

# Barriers to pre-dialysis education in hemodialysis patients with end-stage renal disease in Kingdom of Saudi Arabia

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Received: November 2022 Accepted: December 2022; Published: December 30, 2022.

Citation: Areej I. Al-Hazmi et al. Barriers to pre-dialysis education in hemodialysis patients with end-stage renal disease in Kingdom of Saudi Arabia World Family Medicine. December 2022 - January 2023 Part 2; 21(1):61-69

DOI: 10.5742/MEWFM.2023.95251558

## Abstract

**Background:** Adequate pre-dialysis education was found to help patients select the best modality at the time dialysis is needed.

**Objectives:** To identify the barriers to pre-dialysis education in the nephrology clinics among end-stage renal disease (ESRD) in the Kingdom of Saudi Arabia (KSA).

**Methods:** We did a multi-center, cross-sectional study on 221 patients. A questionnaire was used to collect data about patients' demographics, the primary cause of renal failure, and barriers to pre-dialysis education in the nephrology clinic. We selected the healthcare providers randomly from the same centers.

**Results:** The leading cause of renal failure was diabetes mellitus (DM) in 24.9% of the Patient participants. About 64.7% were with hemodialysis, and 35.3% had peritoneal dialysis. The distance to the nephrology clinic is more than 50 km, about 63.7%. About 65.2% have followed up in the CKD clinic, and dietitians have seen 64.3% in the clinic. Dialysis educators have previously seen 59.7%. About 68.8% of the participants had the chance to understand dialysis modality before the commencement of treatment. The barriers from healthcare participants point out are 43.5 % of participants have no CKD clinic, 74% are without a multidisciplinary team, 61% evaluate more than 15 patients every

clinic, and 43.5% assess patients with advanced chronic kidney disease every three months or more. 47.8% found many services in their hospital required to refer patients to another hospital because lack of nephrologists per 74% of participants, and 39% of them indicated no peritoneal dialysis unit. And 47.8% found no sociopsychology services play a role as a barrier.

**Conclusion:** The barriers to pre-dialysis education studied in this paper from patients and healthcare providers points. That included the deficiency of a formal structured multidisciplinary chronic kidney disease clinic, lack of psychosocial support for CKD patients, and patients required to travel between hospitals more than 50 kilometers to get renal services.

**Key words:** barriers, pre-dialysis, education, hemodialysis, ESRD, Saudi Arabia.

## Introduction

Pre-dialysis education is an important step in the visit before dialysis application. Effective and sufficient pre-dialysis education can delay the progression of chronic kidney disease, and the need for urgent dialysis, prepare patients to make the best modality selection before dialysis is needed and reduce the hospital staying duration (1). This education assures that the patient knows the process, mechanism, benefits, side effects, indications, contraindications, and how to improve the outcomes in the future.

Among Saudi patients, about 20,000 patients are on dialysis (2). It is rapidly growing with increased concern about prolonging survival via decreased risk of cardiac events and improved life quality (3). Most of these patients started on dialysis unplanned using central catheters (4). Pre-dialysis education will influence the choice of home dialysis modality (5).

Conventional hemodialysis is still the most common dialysis modality compared to home modalities such as peritoneal dialysis, which have multiple advantages, especially for a younger patient with end-stage renal disease (6). Even with no mortality superiority associated with peritoneal dialysis, the quality-of-life improvement is an indicator of this modality (7).

The barriers to home dialysis modalities that could affect the situation differ from patient to patient depending on many factors like the patient and doctor's different cultures or languages, different levels of education, and enough time to conduct enough amount of information (8,9). Moreover, in 2007 a study by Dr. Merlin C Thomas was published, which indicated that patients exposed to pre-dialysis education have better control for blood pressure, calcium, and phosphate and less chance for urgent dialysis (10).

This study aimed to identify barriers to pre-dialysis education for end-stage renal disease (ESRD) patients at the nephrology clinic according to patients' and healthcare providers' views. And some solutions will be included as recommendations to improve adherence to pre-dialysis education and enhance cost-effective management.

## Methods

### Study design, setting, and time

A multi-center, cross-sectional, observational study was done in five different dialysis centers around Saudi Arabia from February 2022 to November 2022. The study centers involved the following regions: western, central, eastern, southern, and northern, and variable numbers of patients and healthcare providers were selected.

