

*Original article*

## Health Literacy and Quality of Life of Diabetic and Non-Diabetic End Stage Renal Disease Patients

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### Abstract

**Introduction.** Chronic kidney disease (CKD) negatively affects physical, mental and social quality of life (QoL) of patients, and requires an adequate level of health literacy (HL) for better management. End-stage renal disease (ESRD) diabetic patients have worse QoL compared to non-diabetic HD patients. This study aims to estimate the HL levels of diabetic and non-diabetic ESRD patients, also to assess the association between HL and QoL in ESRD patients.

**Methods.** This descriptive study of ESRD patients was conducted in dialysis units in Ankara. It included 446 patients, 223 ESRD patients with diabetes and 223 without diabetes. Patients' data were collected using face to face interviews. Test of Functional Health Literacy in Adult was used to assess HL and SF-36 to assess QoL.

**Results.** DM cases, verbal, numerical and general HL scores were lower than non-DM cases ( $p < 0.001$ ). DM cases had lower scores of QOL than non-DM cases. The mean scores of physical functioning, role limitation due to emotional problems, energy, general health, physical health and mental health were found lower in cases with DM than non-DM cases ( $p < 0.001$ ). There was a statistically positive correlation between level of HL and PHC scores ( $p < 0.001$ ) and MHC scores ( $p < 0.001$ ).

**Conclusion.** QoL and HL levels are lower in diabetic patients than non-diabetics. Effective strategies should be considered to increase QoL among ESRD patients with low levels of HL, and health professionals should be more aware of the association between HL and QoL, especially the cases with DM.

**Keywords:** diabetes mellitus, end stage renal disease, health literacy, quality of life

### Introduction

Chronic kidney disease (CKD) is accepted as an impor-

tant public health problem and it is estimated that 10% of adult population has CKD worldwide [1,2] and CKD prevalence was found to be as high as 15.7% in Turkey [3]. CKD and especially end-stage renal disease (ESRD) negatively affect the physical, mental and social QoL of patients. Good management of the disease decreases the personal burden of the disease and also increases QOL of the patients [4-7].

CKD patients having high level health literacy (HL) deal better with their disease, use healthcare services more effectively and handle their own pathology and its consequences properly [8]. HL is also very important to have better medication adherence, avoid potentially nephrotoxic substances, and avoid risky behaviors such as smoking, high dietary salt intake, and lack of exercise in CKD [9].

Diabetes mellitus (DM) is a major public health problem worldwide, patients have higher risk of life-changing and life-treating complications. The patients with DM have higher risk of hypertension, dyslipidemia, cardiovascular complications [10]. DM also plays a major role in the pathogenesis of CKD and it is believed that DM accounts for 30-50% of all CKD cases and affects 285 million (6.4%) adults worldwide [11,12]. Although the patients with DM are expected to have higher quality of life (QoL) due to frequent use of health services, QoL in diabetic HD patients is worse than non-diabetic HD patients [13,14]. On the other hand, Bailey indicates that some studies found association between limited HL and complications in DM cases [15]. Limited HL can also have adverse effect on QoL of ESRD patients and especially the patients with DM. We aim to estimate the HL levels of diabetic and non-diabetic ESRD patients, also to assess the association between HL and QoL in ESRD patients.

### Material and methods

Descriptive study of ESRD patients with and without DM was conducted in dialysis units in Ankara.

### Population and Sample Selection Criteria

G\*Power (version 3.0.10) and Power Analysis and Sample Size package program were used to determine the sample size ( $\alpha=0.05$  and  $\beta=0.10$ ). Inclusion criteria were 40 years of age and over, hemodialysis duration over three months, and without immunosuppressive therapy. Gender and age groups were accepted as matching criteria to select ESRD patients with DM and without DM. Patients with communication problems, heart failure, active infection or malignancy were not included in the study.

