



## RESEARCH ARTICLE

### Determinants of End-Stage Renal Disease Knowledge among Patients on Chronic Dialysis

Mohammed Mohammed Alhaji<sup>1</sup>, Nurul Ainina Suprem<sup>1</sup>, Hashmet Parveen<sup>1</sup>, Nur Hanisah Johan<sup>2</sup>, Lim Yee Yin<sup>2</sup>, Ruzita Ghani<sup>2</sup>, Emma Othman<sup>2</sup>, Muhammad Abdul Mabood Khalil<sup>2</sup>, Chong Vui Heng<sup>2</sup> and Jackson Tan<sup>1,2\*</sup>

<sup>1</sup>PAPRSB Institute of Health Sciences, Universiti Brunei Darussalam, BE1410, Brunei Darussalam

<sup>2</sup>RIPAS Hospital, Bandar Seri Begawan, BA1710, Brunei Darussalam

#### ARTICLE INFO

Received: Nov 15, 2018

Accepted: Dec 18, 2019

#### Keywords

Chronic kidney disease  
End Stage renal disease  
Knowledge  
Brunei Darussalam  
Asia

#### ABSTRACT

This study aimed to investigate the level of end-stage renal disease (ESRD) knowledge among patients on peritoneal dialysis and haemodialysis and test associations between the level of their ESRD knowledge with sociodemographic and clinical variables. An in-centre cross-sectional study was conducted on a randomly selected 178 dialysis (57 peritoneal dialysis and 121 haemodialysis) patients receiving renal care at Rimba Dialysis Centre, Brunei, of which 50.6% (n=90) were females and 49.4% (n=88) were males. A validated, structured 10-Item ESRD knowledge questionnaire (with score scale of 0-10; and classified as <5 limited, 5-7 moderate, and 7-10 substantial knowledge) was self-administered by the respondents to assess their ESRD knowledge. Additional sociodemographic information was collected, and clinical variables were extracted from their dialysis records. The mean age of the respondents was 50.1 (SD=13.57) years. The mean knowledge score of the patients was 5.84 (SD=2.29), indicating moderate knowledge among ESRD patients on dialysis. Higher educational attainment (P<0.001), higher income (P=0.041), longer duration on dialysis (P=0.008), and dialysis initiation at a younger age (P=0.001) were significantly associated with better ESRD knowledge. On the other hand, the type of dialysis modality (P=0.117), age (P=0.106), employment status (P=0.662), marital status (P=0.187), dietary restrictions; potassium and phosphate (P=0.182), systolic blood pressure (P=0.172), diastolic blood pressure (P=0.062), intra-dialytic weight gain (P=0.592) and dialysis adequacy (P=0.977) were not associated with ESRD knowledge. Most patients, especially those with low income and education status demonstrated limited knowledge regarding ESRD and treatment, suggesting the need for educational interventions.

#### \*Corresponding Author:

drjacksontan@yahoo.co.uk

#### INTRODUCTION

The poor disease-related knowledge of patients is recognized as a key issue that should be addressed to improve adherence to treatment and regimens among dialysis patients (Wright-Nunes et al., 2011; van Dulmen et al., 2007). End-stage renal disease (ESRD) patient's non-adherence to treatment, in addition to placing a substantial economic burden on healthcare systems, threatens their prognosis and well-being (Sayin et al., 2007). Recently, the quality of life (QOL) and life expectancy of patients undergoing chronic dialysis have improved substantially (Alhaji et al., 2018a; Mujais et al., 2009; Sayin et al., 2007). This was

achieved partly as a result of successful attempts at improving patients' adherence to treatment through some commonly used clinical, behavioural and educational strategies (Shukla and Kaur 2012; van Dulmen et al., 2007). The educational strategies had been shown as significant predictors of treatment adherence and making informed choices among ESRD patients (Chan et al., 2012; Karaeren et al., 2009) such as acceptance of kidney transplant as a more suitable renal replacement therapy (RRT) option, compared to dialysis modalities (Farah et al., 2018; Tan et al., 2014). However, there is a paucity of studies that assessed the level of knowledge of ESRD and treatment options

among ESRD patients across Asia, including Brunei Darussalam (Green et al., 2013; Chan et al., 2012; Rantanen et al., 2008), even though the prevalence of ESRD in Brunei Darussalam had steadily increased from 1347 person per million (ppm) in 2010 to 1694 ppm in 2015 (Tan et al., 2014). The impact of CKD on the development of atherosclerosis-related complications like cardiovascular diseases, hypertension, stroke and transient ischemic attack is widely recognized and reported. This could be related to the stiffening of arteries with subsequent occlusion and impedance of blood supply to important organs like heart and brain. It can also compromise supply to kidneys leading to perpetuation and exacerbation of underlying CKD. Common etiological causes of CKD like diabetes mellitus and vasculitis can also independently cause worsening of atherosclerosis. Locally, cardiovascular diseases and stroke accounted for more than 50% of deaths in the ESKD population (Tan, 2013).

