

**UNIVERSITY OF SOUTHAMPTON**

**FACULTY OF HEALTH SCIENCES**

**Pre-Dialysis Education and Information and the Relationship to Dialysis  
Treatment Type in the Kingdom of Saudi Arabia**

by

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Thesis for the degree of Doctor of Clinical Practice

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## **ABSTRACT**

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### **PRE-DIALYSIS EDUCATION AND INFORMATION AND THE RELATIONSHIP TO DIALYSIS TREATMENT TYPE IN THE KINGDOM OF SAUDI ARABIA**

Reem Saeed Alhameedi

Patients with End Stage Renal Disease (ESRD) face major challenges in their lives regarding dialysis therapy for survival, challenges which include making informed treatment choices. No research has been found which investigates what information, or education, patients in the Kingdom of Saudi Arabia (KSA) receive, nor what factors influence the choices made and treatments gained. This issue has been the impetus for this survey research that was designed to determine what information patients in KSA have been given and to identify patients' perceptions of the factors that influence the treatment they receive. The data will be used to develop recommendations informing pre-dialysis education for ESRD in KSA.

The questionnaire from the USA study by Mehrotra et al. (2005) was utilised, with additional questions related to patients' views and recommendations for pre-dialysis education. ESRD patients who were  $\geq 18$  years and who had been receiving dialysis, for at least 3 months to 1 year, were recruited from four hospitals in the western region of the KSA.

Ninety-two patients out of 100 patients recruited completed the questionnaire (a response rate of 92%). The majority (61.9%) of participants were receiving haemodialysis (HD); 38% received peritoneal dialysis (PD). Nearly 20% of patients were not given any option about which treatment they received, although for many this was for clinical reasons. Almost 60% of patients were given a delayed treatment option; i.e. they received an option either after their treatment commenced or less than 1 month before they started dialysis. There was a significant association between participants rating the dialysis education/information as 'poor' or 'totally inadequate' and receiving HD ( $p=0.000$ ) and between patients' needs for additional information and treatment type (HD) ( $p=0.000$ ). Binary logistic regression indicated that having someone at home to help with treatment was a predictor for patients who opted for PD.

The study provided evidence that just under 20% had no, or delayed, presentation of treatment options. Just over 60% of patients were placed on HD and generally were not satisfied. Recommendations to improve pre-dialysis education include the patient's right to be informed about available treatment options, the provision of more educational materials, and increased time to be spent on education for patients. The provision should be adjusted according to patients' needs, level of education, and consideration made of family involvement in decisions.



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# DECLARATION OF AUTHORSHIP

I, REEM ALHAMEEDI

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## **Pre-Dialysis Education and Information and the Relationship to Dialysis Treatment Type in Kingdom of Saudi Arabia**

and the work presented in the thesis are both my own, and have been generated by me as the result of my own original research. I confirm that:

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# Definitions and Abbreviations

APD	Automated Peritoneal Dialysis
BUN	Blood Urea Nitrogen
BMI	Body Mass Index
CAPD	Continuous Ambulatory Peritoneal Dialysis
CKD	Chronic Kidney Disease
CHF	Congestive Heart Failure
CAD	Coronary Artery Disease
CM	Conservative Management
CG	Control Group
CASP	Critical Appraisal Skills Programme
DM	Diabetes Mellitus
ERBP	European Renal Best Practice
EG	Experiment Group
EP	Education Process
ESRD	End Stage Renal Disease
EKPF	European Kidney Patients Federation
eGFR	estimated Glomerular Filtration Rate
INDIAL	Information on Dialysis
GFR	Glomerular Filtration Rate
GOVNon-MOH	Governmental Non-Ministry of Health
HBM	Health belief model
HD	Haemodialysis
HDL	High Density Lipoprotein
HTN	Hypertension
KDOQI	Kidney Disease Outcomes Quality Initiative
LL	Literacy Level
MoH	Ministry of Health

PDA's	Patient Decisions Aid Tools
PD	Peritoneal Dialysis
RCTs	Randomised Controlled Trials
RRT	Renal Replacement Therapy
RRTOE	Renal Replacement Therapy Options Education
REALM	Rapid Estimate of Adult Literacy in Medicine
SCOT	Saudi Centre for Organ Transplantation
S-TOFHLA	Short Test of Functional Health Literacy in Adults
TRA	Theory of Reasoned Action
TPB	Theory of Planned Behaviour

# 1. Chapter 1 Introduction

## 1.1 Introduction

The aim of this research study has been to examine the pre-dialysis education and information provided to patients with end-stage renal disease (ESRD) in the western region of the Kingdom of Saudi Arabia (KSA), as well as investigating the factors the patients themselves perceived as influencing the type of dialysis treatment they received. The purpose was to develop recommendations to enhance pre-dialysis education programmes for ESRD patients in western SA.

This chapter provides the context for the study. It is important to note that the initial focus changed during the study. I originally set out to examine pre-dialysis education across the eight hospitals in one region of KSA. The pilot phase was conducted at the hospital where I worked as a dialysis nurse and as an educator. This hospital had a nephrology clinic and dialysis clinic available for patients with ESRD, but the provision of information about treatment options was not clear. My experience as a nurse in this hospital (see section 1.6) led me to believe that it was important to inform patients, who were undergoing treatment, about the options available for them. However, when I progressed to the main study, following an initial contact with hospitals, it was not clear if the hospitals provided a structured pre-dialysis education programme for their ESRD patients or if they did not.

For the main study, four out of eight hospitals in the western region agreed to take part in the study. Three of the others were military hospitals and did not wish to participate, and another hospital was not possible to reach or contact after several attempts were made. From the initial work, it was evident that the four hospitals in the main study only provided patients with limited information, which varied and therefore could not be construed as an educational programme. This finding was subsequently supported by the data from the main study. For example, the results showed that the patients in these hospitals did not feel they received valuable 'education' as such, because the time spent in listening to information was "too short" and also that the provided information about the available treatment options was inadequate. As a result, I changed the focus of the study to examine what information *or*

education patients with ESRD were receiving about renal replacement therapy (RRT) in the KSA, and what their views were about the appropriateness of that information. Even though the focus of the study was refined in order to reflect the actual context, and obtain the best data to address the revised research questions, the ultimate aim of this study: ‘to develop recommendations for pre-dialysis education programmes for ESRD patients in the KSA’, remained unchanged.

This chapter begins by considering the topics of kidney function, kidney failure and ESRD. Specifically, it provides an overview of ESRD, its epidemiology and how it is treated. The current treatment utilisation rates worldwide and in the KSA, the setting for the research, are also examined. Finally, to establish the context, the history of dialysis treatment in the KSA is also reported.

## **1.2 Kidney function and failure**

A description of the function of the kidneys, and their impact on people’s health when they fail, is provided in this section. The principal function of the kidneys is to keep the composition of the extracellular fluid (consisting of salt, acid nutrients, and other constituents) constant, in order to maintain a stable internal environment (homeostasis) for optimal cell and tissue metabolism. Kidney function is assessed by the glomerular filtration rate (GFR), which is the volume of fluid filtered by the kidneys per unit of time (Kahan and Ashar (2008). The kidneys regulate the excretion of water, salt, potassium, calcium, acid, and many other elements, whatever the intake of these substances may be (Walser & Thorpe 2010). The kidneys also play a vital role in the production of Vitamin D and various hormones, including:

- Angiotensin: which raises blood pressure by constricting blood vessels;
- Aldosterone: an important regulator of sodium excretion;
- Erythropoietin: a hormone that stimulates the bone marrow to produce more red cells when needed; and
- Prostaglandins: which help regulate blood pressure, sodium excretion and other functions.

Kidney failure occurs because there is a loss of some (but not all) of the organ's filtration capacity, which is clinically identified by a reduced GFR. Many kinds of kidney disease, such as *acute* kidney failure, are rapidly reversible. However, *chronic* kidney failure is generally irreversible and often progressive



(Walser & Thorpe 2010). The Kidney Disease Outcomes Quality Initiative (KDOQI guidelines 2002) identifies the five stages of chronic kidney disease (CKD), the classification of which is based on the presence of kidney damage and/or the level of kidney function (Goolsby 2002) (see Table 1.1). This study focuses on patients with ESRD who are at stage 5CKD i.e. when the kidneys go into failure. Without treatment, such condition is life threatening.

**Table 1.1 Classification of chronic kidney disease (CKD)**

Stages	Description	GFR (ml/min/1.73 m <sup>2</sup> )
1	Kidney damage with normal or (High)↑ GFR	≥90
2	Kidney damage with mild (Low)↓ GFR	60-89
3	Moderate (Low)↓ GFR	30-59
4	Severe (Low)↓ GFR	15-29
5	Kidney failure (ESRD)	<15 (or dialysis)

### 1.2.1 The definition and characteristics of End-Stage Renal Disease

In most patients with ESRD, the kidneys are no longer capable of removing waste products from the patient's circulating blood, and the GFR falls to <15 ml/min/1.73 m<sup>2</sup> (Kahan & Ashar 2008). The estimated GFR is thus the best overall index of the level of kidney function. It can be estimated from serum creatinine levels using predictive equations, namely the Cockcroft-Gault equation and the Abbreviated MDRD (Modification of Diet Study equation) (Levey et al. 2003), which also considers the person's age, sex, race, and body size; men are more susceptible to kidney failure than women. Genetic and familial predisposition for kidney failure are risk factors, while polycystic kidney disease, diabetes mellitus (DM), and hypertension (HTN) are common causes of ESRD globally (Walser & Thorpe 2010). In the KSA, DM and HTN are the major causes of ESRD (SCOT 2010). Patients with ESRD must confront physiological and psychological challenges including chronic fatigue, dietary and fluid restrictions, changes in economic status, and the high cost of healthcare (Clarkson & Robinson 2010). Kidney disease is therefore an important healthcare concern because of the economic costs of renal replacement, as well as the effect on patients' quality of life (Monfared et al. 2009). RRT is expensive and consumes a large proportion of any country's health budget relative to the number of patients (Drukker et al. 2012). Reports

of the cost of both HD and PD in 46 countries across the world (20 developed and 26 developing) show that the cost of HD was between 1.25 and 2.35 times the cost of PD in 22 countries, and between 0.22 and 0.90 times the cost of PD in 9 countries (1 developed and 8 developing). Developed countries can provide PD at less cost than HD. In developing countries data were mixed, but in most cases PD can be provided at similar cost to HD (Karopadi et al. 2013).

### 1.2.2 Epidemiology of End-Stage Renal Disease

The prevalence rates and the impact of ESRD disease vary across the world and between different countries. There is evidence that the number of patients with ESRD worldwide is increasing (Klarenbach et al. 2014). Estimates have suggested that the prevalence in Japan is higher than 2,000 per million population (pmp), while it is approximately 1,500 pmp in the United States and 800 pmp in the European Union (Barsoum 2006). The mean prevalence of ESRD in the Middle East was estimated (in 2009) to be lower, at 430 pmp, with the total number of patients with ESRD standing at 100,000 (Najafi 2009). However, a Saudi report estimated the prevalence of ESRD in the KSA in 2015 to be 1,100 pmp (Al-Sayyari & Shaheen 2011). The rapidly increasing global incidence rate of ESRD explains the significant attention being paid to CKD worldwide, as well as the considerable cost of RRT (Barsoum 2006). The prevalence rates and the impact of kidney disease vary across the world, depending on different countries.

## 1.3 Renal Replacement Therapy

When patients acquire ESRD, kidney function can only be replaced by dialysis or by kidney transplantation. Kidney transplantation is considered the modality of choice for suitable patients (Maxwell & Physicians 2008). However, lack of organ availability, increasing patient age, and the burden of comorbid disease limit transplantation for most ESRD patients (Mendelssohn et al. 2009). As a result, planning for dialysis usually begins during Stage 4 of the patient's CKD. In medicine, dialysis refers to "*the clinical purification of blood, as a substitute for the normal function of the kidney*" (Oxford 2013a). The two types of dialysis are haemodialysis (HD) and peritoneal dialysis (PD). HD involves circulating the patient's blood through an extracorporeal device, where it is exposed to an isotonic dialysis solution through a semi-permeable membrane

(Maxwell & Physicians 2008). HD is generally performed in the hospital but can also be done at home. In PD, the peritoneal membrane is used as a semi-permeable membrane. A volume of dialysate solution, or dextrose-containing salt solution, is infused into the peritoneal cavity. Waste products and extra water then move away from the blood capillaries surrounding the peritoneal cavity by diffusion and osmosis (Daugirdas et al. 2006). Before the patient begins PD, a catheter must be inserted surgically into the abdomen (Daugirdas et al. 2001). PD is generally performed at home but can be done in the hospital.

### **1.3.1 Haemodialysis**

HD involves the removal of waste products, such as creatinine and urea, by diffusion,<sup>1</sup> and the removal of excess water by ultrafiltration<sup>2</sup> from the blood by the use of a dialyser (Henrich 2012). HD can be performed on either an intermittent or a continuous schedule. A continuous schedule is usually preferable in critical care, providing 24 hour control, and continuous arterio-venous haemofiltration (CAVH). Blood is diverted, usually from the femoral artery, and returned to the femoral vein (Walker & Whittlesea 2011). This type of treatment can be done in a centre or at home. The cost of HD is considerable, as it requires specially trained staff and is seldom undertaken outside of a dialysis unit (Walker & Whittlesea 2011). On the other hand, the availability of home HD varies from country to country, depending on national policies and local medical opinion. It is estimated to be used in only 10% of all patients receiving HD throughout the world (Drukker et al. 2012).

#### **1.3.1.1 Advantages and disadvantages of haemodialysis treatment**

HD is an effective method to remove waste products. It is undertaken by trained professionals at dialysis centres and thus its success relies heavily on the competence of the staff using the method (Maxwell & Physicians 2008).

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<sup>1</sup> Diffusion describes the spread of particles through random motions from a region of high concentration to a region of lower concentration

<sup>2</sup> Ultrafiltration is a variety of membrane filtration in which hydrostatic pressure forces a liquid against a semi-permeable membrane. Solids and solutes of high molecular weight are retained, while water and low molecular weight solutes pass through the membrane

HD can be performed intermittently, which allows for time off the treatment, and dialysis is separated from the home environment (Maxwell & Physicians 2008). Another advantage of HD is that it does not require the patient to have supplies and equipment at home (Wuerth et al. 2002). HD can also be used in patients who have undergone recent abdominal surgery or for whom PD is not suitable (Walker & Whittlesea 2011).

However, there are two types of complications to be considered: vascular-related complications and dialysis-related complications. The main problems of HD are those associated with vascular access. For example, thrombosis is the most common cause of short-term access failure and hospitalisation. Infection is the second most common form of vascular access loss in long-term HD patients (Challinor & Sedgewick 1998). A complication related to dialysis is disequilibrium syndrome, which consists of headache, nausea and confusion, resulting from the rapid removal of urea from the extracellular fluid, rather than from the brain, which leads to cerebral oedema (Siroky et al. 2004). Other common complications are bleeding, vomiting, muscle cramps, and hypotension during dialysis sessions. The disadvantages of HD also include the physical fluctuations of the patients, the use of needles, the dietary restrictions, and the need for transportation to and from the dialysis centre (Wuerth et al. 2002).

### **1.3.2 Peritoneal dialysis**

In PD, the peritoneal membrane is a semi-permeable membrane. A volume of dialysate solution, or dextrose-containing salt solution, is infused into the peritoneal cavity. Waste products and extra water will move away from the blood capillaries surrounding the peritoneal cavity by diffusion and ultrafiltration (Daugirdas et al. 2006). For a patient to start PD, a catheter must be inserted surgically into the abdomen.

#### **1.3.2.1 Advantages and disadvantages of peritoneal dialysis**

The main advantages of PD are its portability and low cost. It is also easy to learn, although training is required. This treatment method allows for gradual fluid removal (Henrich 2012). The anaemia in ESRD patients is also less severe with PD, due to lower blood loss (Khanna & Krediet 2009). Other advantages according to patients are: greater independence and control, flexible treatment

schedule, less restricted diet, care managed at home, and no needles are required (Wuerth et al. 2002).