### Study population

The inclusion criteria for patients were those aged 18 years or higher, who have an end-stage renal disease (i.e. GFR < 15 mL/min/1.73 m<sup>2</sup>), and who are on dialysis. The inclusion criteria for healthcare providers who are involved in dialysis care include nephrologists, vascular surgeons, interventionalists, access coordinators, dialysis nurses, social workers, and clinical pharmacists. The exclusion criteria were patients or healthcare providers unable to consent or complete the interview/questionnaire.

### Sampling technique and sample size

Using the Raosoft sample size calculator; Using 5% as a margin of error and 95% as a confidence interval, and 50% as response distribution, we assume that 230 patients would be adequate to ensure the generalizability of responses. We assume the response rate is 50%, as responses are not known because no identical article was published in Saudi Arabia exist. Fifty-five patients were recruited from each region with a non-probability consecutive sampling technique. A total of 221 patients were included in this study. We excluded nine patients for incomplete forms. We selected the healthcare providers randomly from the same centers.

### Randomization

It is a nonrandomized study. We recorded informed consent for participants. And all the non-eligible or who did not complete the questionnaires are excluded. We collected participants' responses until we reached the target number per region. To minimize selection bias at the patient level, consecutive patients from each center who meet entry criteria were enrolled.

### Data collection and management

Consented patient and healthcare provider participants completed for a pre-tested, validated questionnaire. We collected demographic data, the participant's current modality of dialysis, the duration of the pre-dialysis clinical visits, the availability of a source of information, and the availability of the multidisciplinary medical team.

### Statistical analysis

This study uses a measure of association to identify the relationship between two or more variables. Parametric approaches describe the numerical data, and percentages represent variation. The comparison between groups was made by p-value calculation using the variable rate, and P-values were considered statistically significant at  $P < 0.05$ . The Statistical Package for the Social Sciences version 23.0 was used for analysis (IBM Corporation, Armonk, NY, USA).

## Results

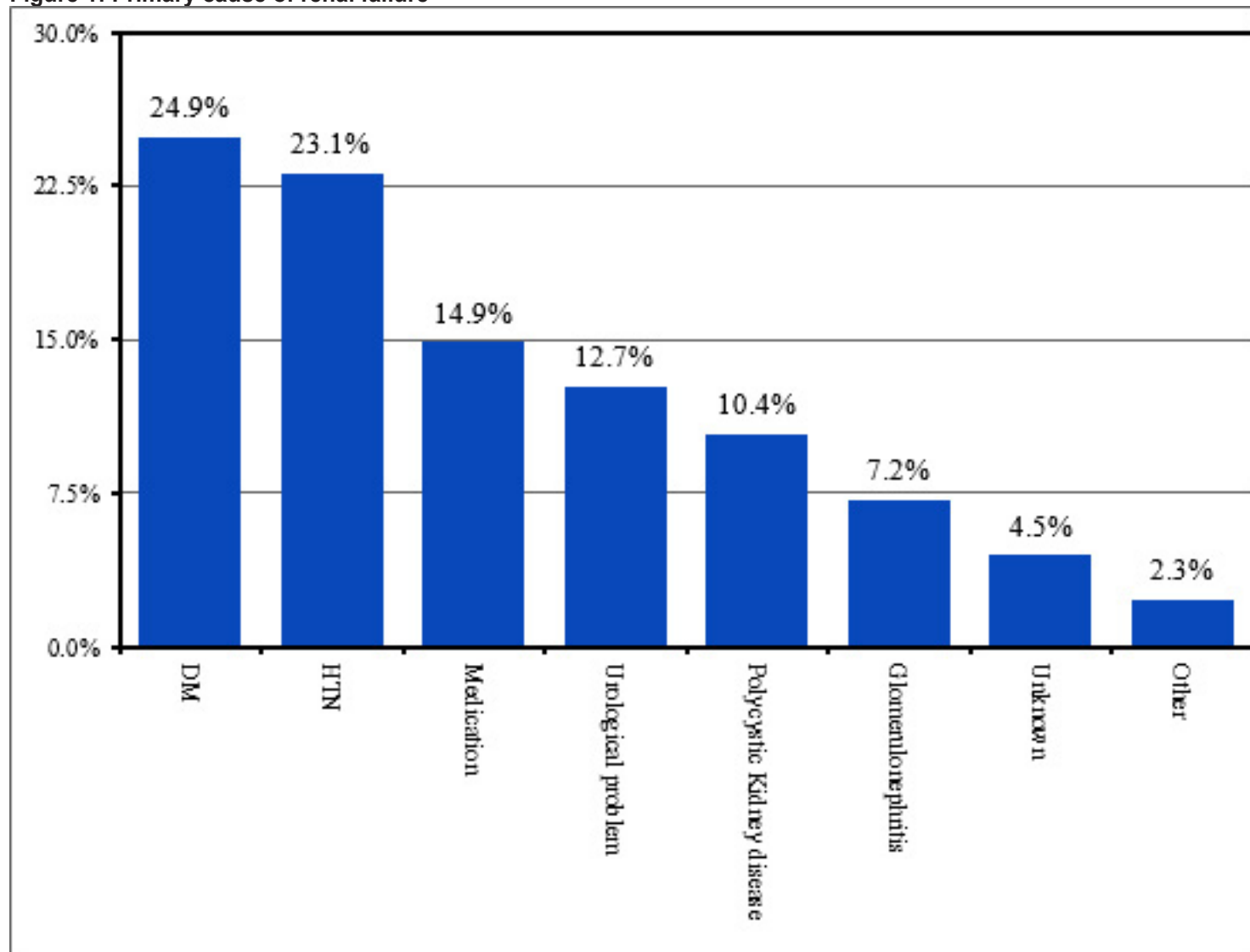
We included a total of 221 participants in the current study. 115 (52%) were females, and 106 (48%) of the participants were males. About 43 (19.5%) of the participants were within the age group of 66 - 75 years old, and 42 (19%) were within the age group of 56 - 65 years old. 34 (15.4%) of the participants were within the age group of 18 - 25 years old, 30 (13.6%) of the participants were within the age group of 26 - 35 years old, 29 (13.1%) were within the age group of 46 - 55 years old. 26 (11.8%) were within the age group of 36 - 45 years old, and 17 (7.7%) were within the age group of 76 - 85 years old. About 61 (27.6%) of the participants were from the western province, 59 (26.7%) were from the eastern, 49 (22.2%) were from the southern, 43 (19.5%) were from the central, 9 (4.1%) were from the northern province. Regarding dialysis modalities, about 143 (64.7%) of the participants were with hemodialysis and found 78 (35.3%) to be with peritoneal dialysis (Table 1).

