



Original Article

Health literacy, negative emotional status, and self-care behaviors in dialysis

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Abstract

Introduction: Renal failure patients with low health literacy are at an increased risk for poor self-care and negative health outcome. The purpose of the present study was to examine the prevalence of low health literacy, differences in negative emotional status and self-care behaviors by health literacy levels, and the mediating role of negative emotions on the relationship between health literacy and self-care among patients undergoing dialysis.

Materials and Methods: In the cross-sectional study, we recruited 240 consecutive patients diagnosed with End Stage Renal Disease (ESRD) who had scheduled appointments at Tehran University of Medical Sciences-affiliated dialysis units from March 2014 until June 2014 based on the inclusion criteria. Instrument include: Mini Mental State Exam, Short test of Health Literacy for Adults, Depression, Anxiety and Stress Scale-21 and Self-Management Scale.

Results: The findings indicated that health literacy was inadequate in 25%, marginal in 9.8%, and adequate in 65.2% of the cases. Depression, anxiety, stress and self-care scores differed significantly by health literacy levels ($P < 0.001$, $P < 0.02$, $P < 0.004$, $P < 0.001$ respectively). Post-hoc pairwise comparisons indicated that those with inadequate health literacy had higher depression, anxiety and stress scores, and lower self-care compared to those with marginal or adequate health literacy. Regression analyses indicated that, after controlling for education, health literacy was significantly associated with depression, anxiety, stress and self-care. In addition, depression, anxiety and stress were mediators of health literacy and self care relationship.

Conclusion: These findings demonstrate the high prevalence of low health literacy. It also shows that health literacy is an important consideration in promoting mental health and self-care behaviors among patients under dialysis.

Keywords: Emotion, Health literacy, Self-care

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Introduction

The high prevalence of chronic kidney disease (CKD) is now considered a major public health problem. According to the Centers of Disease Control and Prevention (2014), more than 10% of adults in the United States have chronic kidney disease, and it is estimated by 2020 there will be more than 750,000 people with end stage renal disease (ESRD) (1). The

prevalence of CKD among the Iranian population is known to be high. The age adjusted prevalence of CKD stages 3 to 5, in Iran estimated using the simplified MDRD equation is 14.9% (95% CI 14.2,15.5) (2). The prevalence and incidence of ESRD are 357 per million population (pmp) and 66 pmp, respectively, and 48.5% are treated with hemodialysis therapy (3). Patients suffering from kidney disease experience greater negative affect such as anxiety and depression than healthy individuals (4). Depression has been identified as the most common psychiatric illness in patients with ESRD (5) which may influence self-care behaviors and reduce well-being

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and quality of life of patients undergoing dialysis (6).

Health literacy which is a key determinant of chronic disease self-care behavior has been increasingly recognized as an important issue in public health practice and research (7). The National Institute of Health define health literacy as “the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions” (8). Compared to patients with adequate health literacy, those with low health literacy are 1.5-3 times more likely to experience poor health outcomes (9). They are more likely to have difficulty in understanding healthcare professionals, written health materials/health label, processing health information, and navigating health care environments, as well as, restricted health-related knowledge, limited use of preventive care and less self-care behavior such as medication adherence. In addition, inadequate health literacy is linked to higher depressive symptoms, higher anxiety level, lower quality of life, a higher risk of mortality, frequent hospitalization and higher health care costs (10).

Several conceptual models have been developed to clarify the mechanisms through which health literacy is associated with health actions such as self-care (11-13). It has been proposed that health literacy influences health actions through its effect on health-related knowledge (11), self-efficacy (14), and health beliefs (15). Despite the increasing scholarly researches on health literacy and its association with self-care in patients with chronic conditions, there has been limited research studying the role of health literacy in patients with kidney disease (16), and to our knowledge, no study has examined the relationship between health literacy and self-care behaviors in patients under hemo-dialysis. Based on past research and in light of these considerations, the primary goals of this study were to investigate health literacy in kidney disease and the mediating role of negative emotional states on the relationship between health literacy and self-care. We hypothesized that health literacy influences self-care both directly and indirectly through its effect on negative emotional states.