On the other hand, the main disadvantages of PD are the complications associated with the access, as well as those associated with the actual procedure. The most common complications are infection, such as peritonitis and exit site infection, and peri-catheter leakage, which usually becomes evident soon after dialysis initiation, as a result of the misplacement of the catheter. Outflow failure is another complication, as is hernia formation, due to increased intra-abdominal pressure from the installation of dialysis fluid into the peritoneal cavity (Henrich 2012). Lipid derangement is common because of using a dextrose dialysis solution, which can result in high glucose absorption (Henrich 2012). Inadequate dialysis can occur because the peritoneal membrane may lose its permeability because of recurrent peritonitis. Other practical disadvantages are: permanent catheter and daily dialysis, body image changes, and the need for storage space for supplies (Wuerth et al. 2002).

The following are the two types of PD identified by Daugirdas et al. (2001):

#### **1.3.2.2 Continuous Ambulatory Peritoneal Dialysis (CAPD)**

In Continuous Ambulatory Peritoneal Dialysis (CAPD), dialysis solution is infused into the abdomen frequently, about four to six times per day. The procedure is performed manually and depends on gravity for solution movement into, and out of, the abdomen.

#### **1.3.2.3 Automated Peritoneal Dialysis (APD)**

In Automated Peritoneal Dialysis (APD), a machine (referred to as a cycler) is used to automatically cycle dialysis solution into, and out of, the abdominal cavity. The patient carries the PD throughout the day but performs no exchanges. At bedtime, the patient hooks up to an automated cycler for between 8 to 12 hours, and the cycler machine will move dialysis solution in and out of his/her abdomen during the course of the night. In the morning, after the dwell period (the time that dialysis solution remains in the abdominal cavity), the patient disconnects from the cycler and is free to go about daily activities.

Both types of PD have advantages and disadvantages. For instance, CAPD has the advantage of being cost effective and has no need for electricity, as it can be performed manually anywhere, 24 hours a day. On the other hand, APD is more expensive, electricity is always needed, it is difficult to transfer, and dialysis can only be performed for a maximum of 12 hours a day (Daugirdas et al. 2006).

However, patients on APD can carry out their daily activities more freely than patients on CAPD, as there are no exchanges during daytime. Also, a great advantage of APD is the ability of the machine to calculate the timing of the exchanges; also and the patient does not have to wait for a draining period (Daugirdas et al. 2006).

### **1.3.3 Dialysis Modality Utilisation**

HD is the most common treatment modality worldwide for ESRD (Cosgrove 2011). To illustrate the balance between HD and PD, Jain et al. (2012) estimated that, in 2008, there were approximately 196,000 patients, from 130 countries worldwide, using PD; however this represents just 11% of the dialysis population. Nevertheless, the use of PD/HD varied greatly between countries, with estimates of PD utilisation ranging from 6% to 74%. In 2007, Mexico had the largest population using PD in the world, with 74% of patients on PD and 26% on HD (Cueto-Manzano & Rojas-Campos 2007). In the UK, the renal registry reported that, after 90 days of dialysis treatment, 70% of ESRD patients received HD, 20% received PD and 10% had functioning kidney transplants (Castledine et al. 2014). In the USA, the prevalence of PD is approximately 7% compared to more than 90% for HD (Chaudhary et al. 2011). This is similar to other countries, where the proportion of ESRD patients being treated by HD in Korea, Malaysia, and Taiwan is 80%, 88%, and 91.5%, respectively (Li et al. 2011). Japan, however, has the lowest proportion (>4%) for PD patients compared to other countries (Mizuno et al. 2011).

### **1.3.4 History of dialysis in the KSA**

There is little 'official' data regarding the practice of dialysis in developing countries, mainly due to a lack of renal registries. Since the early 1970s, major developments in RRT in the KSA have included the expansion of clinical

services, with a governmental focus and emphasis being placed on providing more services. The available report from the KSA identified that, in 2010, there were 177 dialysis centres in the KSA, with 4,264 machines (HD) catering for 11,437 (55.1%) patients on HD and only 1,196 (5.7%) patients on PD (SCOT 2010). See Table 1.2 for details of the number of patients from 2006 to 2010 and the treatments they received, plus transplantations and follow-up rates (SCOT 2010). These figures show that there is not much difference in the increase in provision between the two forms of dialysis; however, what can be observed is that HD still significantly exceeds PD.

**Table 1.2 Distribution of renal replacement therapy in KSA (SCOT Data)**

<b>Year</b>	<b>Total Patients on RRT</b>	<b>Transplantation and Post-Follow-Up N (%)</b>	<b>Patients on Haemodialysis N (%)</b>	<b>Patients on Peritoneal Dialysis N (%)</b>
2006	17,705	8,172 (46.1%)	8,761 (49.4%)	772 (4.3%)
2008	19,334	8,166 (42.2%)	10,203 (52.7%)	965 (4.9%)
2009	20,113	8,073 (40.1%)	10,928 (54.3%)	1,112 (5.5%)
2010	20,731	8,098 (39%)	11,437 (55.1%)	1,196 (5.7%)

There appears to be a number of reasons why PD is not used as often as HD in the KSA. In the KSA patients are offered PD as an alternative therapy when HD or transplantation is unavailable, which can give patients the impression that they are being offered a second-class treatment option (Abu-Aisha & Paul 1994). Some patients are not offered PD for clinical reasons, such as lack of vein/arterial access or cardiovascular instability (Youmbissi et al. 2001). The greater use of HD may be due to physician bias, which has been reported to be the most limiting factor in the KSA (Souqiyyeh & Shaheen 2006). Some nephrologists consider PD unsuitable for patients in the KSA because patients are often not well-educated and have low treatment compliance, which results in high infection rates (Abu-Aisha & Paul 1994). These findings may explain the lower rates of PD use in the KSA compared to other countries. Studies by Abu-Aisha and Paul (1994) and Souqiyyeh and Shaheen (2006) both confirmed that the use of PD did not vary over the 12 year period from 1994 to 2006. No

other studies in the KSA have been found which have explored how patients were placed on dialysis treatment, or what factors influence the type of dialysis treatment provided.

## **1.4 Professional focus**

When patients with CKD reach ESRD, they need to deal with the challenges of requiring dialysis therapy for their survival. When patients reach ESRD, they need to understand their illness, available treatments, and the impact that ESRD will have on their lives. Therefore, early education of patients can offer potential benefits in treatment outcomes, by reducing anxiety and maximising intervention (Clarkson & Robinson 2010). However, patient education that merely provides patients with information is not sufficient (Falvo 2010), as it does not necessarily help them to make choices. Patients must be educated about all types of dialysis modalities, so that they are able to make informed choices about their treatment. Doctors and nurses play a critical role in this education (Cropper 2004). Many studies worldwide have investigated how patients with ESRD are informed about RRT through the provision of information, or formal pre-dialysis education programmes (Klang et al. 1999; Mehrotra et al. 2005; Covic et al. 2010; Morton et al. 2010a).

As a specialist renal nurse and educator in the KSA, during my clinical practice, the hospital where I worked did provide information about dialysis care to the ESRD patients. This consisted of one or more discussions with doctors during their medical consultations, as well as the provision of written information. However, I observed that the type and extent of information about RRT, provided to patients at this hospital, was not standardised. Additionally, there were no established national guidelines for pre-dialysis education programmes for patients with ESRD. Therefore, due to the lack of guidelines or a standard education programme, patients may not receive adequate information and understanding about their disease and/or their treatment options. The overall aim in my research is to examine the education or information that ESRD patients at other hospitals receive, in order to develop recommendations for the improvement of pre-dialysis education for ESRD patients in western SA, and thus to ensure high quality patient care.



## **1.5 The structure of the thesis**

Chapter Two discusses the learning theories that are important within health education, and the theories that help to explain why people behave as they do. The chapter also considers how decisions are made in a health context, and the cultural factors that have a bearing on health education in the KSA. Patient education and the differences between the provision of information and of education are also a focus of this chapter.

Chapter Three provides an overview of the existing literature relevant to the thesis; for example the relationship between pre-dialysis education and the factors influencing patients' selection of treatment types. The literature focusing on approaches to improve pre-dialysis education concerning ESRD is then discussed. The penultimate section specifically reviews the current literature on pre-dialysis education regarding ESRD, including published studies in the KSA. Gaps in the literature, in relation to pre-dialysis education for ESRD in the KSA, are identified. Finally, the research questions and objectives that were refined, as a result of the review, are presented.

Chapter Four is divided into four sections. Section one outlines the study design, the rationale behind the study, and the methods employed. Section two delineates the aims, methods, and key findings of the pilot study. Section three describes the methods of the main study and their justification; including the sampling strategy, the inclusion and exclusion criteria with regard to recruitment, ethical factors, the development of the main study questionnaire, and the data collection process. Section four describes the aims and method of the national audit of hospitals with dialysis centres in the KSA.

Chapter Five presents the main study results, which include the type and nature of pre-dialysis education or information patients said they had received, how patients' treatment decisions were made, and patients' perceptions of the factors influencing the treatment type. The findings used both descriptive and statistical analyses and the results of correlations between relevant variables are reported. In addition, where appropriate, the results of the regression analyses that were conducted to identify any predictors of the types of treatment participants received, are also presented. Also, the findings of the national audit of hospitals with RRT options in the KSA are included.

Chapter Six provides a discussion of the main study findings in the light of previous studies. Patients' views and recommendations from the research for improving pre-dialysis education programme are then discussed.

Chapter Seven presents conclusions and recommendations for developing a pre-dialysis education programme for patients with ESRD in the KSA. It also presents the strengths and limitations of the study, the clinical implications, and proposed directions for future research.

## **2. Chapter 2. Background**

### **2.1 Introduction**

Kidney transplantation is the preferred treatment method for patients with ESRD, and most patients are placed on dialysis while waiting for transplantation. Comparison of dialysis modalities is difficult because randomised controlled trials, in which clinicians and patients are 'blinded' as to the treatment group, are not possible (Rubin et al. 2004).

Overall, there is no clear evidence of the survival advantages of one treatment over the other (Lee et al. 2008; Mehrotra et al. 2011). However, early access to renal services, so that access to dialysis may be provided in advance of need, can improve patients' outcomes and prevent the urgent start of HD, since the urgent start of HD has been linked to infection and high mortality (Lee et al. 2008). To improve the patient's outcome, dialysis should be started as a planned process, after a period of pre-dialysis, designed to prepare the patient for treatment (Marrón et al. 2005; Murphy et al. 2008). This chapter discusses learning theories related to health education, health beliefs and their impact on how patients react. It also refers to health literacy and patient education, and the role of patients and staff in the education process. Finally, it considers patient education in the KSA.

### **2.2 Learning theories underpinning health education**

The focus of this research is an exploration of the information that patients with ESRD receive. The aim is then to provide recommendations for pre-dialysis education in the KSA. This section will review a selection of learning theories that can help to understand and explain how people learn and it will consider those theories that could be applied within the context of patient education. Learning implies the integration between the learner and his or her social or cultural environment and an internal psychological process of explanation and gaining (Illeris 2009).

John Watson (1878-1958), the founder of behaviourism, asserted that as consciousness could not be reliably studied, it should not be studied at all.

## Background

Instead, it was suggested that the main focus for the psychologist should be on observable, measurable behaviour and how it varies with experience (Hergenhahn & Olson 2005). Key behaviourist thinkers, including Thorndike, Pavlov and Skinner, hypothesised that learning is a change in observable behaviour caused by external stimuli in the environment (Thompson 2012). In the context of patient education, it could be hypothesised, with reference to behaviourism, that patients provided with information in an understandable way by the educator (external stimuli) about their illness and treatment options, are likely to comply and make appropriate decisions about their treatment.

Thorndike was one of the key behaviourists who believed that educational practice should be studied scientifically, and that the more that is discovered about the nature of learning, the more could be applied to teaching practice (Hergenhahn & Olson 2005). According to Thorndike, the basis of learning was an association between sense impressions and impulses to action, known as a “bond” or “connection”. Thorndike’s main contribution to psychology was the so called Law of Effect (Bower & Hilgard 1981). Thorndike suggested that good teaching involves knowing what ‘the educator’ wants to teach and therefore what material to present and what responses to look for; in other words, having clear educational objectives (Hergenhahn & Olson 2005). However, according to Thorndike, the learner’s behaviour is determined by external reinforcement (reward and punishment) and not by intrinsic motivation (Hergenhahn & Olson 2005). Thorndike’s theory is applicable in terms of the need for educational objectives for good teaching and, as such, it can be extended to the context of patient education.

On the other hand, Skinner applied his theory to the education process and purported that learning is effective if (a) the information is presented in small steps, (b) the learner is given rapid feedback on their learning, (c) they are told immediately after whether they have learned the information correctly or not and (d) the learner is given space to learn by themselves (Hergenhahn & Olson 2005). This operant conditioning theory presumes that programmed learning, which comprises the four features aforementioned, is a good teaching strategy that can also be applied to health education.

This current study examines the present condition of pre-dialysis education within the KSA and whether the four principles of Skinner's theory are represented in the current practice of government hospitals. Applying this theory, it could be hypothesised that the structure of the pre-dialysis education programme should encompass the four features identified by Skinner, alongside a set of clear educational objectives. In the event that one or more of the principles are found to be absent in pre-dialysis education programmes in the KSA, this study aims to deliver recommendations to improve the present method of communicating dialysis information to patients. However, in reality, for patients with chronic illnesses, there are other factors, which must be taken into consideration when providing education or information to them, such as the recipients' beliefs about health and illness, cultural traditions and even religious beliefs about their treatment or medical management. Therefore, when designing an education programme, these factors need to be understood and incorporated.

In the 1960s, cognitivism replaced behaviourism as the dominant learning paradigm. This 'school' proposes that learning comes from mental activity such as memory, motivation, thinking and reflection. It focuses on the transmission of information from someone who knows, to the learner who does not know (Thompson 2012). Cognitive theorists emphasise the role of subjective hypotheses and expectations held by individuals; believing that a perceived barrier can act as an impediment to engaging in recommended behaviour (Glanz et al. 2008). On the other hand, a constructivist perspective suggests learning is an active contextualised process of constructing knowledge, rather than merely acquiring it. The learner brings experience and cultural factors to a situation.

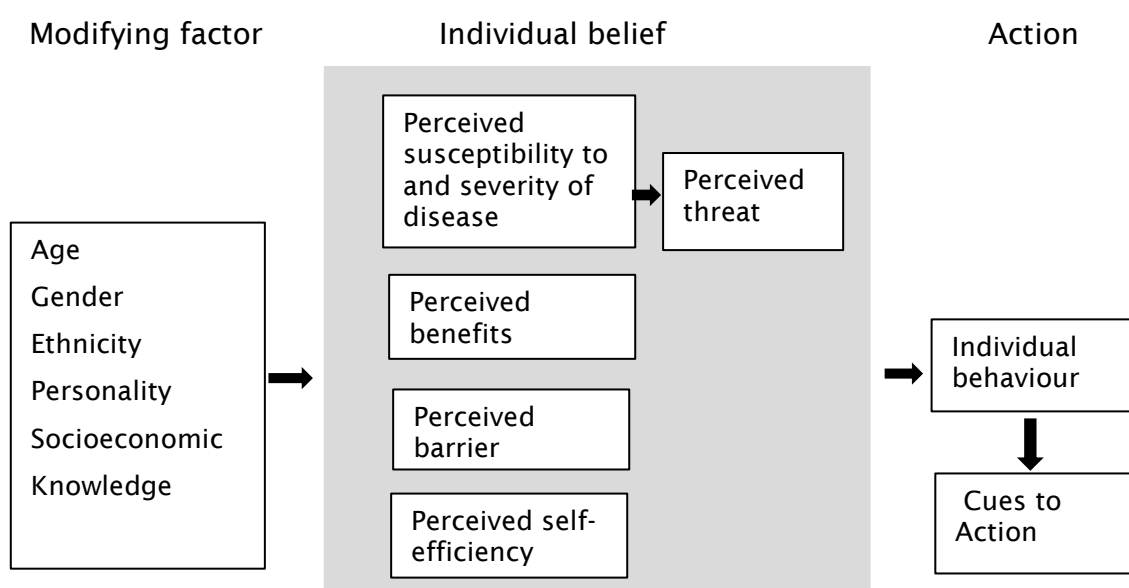
In summary, according to relevant learning theories discussed in this section, learning is (according to behaviourists) a change in observable behaviour. According to Skinner's theory, education needs clear objectives, and an educator is considered (to be an *external stimulus* or a *supplier of external stimuli*) an 'external stimuli'. According to Thorndike's theory, the educator should know what to teach and what materials to present. This will help in providing recommendations to improve the practice of pre-dialysis education in the KSA. The next section will discuss health education and related theories of health behaviour.