**Table 1: Characteristics of the study participants (n=221)**

Variable	Category	Frequency	Percent
Gender	Male	106	48%
	Female	115	52%
Patient age (in years)	18 - 25	34	15.4%
	26 - 35	30	13.6%
	36 - 45	26	11.8%
	46 - 55	29	13.1%
	56 - 65	42	19%
	66 - 75	43	19.5%
	76 - 85	17	7.7%
Province	Western	61	27.6%
	Central	43	19.5%
	Eastern	59	26.7%
	Southern	49	22.2%
	Northern	9	4.1%
Primary cause of renal failure	DM	55	24.9%
	HTN	51	23.1%
	Medication	33	14.9%
	Urological problem	28	12.7%
	Polycystic Kidney disease	23	10.4%
	Glomerulonephritis		
	Unknow	16	7.2%
	Other	10	4.5%
Dialysis Modalities	Hemodialysis	143	64.7%
	Peritoneal Dialysis	78	35.3%

We found the cause of end-stage renal disease in about 55 (24.9%) of the participants is diabetes mellitus (DM), hypertension was in about 51 (23.1%) of the participants, medications were the cause in about 33 (14.9%) of the participants, 28 (12.7%) of the participants, the cause was to be a urological problem; and polycystic kidney disease was the cause in about 23 (10.4%), Glomerulonephritis was the cause in about 16 (7.2%) of the participants, 10 (4.5%) with unknown cause, and in about 5 (2.3%) the cause of the end-stage renal disease was another cause (Figure 1).

**Figure 1: Primary cause of renal failure**



Approximately 69 (31.2%) of the participants were diagnosed with chronic kidney disease (CKD) less than six months before starting dialysis, 64 (29%) within 6 months to 1 year, 41 (18.6%) at the same time started hemodialysis, 34 (15.4%) about 1 to 3 years before starting dialysis, and 13 (5.9%) of the participants were diagnosed with CKD more than three years before starting dialysis. About 148 (67%) had a previous follow-up in the nephrology clinic, and the remaining participants, 73 (33%), with no follow-up. 68 (30.8%) had followed up in the clinic for less than six months, 63 (28.5%) followed up six months to one year, 64 (29%) had followed up six months to one year, 46 (20.8%) had 1 to 3 years follow up, and 44 (19.9%) had followed up in nephrology clinic for more than three years. 150 (67.9%) had a nephrology clinic in the same city of their living, 80 (36.2%) the distance to the clinic was less than 50 kilometers (km), 58 (26.2%) distance was 50 to 100 (km) distance, 35 (15.8%) was from 101 to 200 km, and found the space to be more than 200 km for about 48 (21.7%) of the participants.