### Variables and Scales

Socio-demographic characteristics and health behaviors, history of disease, clinical and laboratory findings, health related quality of life scale (Short Form-36; SF-36) [16] and health literacy scale (Test of Functional Health Literacy in Adults; TOFHLA) [17] were included in the questionnaire of this study. SF-36, questionnaire was developed for the assessment of the health related QoL. It comprised 8 sub dimensions and physical health (PHC) and mental health (MHC) components. Turkish reliability and validity studies were done by Koçyiğit *et al.* in 1999. Cronbach alpha coefficients of each subscale and components were found to be 0.732 to 0.761 [18]. Parker *et al.* (1995) developed the TOFHLA which had verbal and numerical parts. The Turkish adaptation of this test was carried out by Üçpunar in 2014, and Cronbach alpha was 0.523 for the verbal skills, and 0.732 for the numerical skills [19].

### Data Collection and Analysis

Data collection was conducted between May 12 and November 25, 2016. During the study, a total of 14 dialysis centers (four governmental and ten private), 223 DM (91 women and 132 men) and 223 non-DM (91 women and 132 men) were interviewed by two trained nurses. Statistical Package for Social Science (SPSS) 21 package program was used for the statistical analysis of the data. Chi-square test, Mann Whitney U and Spearman correlation were used in the analyses. Two logistic models were used to determine the factors affecting PHC and MHC of QoL. The quality of life (PHC and MHC) scores were divided by the median value and the backward stepwise logistic regression model were applied. PHC was cut to the median value of "45" and the MHC to the median value of "57". The reason of not using linear regression was that the data of QoL (PHC and MHC) was not normally distributed. The variables used in logistic models were age (numeric variable), gender (Ref: female), diabetes status (Ref: having DM), education status (Ref: illiterate),

hypertension status (Ref: having hypertension), coronary heart disease (Ref: having coronary heart disease), hyperlipidemia (Ref: high hyperlipidemia), CKD history in the family (Ref: positive familial CKD history), followed up in nephrology clinic (Ref: followed up in nephrology clinic), the duration of CKD (numerical), the duration of hemodialysis (numerical), known cause of the CKD (Ref: known cause) and the health literacy level (Ref: insufficient level).

This study was approved by Hacettepe University Non-Interventional Ethics Board (dated 22 March 2016 and GO16/03-07). Written permission was obtained from Ministry of Health and dialysis centers. The patients were informed before the interview, and the questionnaires were filled after signing the consent.

### Results

The sociodemographic characteristics of ESRD patients with and without DM were similar in the study. There were no statistically significant differences between gender, age, educational status, marital status with and without diabetes mellitus (Table 1).

**Table 1.** Age, gender and educational status of ESRD patients with and without DM

	ESRD Patients				p
	DM		Non-DM		
	n	%	n	%	
<b>Gender</b>					1.0
Male	132	59.2	132	59.2	
Female	91	40.8	91	40.8	
<b>Age Group</b>					0.200
40-49	16	7.2	15	6.7	
50-59	45	20.2	62	27.8	
60-69	104	46.6	83	37.2	
70-79	51	22.9	52	23.4	
80+	7	3.1	11	4.9	
<b>Educational Status</b>					0.096
Illiterate	33	14.8	29	13.0	
Literate	17	7.6	7	3.1	
Primary school	92	41.3	94	42.2	
Secondary school	27	12.1	26	11.7	
High school	35	15.7	32	14.3	
University	19	8.5	35	15.7	
<b>Total</b>	223	100,0	223	100,0	

In non-DM cases, verbal, numerical and general HL scores were higher than DM cases ( $p<0.001$ ). Non-DM cases had higher scores in all subscales of SF 36 scale than DM cases. The mean scores of physical functioning, role limitation due to emotional problems, energy, general health, PHC and MHC were found higher in cases without DM than DM cases ( $p<0.001$ ). (Table 2). In the study, 76.2% of ESRD patients with DM had inadequate level of HL, this percentage was 55.2% for non-DM patients. Sufficient HL was three times more in non-DMs (17.5%) than DM (5.4%).