## 2.3 Health education and health behaviour theories

For a health education programme to be effective it should be designed with a thorough understanding of the recipient's health status and social characteristics, values, attitudes and beliefs (Glanz et al. 2008). The following section discusses some of the theories concerning health beliefs and attitudes in relation to health behaviour and health education. The Kingdom of Saudi Arabia (KSA) is known for its strong religious beliefs and traditional heritage. It was therefore necessary to explore theories related to health beliefs and behaviours and to consider how cultural and religious beliefs can influence patient choices or perceptions of their treatment choices.

### 2.3.1 Health belief model

The health belief model (HBM) was developed in the 1950s by social psychologists in the USA, to enhance the effectiveness of health education programmes (Rosenstock 1966). The model was later expanded to study people's behavioural responses to symptoms, illness, and adherence to their treatment regime (Kirscht 1974). The HBM has been applied to the prediction of a broad range of health behaviour amongst a range of people; the main areas being: preventative health behaviour, health-risk, and particularly adherence to recommended medical regimens (Conner & Norman 2005). The structure of HBM is illustrated in figure 2.1.



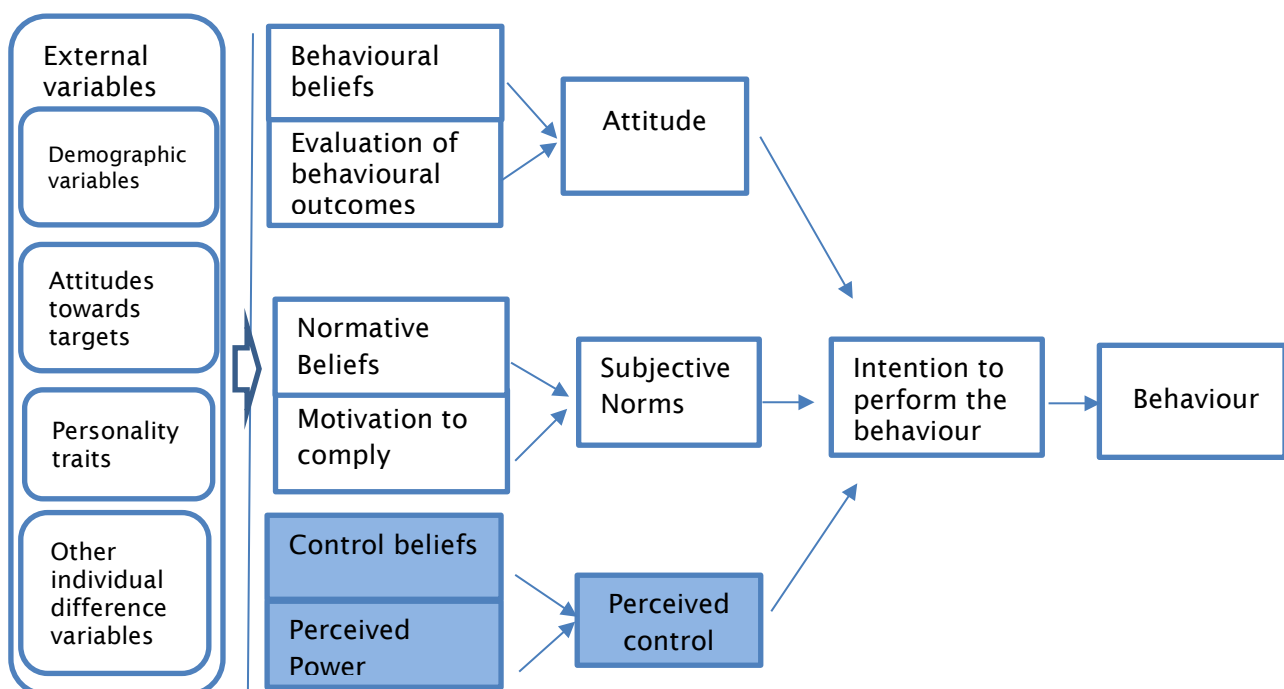
**Figure 2.1** The health belief model, adapted from Glanz et al (2008)

The major constructs of HBM are 1) individual belief which includes perceived susceptibility, perceived severity, perceived benefits and barriers, and 2) the modifying factors such as age, gender and socioeconomic factors that can influence perceptions (Glanz et al. 2008). This model can be applied to health education, especially in relation to the education of patients with ESRD. For example, the patients' beliefs about the severity of their condition and the need for dialysis (perceived severity), as well as the fatal consequences of illness without medical treatment or without dialysis (perceived threat), can all influence their behaviour. Also, patients' beliefs about the benefits of different treatments choices (perceived benefits) and perceived barriers to particular treatment options, such as contraindication to specific dialysis type, can also influence behaviour. These beliefs could influence patients' reactions to the treatment and the decisions of treatment options.

The health belief model (HBM) was the first to assume that a patient's belief in his or her personal susceptibility to, and the severity of, a health condition are important variables influencing the decision to take action (Rankin et al. 2005). If the health care provider ascertains that the patient does not believe that he or she is susceptible (personal susceptibility) to the severity of the condition, the first step is to provide more information about the health threat if it were to be left untreated (Rankin et al. 2005). With regard to dialysis treatment, some patients with ESRD believe that they do not need dialysis for the rest of their lives; they think it is a disease that can be cured by medication or by a few dialysis sessions. Therefore, it is important to ensure that the patient fully understands his or her illness and is made aware of the treatment options available. In addition, the benefits, barriers and cost of treatments are important factors to consider when attempting to educate patients. According to Conner and Norman (2005), HBM has the advantage of specifying a discrete set of common-sense beliefs that appear to explain or mediate the effect of the demographic variables on health behaviours, and those beliefs are amendable to change through educational intervention. In this regard, this thesis will explore factors described by the patients as influencing their treatment choices. By seeking an understanding of those factors that influence patients' treatment choices, this study endeavours to utilise these insights to provide recommendations to design and develop a pre-dialysis education programme, tailored to meet the needs of individual patients in the KSA.

### 2.3.2 The theories of reasoned action and planned behaviour

The theory of reasoned action (TRA) focuses on the concepts concerning individual motivation in acquiring a specific behaviour (Glanz et al. 2008). TRA was developed in 1967, and it suggests that intention is the best single predictor of behaviour. Ajzen (1988) introduced the additional construct of perceived behavioural control as another predictor of both intention and behaviour, to account for factors outside individual control that may affect intention and behaviour, calling his extension of TRA, ‘the theory of planned behaviour’ (TPB). This inclusion was based on the idea that behavioural performance is determined by motivation (intention) and ability (behavioural control) (Glanz et al. 2008). Behavioural controls include relevant skills, abilities and barriers or facilitators to perform the behaviour (Fishbein & Ajzen 2011). According to the theory, human social behaviour follows spontaneously from the beliefs that people possess about the behaviour, such as the positive or the negative consequences they might experience if they engage in the behaviour. These “behavioural beliefs” are assumed to determine people’s attitudes towards performing the behaviour. Also people form the belief that important individuals or groups in their lives would approve or disapprove of their behaviour; these descriptive normative beliefs produce a perceived norm (Fishbein & Ajzen 2011). The TRA/TPB model is presented in figure 2.2.



**Figure 2.2 Presentation of the action model/theory of planned behaviour**



(Glanz et al.2008)

These theories have been used in health prevention, risk management and smoking cessation (Glanz et al. 2008). Components can be applied in the field of pre-dialysis education; for example, when considering a patient's normative beliefs about the importance of having significant people in their life present when making decisions about whether to receive dialysis or not. According to Glanz et al. (2008) the educator should identify the construct that is most closely related to behavioural intention and decide what behavioural, normative and control beliefs should be used to focus intervention on education (Glanz et al. 2008). For instance, if the educator knows what behavioural beliefs and normative beliefs the patients hold towards the behaviour (starting dialysis treatment), then pre-dialysis education should focus on discussing those issues when providing information or education to patients with ESRD. Both the HBM and the TRA/TPB can be considered when designing pre-dialysis education programmes for patients with ESRD in the KSA. However, this thesis focuses on identifying the information or education ESRD patients receive prior to dialysis treatment, and what factors influence their choices, in order to provide recommendations for practice in the KSA. Therefore, the focus of the study is about the choice between treatment types. These theories have primarily been used within health prevention research. Nevertheless, both theories can be considered when devising a theoretical framework for the health belief aspects of pre-dialysis education.

## **2.4 Cultural effects on the health context**

Health beliefs, norms and culture play an important role in people's lives in the KSA. This section discusses the effect of culture on life, health behaviours and health decisions of patients in the KSA. Culture is composed of norms, values, and beliefs which guide and influence actions (Sobo & Loustau 2010). According to Ramachandran (2009), culture refers to organised patterns of customs, habits, attitudes, and values that are passed from generation to generation. It consists of shared behaviours that are approved by society. Norms refer to expectations about human behaviour (MacLachlan 2006). They inform a set of standards of appropriate behaviour and those standards are based on cultural values.

## Background

The link to religion is an important one; Islam is the only practicing religion in the KSA. Muslims believe that nothing can take place without the consent of Allah; illness and suffering are regarded as a means of purification, and as punishment for wrongdoing (Hollins 2009; Rassool 2014). Islam can be regarded as a religious-cultural phenomenon, whereby the behaviour of the believers is shaped by religious values and practice rather than purely by cultural practice (Rassool 2014).

According to Sobo & Luostuana (2012), culture affects perceptions and experiences of health and illness in many ways. Thus, studying the different elements of culture helps to understand the social group, as well as the link between the cultural context and human behaviour related to illness. Also, cultural differences in diagnostic disclosure, when informing the patients of the diagnosis, could affect the type of information that is shared between clinician and client (MacLachlan 2006). For instance, Muslims would not expect to have medical information discussed directly with the patients, but rather with a relative of the patient. Also, women may not wish to make important medical decisions without their husband or father present (Hollins 2009). Another important issue is the cultural norm of modesty that, for example, discourages direct eye contact between women and unrelated males. It is also inappropriate for women and men to shake hands (Rassool 2014). The KSA is strongly affected by cultural traditions and religious beliefs, as can be observed in the separation of gender in worship and some public places (Alamri et al. 2014).

There is always gender segregation in the KSA. A study by Karout et al. (2013) was conducted in the KSA described the experiences of women who were admitted to maternity wards and their perceptions of cultural diversity presented by health care providers. The findings of that study showed that there were preferences among Saudi women to be with a female rather than a male during birth. In addition, they considered the importance of privacy, especially in the presence of male health care professionals (Karout et al. 2013). It is not uncommon for health care professionals to be from different cultural backgrounds to their patients. For example, there are significant numbers of nurses from other countries who work in the KSA. Karout et al. (2013) therefore recommended that healthcare providers from different

cultural backgrounds should be introduced to the cultural differences of people in the KSA.

Oliver et al. (2011) reported that “*violating the human body, whether living or dead, is forbidden in Islam. (p.2)*” Conversely, selflessness is considered a highly valued precept and the act of saving a life is placed highly in the Qur’an. The solution to this conundrum lies in the principle that ‘*necessity overrides prohibition.*’ This concept has been used as the basis of a formal decision by the UK Muslim Law Council to issue a religious ruling that organ transplantation is entirely in line with the beliefs of Islam. Hence, live donation is seen as an act of merit in the UK. Prior to the UK ruling, the Islamic Jurisprudence Assembly Council in the KSA approved deceased and live donation in a landmark decision in 1988 (Oliver et al. 2011). However, despite these rulings, many Muslims are still reluctant to receive an organ donation, particularly in respect of a deceased donation, which only amounted to 25% of the total renal transplant cases in the KSA (Oliver et al. 2011).

This section has discussed the cultural and religious issues concerning people in the KSA. As mentioned here, hospital wards, including dialysis units, are divided into male and female areas. Another consideration that could affect the recommendations of this study would be Muslim women’s preference to be treated by female doctors (Taheri 2008); This is an issue obviously informed by the availability of female medical staff. These suggestions are consistent with adhering to the rules of modesty regarding the relationship between males and females in the KSA. Also, the importance of the family member’s presence during diagnosis, and for treatment decisions, should be considered when providing pre-dialysis education to patients in the KSA. The next section discusses decision-making in the health context and its applicability in the KSA.

## **2.5 Decision-making in the health context**

In health education, some patients have more than one option for their treatment regime or plan. This is particularly the case for patients with ESRD who require RRT, with the different dialysis options, or a plan for a pre-emptive transplant. Decision-making is an essential part of the health care process when patients have more than one treatment option. In any situation where a

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decision is to be made, three questions must be addressed. First is the normative issue, which refers to how decisions are best made. Second, the descriptive question, which asks how decisions are actually made. Lastly, the perspective question, which asks how a theory can best be used to improve decisions (Chapman & Sonnenberg 2003). The normative model of medical decision-making is under the umbrella of decision theory and decision analysis. One of the methods to deal with decision making is to present all the information to the patient and allow him or her to incorporate personal preferences and reach a final decision (Chapman & Sonnenberg 2003). However, this approach is not so applicable to patients in the KSA, due to cultural factors such as strong family ties, which translate to a lack of autonomy in the decision-making process. Thus, the patient would invariably need to involve family members before making a final decision in selecting his or her treatment.

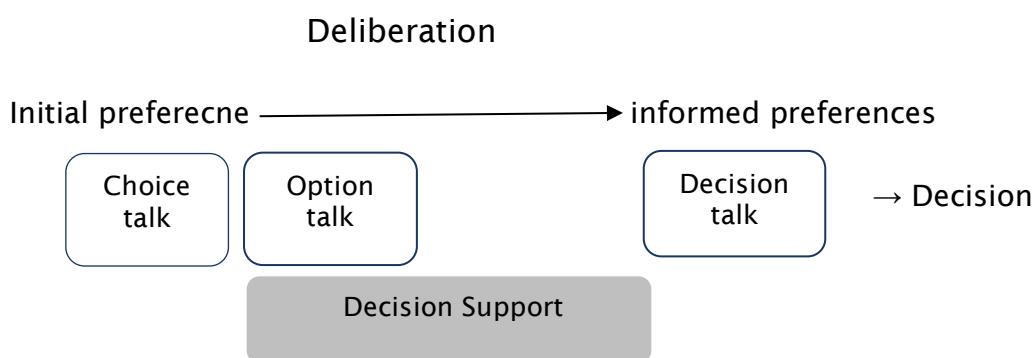
### 2.5.1 Shared decision-making (SDM)

Shared decision-making is defined as a “decision-making process jointly shared by patients and their health care provider” (Edwards & Elwyn 2009). With regard to patients with ESRD, decisions about dialysis treatment have to be made. There are different types of RRT and the importance of providing patients with unbiased information about the treatment options is paramount. Whilst the rhetoric is that patients should be involved in the decision-making process in Saudi Arabian society, culture and customs play a role with regards to major treatment decisions. There is an emphasis on the family role in decision-making about illness and treatment, especially if the decision involves female patients and obtaining informed consent (Hamdan 2005). As mentioned before, there are cultural expectations regarding gender roles, such that males in Saudi families are considered the primary decision-makers. Therefore, the decision-making process in the KSA needs to include family members.