Materials and Methods

In this cross-sectional study we recruited consecutive patients diagnosed with ESRD who

had scheduled appointments at Tehran University of Medical Sciences-affiliated dialysis units from March 2014 until June 2014. Eligible participants were clinic patients, age 20 years to 64 with a diagnosis of ESRD in the medical record, and a clinic appointment for receiving dialysis, had no other health problems. Patients were ineligible if they did not speak or understand Persian or if the research assistant determined (by interaction or Mini-Mental State Examination score >23) they were too ill or cognitively impaired to participate. A total of 240 patients under dialysis were identified as eligible from dialysis clinic at four sites. Then, written informed consent was obtained after the research had been explained to them, and participants were assured that they were free to participate or to decline to participate or to withdraw from the research at any time. All who provided written consent were given the questionnaires. Of these, 9 refused participation and 27 failed to complete all questionnaires. Trained research assistants collected data from participating patients. Of these, 9 refused participation and 27 failed to complete all questionnaires.

Measurement instruments

a) Mini-Mental State Exam (MMSE): The 11-item mini mental state examination (MMSE) is the most commonly used instrument for screening cognitive functioning on a 0 to 30-point scale: orientation to time (5 points), place (5 points), registration (3 points), attention and calculation (5 points), recall (3 points), language (8 points), and visual construction (1 point)(17). Scores 22 and less indicate cognitive impairment, therefore individuals with a score less than 24 were excluded from participation in this study (18). The questionnaire showed strong validity and reliability in Iranian samples. Cronbach's alpha has been reported 0.81 for the questionnaire in an Iranian sample indicating it has good internal consistency (19).

b) Short Test of Functional Health Literacy Adult (S-TOFHLA): Health literacy was measured using the Short Test of Functional Health Literacy, a fully validated measure of health literacy that includes an assessment of reading comprehension, as well as numeracy. Scores range from 0–100 and are divided into three levels of health literacy: a score 67 corresponds to adequate health literacy, a score of 54-66 delineates marginal health literacy, and a score 53 represents inadequate health literacy. Cronbach's alpha has been reported 0.68 for the 4

Numeracy items and 0.97 for the 36 items in the 2 prose passages. Iranian version of the questionnaire had good reliability and validity (20). Cronbach's alpha for the Iranian version of the questionnaire was .78 for reading comprehension and .69 for numeracy scale (21).

c) Depression, Anxiety, Stress Scale (DASS): Negative emotional states were assessed using the Depression, Anxiety, Stress Scale (DASS) presented by Lovibond (1995). The DASS is a commonly used instrument designed for the assessment of depressive symptoms, anxiety and stress with good psychometric properties including strong reliability and validity (22). The overall Cronbach's alpha of the Iranian version was 0.91 indicating strong internal consistency (23). DASS-21 is not a categorical measure of clinical diagnoses, but the scale could be useful for identifying individuals who were at high risk of mental health problems.

d) Self Management Behavior: The Self-Management in patient with chronic kidney disease questionnaire is a self-report measure, consisting of five subscales: communication with caregivers, partnership in care, self-care, self-advocacy, and medication adherence. All five subscales had strong validity and reliability (24). In the present study, self-care subscale was used to assess self-care behaviors in patients with kidney disease.

The subscale was forward and back translated using a multistep method to ensure the quality of the translation (25), and then pilot-tested with 30 patients to test reliability in Iranian sample. The pilot study of self-care subscale showed that Cronbach's alpha of 0.81, which is a normally acceptable value in literacy studies.

Table 2 showed that depression, anxiety and stress scores differed significantly by health literacy level ($F(2, 201)=10.6, P<0.001$), ($F(2, 201)=3.8, P<0.02$) and ($F(2, 201)=5.7, P<0.004$), respectively.

Post-hoc pairwise comparisons indicated individuals with inadequate health literacy had significantly higher depression scores (mean=17.7) than those with either marginal (mean=9.9, $P=0.001$) or adequate health literacy (mean=11.3, $P<0.001$). For anxiety, individuals with inadequate health literacy had significantly higher anxiety scores (mean=16.1) than those with either marginal (mean=12.3, $P=0.02$) or adequate health literacy (mean=12.4, $P=0.007$).