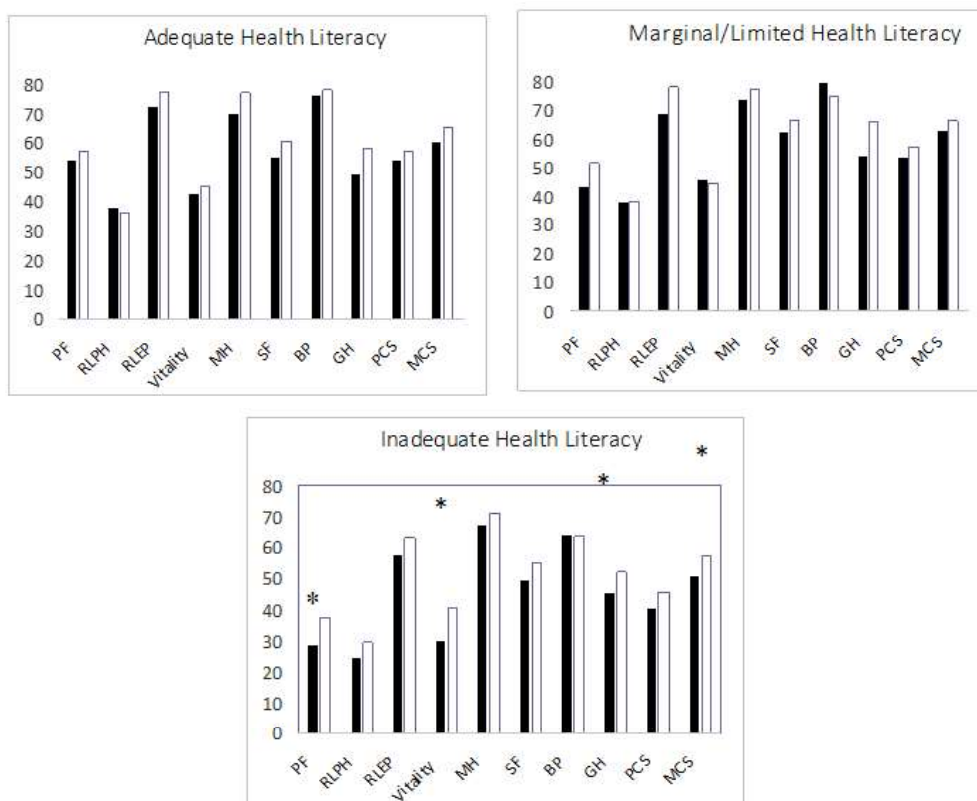
**Table 2.** Distribution of TOFLHA and SF-36 scores in ESRD patients with and without DM

	ESRD Patients				p*
	DM		Non-DM		
	Mean	SD	Mean	SD	
<b>TOFLHA</b>					
Verbal	23.29	10.53	28.58	11.60	<0.001
Numerical	22.04	9.95	25.96	10.57	<0.001
General	45.34	18.14	54.55	20.04	<0.001
<b>SF-36</b>					
Physical functioning	32.58	28.29	44.75	29.71	<0.001
Role limitation due to physical health	27.47	37.66	33.14	38.52	0.08
Role limitation due to emotional problems	60.08	43.91	70.28	41.40	0.008
Vitality	33.38	27.30	42.22	28.37	<0.001
Mental health	68.94	24.08	73.85	20.21	0.06
Social functioning	51.79	42.70	58.86	40.09	0.06
Bodily pain	67.43	33.59	69.04	31.69	0.73
General health	46.82	26.00	57.00	26.89	<0.001
Physical health compound	43.57	23.53	51.13	23.78	<0.001
Mental health compound	53.45	25.16	61.25	24.46	<0.001

\*Mann-Whitney U test

In the adequate level of HL group there was no statistical significance for QoL between DM and non-DM cases. The patients without DM had significantly higher score of general health than the patients with DM in the marginal health literacy level. The patients

without DM had significantly higher scores of physical functioning, energy, general health status, and MHC than the patients with DM in inadequate health literacy level (Figure 1).