Elwyn et al. (2012) proposed a model of how to achieve shared decision-making. They described three key steps of SDM for clinical practice:

- a) ‘choice talk’ which refers to the importance of making sure that the patient is aware that different options and choices are available;

- b) 'options talk' refers to providing more detailed information about the options available and
- c) 'decision talk' refers to helping the patients to consider preferences and decide what is best for them, using decision support such as leaflets, discussions and other decision aids (Elwyn et al. 2012). See figure 2.3 for shared decision-making model



**Figure 2.3 Shared decision-making model** (Elwyn et al. 2012)

These steps can be applied when introducing shared decision-making for patients with ESRD when discussing treatment options, in order to get them involved in the treatment choices. However, in the KSA there is no evidence regarding how decisions about dialysis treatment are made. According to Elwyn (2012), if patients come from cultural backgrounds where individuals tend not to make autonomous decisions, this can be a difficulty. This is likely to be the case in the KSA, where patients consult family members before making decisions about their treatment management or their treatment options. However, Politi et al. (2013) argued that SDM does not mean patients and doctors should share equal responsibility in the final decision, as well as it being important to understand the difference between deliberation and determination. Elwyn et al. (2012) suggested that a decision-making process has two phases: *a) deliberation* which includes information and knowledge gain, appraisal of knowledge sufficiency, and a preference construct and *b) determination*, which refers to adding deliberation inputs and making a choice. Therefore, patients might want to be involved in the deliberation phase and consider the information about the different treatment types. On the other hand, when making a choice, patients want the doctor's opinion. This is likely to be the case in the KSA where patients want to be informed about the illness

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and treatment options, but are hesitant to make an individual decision. Thus, patients appreciate the doctor's recommendation for what is best.

This research is attempting to provide evidence about what information patients with ESRD receive about their treatments options, about the level of their involvement in the treatment choices and what factors influence their choice. Shared decision-making can be used as the theoretical framework for the recommendations emanating from this study, where the concept of sharing the decision-making process between the patient and the healthcare provider is underlined. However, it must be understood that the healthcare provider shares only in the decision-making process and not in determining the actual decision itself. As was outlined in the model for shared decision-making proposed by Elwyn et al. (2012), the healthcare provider must explain that patients have a choice and that there are treatment options. Lastly, the healthcare provider facilitates the decision talk by providing materials appropriate for use within the context of the patient's circumstances.

These concepts can be used to develop the recommendations that are the final objective of this study. By utilising an amalgamation of the theoretical concepts of the health belief model, theory of reasoned action and Elwyn et al.'s (2012) model of shared decision-making. It is hoped that the findings in this study can be used to identify the factors that influence treatment and develop recommendations for a consistent and structured pre-dialysis education programme that is especially suited for use within the religious and socio-cultural milieu in Saudi Arabia.

## 2.6 Patient education

There are various definitions of patient education. The American Academy of Health Physicians (American academy of family physician 2000) define patient education as "*the process of influencing patient behaviour and producing a change in the knowledge, attitudes and skills necessary to maintain or improve health*" (p.1712). It has also been suggested that patient education empowers patients to make informed decisions about their health where empowerment is "*the process of enabling individuals to make informed decisions about their personal health-related behaviour*" (Bellamy 2004, p.359). On the other hand, others such as Rankin et al. (2005) have argued that patient education is not

just the provision of information, or an education intervention such as counselling or behavioural instruction, but entails the educator having the skills to assist the patient in interpreting and applying the information in self-care practice (Rankin et al. 2005). While patients' acquisition of knowledge is often an essential component of patient education, it should not be the only component (Bellamy 2004).

Falvo (2010) viewed patient education as providing patients with information, but noted that, for it to be effective, education must involve teaching patients either "formally" or "informally." Informal patient teaching takes place during clinical encounters, when the intended purpose of the interaction between the patient and the health professional does not involve teaching the patient, although the information presented should be clear and organised based on the patient's level of need. Conversely, formal approaches to patient teaching consist of predetermined times for patient education on specific topics, such as preoperative care or specific information on chronic diseases, and can take the form of discussion and information exchange between the patient and the health professional (Falvo 2010).

## **2.7 The role of the patient**

The most common obstacles nurses experience regarding the effective provision of patient education relate to motivating patients and achieving patient compliance (Rankin et al. 2005). Human experience is influenced by culture; sickness and perceptions of illness are viewed differently across cultures. Religion can also sometimes affect people's motivation towards education. Patients' levels of education can also affect the effectiveness of patient education. The following section describes the patients' role in patient education.

### **2.7.1 Motivation**

Redman (2007 p3) defined motivation as:

*"A term that describes forces acting on or within an organism that initiate, direct, and maintain behaviour".*

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Motivation can be either intrinsic or extrinsic. Intrinsic motivation factors include the patient's anxiety level and success in past educational settings. Extrinsic motivation factors include the learning environment and interaction in the learning process (Rankin et al. 2005). According to Bastable et al. (2010), facilitating and blocking factors that shape motivation are classified into three major categories: personal attributes such as physical and psychological components of the individual learner; environmental influences; and learner relationship systems, such as those of significant others, family, and community (Bastable et al. 2010). Healthcare providers can do their best to enhance the learning situation and to use extrinsic motivation factors, but motivation is mainly an inner drive (Rankin et al. 2005). Motivation is also determined by the patient's sense of responsibility to learn because, if patients are not interested or motivated, no matter how much education is provided, learning will not occur (Rankin et al. 2005).

### 2.7.2 Level of education

Patients with a good command of their language are more likely to comprehend what an educator is saying (Wild 2002). In the KSA, the overall adult literacy rate is 86.55% (Oxford 2013b). Recent educational efforts are evident in the substantially improved literacy rate among younger Saudis; for those between the ages of 15-24, the literacy rate has improved to 97.8% (Oxford 2013b). If one considers this problem in relation to the concepts and procedures that need to be taught to dialysis patients and their families, it is apparent that the information given must be clear, unambiguous, and readily understood (Wild 2002). However, it is possible to address issues around lower levels of education in maintaining the effectiveness of patient education. For example, using other methods than written handouts and booklets for educating illiterate patients, including the use of pictures and different colours, has been shown to be effective in facilitating patients' understanding (Owen et al. 2009).

### 2.7.3 Adaptation

Illness creates a sense of uncertainty and unpredictability. Teaching patients can restore a sense of control and decrease their sense of powerlessness (Falvo 2010). Denial is a coping strategy used to refute the reality of the situation and



can negatively impact teaching efforts, as well as adherence to treatment regime (Falvo 2010). In the case of denial, the patient does not want to know about the condition. In such cases, straightforward explanation of the disease and its consequences if not treated may be necessary in order to save the life of the patient. Babcock & Miller (1994) argued that well-informed clients tend to become better adapted as they learn to cope with chronic disease (Babcock & Miller, 1994). On the other hand, some patients cope with illness by wanting to know everything about their condition and treatments in order to decrease their fear and help them take control of their situation (Falvo 2010). It is arguable that health professionals should tell the truth about chronic disease (Bloch 2003). For example, patients with renal failure, as well as their families, need to know that this illness is fatal without dialysis or transplantation, along with the complications associated with the disease. Bloch (2003) suggested that if professionals are too gentle with renal patients and their families, they can increase anxiety levels among the patients and their caregivers because not much information were shared with them.

#### **2.7.4 Anxiety levels**

Clients and their families reported that their anxiety levels and concerns interfere with their ability to comprehend material that would be quite understandable under normal circumstances (Babcock & Miller 1994). Regarding dialysis education, Uttley and Prowant (2000) illustrated that pre-dialysis counselling and education of patients and families can be very helpful in reducing anxiety. They recommended an initial meeting with the patient and family to identify learning needs and to dismiss rumours and incorrect conceptions about renal failure and dialysis. This initial contact should be followed by providing written information about the signs and symptoms of kidney failure, together with an overview of treatment. Gradual provision of information, when the patient is judged ready to receive it, can reduce anxiety and increase receptiveness to further information, which the patients can integrate into their lives (Falvo 2010).

## **2.8 The role of staff in patient education**

For patient education to be successful and effective, the staff delivering the education must also have the skills necessary to understand the different individual patient's characteristics. Those staff also need to provide the education in a manner that is comprehensible to each individual recipient. The next sections explain some of the main skills that staff delivering patient education should have.

### **2.8.1 Assessment**

The educator should have the ability to assess the client's skills, attitudes, and cognitive abilities, as well as whether they would be able to understand the information (Babcock & Miller 1994). Another important issue that needs to be examined during the assessment phase of patient education is the degree of responsibility an individual wishes to take for the management of his/her health needs. This 'responsibility issue' involves consideration of the patient's motivation and health beliefs (Thomas 1998). Also, in terms of assessing readiness to learn, here readiness refers to evidence of motivation at a particular time (Redman 2007). No matter how important the information or how much the patient needs it, if the patient is not ready to learn, the information will not be absorbed because anything affecting the patient's psychological comfort (such as fear or anxiety) can influence that patient's ability and willingness to learn (Bastable 2006). Assessment of what an illness means, from the patient's cultural and religious perspective, is also important in determining readiness to learn, since language is a part of culture and can prove to be an obstacle to learning if the staff or nurse and the patient do not fluently speak the same language or understand these cultural influences.

In the KSA, language and cultural barriers may increase the risk of miscommunication between staff and patient. Aldossary et al. (2013) investigated the perceived health promotion practice of staff nurses in the KSA. This was achieved by surveying the views of nurses (n=614), doctors (n=130), and patients (n=322) in 10 hospitals located in the eastern province of Saudi Arabia. They found that doctors and patients were less confident than the nurse participants about nurses' skills in specific areas of health promotion, such as sufficient language and cultural competency ( $p < 0.0005$ , respectively).

The majority of patients (n=277, 89.9%) also agreed that the nurses should give priority to acute care rather than health promotion counselling ( $P<0.0005$ ) and that patients get annoyed when the staff nurse asks about health-related behaviours, especially when not directly related to their presenting health problems ( $p=0.001$ ) (Aldossary et al. 2013). These findings show some of the cultural issues evident in the KSA. Such issues could be because most of nurses are from different cultural backgrounds and speak different languages other than Arabic. A previous report by Karout et al. (2013) suggested that to overcome this obstacle it is necessary to increase awareness among healthcare providers about the relevant beliefs and cultural or religious practice issues as understood and practiced in Saudi Arabia. The next section discusses how these matters affect communication between staff and patients.

### **2.8.2 Communication skills**

Effective communication is fundamental for patient education. Communication skills are transferable across different life and practice circumstances (Sully & Dallas 2005). Communication involves sending and receiving messages between two or more people (Timby 2009) using verbal and nonverbal methods. In a healthcare setting, the nurse plays a major role in providing information to patients regarding their treatment regimen or plan. Therapeutic verbal communication takes place when words and gestures are used to achieve particular objectives (Timby 2009). Additionally, nurses should observe nonverbal communication, such as body language or facial expressions, and questions that indicate that the client or patient has understood the message. Nurses sometimes use medical language when communicating with patients. Jargon and clinical terminology can be frightening and confusing to patients, and therefore should be avoided, especially with clients with a lower level of education (Wild 2002). Findings from a qualitative study in the UK by Iles-Smith (2005) aimed to explore the perceptions and experiences of pre-dialysis patients. It demonstrated that unfamiliar technical jargon used by health care staff, together with the high levels of anxiety experienced by patients, lead to patients experiencing difficulty processing the information offered to them (Iles-Smith 2005).

There is evidence that increased quality of communication, between healthcare providers and patients, improves patients' satisfaction with treatment and is

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associated with higher levels of self-management (Glasgow et al. 2001). It was also shown that it is beneficial to collaborate with patients on their care plans and management, rather than to simply prescribe regimens and expect patients to adhere to them (Glasgow et al. 2001). Sometimes staff perceive non-compliance as the only way a patient can exhibit some control over the situation (Simmons 2009). The patient gaining advice from the healthcare provider, and then deciding which strategies to put into practice, can achieve this. Hence, the patient and the care provider working together is more likely to result in the patient adhering to the self-care management plan, because he or she has contributed to it. This is the ideal situation. However, in the KSA communication obstacles are common, as most nurses do not speak Arabic since the nursing workforce consists largely of migrant nurses, with only 10.8% of nurses being Saudi (Aldossary et al. 2013). Previous studies in the KSA reported that the majority of doctor and patient participants highlighted cultural and language barriers as a hindrance to the health promotion activities of staff nurses (Aldossary et al. 2013; Karout et al. 2013). Therefore, for effective education, the staff delivering the education should speak the same language as the patient or use a translator during the education sessions.

### **2.8.3 Patience and consistency**

Patient education can be very time consuming, and staff need to have patience with their patients and be consistent during teaching sessions. According to Uttley & Prowant (2000), patience needs to be shown at all times, especially during the teaching sessions, because some of the procedures may need to be repeated several times before the patient is able to perform them correctly. Another point is to allow questions and to continue to encourage patients and families throughout the training process. Consistency is another very important factor in any teaching programme, because the patient can become confused, and therefore make mistakes in the procedures in which they were trained (Uttley & Prowant 2000). Patience and consistency shown by the educator can help the patient understand better and feel more comfortable during the education session.

### **2.8.4 Sense of humour**

Laughter is a positive emotion that stimulates a positive attitude. Some

individuals use humour as a coping mechanism or as a way to maintain a sense of self (Falvo 2010). Uttley & Prowant (2000) indicated that a sense of humour in a nurse-client relationship can reduce the stress level of patients or relatives and can relieve and disperse a difficult or tense situation. Sundeen et al. (1994) pointed out that sharing laughter can cause the nurse and client to feel closer to each other and help clients to cope with fears and anxiety. Thus, when the educator establishes a climate of mutual trust and safety, the learning environment becomes a positive motivator and, by introducing fun into the learning situation, the healthcare provider can make the pleasure of learning become a positive force (Rankin et al. 2005).

## **2.9 The role of family in patient education**

The family is the patient's primary support system, which plays an important role in the patient's life and health (Falvo 2010). The role of family in education is considered a key variable influencing positive patient outcomes (Bastable et al. 2010). Family involvement in the education and in the decision making process can decrease the stress of hospitalisation and can assist the patient in carrying out their treatment recommendations (Falvo 2010). Family members can help patients to understand the information and clarify questions that patients might be hesitant to ask (Falvo 2010). However, according to Bastable et al. (2010), health professional educators need to assess what the caregiver or relative feels about providing supportive care and about learning the necessary information. Furthermore, understanding how the family contributes to the patient's ability or willingness to follow the health care professional's recommendations can be valuable in conducting patient teaching (Falvo, 2010).

Concerning educating patients with ESRD, family involvement can be considered when the patient needs to make decisions about their treatment options. A family member or significant other can influence what treatment choice is best, whether this be home dialysis or in-centre dialysis. For example, PD needs to be conducted at home and, therefore, the family member can take the role of primary caregiver. If that is the case, the health care professional should extend patient teaching to include the family member and to assist them with adjustment to the caregiver role (Falvo, 2010).

## 2.10 Health literacy

Health literacy is important when educating patients because patients need to understand health information and are often asked to make key health decisions (Osborne 2012). Health literacy is defined as:

*“A shared responsibility between patients (or anyone on the receiving end of health communication) and provider (or anyone on the giving end of health communication). Both must communicate in ways the other can understand” (Osborne 2012, p.5).*

A study in the USA by Gazmararian et al. (2003) indicated that a patient's health literacy level was an independent predictor of the patient's knowledge about his/her chronic illness. A population of 653 patients with chronic diseases was surveyed using the Short Test of Functional Health Literacy in Adults (S-TOFHLA), which included actual materials a patient might encounter in the healthcare setting. This information consisted of two parts: (1) reading comprehension and (2) numeracy. Patients with inadequate health literacy were significantly ( $p < 0.05$ ) less likely to correctly answer 8 of the 20 asthma questions, 5 of the 11 diabetes questions, 4 of the 16 CHF questions, and 8 of the 25 hypertension questions.

