء سيخبرونني بأنفسهم.

ج. الشهور بالدوار أمر طبيعي ولا يتطلب احتياطات إضافية .

د. لمنع إصابات القدم ، يمكنني ارتداء أحذية أكبر من مقاسي المعتاد

13. ماذا يجب أن تفعله إذا شعرت بعدم الارتياح أو بتوعك بعد تناول الدواء الموصوف؟

26. أي من العبارات التالية عن الوقاية من العدوى لمرضى غسيل الكلى صحيحة ؟

أ. قبل غسيل الكلى ، يمكنني غسل الموقع بالماء والصابون النظيف .

ب. بعد تركيب وعاء دموي اصطناعي ، يجب أن أحافظ علي نظافة الجرح .

ج. يجب أن أغسل جسدي بقطعة قماش مبللة فقط لتجنب الماء الزائد علي الجرح .

د. عندما يكون هناك احمرار أو علامات تورم حول الجرح ، يجب علي الذهاب إلي المستشفى علي الفور ، وفي حالة وجود نزيف ، يجب الا أضغط علي الجرح

أ. يجب علي الاتصال بأخصائي الكلي علي الفور أو الذهاب إلى غرفة الطوارئ إذا لم أتمكن من الوصول إلي أخصائي الكلي.

ب. ربما أنني أضخم الأمور أكثر من مجرد التفكير في الأشياء ولا داعي للقلق.

ج. يجب أن أتوقف عن تناول الدواء علي الفور ، لكن لا داعي لإبلاغ الطبيب.

د. يجب أن استمر في تناول الدواء لأن الطبيب يقول إنه لا يمكنني التوقف عند الرغبة