**Fig. 1.** The level of health literacy and QOL dimensions in DM and non-DM Patients (PF: Physical Functioning, RLPH: Role Limitation Due to Physical Health, RLEP: Role Limitation Due to Emotional Problem, MH: Mental Health, SF: Social Functioning, BP: Bodily Pain, GH: General Health, PCS: Physical Compound Summary, MCS: Mental Compound Summary, Black bars: With DM, White bars: Without DM, \*Significant Result with Mann-Whitney U test)

PHC of quality of life was 3.979 times higher in males, it was decreasing with age (0.967); and also 1.761 times higher in patients without CVDs, 2.299 times higher in high school and upper educated patients. MHC of QoL was 2.058 times higher in males, 1.562 times higher in

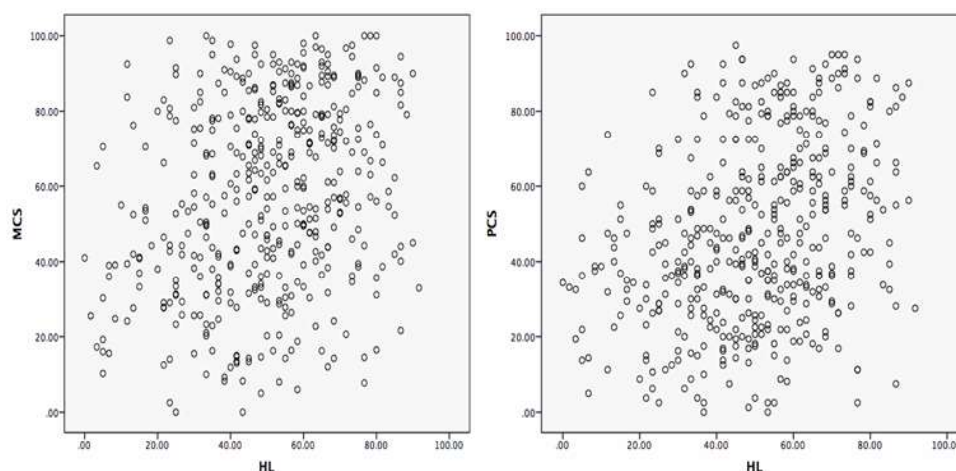
the patients without DM, 1.582 times higher in the patients with having CKD family history (Table 3).

There was a statistically significant positive correlation between level of HL and PHC scores ( $r=0.311$   $p<0.001$ ) and MHC scores ( $r=0.263$ ,  $p<0.001$ ), but it was not very strong (Figure 2).

**Table 3.** Logistic regression models for physical and mental compound summaries of QOL

	p	Exp ( $\beta$ )	95% Confidence Interval	
<b>Physical Health Compound</b>				
Male	<b>0.000</b>	3.979	2.445	6.475
Age	<b>0.004</b>	0.967	0.945	0.989
Not having cardiovascular diseases	<b>0.012</b>	1.761	1.131	2.741
Education status (ref: illiterate)	<b>0.001</b>			
Graduated from primary school	0.732	0.900	0.494	1.640
Graduated from high school and over	<b>0.021</b>	2.299	1.132	4.670
Constant	0.332	2.291		
<b>Mental Health Compound</b>				
Male	0.000	2.058	1.394	3.038
DM Status	0.022	1.562	1.065	2.291
Not having relatives with cardiovascular diseases	0.059	1.582	0.983	2.547
Constant	0.000	0.376		

**Physical Health Compound:**  $R^2=0.168$  (Cox ve Snell), 0.225 (Nagelkerke), 0.038 (Hosmer ve Lemeshow Test) **Mental Health Compound:**  $R^2=0.050$  (Cox ve Snell), 0.067 (Nagelkerke), 0.661 (Hosmer ve Lemeshow Test)



**Fig. 2.** The correlation between physical and mental health components and HL

## Discussion

This study was conducted in total of 446 ESRD cases to estimate the effect of health literacy on quality of life and the difference between diabetic patients with DM and non-diabetic patients in four government and ten private dialysis centers located in Ankara city.