With regard to dialysis patients in Australia, Owen et al. (2009) tested the literacy level (LL) of 254 dialysis patients using the Rapid Estimate of Adult Literacy in Medicine (REALM). A total of 152 patients completed the test while 102 were excluded due to insufficient English proficiency or low vision. The median score was 52 out of a maximum of 66 (range 4-66), which indicated a literacy level of years 7-8 schooling (Owen et al. 2009). As it was suggested that educational materials should be written at three levels below the education level of the patient population, the education brochures were modified to achieve this. Reassessment of the revised materials indicated that the changes consistently improved their readability. Comprehension of pre-dialysis education materials is essential for the successful transition from ESRD to dialysis. In the KSA, one study by Alamari (2012) measured health literacy using a validated Arabic version of the S-TOFHLT. The results showed that out of a total of 205 visitors and patients, 83.9% were categorised as having adequate literacy, while 10.2% were categorised as exhibiting marginal literacy,

and 5.9% displayed inadequate literacy. Alamari (2012) also demonstrated a significant association between the health literacy score and the level of education ( $p=0.000$ ), gender ( $p=0.010$ ), and Internet usage ( $p=0.04$ ) (adjusted R square is 0.390). The research by Alamari (2012) was the only study found that was conducted in the KSA to assess health literacy, and it identified an association between the health literacy score and the level of education of the participants. However, there were no details included regarding the type of associations. Nevertheless, that work did provide evidence of health literacy in the KSA as it addressed the needs of those with low or inadequate health literacy in education programmes in the KSA.

Limited health literacy may have an impact on accessing preventative health services, as well as an effect on a patient's understanding of the disease and treatment options. People with ESRD are often placed in a situation where they are required to make a choice regarding whether to commence RRT, without having any previous experience of these therapies (Campbell & Duddle 2010). An understanding of the potential for limited health literacy in people with ESRD can encourage nephrology nurses to alter their communication styles and educational materials, in order to improve the health professional/patient interaction (Campbell & Duddle 2010). For example, they can include different educational materials, such as posters, audio-visual materials, and videotapes that patients can watch at the unit during the educational sessions.

In the UK, Simmons (2009) explored the implementation of Orem's self-care theory in patients receiving HD, with a focus on the lifestyle changes caused by dialysis, through a literature search of studies involving adults receiving haemodialysis and self-care management publications. Orem's theory suggests that people have a natural ability for self-care and that nurses should focus on effecting those abilities (Orem et al. 1995). According to Simmons (2009), self-care for the dialysis population includes many dimensions, such as following the prescribed medical regime, medication, haemodialysis treatment, knowledge of kidney disease and the signs of complications. A self-care deficit occurs when a patient new to dialysis lacks the knowledge to participate in self-care. Simmons (2009) argued that nephrology nurses can help with these changes by providing education to patients to encourage self-care, and by supporting them to become involved as active members of the healthcare team

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through participating in decision making (Simmons 2009). Dialysis patients can particularly benefit from education that includes preventative techniques for those at risk of developing ESRD, teaching prior to the initiation of dialysis, and ongoing education regarding the management of lifestyle changes (Simmons 2009).

### **2.1.1 Patient education in the KSA**

In general, there is little evidence evaluating patient education in the KSA, nor understanding of how it is organised and structured. There is, however, some limited data regarding the education of diabetic patients in the KSA. Al-Shahrani et al. (2012) studied the effectiveness of a five-day diabetic educational programme for 438 patients, led by the unit. A significant improvement was observed among all metabolic diabetic parameters, except for high density lipoprotein (HDL), after one year ( $p < 0.0001$ ). The authors therefore recommended that structured educational programmes led by a trained professional health team should become an essential part of diabetes care (Al-Shahrani et al. 2012). This study was the only one found that examined health education programmes in the KSA.

#### **2.1.1.1 Pre-dialysis education**

People who are diagnosed with a specific disease often experience not only the symptoms, but also the stress associated with their prognosis, as well as having to make decisions about medical care (Glanz et al. 2008). When patients with CKD reach ESRD, it can be a significant challenge for them to accept that they need dialysis therapy to survive. They must understand their treatment options in order to maintain their health, including the differences between the three available treatments for RRT i.e. HD, PD, and renal transplantation or the option of conservative management (CM) if the patient decides not to commence RRT. Thus, the timing and channels of educating patients with chronic disease such as CKD should be considered carefully because the illness may compromise their ability to attend to or actually absorb new information (Glanz et al. 2008). Regardless of their educational backgrounds, people with a chronic condition such as CKD can find navigating the healthcare system and deciphering information on RRT challenging (Campbell & Duddle 2010). The provision of pre-dialysis education is an



important part of any dialysis service (Owen et al. 2009). Preparation for RRT, as included in the K/DOQI clinical practice guidelines (KDOQI 2006), recommends beginning education once a patient reaches stage 4 CKD. This allows patients and their families adequate time to assimilate the information and consider the treatment options, and also allows time for staff to train patients who choose home dialysis. The education should be provided not only to the patient but also to other individuals who are likely to influence the patient's decision and be involved in their care, including: family members, close friends, and care providers (KDOQI 2006).

## 2.12 Conclusion

This chapter has provided an overview of learning theories of relevance to patient education, as well as defining and describing the importance of patient education. Issues such as patient characteristics that can be barriers or alternatively aids to the effectiveness of education programmes, such as motivation, adaptation to disease and patients' anxiety levels and concerns towards treatment, are discussed. The importance of patients' education levels, and cultural and health beliefs that can affect a patient's reception of information, were also described.

The necessary skills needed by staff providing the education were considered. These included the ability to assess the clients' attitudes and to understand the information required. In addition, the evidence of the importance of the quality of communication between healthcare provider and patients was discussed in relation to the KSA. Different definitions of health literacy were also included with reference to studies that have explored how literacy levels influence patients' education and how education materials should be altered according to those literacy levels.

The context of patient education in the KSA was discussed with reference to the Saudi study regarding a diabetic educational programme. The importance of giving pre-dialysis education to patients with ESRD was also explained. The following chapter reviews the literature on pre-dialysis education, evidence regarding those factors that influence the patient's selection of treatment options, how the chosen option is developed and delivered, and what it

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includes. The chapter also identifies a gap in the literature with regard to the lack of Saudi reports.

## **3. Chapter 3 Literature Review**

### **3.1 Introduction**

The objectives of the literature review, and hence this chapter, is to understand more about the research and work that has been undertaken on pre-dialysis education for ESRD patients. This is to inform my study of pre-dialysis education among Saudi ESRD patients. The chapter will provide critical reviews of the available evidence-based studies about pre-dialysis education, including appraisal of the methodologies used in those studies, and identify the factors that patients considered influential in their treatment choices. The chapter investigates the evidence around other important aspects of pre-dialysis education, such as the content, approach adopted, and timing of the pre-dialysis education programmes.

The chapter begins with a brief overview of the search strategy, followed by a review of the literature related to pre-dialysis education and dialysis treatment options. Next, pre-dialysis education and treatment choice of self-care dialysis are discussed, followed by identification of the gaps in the literature, the justification for the study, and the research questions. It should be noted from the outset that literature related to patient education in the KSA is limited, due to the lack of studies in this field.

### **3.2 Literature search strategy**

Literature reviewing is an essential part of research. According to Stommel and Wills (2004), a researcher surveying the literature in a particular area should understand the limitations of the available evidence, as well as what is known, and what needs to be known, in the field. This allows the researcher to identify gaps in the knowledge base and to narrow down the research questions.

#### **3.2.1 Reference sources for the literature search**

The University of Southampton library catalogue (Web-CAT), which provides access to various sources of evidence, including electronic journal articles, books, and theses, was used for the search. Electronic databases included in the literature search are listed in Table 3.1. Grey literature, such as technical

reports, conference proceedings, and clinical care guidelines are also reviewed. This grey literature was of use in providing guidelines and key principles for inclusion in educational programmes for patients with ESRD. The reference list of identified citations was also searched manually in order to locate additional literature that had not been identified electronically. This approach provided access to some little-known Saudi studies. Additional citation tracking was also employed for key papers.

**Table 3.1 Electronic databases**

Full Name of Electronic Database	Abbreviation	Description
The Cumulative Index to Nursing and Allied Health Literature	CINAHL	The major electronic database that indexes almost all nursing research published in English. It is available from 1982 to present and includes 350,000+ records.
Medical Literature Online	MEDLINE	The major electronic database that includes biomedical research reference materials. Includes electronic coverage of more than 3,800 journals from 1966 to present, and has in excess of 9 million+ records.
E-Journals	E-Journals	Provides article-level access to thousands of e-journals available through EBSCO subscription services.
Web of Knowledge	–	This resource represents a comprehensive index for life sciences and biomedical research, including meeting abstracts, journals, books, and patents. It contains more than 5,000 international resources from 90 countries (1926–present) (Supino & Borer 2012).
PubMed	–	Premier database of biomedical literature, primarily MEDLINE (1947–present) (Supino & Borer 2012)
The Allied and Complementary Medicine Database	AMED	A unique bibliographic database produced by the Health Care Information Service of the British Library. It covers a selection of journals in complementary medicine, palliative care, and several professions allied to medicine. It covers the years from 1985–present and is supplied by Ovid (National Institute for Health and Care Excellence 2014).
Electronic Thesis Online Service	ETHOS	ETHOS is the UK's national thesis service, which aims to maximise the visibility and availability of the UK's doctoral research theses. There are approximately 350,000 records from over 120 institution (ETHOS 2014).
E-Book Collection		Allows searching and viewing of the full

Full Name of Electronic Database	Abbreviation	Description
(EBSCOhost)		text of eBooks.

Some examples of the academic journals that were most relevant to the clinical aspects of this study included *Saudi Journal of Kidney Disease and Transplantation*, *Nephrology Dialysis Transplant*, *American Society of Nephrology*, *International Society of Peritoneal Dialysis*, and *Journal of Advanced Nursing*. An alert was set up for these journals for the most up-to-date studies and evidence.

### 3.2.2 PICO framework

The aim of the literature search was to identify relevant references relating to the research questions, i.e. what is known about dialysis and pre-dialysis education, and what factors influence the choice of dialysis modality? The first step in a literature review is to convert the research question into a search strategy to identify relevant keywords in order to facilitate an effective database search. A standard approach, known as the PICO framework (Ebrahim & Bowling 2005), was employed to identify the keywords necessary to focus the search strategy. PICO uses three to four components to structure the research questions and to construct a search strategy: The Population of Interest (P); The Intervention (I); The Comparison (C); and The Outcome (O). Keywords for this research were generated using the PICO framework for each of the key components of the research questions, and additional similar keywords were generated based on the primary key words. Table 3.2 reports the process.

**Table 3.2 Use of the PICO framework to generate keywords for the literature search**

<b>PICO Framework</b>	<b>Keywords Selected for this Project</b>	<b>Keywords Selected for Assisting the Literature Search</b>
P: Population	Dialysis patients >18 years	<ul style="list-style-type: none"> <li>• Haemodialysis/HD</li> <li>• Peritoneal dialysis/PD</li> <li>• Dialysis patient</li> </ul>
I: Intervention	Pre-dialysis education	<ul style="list-style-type: none"> <li>• Patient education</li> <li>• Patient information</li> <li>• Effect of pre-dialysis education</li> </ul>
C: Comparison	None	<ul style="list-style-type: none"> <li>• None</li> </ul>
O: Outcome	Dialysis treatment type	<ul style="list-style-type: none"> <li>• Dialysis modality</li> <li>• Dialysis modality selection</li> <li>• Treatment options</li> <li>• Renal replacement therapy/RRT</li> <li>• Patient selection</li> </ul>

The next stage was to identify any other synonyms or abbreviations that are used to describe the four components to be included in the literature search (Ebrahim & Bowling 2005). For example, if the search term is 'dialysis treatment type', alternative words can be used to search the database, such as 'dialysis modality', while for the keyword treatment options, 'modality selection' was also included. In addition, abbreviations such as HD for haemodialysis and PD for peritoneal dialysis were included.

### 3.2.3 Keywords

The following keywords were used in the search to identify relevant citations and to increase the search yield:

- Haemodialysis
- Peritoneal dialysis
- Dialysis modalities
- Dialysis treatment
- Patient education
- Patient information

- Dialysis patient
- Renal replacement therapy
- Pre-dialysis education
- Effect of pre-dialysis education
- Modality selection
- Dialysis modality selection
- Treatment options
- Patient selection

Boolean operators such as 'OR' and 'AND' were included where relevant.

### 3.2.4 Inclusion and exclusion criteria

It is important for literature searches to incorporate inclusion and exclusion criteria in order to narrow the results. A decision was made to review studies from 1994 to be able to include Abu-Aisha and Paul's (1994) Saudi study on dialysis, even though this is now a relatively old study (see Table 3.3).

**Table 3.3 Inclusion and exclusion criteria for the literature search**

Inclusion Criteria	Exclusion Criteria	Rationale
Full text research article or thesis.	Not research based.	To obtain primary research resources.
Report or guideline for pre-dialysis education.	Report or guideline not related to dialysis education.	The study focuses on dialysis education.
Focuses on patient education, pre-dialysis education, and patient choices.	Not related to patient education and pre-dialysis education.	The study focuses on the provision of pre-dialysis education for patients with ESRD.
Related to adults with ESRD aged >18 years.	Related to children aged <18 years.	Adults are the target group for the study to improve pre-dialysis education.
Related to patients with CKD stage 4 not receiving dialysis and 5 ESRD receiving dialysis treatments.	No exclusion	This study focuses on patients with ESRD who are about to start dialysis or who are receiving dialysis treatment.
Published from 1994–2014.	Published before 1994.	To increase the number of studies conducted in the KSA and other countries.
In English or Arabic language.	Conducted in language other than English or Arabic.	No funding was available for translation.

### 3.2.5 Search results

The initial literature search was conducted in the Faculty of Health Sciences at the University of Southampton during the period of November 2010 to May 2012, using the university's library catalogues (Web-CAT and TDNet for E-Journals) and computerised information systems, which included electronic databases (CINAHL, MEDLINE, Web of Knowledge and AMED). This was prior to the beginning of the fieldwork for the study. Subsequent searches were also conducted from 2013-2015, when the study was underway and the thesis was being prepared. Table 3.4 reports the search results.

**Table 3.4 Search results from the electronic databases**

<b>Keywords</b>	<b>Electronic databases included CINAHL, MEDLINE, AMED, E-Journals, E-Book Collection (EBSCOhost) and PubMed</b>	<b>Number of articles identified after duplication removed, and application of inclusion and exclusion criteria</b>
Haemodialysis AND peritoneal dialysis	3,954	-
Patient education	153,104	-
Dialysis modalities	1,084	-
Patient education OR patient information OR pre-dialysis education	243,886	-
Patient education OR pre-dialysis education AND dialysis modality selection	162,363	-
Dialysis treatment AND patient education	1,255	-
Treatment choices OR modality selection OR treatment options	238,837	-
Dialysis treatment AND patient education AND treatment choices OR modality selection OR treatment options	235	21
HD, PD AND patient education	44	2
Patient education AND dialysis patient	353	5



Patient education AND renal replacement therapy	1	1
Dialysis modality selection	109	8
Pre-dialysis education	13	1
Effect of pre-dialysis OR patient education AND dialysis modality	27	1
Pre-dialysis education AND treatment options	11	1
HD, PD or dialysis modalities OR renal replacement therapy	117	-
Total related references	793	40

The two stages of the literature search are presented in Tables 3.5 and 3.6 respectively. 'Stage one was undertaken between 2010 and 2012 and it included studies that had been published before conducting the main study and therefore could potentially inform the study design (See Table 3.5). After the fieldwork had been completed, subsequent searches to update the literature were conducted as stage two, between 2013 and 2015. These studies included those that were published after the main study and so could be taken into account during the discussion of the main study findings (See Table 3.6).