Concerning the frequency of follow-up, about 71 (32.1%) of the participants followed up every four months, 64 (29%) every three months, 60 (27.1) twice a year, and 26 (11.8%) followed up every month. About 144 (65.2%) were followed up in the CKD clinic, and 142 (64.3%) were seen by a dietitian. The dialysis educator evaluated about 132 (59.7%) of the participants were evaluated by a dialysis educator. Only 94 (42.5%) of the participants had previously been seen by a social worker, and 152 (68.8%) of the participants had the chance to understand dialysis modality before the commencement of treatment (Table 2).

The questionnaire healthcare participants raised many barriers to pre-dialysis education, 43.5 % of participants have no CKD clinic in their institution, 74% without a multidisciplinary team, 61% evaluate more than 15 patients every clinic, and 43.5% of them assess patients with advanced chronic kidney disease every three months or more. Also, 47.8% found many services in their hospital required to refer patients to another hospital because lack of nephrologists per 74% of participants, and 39% of them indicated no peritoneal dialysis unit. Approximately 74% thought one of the significant barriers is difficulty accepting dialysis as a treatment by patients, and 47.8 found no sociopsychology services play a role as a barrier (Table 3).



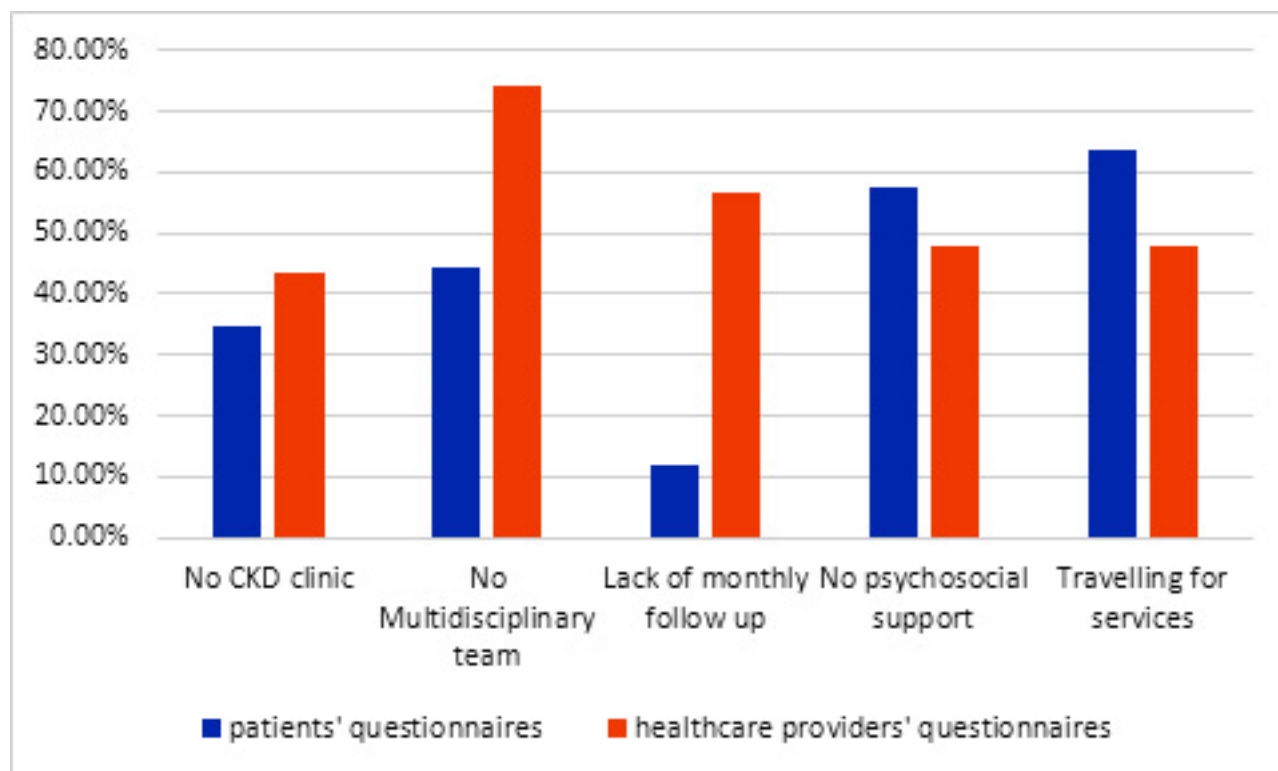
Table 2: Barriers to pre-dialysis education according to patients' questionnaires