People with low levels of HL have poorer chronic disease management, which increases mortality in ESRD [9, 20]. Taylor *et al.* evaluated 12,324 patients in 20 studies, but they were not all hemodialysis patients [8]. They found the median prevalence of limited HL level as 23% in all patients, and 27% (CI 19%-35%) in patients on dialysis. In the review of Taylor *et al.*, the prevalence of limited HL was found to be between

8.4-49% in five studies that used STOFHLA and there was no significance between group heterogeneity in these studies. In our study, the level of inadequate HL was higher in patients with DM (76.2%) compared to patients without DM (55.2%), but it was higher from all of the mentioned studies in the review conducted by Taylor *et al* [8]. Lai *et al.* also indicated that ESRD with DM need more health information to improve self-management, especially improve their communicative and critical HL as well as functional HL [21]. Bailey *et al.* also declared there was association between limited HL and adverse outcomes in DM cases [15]. DM patients with limited HL would have more probability of being ESRD because of insufficient self-management skills.

In this study, scores of general, PHC and MHC in SF-36 were found higher in non-DM cases than DM cases, physical functioning meaning limitation in self-care activities, role-emotional meaning having problems with daily activities as a result of emotional problems and vitality meaning feeling tired, were statically higher in non-DM cases. Gumprecht *et al.* [13] and Soleymanian *et al.* [14] presented the same findings in their studies. Hortemo *et al.* indicated that having ESRD as a long-term complication or comorbidity contribute for a decrease QoL level in DM patients [22]. Soleymanian *et al.* also indicated that the underlying comorbidities can independently and significantly affect the QoL in hemodialysis patients with DM [14].

The sociodemographic characteristics of the patients significantly affect the level of PHC and MHC of QoL in our study. Age is an important determinant for progress of the disease. Increasing age significantly decreased PHC and MHC of QoL; which is in line with the studies of Bayoumi *et al.* [23], Mcadams-Demargo *at al.* [24] and Seica *et al.* [25]. Higher level of education also increased significantly QoL in our study similar to the other studies [23,24]. Educational level could be accepted as a socioeconomic determinant, higher educated people could reach and use health care services more effectively than lower educated people; also educational level is an important determinant of HL. We also found male patients had higher level of PHC and MHC of QoL than women; The studies conducted by Mcadams-Demargo *at al.* [24] and Seica *et al.* [25] showed that male patients had higher QoL; but Bayoumi *et al.* found differently, female patients had higher QoL [23]. The review of Cobo *et al.* emphasized that gender differences have resulted in the pathogenesis of disease and new developed treatment opportunities [26]. Gender inequality or cultural determinants can play a role to decrease quality of life in women in our society. Having CVD is affecting PHC of QoL and having a relative with CVD as a risk factor of MHC of QoL in our study. Studies confirmed the significance of CKD on the development of CVD, complications or comorbidity with ESRD decreased QoL or healthy lifestyle behaviors [27]. We found correlation between HL and QoL in our study. Health literacy, which is important both in health care and personal care, affects QoL in ESRD patients. This can be regarded as a supporting finding that HL is the factor affecting QoL, which is the basic hypothesis of the research. In our logistic models, health literacy is not found as an explanatory variable, low HL in general may have led education to become more prominent. Couture *et al.* found no relationship between HL and QoL in hemodialysis cases [28]. However, the relation between HL and QoL was found in patients with hypertension by Wang *et al.* [29], in older patients with long term illness by Panagiotti *et al.* [30], in breast, lung, prostate, and colorectal cancer patients by Halverson *et al.* [31], and in the patients with ischemic heart diseases by

Alejandro Gonzales-Chica *et al.* [34]. We think that it is necessary to investigate the association between HL and QoL by using quantitative studies to explain the effect of sociodemographic and cultural factors on HL and QoL.