The search using individual keywords generated a large number of references. Therefore, a combination of terms was used to obtain the appropriate references to focus the results solely on the primary research question. The six electronic databases generated a total of 793 references. The abstracts and titles were reviewed and irrelevant citations and duplicated studies were identified. After the inclusion and exclusion criteria were applied, and the irrelevant studies removed, the remaining 40 studies directly related to pre-dialysis education and dialysis modality options; including three studies conducted in KSA. There was no specific Saudi database capable of searching Saudi studies and, therefore, networking and reference checking of other Saudi studies were performed to attempt to identify more Saudi data. Nevertheless, no additional citations were identified by this method. Therefore, the 40 most relevant articles identified by the literature search are as listed in Table 3.5 and in Table 3.6.

**Table 3.5 Studies included in the literature review: stage one**

#	Studies Included	Publication Year	Study Design
1	Klang, B., Björvell, H., & Clyne, N. (1999). Predialysis education helps patients choose dialysis modality and increases disease specific knowledge. <i>Journal of Advanced Nursing</i> , 29(4), 869-876.	1999	Experimental study: a) Pre-dialysis treatment questionnaires. b) Questionnaire 3–9 months after dialysis treatment.
2	Gomez C, Valido P, Celadilla O, Bernaldo De Quiros A and Mojon M (1999) Validity of a standard information protocol provided to end-stage renal disease patients and its effect on treatment selection. <i>Perit Dial Int</i> 19(5): 471-477	1999	Multi-centre controlled study
3	Piccoli, G., Mezza, E., Iadarola, A., Bechis, F., Anania, P., Vischi, M., Lacuzzo, C., Massimo, G., Martino, B., Garofletti, Y., Giraudo, G., Jeantet, A., & Segoloni, G. (2000). Education as a Clinical Tool for Self-Dialysis. <i>Advanced in Peritoneal Dialysis</i> , 16, 186-190.	2000	Mixed method: longitudinal questionnaires and interviews
4	Golper T (2001) Patient education: can it maximize the success of therapy? <i>Nephrol Dial Transplant</i> 16([Suppl 7]): 20-24	2001	Survey
5	Wuerth, D. B., Finkelstein, S. H., & Schwetz, O. (2002). Patients' descriptions of specific factors leading to modality selection of chronic peritoneal dialysis or haemodialysis. <i>Perit Dial Int</i> , 22, 184-190.	2002	Qualitative (face-to-face structured interview)
6	Levey AS, Coresh J, Balk E, Kausz AT, Levin A, Steffes MW, Hogg RJ, Perrone RD, Lau J and Eknoyan G (2003) National Kidney Foundation Practice Guidelines for Chronic Kidney Disease: Evaluation, Classification, and Stratification. <i>Annals of Internal Medicine</i> 139(2): 137-147	2003	NKF Guidelines
7	Goovaerts, T., Jadoul, M., & Goffin, E. (2005). Influence of a Pre-Dialysis Education Programme (PDEP) on the mode of renal replacement therapy. <i>Nephrology Dialysis Transplantation</i> , 20(9), 1842-1847.	2005	Observational retrospective study
8	Iles-Smith H (2005) Perception and experiences of pre- dialysis patients. <i>EDNA-ERCA Journal</i> 31(3): 130-133.	2005	Qualitative study

#	Studies Included	Publication Year	Study Design
9	Mehrotra, R., Marsh, D., Vonesh, E., Peters, V., & Nissenson, A. (2005). Patient education and access of ESRD patients to renal replacement therapies beyond in-centre haemodialysis. <i>Kidney Int</i> , 68(1), 378-390.	2005	Cross-sectional questionnaire survey
10	Manns, B. J., Taub, K., Vanderstraeten, C., Jones, H., Mills, C., Visser, M., & McLaughlin, K. (2005). The impact of education on chronic kidney disease patients' plans to initiate dialysis with self-care dialysis: A randomized trial. <i>Kidney Int</i> , 68(4), 1777-1783.	2005	Randomised controlled trial
11	Marrón B, Martínez Ocaña JC, Salgueira M, Barril G, Lamas JM, Martín M, Sierra T, Rodríguez-Carmona A, Soldevilla A and Martínez F (2005) Analysis of patient flow into dialysis: role of education in choice of dialysis modality. <i>Peritoneal Dialysis International: Journal Of The International Society For Peritoneal Dialysis</i> 25 Suppl 3: S56-S59	2005	Multicentre retrospective study
12	Lindley EJ, Thomas N, Hanna L, Walker D, Milo E, Koupatsiari T, De Vos J-Y, Sedgewick J, Pugh-Clarke K, O'kane F, Treloar G, Pegoraro M, Marti A, Muroma-Karttunen R, Murcutt G, Shaldon S, Hoenich N, Brooks D, Pilley K, Küntzle W and Goovaerts T (2006) PRE-DIALYSIS EDUCATION AND PATIENT CHOICE: Summary of the EDTNA/ERCA Journal Club Discussion, Spring 2006. <i>Journal of Renal Care</i> 32(4): 214-220	2006	An e-mail survey of 23 EDTNA/ERCA participants from 12 countries
13	Kdoqi NKF (2006) KDOQI Clinical Practice Guidelines and Clinical Practice Recommendations for 2006 Updates: Hemodialysis Adequacy, Peritoneal Dialysis Adequacy and Vascular Access. <i>Am J Kidney Dis</i> 48: S1-S322(Suppl 1)	2006	KDOQI Guidelines
14	Hijaili, F., Tamim, H., Ghamdi, G., Flaiw, A., Al-Juhani, A., & Taher, S. (2007). Level of health awareness of Saudi patients on renal replacement therapy. <i>Saudi Medical Journal</i> , 28, 747-751.	2007	Cross-sectional survey by questionnaire
15	Winterbottom A, Conner M, Mooney A and Bekker HL (2007) Evaluating the	2007	Cross-sectional survey

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#	Studies Included	Publication Year	Study Design
	quality of patient leaflets about renal replacement therapy across UK renal units. <i>Nephrology Dialysis Transplantation</i> 22(8): 2291-2296		
16	Ormandy P, Hulme C, Caress A, Macdonald J, O'donoghue D and Crane D (2007) Identifying chronic kidney disease patients' priorities and preferences for information topics. <i>University of Salford: Institute for Health and Social Care Research Report</i>	2007	Mixed methods
17	Buck J, Baker R, Cannaby A-M, Nicholson S, Peters J and Warwick G (2007) Why do patients known to renal services still undergo urgent dialysis initiation? A cross-sectional survey. <i>Nephrology Dialysis Transplantation</i> 22(11): 3240-3245	2007	Retrospective survey
18	Finkelstein, F. O., Story, K., Firanek, C., Barre, P., Takano, T., Soroka, S., Mujais, S., Rodd, K., & Mendelssohn, D. (2008). Perceived knowledge among patients cared for by nephrologists about chronic kidney disease and end-stage renal disease therapies. <i>Kidney Int</i> , 74(9), 1178-1184.	2008	Questionnaire survey
19	Ormandy P (2008) Information topics important to chronic kidney disease patients: a systematic review. <i>Journal of Renal Care</i> 34(1): 19-27	2008	Systematic review
20	Lee, A., Gudex, C., Povlsen, J. V., Bonnevie, B., & Nielsen, C. P. (2008). Patients' views regarding choice of dialysis modality. <i>Nephrology Dialysis Transplantation</i> , 23(12), 3953-3959.	2008	Qualitative (focus group interviews)
21	Murray, M. A., Brunier, G., Chung, J. O., Craig, L. A., Mills, C., Thomas, A., & Stacey, D. (2009). A systematic review of factors influencing decision making in adults living with chronic kidney disease. <i>Patient Education and Counseling</i> , 76(2), 149-158.	2009	Systematic review of 40 studies on factors influencing decision making in patients with CKD
22	Al-Jahdali H, Bahroon S, Babgi Y, Tamim H, Al-Ghamdi S and Aa. A-S (2009) Advance care planning preferences among dialysis patients and factors influencing their decisions. <i>Saudi J</i>	2009	Cross-sectional survey

#	Studies Included	Publication Year	Study Design
	<i>Kidney Dis Transpl</i> 20: 232-9		
23	Heatley SA (2009) Optimal Referral Is Early Referral. <i>Perit Dial Int</i> 29 (Supplement_2): S128-131	2009	Survey
24	Lewis AL, Stabler KA and Welch JL (2010) Perceived informational needs, problems, or concerns among patients with stage 4 chronic kidney disease. <i>Nephrology Nursing Journal</i> 37(2): 143-149 7p	2010	Qualitative interviews
25	Morton, R. L., Howard, K., Webster, A. C., & Snelling, P. (2010). Patient Information about Options for Treatment (PINOT): A prospective national study of information given to incident CKD Stage 5 patients. <i>Nephrology Dialysis Transplantation</i> , 26(4):1266-74	2010a	Prospective national multi-centre cohort
26	Morton RL, Tong A, Howard K, Snelling P and Webster AC (2010b) The views of patients and carers in treatment decision making for chronic kidney disease: systematic review and thematic synthesis of qualitative studies. <i>BMJ (Clinical Research Ed.)</i> 340: c112-c112	2010b	Systematic review and thematic analysis of qualitative studies
27	Chanouzas, D., Ng, K. P., Fallouh, B., & Baharani, J. (2012). What influences patient choice of treatment modality at the pre-dialysis stage? <i>Nephrology Dialysis Transplantation</i> , 27(4), 1542-1547.	2012	Cross-sectional questionnaire survey
28	Liebman SE, Bushinsky DA, Dolan JG and Veazie P (2012) Differences between dialysis modality selection and initiation. <i>American Journal of Kidney Diseases</i> 59(4): 550-557	2012	Retrospective cohort study

Table 3.6 Studies included in the literature review: stage two

## Literature Review

#	Studies Included	Publication Year	Study Design
29	Ribitsch, W., Haditsch, B., Otto, R., Schilcher, G., Quehenberger, F., Roob, J. M., & Rosenkranz, A. R. (2013). Effects of a Pre-dialysis Patient Education Programme on the Relative Frequencies of Dialysis Modalities. <i>Peritoneal Dialysis International</i> , 33(4), 367-371.	2013	Retrospective single-centred cohort study
30	Harwood, L., & Clark, A. M. (2013). Understanding pre-dialysis modality decision making: A meta-synthesis of qualitative studies. <i>International Journal of Nursing Studies</i> , 50(1), 109-120.	2013	Systematic review using a meta-synthesis of 16 qualitative studies on dialysis modality selection
31	Maaroufi A, Fafin C, Mougél S, Favre G, Seitz-Polski B, Jeribi A, Vido S, Dewisme C, Albano L, Esnault V and Moranne O (2013) Patients' preferences regarding choice of end-stage renal disease treatment options. <i>American Journal of Nephrology</i> 37(2): 359-369 11p	2013	Single-centre prospective cohort study
32	Hassanien AA, Majeed A, Watt H and Basri N (2013) Review of pre end-stage renal disease care in the western region in Saudi Arabia. <i>Journal of Diabetes Research and Clinical Metabolism</i> 2(1)	2013	Cross-sectional survey
33	Winterbottom A, Bekker HL, Conner M and Mooney A (2014) Choosing dialysis modality: decision making in a chronic illness context. <i>Health Expectations</i> , 17(5): 710-723.	2014	Qualitative study
34	Van Biesen W, Van Der Veer SN, Murphey M, Loblova O and Davies S (2014) Patients' perceptions of information and education for renal replacement therapy: an independent survey by the European Kidney Patients' Federation on information and support on renal replacement therapy. <i>PLOS ONE</i> 9(7): e103914-e103914	2014	Survey
35	Prieto-Velasco M, Quiros P, Remon C and Spanish Group for the Implementation of a Shared Decision Making Process for RRTCWPDaT (2015) The Concordance between Patients' Renal Replacement Therapy Choice and Definitive Modality: Is It a Utopia? <i>PLOS ONE</i> 10(10): e0138811	2015	Observational prospective multicentre registry

#	Studies Included	Publication Year	Study Design
36	Van Den Bosch J, Warren DS and Rutherford PA (2015) Review of predialysis education programs: a need for standardization. <i>Patient Preference &amp; Adherence</i> 9: 1279-1291	2015	Literature review
37	Isnard Bagnis C, Crepaldi C, Dean J, Goovaerts T, Melander S, Nilsson E-L, Prieto-Velasco M, Trujillo C, Zambon R and Mooney A (2015) Quality standards for predialysis education: results from a consensus conference. <i>Nephrology Dialysis Transplantation</i> 30(7): 1058-1066	2015	Guidelines for pre-dialysis education, consensus conference
38	Jayanti A, Neuvonen M, Wearden A, Morris J, Foden P, Brenchley P and Mitra S (2015) Healthcare decision making in end stage renal disease-patient preferences and clinical correlates. <i>BMC Nephrology</i> 16(1): 1-17	2015	Cross-sectional study of 535 ESRD patients and 30 pre-dialysis patients prospectively
39	Goovaerts T, Bagnis Isnard C, Crepaldi C, Dean J, Melander S, Mooney A, Prieto-Velasco M, Trujillo C, Zambon R and Nilsson E-L (2015) Continuing Education: Preparing Patients to Choose Renal Replacement Therapy. <i>Journal of Renal Care</i> 41(1): 62-75	2015	Expert conference consensus
40	McCarthy K, Sturt J and Adams A (2015) Types of vicarious learning experienced by pre-dialysis patients. <i>SAGE Open Medicine</i> 3: 2050312115580403-2050312115580403	2015	Qualitative study. Unstructured interviews

Of the forty studies published between 1999 and 2015, thirty-seven (92.5%) related to western countries, with only three (7.75%) published in the KSA. The next section will summarise and critique these citations, as well as identify the current gaps in the literature in relation to pre-dialysis education.

### **3.3 Studies on pre-dialysis education and treatment choices**

The importance of pre-dialysis education, and its impact on the selection of treatment modalities, has been discussed in the literature and focuses on three specific areas: (a) studies assessing ESRD patients' information and knowledge of treatment options; (b) studies of pre-dialysis education programmes and adequacy of information for ESRD; and (c) studies identifying factors influencing ESRD patients' choice of dialysis treatment. All but one of these studies was conducted in Europe and Canada. To date, there is a distinct paucity of research from within the KSA. The only study conducted in the KSA, a cross-sectional questionnaire survey, explored ESRD patients' understanding of their disease and treatment options (Hijaili et al. 2007).

#### **3.3.1 Studies exploring patients' information and knowledge of treatment options**

There were three studies that explored ESRD patient information and knowledge about their treatment options, providing evidence as to whether the provision of patient education to ESRD patients was sufficient. Klang et al. (1999), in a study in Sweden, explored whether providing an education programme enabled the ESRD patients to access the necessary information to make a decision about treatment options. The participants in the experimental group (EG) were referred to a pre-dialysis education programme and asked to complete questionnaires assessing disease knowledge and the amount of information received before starting dialysis, and then again 3–9 months after starting dialysis. All patients (N=28) in the EG said that they had sufficient knowledge to choose a dialysis modality, compared with 22 of 28 patients in the control group (CG) (N=22,  $p<0.01$ ). However, there were some limitations to this study, which lead to questions about the validity of its findings. There was no indication of how patients were allocated to either group, and the CG participants were not given the questionnaire before they began dialysis. The results showed that both groups had similar levels of knowledge after starting dialysis (EG: N=28,  $r=0-4$ ; CG: N=28,  $r=1-5$ ), although the EG reported a better basis for choosing a treatment modality. This study indicated that providing education appeared to be important in enabling patients to choose the proper



treatment, although the highlighted methodological limitations prevent a definitive conclusion.