For stress, individuals who had inadequate health literacy reported significantly higher stress scores

(mean=15.9) than those with either marginal (mean=9.2, $P=0.005$) or adequate health literacy (mean=11.6, $P=0.004$). There was no significant difference between groups with marginal and adequate health literacy regarding depression ($P=0.49$), anxiety ($P=0.99$) and stress scores ($P=0.26$).

For self-care behaviors, three-ways ANOVA revealed that self-care scores varied significantly by level of health literacy ($F(2, 201)=16.3, P<0.001$). Post-hoc pairwise comparisons showed that individuals with inadequate health literacy had significantly lower scores in self-care (mean=6.3) than those with either marginal (mean=7.7, $P=0.005$) or adequate health literacy (mean=8.1, $P<0.001$). There was no significant difference between marginal and adequate health literacy ($P=0.41$).

Using the SPSS version 21 (IBM New York, USA), Chi-square analyses were conducted to examine differences among health literacy levels for categorical variables (i.e., education level, employment, age group, sex, insurance, and marital status).

Three-way ANOVA with post hoc pairwise comparisons using Fisher's test of least significant differences (LSD) was conducted to examine differences among health literacy levels for continuous variables (i.e., depression, anxiety, stress and self-care). To test mediating effects of negative emotions, mediation analysis was conducted using bivariate regression and Sobel test as proposed by MacKinnon, Fairchild, and Fritz (26). For all analyses, P values of <0.05 were considered statistically significant.

Results

A total of 204 men and women undergoing dialysis completed all measures noted above. Participants were, on average, 50.9 ± 10.9 years old. As shown in Table 1, the majority of the sample was male (58.8%), married (71.2%), retired (35.3%), had elementary school education (44.6%), and had health insurance (97.1%). Approximately one fourth ($n=51, 25\%$) of the sample had limited health literacy according to the S-TOFHLA. According to the table 1, health literacy was significantly associated with education; participants with higher education had higher level of health literacy ($\chi^2=19.7, P=0.003$).

There were no significant relationships between health literacy levels and other socio-economic variables.

Table 1: Demographic characteristics of hemodialysis patients

	Total sample (%)	Inadequate	Marginal	Adequate	P
Gender					0.78
Male	58.8	26.7	10	63.3	
Female	22.1	22.6	9.5	67.9	
Age (year)					0.81
20-29	7.8	18.8	12.5	68.8	
30-39	6.9	28.6	0	71.4	
40-49	17.2	20.0	5.7	74.3	
50-59	42.6	27.6	10.3	62.1	
60-64	25.5	25.0	35.0	24.1	
Education					0.003
Elementary	44.6	30.8	11.0	58.2	
Middle School	14.7	33.3	20.0	46.7	
High School	26.9	9.1	3.6	87.3	
Higher education	13.7	28.6	7.1	64.3	
Employment					0.43
Employed	22	22.9	6.7	70.4	
Housewives	25.9	21.7	39.2	39.1	
Un-employed	13.2	45.0	11.7	43.3	
Retired	35.3	20.2	15.8	64	
Others	3.4		0	78.3	
Marital Status					0.52
Married	71.2	22.6	8.2	69.2	
Single	16.6	17.6	14.7	67.6	
Other	12.2	27.4	12.5	62.5	
Insurance					0.45
Insured	97.1	24.2	10.1	65.7	
Un-insured	2.9	50.0	0	50	

Table 2: The relation of depression, anxiety, stress and self-care behaviors by health literacy levels among hemodialysis patients

	Total	Levels of Health Literacy			P
		Inadequate	Marginal	Adequate	
Depression	12.8±9.3	17.7±9.1	9.9±7.2	11.3±9.0	<0.001
Anxiety	13.3±8.5	16.1±7.6	12.3±9.9	12.4±8.5	<0.02
Stress	12.4±9.1	15.9±9.0	9.2±8.6	11.6±8.9	0.004
Self-care	7±2.1	6.3±2.1	7.7±1.2	8.1±1.9	<0.001

Bivariate analysis (Table 3) showed that Health literacy was positively related to kidney disease self-care behaviors (=0.04, SE=0.006), while it was negatively related to depression (=-0.15, SE=0.03), anxiety (=-0.11, SE=.03), and stress

(=-0.1, SE=0.03). Also, depression (=-0.05, SE=0.02), anxiety (=-0.04, SE=0.02) and stress (=-0.04, SE=0.02) were negatively associated with self-care behavior.