Keeping in view, this study was conducted to determine the level of ESRD knowledge and associations with sociodemographic and clinical variables among ESRD patients on chronic dialysis in Brunei Darussalam. The preliminary findings from this study will help to formulate the guidelines for developing patient-centred educational strategies.

## MATERIALS AND METHODS

### Study design, setting, sampling and participants

A single in-centre cross-sectional study was conducted among 178 ESRD patients (121 haemodialysis and 57 peritoneal dialysis) receiving renal care at Rimba Dialysis Centre (RDC), Brunei Darussalam. The sample represents 25.4% of the total patients on any form of RRT in Brunei at the time of the study. The sample sized was determined as follows: medium effect size ( $d=0.5$ ) assumed,  $\alpha=0.05$  and power ( $1-\beta$ )

(Cunningham and McCrum-Gardner, 2007) showed that a minimum sample of 172 was required to attain the study power of 90% (Faul et al., 2007). Consequently, ESRD patients who satisfied the eligibility criteria (aged  $\geq 18$  years, ESRD on either chronic haemodialysis or peritoneal dialysis for at least 3 months, absence of physical or mental impairment that could impede participation, and a written consent) were enrolled and self-administered a validated structured 10-item ESRD knowledge questionnaire. The study period lasted for 2 months (February–March 2016). Additional clinical data were extracted from the respondents' respective dialysis records.

### Instrument, scoring and other variables

An open-ended structured 10-item knowledge questionnaire (Table 1) in Brunei-Malay was self-administered by the sample ESRD patients. The structured questionnaire was purposely designed by the research team to address issues that were commonly raised during interactive clinical sessions with patients with chronic kidney disease (CKD) in Brunei, and was pretested and validated in the CKD population ( $n=31$ ) receiving renal care at RDC, Brunei (Cronbach's  $\alpha=0.78$ ; un-rotated variance=63.1% with Eigenvalue  $>1$ ) (Alhaji et al. 2018b). The questionnaire measured basic knowledge in 3 areas (ESRD, diet, and medication). Incorrect response was scored '0', and each correct answer was scored "1", giving a possible maximum score of 10 and a minimum score of 0. Any score between 1-4 was considered limited knowledge; 5-7, moderate knowledge and 8-10 substantial knowledge. Other variables were extracted from the patients' dialysis folders, including dietary control (average of the last three measurements of serum potassium and phosphate), and blood pressure (diastolic and systolic, mmHg) recordings of the last three dialysis sessions, and mean inter-dialytic weight gain (IDWG) defined as weight gain between two consecutive dialysis sessions

**Table 1: Structured 10-item knowledge questionnaire on ESRD and answers**

S/N	Question	Answer(s) <sup>a</sup>
1	People can still survive with just one kidney	True
2	Do you know the cause of your kidney disease?	Diabetes Mellitus, Hypertension, Others (e.g. Obesity...)*
3	What are the three types of renal replacement therapy available for patients with end stage renal disease?	Haemodialysis, Peritoneal Dialysis, Kidney Transplant*
4	Lower risk of infection and longer life are among the advantages of a fistula access as compared to vascular catheter or permanent (perm) catheter.	True
5	Is it important to keep the target or 'dry weight' at a controlled level	True
6	Is it important to keep blood pressure at a controlled level?	True
7	EPO (Recormon/Expres) is given to kidney disease patients to control their glucose (sugar) level	False
8	Phosphate binders (Calcium Carbonate) is taken on an empty stomach	False
9	Green apples, pears and cabbages are low in potassium and are safe to eat in moderation	True
10	Fizzy drinks, soy products and seafood are low in phosphate and are safe to eat in moderation	False

<sup>a</sup>Not shown in the administered questionnaire \*Mentioning at least 2 of the possible answers earns the patients a full mark (1).

over two days. The extracted clinical parameters were defined as poor or abnormal if: blood pressure is high (systolic >140mmHg, and diastolic >90mmHg); dialysis adequacy were urea reduction ratio >65% (Haemodialysis), and Kt/V > 1.8 (Peritoneal Dialysis); pre-dialysis serological values of potassium was >6.0 mmol/L, and serum phosphate was > 1.8 mmol/L; and IDWG of >1.5kg.