Other studies, however, did not support the notion that providing patient education improves patients' knowledge regarding treatment options. Finkelstein et al. (2008) conducted a questionnaire survey of 676 Canadian stage 3-5 CKD patients to measure their perceived knowledge about the treatment options. The findings demonstrated that participants had inadequate knowledge and understanding of their treatment options, lacked understanding of the pros and cons of treatment options, and had the least knowledge about PD compared to other treatment options. In the study by Finkelstein et al. (2008), 43% of patients reported no knowledge of HD, 57% reported no knowledge of CAPD, and 66% reported no knowledge of APD. Also, some 35% indicated no knowledge of any modality. The authors also demonstrated a highly significant correlation between the perceived knowledge of various ESRD therapies and patients' perceptions of their understanding of the advantages and disadvantages of the available treatment options ( $p < 0.0001$ ,  $N = 676$ ), thus highlighting the importance of providing patients with adequate knowledge. Furthermore, the perceived knowledge concerning PD was lower than the knowledge of HD or transplantation across patients at all stages of CKD and at all levels of frequency of nephrology visits ( $p < 0.001$ ,  $N = 676$ ; the  $r$  values were not provided in this paper). The findings from Finkelstein et al. (2008) highlighted the need for patient education programmes to provide patients with knowledge and information that is appropriate to their level of education, in order to ensure that no patients are excluded from the benefits of such programmes. Nevertheless, the inclusion of patients with CKD stage 3, which is an earlier stage of the disease, could have affected the findings.

The European Kidney Patients Federation (EKPF) conducted a survey of 3867 patients from 36 countries to explore the European patients' perceptions regarding information, education and involvement in the modality selection process (Van Biesen et al. 2014). The findings showed that although the majority of respondents (73.8%) reported that they had been provided with information about kidney disease and RRT, more than a third (39.3%) did not remember anyone talking to them about treatment options. Also, respondents

were more satisfied with the information provided about in-centre HD (90%) and transplantation (87%), compared to information on home-based therapies [PD (79%) and home HD (61%)].

These findings were similar to those from Finkelstein et al. (2008), which indicated that large numbers of patients had not been provided with information about home dialysis therapies. However, participants in the EKP survey (Van Biesen et al. 2014) were, in general, more positive, evaluating the information as 'very helpful' (46.1%) or 'somewhat helpful' (32.3%). The studies by Klang et al. (1999), Finkelstein et al. (2008) and Van Biesen et al. (2014) were conducted in western countries. All had similar findings with regard to patients' lack of knowledge about the treatment options, or that patients did not receive information about all alternative dialysis treatment options.

In central SA, Hijaili et al. (2007) surveyed 143 patients with ESRD who were on RRT in one hospital to assess their awareness of their disease and the treatment options available to them. A twenty-two item questionnaire was given to randomly selected patients on RRT (40 on HD, 61 on PD and 42 with a working renal transplant). The overall awareness score was calculated as percentages of correct answers, a point was given for each correct response, whereas no point was given for each wrong or missing response. The maximum score for the questionnaire is the total correct point of 56, which was denoted as 100%. For all the following categories (causes of renal failure, biology of the kidney, symptoms of kidney disease, therapeutic options available, and national kidney patients support facilities) combined together, the overall score was 45.9%. The lowest scores were found for the awareness of national kidney patient support facilities (36.8%) and for the awareness of the therapeutic options available (43.2%). Hijaili et al. (2007) reported that approximately 60.1% of the patients had secondary education or less. However, a comparison between patient groups showed that PD patients had the highest mean score of 'level of awareness' of their disease and treatment options (54.4%), followed by HD (44.3%) and patients on renal transplant (35.1%) ( $p=0.005$ ). These findings were statistically significant in all categories ( $p<0.0001$ ). This study provided evidence of a lack of awareness among patients with regard to kidney disease and treatment options. The authors suggested that this could have been because (1) patients on PD often carried

out the treatment at home and therefore received continuous training, and (2) patients accepted for PD tended to be younger and more educated (Hijaili et al. 2007). However, the findings presented did not include data related to this issue. In addition, the study did not include justification for considering missing data. There was also no explanation as to how randomisation was achieved. The research by Hijaili et al. (2007) did not offer an analysis regarding which factor or factors might predict the treatment types. However, it was the only study conducted in the KSA to examine patients' awareness of their disease, and therefore it was included. The study was carried out in one centre in the central region of SA, whereas the present study was undertaken in the western region of the SA. Nevertheless, both Hijaili et al. (2007) and the current study addressed some of the same issues, such as patient knowledge about their disease, together with their education levels; therefore their findings can be compared.

These four studies (Klang et al.1999; Hijaili et al. 2007; Finkelstein et al.2008; van Biesen et al. 2014) explored patients' knowledge about their treatment options. One showed that education helped patients to choose the most suitable treatment for them (Klang et al.1999). Finkelstein et al. (2008) identified a lack of, or at least inadequate knowledge among, patients and emphasised the need for educational programmes structured according to the patients' level of understanding. Three studies were published in western countries. The one study from the KSA provided valuable evidence about the lack of awareness and knowledge among Saudi dialysis patients. Another important finding is that over 60% of patients were only educated to secondary level or lower (Hijaili et al. 2007). This education level issue must be taken into consideration when improving pre-dialysis education available to patients in the KSA. Table 3.7 provides a summary of the studies included in this section. Studies of patients' knowledge of kidney failure and treatment are lacking in the KSA. The following section will include studies of pre-dialysis education and information.

**Table 3.7 Studies investigating patients' knowledge of their disease and treatment options**

<b>Authors/ Date</b>	<b>Aims</b>	<b>Design/Methods</b>	<b>Sample Characteristics</b>	<b>Results</b>	<b>Limitations/Remarks</b>
Klang et al. (1999)	To evaluate the effect of a patient education programme and study the patients' perceptions of dialysis.	Experimental study a) Pre-dialysis treatment questionnaires b) Questionnaire 3–9 months after starting dialysis treatment.	Experimental group n=28 patients compared to comparison group n=28.	Patients in EG had sufficient knowledge to participate in choosing dialysis modality compared with 22 of 28 patients in the CG ( $p<0.01$ ).	Patients were not randomly assigned to either group.
Hijaili et al. (2007)	To assess health awareness of patients on RRT in KSA.	Cross-sectional survey by questionnaire.	143 randomly selected adult patients on RRT (40 on HD, 61 on PD and 42 with renal transplant).	Low scores for awareness were found with regard to the therapeutic options available category (43.2%); PD group had the highest mean score of total score across categories of 54.45% followed by HD 44.3% and finally the transplant group	No explanation how randomisation was achieved.

Authors/ Date	Aims	Design/Methods	Sample Characteristics	Results	Limitations/Remarks
				35.1%; $p < 0.0001$ in all question categories.	
Finkelstein et al. (2008)	To identify patients' knowledge and education of CKD as well as concerning therapeutic options for ESRD.	Survey Self-administered questionnaire.	676 patients who were stage 3–5 CKD and had clinical data available.	Significant correlation between knowledge of ESRD therapies and patients' perceptions of the advantages and disadvantages of the available treatment options ( $p < 0.0001$ ).	$r$ value was not provided.
Van Biesen et al. (2014)	To explore European patients' perceptions regarding information, education and involvement on the modality selection process	Survey	3867 patients from 36 countries in Europe	73% reported to have been provided with information. 39.3% did not remember any talk about treatment options	Large scale survey

### **3.3.2 Studies of pre-dialysis education and adequacy of information for ESRD patients**

Four studies have examined the quality of pre-dialysis education and information (see Table 3.8). They identified that the quality of the existing pre-dialysis education programmes was inadequate and that some educational programmes provided insufficient or unclear information, an outcome which left patients confused.

In Denmark, Lee et al. (2008) conducted six focus group interviews with 24 dialysis patients, three pre-dialysis patients, and 18 relatives in order to explore patients' experiences with different dialysis treatment modalities and patient choices. The main themes that emerged from the interviews were: flexibility and independence; feelings of insecurity; maintenance of normal life; pre-dialysis education; and their involvement in the choices of modality. The data identified that patients showed appreciation for early information, whereas those who did not receive pre-dialysis education wished they had. Patients also suggested that any pre-dialysis information provided was limited, and they felt they needed more information and counselling during the process of becoming dialysis patients. The HD patients considered that they received no formal pre-dialysis education, and all were dissatisfied with the information they did receive. None was given a choice of dialysis modality, while the others who had started dialysis (those on PD) had been involved in choosing the dialysis modality. Their findings also highlighted that relatives wanted to be more involved in the family members' choice of dialysis and wished they had the chance to speak to other patients and their relatives before choosing dialysis. The choices were influenced by clinical factors and recommendations.

**Table 3.8 Studies of pre-dialysis education and adequacy of information for ESRD patients**

<b>Authors/Date</b>	<b>Aims</b>	<b>Design/Methods</b>	<b>Sample Characteristics</b>	<b>Results</b>	<b>Limitations/Remarks</b>
Piccoli et al. (2000)	To study the efficiency of the educational programme	Longitudinal study (questionnaire and interviews)	Followed patients (n=50) through four stages: pre-dialysis phase, dialysis start, optimisation of dialysis and transplantation	12 out of 18 patients (66.6%) who took part in the education programme chose a treatment option that they could undertake themselves (PD or home HD)	Small size Interview results were not included
Lee et al. (2008)	To explore patients' experiences with different dialysis modalities and issues related to patients' choices.	Six focus group interviews	24 dialysis patients, 3 pre-dialysis patients, and 18 relatives.	6 of 24 dialysis patients attended pre-dialysis education; none of the HD patients were given a choice of dialysis treatment; pre-dialysis patients appreciated early information, while those who did not receive formal pre-dialysis education were	Study findings based on one centre's experience; highlighted the fact that HD patients were not offered pre-dialysis education and were not involved in the choice of modality.

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Authors/Date	Aims	Design/Methods	Sample Characteristics	Results	Limitations/Remarks
				dissatisfied.	
Morton et al. (2010a)	To determine the effect of patient and unit characteristics on the type and timing of information provided.	Prospective national multi-centre cohort.	721 incidents stage 5 CKD patients.	85% of stage 5CKD patients received information; small dialysis units with <100 dialysis patients were associated with a higher likelihood of receiving information.	Study of the information provided to incident stage 5CKD patients; 90% response rate.
Winterbottom et al. (2007)	To audit the provision of patient information by renal units and to assess the quality of written information offered to UK patients with ESRD.	Cross-sectional survey of renal units' information provision. Audit questionnaire. Flesch readability formula was used to measure comprehensibility of leaflet.	67 out 105 renal units in the UK completed the questionnaire.	All units (67/67) provided information about HD,97% provided information on PD and 94% on transplantation. In total, 31 different leaflets were provided. Most leaflets were very hard to comprehend.	64% response rate.



With regard to the readability of the information provided to patients, one study has stressed that providing easily understood information is vital for patients. Winterbottom et al. (2007) conducted a cross-sectional questionnaire survey with 105 ESRD patients (64% response rate) from 67 UK renal units, using the Flesch readability formula to measure comprehensibility of leaflets (0–100; difficult–easy to comprehend). They identified that 32 out of 67 of the units provided leaflets but they were different and did not provide standardised information. Eighteen (57%) provided general information on disease and treatment options; four (13%) provided information on HD only, four (13%) provided information on PD only, three on renal transplant (10%), and two on conservative care (CC) (7%). The mean readability score of the 32 leaflets was 48/100, a readability equivalent to life insurance policies, i.e. very hard to comprehend. The average quality score for HD leaflets was 12 (SD 3.1) out of 20; the average quality score for PD was 11 (SD 5.7) out of 20; and the average quality score for transplant was 7 (SD 4.2) out of 20 (Winterbottom et al. 2007). Participants reported that the leaflets lacked key information about the risks and benefits of each treatment, and there were tendencies to emphasise the good points only of HD or PD without describing any limitations. Additionally, none of the leaflets included information to aid or enhance patient involvement in decision making regarding treatment choices (Winterbottom et al. 2007).

Piccoli et al. (2000) evaluated a pre-dialysis education programme for 56 ESRD patients in one unit in Italy. The authors employed a longitudinal questionnaire to evaluate the education programme, designed to follow patients from the pre-dialysis phase to dialysis phase, through the provision of lessons and booklets. The study reported that 53 out of the 56 Italian ESRD patients surveyed indicated they would like to have received further materials regarding their treatment choices (Piccoli et al. 2000).

Apart from the Winterbottom et al. (2007) study others, notably Piccoli et al. (2000) and Lee et al. (2008), were conducted in a single centre. The results might have been affected by the pre-dialysis education programme provided to patients in these centres and, therefore, may have reflected specific education practice, rather than the general education practice. Currently, the KSA has no national guidelines related to educational programmes for dialysis, so

hospitals/dialysis centres may provide different education and information to patients according to those centres' resources and staffing. The present study is a multi-centre study in the western region of the KSA, so the views of different dialysis education services, as well as possible comparisons between findings according to different settings, have been considered.

Multi-centre studies can provide better insight into pre-dialysis education in general, because they do not rely on the approach of one centre or one educational programme, but rather provide wider views and findings, which may be more generalisable to other centres. In a prospective national multi-centre study in Australia, Morton et al. (2010a) found that a significantly high proportion of patients received information prior to the commencement of treatment (95% CI 13.8–19.4,  $p < 0.001$ ), while 85% of stage 5 CKD patients received information about treatment options prior to treatment initiation. The data from this study are scientifically robust. This multi-centre study had a high response rate of 90%. It also identified an association between the size of the dialysis units and the patients receiving information about treatment options. Small dialysis units with fewer than 100 dialysis patients were associated with a higher likelihood of providing information prior to commencing treatment. However, this study showed that a good proportion of the patients (60%) were known to the consultant nephrologists for more than one year, which might explain the high percentage of patients receiving information prior to the initiation of dialysis, compared to previous reports. The present study in the KSA was also a multi-centre study, which highlights the different pre-dialysis education/information provided in different centres. Therefore, the results can be compared to the findings of Morton et al. (2010a).

Previous research, such as that by Klang et al. (1999), Goovaerts et al. (2005) and Lee et al. (2008), has shown that when patients are given information and/or education about treatment options, that knowledge can help them to understand which options are more suitable to treat their situation and so may facilitate their understanding of treatment choices. Given the possibility of cultural differences between patients in Europe, Canada, and the KSA, further research is needed to explore the dialysis education/information provided, as well as the patients' perceptions of factors that influence the dialysis treatment

they receive. The present study investigates what education or information is given to ESRD patients before starting dialysis, in order to provide recommendations for the development of a pre-dialysis education programme in the KSA.

### **3.3.3 Factors influencing the decision regarding dialysis treatment type**

Three systematic reviews (Murray et al. 2009; Morton et al. 2010b; Harwood & Clark 2013) and two research studies (Wuerth et al. 2002; Chanouzas et al. 2012) have explored factors that influence patients' decisions regarding the type of dialysis treatment patients choose. These studies identified factors, including the patient's lifestyle, the influence of their family and doctors, written information, and other demographic factors, which were considered influential in the decisions about treatment type. A summary of the studies and reviews is shown in Table 3.9. This section starts by explaining each systematic review individually and then synthesises the three. After that, it discusses the two research studies (Wuerth et al. 2002; Chanouzas et al. 2012) exploring the factors that influence patients' decisions regarding treatment.