Variable	Category	Frequency	Percent
The time from diagnosis to dialysis started	The same time	41	18.6%
	Less than 6 months	69	31.2%
	6 months to 1 year	64	29%
	1 to 3 years	34	15.4%
	More than 3 years	13	5.9%
Seen in nephrology clinic	Yes	148	67%
	No	73	33%
Assessment duration	Less than 6 months	68	30.8%
	6 months to 1 year	63	28.5%
	1 to 3 year	46	20.8%
	More than 3 year	44	19.9%
The nephrology clinic in your same city	Yes	150	67.9%
	No	71	32.1%
The distance to the clinic	Less than 50 KM	80	36.2%
	50 to 100 KM	58	26.2%
	101 to 200 KM	35	15.8%
	More than 200 KM	48	21.7%
Follow-up frequency per year	Twice a year	60	27.1%
	Every 4 months	71	32.1%
	Every 3 months	64	29%
	Every month	26	11.8%
Follow-up in CKD clinic	Yes	144	65.2%
	No	77	34.8%
Dietitian assessment in the clinic	Yes	142	64.3%
	No	79	35.7%
Dialysis educator assessment	Yes	132	59.7%
	No	89	40.3%
Social worker evaluation	Yes	94	42.5%
	No	127	57.5%
Understand dialysis modality before starting on dialysis	Yes	152	68.8%
	No	69	31.2%

**Table 3: Barriers to pre-dialysis education according to healthcare providers' questionnaires**

Variable	Percent
Number of nephrologists in hospital 4 or less	74%
No CKD clinic	43.5%
No Multidisciplinary team	74%
Patients assessment in clinic every month	56.5%
Number of patients per clinic 15 or more	61%
Patients have difficulty to accepted dialysis as a treatment.	74%
No psychology service	47.8
No peritoneal dialysis unit	39%
Some services need a referral to another hospital	47.8

When we compare patients' and healthcare providers' responses to the significant barriers, both groups react similarly to the lack of a chronic kidney disease clinic, no social or psychological support, and many services that need to travel between hospitals ( Figure 2).

**Figure 2: The significant barriers to pre-dialysis education, according to patients and healthcare providers**

From the healthcare provider's perspective, the no presence of the multidisciplinary team was a significant barrier with a p-value of 0.03. The lack of monthly follow-up was a significant barrier from the patients' perspective, with a p-value < 0.0001 ( Table 4).

**Table 4: The significant barriers to pre-dialysis education, according to patients and healthcare providers**

Variable	Patients' questionnaires	Healthcare providers' questionnaires	p value
No CKD clinic	34.8%	43.5%	0.5
No Multidisciplinary team	44.5%	74%	0.03
Lack of monthly follow up	11.8%	56.5%	< 0.0001
No social or psychological support	57.5%	48%	0.58
Travelling more than 50 km is required for services	63.7%	47.8%	0.36

## Discussion

Assessing barriers to pre-dialysis education is of significant importance as pre-dialysis education for chronic kidney disease patients can help them choose the dialysis modality that best meets their needs and preferences (11). One study found that multidisciplinary pre-dialysis education decreased the mortality rate in end-stage renal disease (12). The current study aimed to identify the barriers to pre-dialysis education in the nephrology clinic.

The demographic characteristics in the paper covered gender, which was equal distribution between males and females. We involved almost all ages, from 18 to 85 years old. The dialysis centers were the sampling source for patients. This population can evaluate pre-dialysis care in general and education in specific and use their experience to highlight the barriers, especially for patients who used peritoneal dialysis. Interestingly we found only one-third 35.3% to be with peritoneal dialysis, and this percentage of participants is similar to the study carried out by Dahlan et al. in which the lack of pre-dialysis education was one of the barriers to considering peritoneal dialysis in 61.6% of participants (13). We included the primary cause of end-stage renal disease; Diabetes Mellitus was the most common cause, a parallel to the study conducted by Al-Sayyari et al. study about CKD in Saudi Arabia (14). It indicates that most patients have chronic conditions, so it is possible to detect chronic kidney disease earlier to benefit from pre-dialysis care.