#### Ethical considerations

Participation was voluntary subject to perusing the given participant information sheet and signing the informed consent form. All information was collected and kept confidential. The research protocol was approved by the Medical Health Research & Ethics Committee (MHREC), Ministry of Health Brunei Darussalam.

#### Statistical analysis

Data were analyzed using the Statistical Package for the Social Sciences (SPSS) version 16.0. Descriptive statistics were depicted with frequency (n) and percentage (%). Association between comparable variables were carried out using either Chi-square test of independence or one-way ANOVA, depending on variables' characteristics. All statistical difference at  $P<0.05$  were considered significant.

## RESULTS

#### Sociodemographic characteristics of the respondents

One hundred and seventy-eight respondent comprising of 57 peritoneal dialysis (PD) and 121 haemodialysis (HD) completed the ESRD knowledge questionnaire. Gender distribution in the study sample was approximately the same (50.9% female and 49.1% male). The mean age was 50.1 (SD=13.57) years. The majority of the respondents were aged between 40-60 years (53.4%); 25.8% aged less than 40 years, and 20.2% were aged below 40 years. Patients were predominantly Malay (95.5%) compared to non-Malay (4.5%); married (72.5%) compared to those who were single (18.0%), and divorced or widowed (9.5%); and the majority had up to secondary school education (66.9%) compared to those educated up to tertiary level (15.7%) or primary level (15.2%), and those without formal education (2.2%). The full profile of the respondents is shown in Table 2.

#### Clinical characteristics of the respondents

The mean age for dialysis initiation among the respondents was 45.33 (SD=14.82) years old, and the majority (71.9%) had spent less than 5 years on dialysis. DM (48.3%) was the most common aetiological disease of ESRD, and chronic glomerulonephritis (11.8) was the least, among the ESRD patients. DM aetiology (61.2%) was more common among patients on haemodialysis compared to just 21.1% of patients on peritoneal dialysis. The

**Table 2: Sociodemographic characteristics of the respondents (n=178)**

Variable	Total (n)	n (%)	
		Peritoneal dialysis	Haemodialysis
Gender			
Male	88	28 (49.1)	60 (49.6)
Female	90	29 (50.9)	61 (50.4)
Age (years)			
<40	36	20 (35.1)	16 (13.3)
40-60	95	30 (52.6)	66 (54.2)
>60	46	7 (12.3)	39 (32.5)
Ethnicity			
Malay	170	53 (93.0)	117 (96.7)
Non-Malay	8	4 (7.0)	4 (3.3)
Marital status			
Single	32	15 (26.3)	17 (14.0)
Married	129	36 (63.2)	93 (76.9)
Divorced/Widowed	17	6 (10.5)	11 (9.1)
Highest education Level			
None	4	0 (0.0)	4 (3.3)
Primary	27	4 (7.0)	23 (19.0)
Secondary	119	38 (66.7)	81 (66.9)
Tertiary	28	15 (26.3)	13 (10.7)
Employment status			
Student	3	3 (5.3)	0 (0.0)
Employed	99	37 (64.9)	62 (51.2)
Unemployed	36	8 (14.0)	28 (23.1)
Retired	40	9 (15.8)	31 (25.6)
Monthly salary (Brunei \$)			
<500	77	19 (33.3)	58 (47.9)
500-1999	62	22 (38.6)	40 (33.1)
2000-2999	19	7 (12.3)	12 (9.9)
3000-3999	13	5 (8.8)	8 (6.6)
>4000	7	4 (7.0)	3 (2.5)

presence of co-morbidities was common in the study sample, with hypertension being the most prevalent (70.2%). The full clinical profile is shown in Table 3.