The Sobel test (Table 4) indicated that

Table 3: Association between health literacy, negative emotional status and self-care among hemodialysis patients

		SE	P	R ²
HL--- > Depression	-0.15	0.029	<0.001	0.12
HL--- >Anxiety	-0.11	0.027	<0.001	0.08
HL--- >Stress	-0.10	0.029	<0.001	0.06
Depression-- > Self-care	-0.045	0.015	0.004	0.04
Anxiety--- > Self-care	-0.038	0.017	0.028	0.02
Stress--- > Self-care	-0.039	0.016	0.01	0.03
HL--- > Self-care	0.043	0.006	<0.001	0.2

Table 4: Mediating effects of negative emotional states among hemodialysis patients

	Z	P
HL--- > Depression	2.6	0.01
HL --- >Anxiety	1.96	0.05
HL--- > Stress	1.99	0.04

depression (z=2.2, P=0.03), anxiety (z=1.96, P=0.05), and stress (z=1.99, P=0.04) were significant mediators of the influence of health literacy on self-care in kidney disease. Taken together, negative emotional States mediate the

relationship between health literacy and self-care behaviors in dialysis patients.

Discussion

The current study examined health literacy and its associated factors among patients undergoing dialysis. Approximately one fourth (25%) of participants had adequate health literacy (65.2%), implying that they had considerable difficulty in understanding and reading information. However, some studies found that the prevalence of low health literacy is much higher in Iranian sample (27,28). The difference may result from the frequent hospitalizations of dialysis patients, their weekly exposure to the medical setting, educational programs or health materials and their interactions with medical staff more than normal population or other diseases.

Our findings indicate that low health literacy is predictor of negative emotional states. Consistent with other studies, greater depressive symptoms were reported in dialysis patients with low health literacy. Similarly, dialysis patients with limited health literacy experienced higher anxiety and stress compared to those with marginal and adequate health literacy (29,30). Higher negative emotional states in patients with inadequate health literacy may be attributable to their limited information about the disease and its management. Consequently, they have low self-efficacy and motivation to cope with their chronic disease and develop more negative responses to it. Also, the high levels of shame associated with limited reading or numeracy abilities may increase depressive symptoms and isolation. The sense of shame causes patients with low health literacy to avoid effective patient-doctor communication and help seeking. They are more dependent on caregivers to get disease-related information and it makes them feel frustrated, weak and ineffective. These negative feelings may lead patients to experience depression or anxiety.

Moreover, depression, anxiety and stress were significantly predictive of self-care behaviors. Consistent with previous evidence (31-33) patients with more limited health literacy had significantly lower self-care scores than did more literate participants. Patients with low health literacy may not be able to read drug labels, medication instructions, and health booklets or understand their health professionals thus causing them to take their medications inappropriately, stop prescribed diet, and choose irrelevant treatment options.

This finding provides empirical evidence to support significance of health literacy in reducing negative emotions and improving self-care. Based on these results, further investigations should be undertaken to design appropriate educational interventions during the initial stages of CKD to prevent ESRD and further increase in burden of kidney failure and disease management.

Our study has several limitations that should be acknowledged. First, the small sample size limits the ability to generalize the findings. We were also not able to compare our model by socio-demographic variables, which may be confounders or moderators. Another limitation is related to measurements used in the current study. S-TOFHLA cannot assess all aspects of health literacy. The results could be important in establishing the role of health literacy in the daily care of patients with kidney disease. In addition, understanding the relationship between health literacy and self-care behaviors should enhance efforts to improve dialysis outcomes.

Conclusion

Our findings highlighted the importance of health literacy promotion, demonstrating a significant association of negative emotions with both health literacy and self-care, and indicating that negative emotional states were significant mediators of the relationship between health literacy and self-care.

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