The Narva et al. study assessed the barriers to pre-dialysis education in the United States. They divided the barriers into three levels patients, healthcare providers, and system levels. They have many similar findings to our study, such as needing a multidisciplinary team, more formal CKD clinics, and limited patient numbers in each clinic. Also, they were looking for methods to improve education using

multimedia and engaging family and groups to support, which is different from this study. They advised focusing on advanced kidney disease patients, one of the inclusions we concentrate on in this paper (15).

Regarding the frequency of the follow-up, 11.8% of the total patients were followed up in the clinic every month from the patients' questionnaire. The explanation for the result is a late diagnosis in many patients and the long distance to the hospital with nephrology services. That differ from the healthcare provider's questionnaire, which indicated 56.5% of the total patients were followed up monthly. The difference in results explains that most patients with earlier diagnoses are the ones who attend the nephrology clinic. The monthly follow-up for stages 4 and 5 carried benefits such as planning access and monitoring for the disease progression. Hirano et al, suggested a frequency of 1.2 months is the suitable follow-up every month for stage 5 CKD (16).

The lack of CKD clinic assessment was similar between the two groups' responses. It has many factors, according to patients, such as late diagnosis, difficulty in accepting dialysis as a treatment, and traveling distance. The healthcare provider's factors included a lack of nephrologists who would influence the pre-dialysis education per one study (17) and no multidisciplinary team. This clinic carries many advantages, such as early planning for access, delayed progression, and providing patients with social support. White et al. found it improves the patient quality of life (18). The traveling distance was a barrier between the two groups; it carried the risk of non-adherence for the follow-up. Also, it is associated with an increased risk of developing complications or death, as stated in the Tonelli et al. study (19).

Collister et al., a scoping review, discussed the importance of multidisciplinary chronic kidney disease clinics beyond mortality reduction or decreased disease progression. It is

cost-effective for the health care program in the country. No single service in the multidisciplinary team will improve pre-dialysis education, but it combines multiple benefits (20). In our study, the lack of an interdisciplinary team was the primary concern of the healthcare provider. It was the same from the patient's perspective if we collected their response to each service in the team, mainly social worker evaluation that explains the difference in response between the two groups. The lack of psychosocial support was a significant concern for both groups. A meta-analysis by Pascoe and his group found psychosocial support helps reduce anxiety and depression among chronic kidney disease patients (21).

About 59.7% of the patient's participants had previously seen by dialysis educator, and two-thirds had the chance to understand dialysis modality before the commencement of treatment. Compared with Alghamdi et al. study, only 35.2% of the participants received dialysis education (22). Despite the exposure to education, it did not affect dialysis modality choice or decreased progression in this population. It increased the need for a formal pre-education program, as recommended by other studies (22).

The study limitation is a small sample size and the use of a self-reported questionnaire that could have a recall bias. And to formal assessment for the type of education that some patients receive, because patients have a different level of awareness and their response to new knowledge is variable, there are many new methods of teaching using digital media or telehealth that we need to consider in further study (23). The study's strength involved patients and healthcare providers comparing their responses, which helped to detect the lack of CKD clinics and the weak role of a multidisciplinary team; we recommend further working in a formal structure of multidisciplinary CKD clinic inspired by the culture of Saudi Arabia. Another strength involved many factors such as traveling distance and social support that raise the concern to work on them, given the small numbers of studies on these two factors among chronic kidney disease patients. The sample selection included patients from all the regions in the country, which is a strength of this study.

## Conclusion

The pre-dialysis education has a significant role to reduced mortality, delaying chronic kidney disease progression, and early planning for access. The barriers to pre-dialysis education studied in this paper from patients and healthcare providers points. That included the deficiency of a formal structured multidisciplinary chronic kidney disease clinic, lack of psychosocial support for CKD patients, and patients required to travel between hospitals more than 50 kilometers to get renal services. Efforts should be directed towards more concentration on pre-dialysis education, which will lead to more patients' understanding of their condition and improve the quality of medical services provided, which will positively affect patients' decision-making and well-being.

## Acknowledgment

The authors gratefully acknowledge the cooperation of all participant patients and health care providers.

## Funding

None.

## Conflicts of interest

No conflicts related to this work.

## Ethical consideration

An ethical approval for the study was obtained from the research ethics committee of Approval of faculty's ethical committee of Al-Baha university, Saudi Arabia.



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