#### Correlation between knowledge with socio-demographic characteristics and dialysis modality

The sample ESRD patients (n=178) demonstrated moderate knowledge with an overall mean score of 5.84 (SD=2.29). ESRD patients who were educated beyond secondary school had substantial knowledge with a mean score of 7.36 (SD=2.16) and more than to those with at least secondary school education (mean=5.87, SD=2.17) and those with primary school education or less (mean=4.35, SD=2.30), and the difference was significant ( $P<0.001$ ). Monthly income was also associated with knowledge score, the higher the income the better the knowledge ( $P=0.041$ ) but the difference was only significantly different between those with less than \$500 and those with more than \$2000 income per month ( $P=0.046$ , Post-hoc test). No association was seen between knowledge and dialysis modality ( $P=0.117$ ), age ( $P=0.106$ ), marital status ( $P=0.187$ ) or employment status (0.662) (Table 4).

**Table 3: Clinical characteristics of the respondents (n=178)**

Variable	Total (n)	n (%)	
		Peritoneal dialysis	Haemodialysis
<b>ESRD aetiology</b>			
Diabetes	86	12 (21.1)	74 (61.2)
Hypertension	41	20 (35.1)	21 (17.4)
Chronic GN	21	7 (12.3)	14 (11.6)
Unknown/Others	30	18 (31.6)	12 (9.9)
<b>Comorbidities</b>			
Diabetes	11	3 (5.3)	8 (6.6)
Hypertension	125	27 (47.4)	98 (81.0)
Dyslipidaemia	77	21 (36.8)	56 (46.3)
IHD	19	4 (7.0)	15 (12.4)
Others	92	36 (63.2)	56 (46.3)
<b>Age at start of dialysis (years)</b>			
<40	65	29 (50.9)	36 (29.8)
40–60	83	23 (40.4)	60 (49.6)
>60	30	5 (8.8)	25 (20.7)
<b>Duration on dialysis (years)</b>			
<5	128	36 (63.2)	92 (76.0)
5–10	33	12 (21.1)	21 (17.4)
>10	17	9 (15.8)	8 (6.6)

IHD-Ischaemic heart disease.

### Association of ESRD knowledge with dialysis-related attributes and clinical variables

There was an association between ESRD knowledge and duration on dialysis (<5 and >5 years), the longer the duration the higher the knowledge scores ( $p=0.008$ ). Similarly, the mean scores were also significantly different between age groups (<40, 40-60, and >60 years) at which dialysis was initiated, the younger the patient the better the ESRD knowledge ( $P=0.001$ ), however, post-hoc test revealed no significant difference between the mean score of '40-60 years old' group and '>60 years old group' ( $P=0.962$ ) (Table 4). On the association of ESRD with clinical variables, adherence to dietary restrictions; potassium and phosphate ( $P=0.182$ ), systolic blood pressure ( $P=0.172$ ), diastolic blood pressure ( $P=0.062$ ), IDWG ( $P=0.592$ ) and dialysis adequacy ( $P=0.977$ ) were all not significantly associated with ESRD knowledge.

## DISCUSSION

Our study suggested that a large proportion of dialysis patients in Brunei Darussalam exhibited limited knowledge with regards to their ESRD treatment, with only those educated up to tertiary level (beyond secondary school) having substantial ESRD knowledge. This finding is comparable with other studies which reported a high prevalence of low health literacy among ESRD patients on dialysis (Green et al., 2013; Cavanaugh et al., 2010). Even though, studies have shown that even chronic kidney disease (CKD) patients under the close care of nephrologists demonstrated a

**Table 4: Association between knowledge with socio-demographic and dialysis modality (n=178)**

Variable	n	Knowledge Score Mean (SD)	P- value <sup>a</sup>
<b>Age (years)</b>			
<40	36	6.44 (2.30)	0.106
40–60	95	5.86 (2.22)	
>60	46	5.37 (2.33)	
<b>Marital Status</b>			
Single	32	6.31 (2.13)	0.187
Married	129	5.82 (2.28)	
Divorced/Widowed	17	5.06 (2.49)	
<b>Highest education Level</b>			
None/Primary	31	4.35 (2.30)	<0.001 <sup>b</sup>
Secondary	119	5.87 (2.07)	
Tertiary	28	7.36 (2.16)	
<b>Employment Status</b>			
Employed	99	5.96 (2.33)	0.662
Unemployed	36	5.78 (2.17)	
Retired/Quit	40	5.58 (2.31)	
<b>Monthly Income (Brunei \$)</b>			
≤500	77	5.40 (2.32)	0.041 <sup>c</sup>
501–2000	62	5.95 (2.19)	
>2000	39	6.51 (2.29)	
<b>Started dialysis at age (years)</b>			
<40	65	6.66 (2.15)	0.001 <sup>d</sup>
40–60	83	5.40 (2.27)	
>60	30	5.27 (2.16)	
<b>Duration on Dialysis (years)</b>			
<5	128	5.16 (2.63)	0.008 <sup>e</sup>
>5	51	6.29 (2.32)	
<b>Dialysis Modality</b>			
Haemodialysis	121	5.85 (1.72)	0.117 <sup>e</sup>
Peritoneal	57	6.30 (1.87)	