There are also some limitations in our study. Information about the patients' illness during the communication between the physician and the patient, lifestyle changes and applications to the health institutions during the treatment process are expected to positively affect the QoL and HL. Information on the physician-patient communication process were not included in our study. Since the patients do not always go to the same hospital for their treatment, we could not use the patient data to reach the detailed progress from hospitals' surveillance systems.

## Conclusion

Diabetic cases had lower levels of both QoL and HL than non-diabetic patients. Considering the increased burden and complications of CKD, suitable initiatives are required to increase health literacy especially in diabetic patients. Effective strategies should be considered to increase in QoL among ESRD patients with low levels of HL, and health professionals should be more aware of the association between HL and QoL, routine check list should be implemented into assessment procedures for ESRD patients. The evaluation of QoL of patients with the qualitative research in relation with the level of HL will shed light on the future interventions.

*Conflict of interest statement:* None declared

## References

1. Fung E, Tamura MK. Epidemiology and public health concerns of chronic kidney disease in older adults. *Adv Chronic Kidney Dis* 2016; 23: 8-11.
2. Weiner DE. Public Health Consequences of Chronic Kidney Disease. *Clin Pharmacol Ther* 2009; 86: 566-569.
3. Suleymanlar G, Utas C, Arinsoy T, *et al.* A population-based survey of Chronic REnal Disease in Turkey-the CREDIT study. *Nephrol Dial Transplant* 2016; 26: 1862-1871.
4. Webster AC, Nagler EV, Mortan RL, Masson P. Chronic Kidney Disease. *Lancet* 2017; 389(10075): 1238-1252.
5. Al Wakeel J, Al Harbi A, Bayoumi M, *et al.* Quality of life in hemodialysis and peritoneal dialysis patients in Saudi Arabia. *Ann Saudi Med* 2012; 32: 570-574.
6. Grzegorzewska AE, Izdebska A, Niepolski L, *et al.* Self-Reported Physical Activity, Quality of Life, and Psychological Status in Relation to Plasma 25-Hydroxyvitamin D Concentration in Patients Treated with Hemodialysis. *Kidney Blood Press Res* 2016; 41: 886-900.
7. Anees M, Batool S, Imtiaz M, Ibrahim M. Socio-economic factors affecting quality of life of Hemodialysis patients and its effects on mortality. *Pak J Med Sci* 2018; 34(4): 811-816.
8. Taylor DM, Bradley JA, Bradley C, *et al.* Limited health literacy in advanced kidney disease. *Kidney Int* 2016; 90: 685-695.