<sup>a</sup>one-way ANOVA test; SD–Standard deviation; <sup>b</sup>All 3 pairs of mean scores are significantly different by post-hoc test (Scheffe procedure); <sup>c</sup>1 pair of mean scores is significantly different by post-hoc test (Scheffe's procedure); <sup>d</sup>2 pairs of mean scores are significantly different by post-hoc test (Scheffe's procedure); <sup>e</sup>Independent t-test.

poor level of ESRD knowledge (Gray et al., 2016; Wright-Nunes et al., 2011; Finkelstein et al., 2008), an important aspect of our findings suggested that sociodemographic factors, more than clinical factors, determine patients level of ESRD knowledge.

Higher education, higher income, longer dialysis duration, early dialysis initiation (age-wise) showed significant association with having higher ESRD knowledge, but not age, marital status, employment status, dialysis modality, or the extracted clinical variables (blood pressure, adherence to dietary restrictions; potassium and phosphate, intra-dialytic weight gain, and dialysis adequacy). The findings suggest that certain group of patients might have better management skills and greater understanding of the

implication of the disease, which might be attributable to their ability to reason at advanced level due to higher education, resources to afford resourceful materials and information, being on dialysis for so long so much as to warrant or demand knowing more about their disease and treatment, or the occurrence of ESRD early in life which might cause increased curiosity about the ailment. Patient education and adherence to treatment go hand-in-hand (Wells, 2015). The significant roles of knowledge in improving treatment adherence rates have been highlighted in previous studies (Deif et al., 2015; Bland et al. 2008), although this relationship is often underrated, particularly in the non-western settings and patients from Asian cultures (Chan et al., 2012). CKD or ESRD knowledge among South Asians is 'abysmally poor', despite the fact that renal disease burden from diabetes mellitus and hypertension are higher than those reported for western population, thereby highlighting an urgent need for an effective educational program that specifically caters for the population (Jafar, 2016; Deif et al., 2015).

More so, a large percentage of Asian patients have tenuous belief in conventional medical therapy and will seek additional alternative advice and remedies to complement existing treatment (Tan 2013), and many of such patients often require facilitators (usually carers, family members and clinicians) to ensure treatment adherence (Griva et al., 2013). In this case, it has been shown that improved knowledge of the disease together with psychological support are potential trappings for improving patients' adherence to treatment (Wells, 2015). Hence, culturally sensitive support with emphasis on low literacy and language support may be beneficial in improving self-management and care among Asian ESRD patients who may not necessarily have the same learning characteristics as their western counterparts (Tuot et al., 2015; Chan et al., 2012). For example, a cross-sectional study involving 372 ESRD patients on haemodialysis enrolled from 17 dialysis facilities in the United States showed that improved self-management and knowledge amongst patients improve QOL and well-being, and may be associated with less hospitalization and occurrence of morbid events (Curtin et al., 2004). Our study is not without limitations. First, we used univariate tests to determine associations between comparable variables. Second, the ESRD knowledge assessed using our ESRD questionnaire might be comparable with other studies.

In conclusion, the majority of patients demonstrated limited knowledge on ESRD. Sociodemographic factors such as education, income, and ESRD-related attributes such duration of dialysis, and early initiation of dialysis were significantly associated with limited knowledge at univariate level, suggesting the need for educational intervention in those groups. More research should be

carried out to confirm and explore additional barriers that impede ESRD knowledge and determine gaps between its linkage with treatment adherence, considering that adherence to dietary restrictions was not strongly associated with ESRD knowledge in this study.

#### **Acknowledgement**

The authors remain grateful to the Nurses at Rimba Dialysis Centre (RDC), Brunei Darussalam for their help in the data collection phase of this study.

#### **Authors' contributions**

MMA and NAS conceived the idea, collected the data and carried out the statistical analyses; HP, EO, NHJ and LYY designed the project materials and participated in consent taking; RG and MAMK reviewed the project materials and pretested them; CVH and JT wrote the draft and EO critically reviewed the final manuscript. All authors reviewed and approved the final manuscript.

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