9. Unruh ML, Weisbord SD, Kimmel PL. Health-related quality of life in nephrology research and clinical practice. *Semin Dial* 2005; 18: 82-90.
10. Lawati JA. Diabetes Mellitus: A Local and Global Public Health Emergency. *Oman Med J* 2017; 32(3): 177-179.
11. Gheith O, Farouk N, Nampoory N, *et al.* Diabetic kidney disease: World wide difference of prevalence and risk factors. *J Nephropharmacol* 2015; 5: 49-56.
12. Kainz A, Hronsky M, Stel VS, *et al.* Prediction of prevalence of chronic kidney disease in diabetic patients in countries of the European Union up to 2025. *Nephrol Dial* 2015; *Transplant Suppl* 4: iv113-iv118.
13. Gumprecht J, Zelobowska K, Gosek K, *et al.* Quality of life among diabetic and non-diabetic patients on maintenance hemodialysis. *Exp Clin Endocrinol Diabetes* 2010; 118: 205-208.
14. Soleymanian T, Kokabeh Z, Ramaghi R, *et al.* Clinical outcomes and quality of life in hemodialysis diabetic patients versus non-diabetics. *J Nephropathol* 2017; 6: 81-89.
15. Bailey SC, Brega AG, Crutchfield TM, *et al.* A collaborative project of the NIDDKM-funded Centers for Diabetes Translational Research Centers' Health Literacy Interest Group. Update on Health Literacy and Diabetes. *Diabetes Educ* 2014; 40(5): 581-604.
16. Ware JE, Snow KK, Kosinski M, and Gandek B. SF-36 Health Survey. Manual & Interpretation Guide The Health Institute, New England Medical Centre, Boston. 1993.
17. TOFHLA (Test of Functional Health Literacy in Adults). Available form: [http://healthliteracy.org.uk/index.php?option=com\\_k2&view=item&id=92:tofhl-test-of-functional-health-literacy-in-adults&Itemid=193](http://healthliteracy.org.uk/index.php?option=com_k2&view=item&id=92:tofhl-test-of-functional-health-literacy-in-adults&Itemid=193).
18. Kocyigit H, Aydemir O, Fisek G, *et al.* Reliability and Validity of the Turkish Version of Short Form-36 (SF-36). *İlaç ve Tedavi Dergisi* 1999; 1: 102-106.
19. Ucpunar E. 2014. *Yetişkinlerde işlevsel sağlık okuryazarlığı testinin uyarılma çalışması [MSc Thesis]*. Ankara: Ankara Üniversitesi; Available from: <http://ulusaltezmerkezi.com/yetiskinlerde-islevsel-saglik-okuryazarligi-testinin-uyarlama-calismasi/> [Accessed 4 January 2017].
20. Abdel-Kader K, Unruh ML, Weisbord SD. Symptom Burden, Depression, and Quality of Life in Chronic and End-Stage Kidney Disease. *Clin J Am Soc Nephrol* 2009; 4: 1057-1064.
21. Lai AY, Ishikawa H, Kiuchi T, *et al.* Communicative and critical health literacy, and self-management behaviors in end-stage renal disease patients with diabetes on hemodialysis. *Patient Educ Couns*. 2013; 91(2): 221-227.
22. Hortemo Osthus TB, von der Lippe N, Ribu L, *et al.* Health-related quality of life and all-cause mortality in patients with diabetes on dialysis. *BMC Nephrology* 2012; 13: 78.
23. Bayoumi M, Harbi AA, Suwaida AA, *et al.* Predictors of Quality of Life in Hemodialysis Patients. *Saudi J Kidney Dis Transpl* 2013; 24(2): 254-259.
24. Mcadams-Demargo MA, Ying H, Olorundare I, *et al.* Frailty and Health-Related Quality of Life in End Stage Renal Disease Patients of All Ages. *Frailty Aging* 2016; 5(3): 174-179.
25. Seica A, Segall L, Verzan C, *et al.* Factors affecting the quality of life of haemodialysis patients from Romania: a multicentric study. *Nephrol Dial Transplant* 2009; 24: 626-629.
26. Cobo G, Hecking M, Port FK, *et al.* Sex and gender differences in chronic kidney disease: progression to end-stage renal disease and haemodialysis. *Clin Sci* 2016; 130: 1147-1163.
27. Iseki K. Role of chronic kidney disease in cardiovascular disease: are we different from others? *Clin Exp Nephrol* 2011; 15: 450-455.
28. Couture EM, Chouinard M-C, Fortin M, and Hudon C. The relationship between health literacy and quality of life among frequent users of health care services: A cross-sectional study. *Health Qual Life Outcomes* 2017; 15: 137.
29. Wang C, Lang J, Xuan L, *et al.* The effect of health literacy and self-management efficacy on the health-related quality of life of hypertensive patients in a western rural area of China: a cross-sectional study. *Int J Equity Health* 2017; 16: 58.
30. Panagioti M, Skevington SM, Hann M, *et al.* Effect of health literacy on the quality of life of older patients with long-term conditions: A large cohort study in UK general practice. *Qual Life Res* 2018; 27(5): 1257-1268.
31. Halverson JL, Martinez-Donatea AP, Paltaa M, *et al.* Health Literacy and Health-Related Quality of Life Among a Population-Based Sample of Cancer Patients. *J Health Commun* 2015; 20(11): 1320-1329.
32. Gonzalez-Chica DA, Mnisi Z, Avery J, *et al.* Effect of Health Literacy on Quality of Life amongst Patients with Ischaemic Heart Disease in Australian General Practice. *PLoS One* 2016; 11(3): e0151079.