Murray et al. (2009) conducted a systematic review focused on CKD patients' decision-making needs, as well as barriers to, or facilitators of, shared decision-making. Forty studies from nine countries were included (34 single studies of which 22 were descriptive studies, five systematic reviews, and one narrative review). Studies were included if they involved adults >18 years old and had been published between 1998 and 2008. The review by Murray et al. (2009) used an explicit approach to assess the quality of the methodology. The quality ratings of the 34 studies ranged from moderate to weak, with three studies scoring a high rating. The authors identified patient-level factors influencing a patient's decision, including: 1) interpersonal relationships, such as the family's opinion; the opinion of healthcare providers and knowledge of other patients' experiences; 2) preservation of current wellbeing and maintenance of current lifestyle; 3) the need for control to maintain individuality and being personally responsible; and 4) patient's personal weighting of benefits/risks. The need for more research was suggested by Murray et al. (2009) to enhance the understanding of how these factors vary across the course of the disease by culture, age, gender, and healthcare delivery system. In addition, future studies examining lifestyle and practical

concerns influencing patients' decision-making can strengthen approaches to patient-centred care in this population (Murray et al. 2009)

Harwood & Clark's (2013) systematic review was conducted using a meta-synthesis of available qualitative studies in this field. Meta-synthesis involves inductive reasoning and interpretation, to allow the researcher to transfer ideas and concepts across the different studies (Britten et al. 2002). The systematic review included 16 qualitative studies (total n=410 participants) exploring patients' selection of dialysis modality. All of the studies were published between 1996 and 2011. The overall quality of the studies was judged to be moderate. The three dominant themes present across the studies were:

- 1) *The illusion of choice*. Across most of the studies, patients perceived that they were provided with choice over modality selection, although medical considerations also forced dialysis choices to be made by the family or nephrologists at a late stage. Patients viewed dialysis decisions as stressful choices between lifesaving dialysis and dying, which reduced the real sense of choice.
- 2) *Personal factors and the minimization of the intrusiveness of dialysis*, i.e. the decision making was influenced by patients' personal preferences, values, and beliefs that the type of dialysis was less disruptive for their quality of life and the importance of maintaining autonomy.
- 3) *Knowledge and social support*. Patients saw acquiring more information about dialysis as essential to decreasing misunderstanding and to help them assess how specific dialysis would impact upon their future lives. This also included other information, such as frequency of dialysis treatment. Location risks and time requirements were also deemed important in decision-making. Across many studies, education was considered important for the family as well, and social support was found to be a factor that affected decision-making. Acceptance of medical advice/information was enhanced by a trusting relationship with the healthcare providers.

Morton et al. (2010b) conducted a systematic review and thematic synthesis of qualitative studies to synthesise the views of patients and carers in decision-making about their treatment, and to determine the factors influencing those decisions. Twenty-two studies that reported the experiences of 375 patients and 87 carers were included. Eighteen studies focused on preferences for dialysis modality, three on transplantation and one on palliative management.

Major themes identified were confronting mortality, lack of choice, gaining knowledge of options and weighing up alternatives. Respondents from 17 studies suggested that the decision of treatment choice was made for them because of medical contraindication or physician preference (Morton et al. 2010b). Eleven of the 18 studies reported that patients and carers did not receive information they wanted about treatment options. A further ten studies reported that constraints on resources, such as limited access to central based dialysis, was the reason for choosing haemodialysis at home or PD (Morton et al. 2010). Ten studies reported the importance of the timing of information and that patients were often too unwell to take in the information or were urged to make a decision by healthcare professional before discussing it with family (Morton et al. 2010b).

**Table 3.9 Studies on the factors that influence the decision regarding dialysis treatment type**

<b>Authors/Date</b>	<b>Aims</b>	<b>Design/Methods</b>	<b>Sample Characteristics</b>	<b>Results</b>	<b>Limitations/Remarks</b>
Harwood & Clark (2013)	To examine how people with CKD make decisions about the type of dialysis modality to use.	Systematic review using a meta-synthesis.	16 qualitative studies between 1996 and 2011.	Three themes emerged: 1. illusion of choice, 2. personal factors, and 3. the imperative of knowledge and support for decisions.	Studies included range of different countries and cultural groups. Two studies were rated as low quality.
Murray et al. (2009)	To identify factors influencing patient involvement in decision making in the context of CKD.	Systematic review.	40 studies published between 1998 and 2008.	Factors influencing decision-making were interpersonal relationships, preservation of current lifestyle and well-being, and personal weightings of benefit and risks.	Clear description of quality rating for studies included.
Wuerth et al. (2002)	To examine the factors that influence patients' choice of modality.	Qualitative structured interview.	40 patients (20 PD, 20 HD).	28 patients reported making choices of their dialysis modality. 83% reported that their physicians influenced these choices.	Random selection of patients by trained interviewer not affiliated with dialysis unit.
Morton et al.(2010b)	To synthesise the views of patients and carer in decision making about treatment and to determine which factors influence those choices	Systemic review and thematic synthesis	18 studies included (14 focused on treatment preferences; three on transplant and one on palliative management)	Main themes include: choosing between life or death, lack of choice, gaining knowledge and weighing alternatives.	Included studies on all RRT options including transplant and palliative management. Thematic synthesis was used to focus on patient and carer preference,

					and decision making for all treatment options
Chanouzas et al. (2012)	To examine how patients' choice of different treatment modalities was influenced by personal demographics.	Survey questionnaires.	242 pre-dialysis patients who had already made choices following standard education.	Patients who had chosen PD scored some factors significantly higher than HD: written information ( $p=0.048$ ), fitting with lifestyle ( $p=0.025$ ), and family home/work ( $p=0.003$ ). Patients who chose HD scored the past medical history factor higher ( $p=0.018$ ).	48.7% response rate.  63% felt that their chosen modality was medically influenced.

Both systematic reviews (i.e. Murray et al 2009; Harwood & Clark 2013) examined studies conducted in western countries, such as the US, Australia, UK, and Canada, although Murray et al. (2009) also included studies from a wider range of countries, such as Japan, Hong Kong, India, and Iran. The studies reviewed by Murray et al. (2009) mainly focused on how the patient made a treatment decision and the provision of information by healthcare professionals related to that decision. Ten of the studies reviewed supported the notion that patients with CKD have need of information about the history of kidney disease and treatment procedures, and that the most common areas of interest were the severity and side effects of treatment. This was observed across several countries, and among new dialysis patients, as well as those who had been on dialysis for several years. However, according to the authors, this evidence was limited to information needs without consideration of the factors influencing patients' decision-making, such as values, resources, and the opinions of others. In addition, no study identified the patients' views on the influencing factors as being either barriers or facilitators to decision making (Murray et al. 2009).

Harwood & Clark's (2013) meta-synthesis indicated the importance of education to family members, because patients tended to rely on their families for support and because the dialysis choice would affect these relatives. Both systematic reviews included different cultural groups, providing evidence regarding the effect of the patients' autonomy, their families, their healthcare providers, and the pre-dialysis education they received on the patients' decisions regarding dialysis treatment type.

Studies of patients' points of view regarding those factors influencing their decisions are essential in the development of pre-dialysis education programmes. In this regard, Chanouzas et al. (2012) surveyed 242 pre-dialysis patients in a single centre in the UK. These patients had already made their treatment choices after receiving standard pre-dialysis education at the centre. The response rate was only 48.7%, which was not high, but was acceptable as long as the results reached statistical significance. The participants were asked to rate the factors affecting their treatment choices on a scale from 0 to 5 (where 0=not applicable and 5=extremely important). The study identified that the factors identified as important for all treatment groups were: their ability



to cope with the treatment modality; the modality fitting with their lifestyle; distance to the centre; the verbal/oral information they received about the modality; and the written information they were presented with regarding the modality. Those factors were identified with a mean score ranging from 2.08 to 2.60, suggesting they were important but not extremely important. These results emphasised the importance of providing good verbal and written information to all patient groups. The factors that were more personalised among patients were fitting modality with lifestyle ( $p=0.025$ ) and the ability to cope with their treatment. Furthermore, certain demographic factors were identified as being predictors of RRT choices. For instance, 'being married' (PD 95.7%, HD 53.8%; conservative management (CM) 41.7%;  $p<0.001$ ) were statistically significant predictors of PD choice. 'Being employed' (PD 33.3%, HD 11.5%, CM 0%  $p=0.015$ ) and 'having another person living at home' (PD 100%, HD 69.5%, CM 50%;  $p=0.003$ ) were also statistically significant predictors of PD choice. Although in general the patients felt they had received adequate information to make their choices, 63% still felt that their chosen modality was medically superior. This means that patients felt their treatment choice was influenced by their medical team's opinion, yet the belief that one choice was medically superior was not discussed or explained by the authors.

Similar findings were reported in the qualitative study conducted in the USA by Wuerth et al. (2002), which examined the factors leading to patients' selection of dialysis type, PD or HD. Of the 134 patients who started dialysis between March 1999 and February 2000, 104 were eligible to participate. Forty of 104 patients (20 PD, 20 HD) were randomly selected and invited to participate in a freestanding PD unit, as were two in a freestanding HD unit, who started dialysis within the preceding six months, were interviewed. Based on patients' comments, a taxonomy of the specific factors that influenced patients' decisions was developed. Patients' responses were grouped into four categories: impact of pre-dialysis education programme, other influencing factors, autonomy/control, and treatment-specific factors. Sixteen out of 20 PD patients selected issues concerning autonomy/control as being primarily responsible for their decisions, such as being able to do treatment at home and being able to continue to work. Eight PD patients also selected treatment-specific factors as being important, such as the ability to perform their own treatment, they did not like the sight of blood in HD treatment, and they

believed that PD would be more comfortable. On the other hand, of the eight who did choose HD, treatment-specific factors were the most commonly cited reasons for opting for HD, such as the ability to have the nurse to perform the treatment, the ability to have treatment three times per week versus seven times per week, and not having to have a tube in their abdomen. All 20 PD patients chose their treatment, while only eight of the 20 HD patients chose their treatment. The 12 HD patients who reported that no treatment choice was offered to them indicated that they relied on the recommendations of their doctors; seven were too sick to make decisions and the other five HD said that their doctor determined the decision with no discussion being presented concerning PD as a treatment choice. This provides further evidence that patients who start HD do so following their doctor's recommendation and suggests the possibility they might not have received pre-dialysis education or an explanation of both treatment types.

The previous section discussed the literature concerning the factors that influence dialysis modality decisions. Three systematic reviews provided rich information and findings from different types of studies. These sources were followed by two studies aiming to explore the patients' points of view regarding the influential factors behind their treatment decisions.

### **3.3.4 Studies of dialysis patients' experiences about treatment decision-making**

This section includes seven studies exploring patients' experiences of information and about treatment decision-making. One was conducted in the KSA, and six studies were undertaken in European countries, four of which were only published after the present study was completed. However, they have been included in the literature review (see Table 3.10) as they inform the discussion of the findings of the present study.

Two qualitative studies were conducted in the UK to investigate patients' experiences of disease and decision-making. In the UK, (Winterbottom et al. 2014) interviewed 20 patients with CKD to explore patients' decision making about dialysis and to understand how their experiences of CKD were associated with treatment choice. Patients were recruited into one of four groups: i) newly referred patients attending the "low clearance clinic" (a clinic

where patients with advanced CKD were informed by their doctors or nurses of the need for dialysis); ii) those who were considering their treatment decision; iii) those who had made their decisions and iv) patients who were interviewed at several time points. Key themes identified included perceptions of the cause of the illness, usefulness of meeting other dialysis patients, perceived role within the decision, and perceived difficulties in choosing dialysis. For example, most were unaware that their kidneys were failing prior to diagnosis, and central to their experience was the lack of specific kidney failure symptoms (Winterbottom et al. 2014). Another key theme that emerged from the data was that patients perceived the “difficult” dialysis decision to be a choice between having and not having dialysis, while the decision about which dialysis option was an “easy” decision. Further, patients expressed negative emotions upon discovering their illness rather than in their description of making their dialysis choice. The authors concluded that information to help patients understand their kidney disease and the need to make choices about dialysis were important (Winterbottom et al. 2014).

**Table 3.10 Studies on dialysis patients' experiences about treatment decision-making**

<b>Authors/ Date</b>	<b>Aims</b>	<b>Design/Methods</b>	<b>Sample Characteristics</b>	<b>Results</b>	<b>Limitation/ Remarks</b>
Maaroufi et al. (2013)	To evaluate patients' preferred treatment modality, and the cause of any mismatch between preference and the treatment delivered.	Single centre prospective cohort study in France.	Patients with CKD and incident dialysis who received an information programme about ESRD treatment options between 2009 and 2011.	228 patient received information delivery: 177 received information before dialysis; 92 received information 1 month after initiation of treatment. The PD preference patients group had a significantly lower BMI and tended to be older (p=0.06).	
Winterbottom et al. (2014)	To understand how patients with kidney failure make their dialysis treatment decision.	Semi structured in-depth interviews.	20 with CKD at different stages of decision-making.	There was a similarity in the patterns of patients with ESRD in response to the illness.  Themes from the data included perception of the cause of illness.	

McCarthy et al. (2015)	To explore the patients' vicarious learning experiences of the pre-dialysis education and treatment decision-making.	Unstructured interviews.	20 pre-dialysis patients.	Three themes of vicarious learning experiences identified by patients: 1)planned learning(formal education); 2) unplanned learning experiences and 3) historical vicarious learning experiences.	
Jayanti et al. (2015)	To study patient preferences for information seeking (IS) and decision-making.	Combined cross-sectional and prospective design.	535 ESRD patients enrolled into the cross-sectional study and 30 patients who started dialysis were prospectively evaluated in five UK centres.	Association of higher decision-making scores with lower age ( $p<0.001$ ), lower comorbidity index scoring ( $<0.001$ ).  Higher education emerged as significant variable for information seeking but not for decision- making ( $p<0.05$ ).	API have high internal consistency (Cronbach's alpha $> 0.70$ ).
Prieto-Velasco et al. (2015)	To determine the impact of a structured	Observational prospective 'registry' in 26	1044 patients registered.	890(86.2%) passed through EP and 569(54.5%) had made a definitive choice by the end of	Structured education programme plus

## Literature Review

	education process (EP) with patient decision aid tools (PDAs) for RRT patients' choice.	Spanish hospitals between 2010 and 2012.		<p>registration, 43% chose HD, 45% chose PD, 3.2% chose pre-emptive living donor TX and 8.4% chose CT.</p> <p>More educated patient started PD than those who did not participate in EP (47.8% vs. 6.5%; Chi-square test <math>p &lt; 0.001</math>).</p>	the use of patient-decision aids tool.
Robinski et al. (2016)	To show the impact of multiple patient characteristics on treatment satisfaction after the choice of RRT.	Observational cross sectional multicentre survey.	780 patients from 50 dialysis centres in Germany.	PD patients reported higher treatment satisfaction (TS) ( $P < 0.001$ ), more autonomy and 'information-seeking personality' ( $P = 0.04$ ), better cognitive functioning ( $P = 0.001$ ) and more successful shared decision-making (SDM) ( $P < 0.001$ ) compared to HD patients.	

A study was conducted in the UK by McCarthy et al. (2015) to explore the patients' vicarious learning experiences of the pre dialysis education and treatment decision making; unstructured interviews were used with 20 participants, guided by grounded theory methodology. The theme of 'vicarious' was subdivided into three types:

- 1) Planned vicarious learning in the form of a formal information day which was offered to all pre-dialysis patients where they met existing dialysis patients;
- 2) Unplanned vicarious influences on the decision-making occurring in clinic waiting areas and the hospital environment, when the patient met someone similar to their cultural background and which resulted in decision making that was peer influenced; and
- 3) Historical vicarious experiences if the patient had a family history of the disease, which could provide prior life experience and influence the decisions about treatment.

In the KSA, ESRD is very common and sometimes it is hereditary, so family history of the disease, as identified by McCarthy et al. (2015), and the unplanned vicarious influences on the decisions, which occurred as a result of random discussion with other patients at the waiting areas, are important factors in decision-making.

The studies by McCarthy et al. (2015) and Winterbottom et al. (2014) explored different aspect of patients' experiences of treatment choices. Winterbottom et al. (2014) showed how patients considered the choice between having to opt for dialysis or no dialysis as more difficult than the choice between different dialysis types. On the other hand, McCarthy et al. (2015) identified vicarious learning experiences of patients that can affect their understanding of treatment and hence the treatment decisions they make.

Patients differ regarding their preferences for information and regarding their desires to be involved in decision-making about their treatment. In the UK, Jayanti et al. (2015) conducted a prospective cross-sectional study of 535 ESRD patients and 30 pre-dialysis patients to evaluate preferences for information-seeking and decision making and to examine clinical, psychological and neurocognitive correlates of 'autonomous' decision-makers versus 'delegators' in ESRD. Participants were recruited from three groups: patients who were pre-

dialysis (A); those receiving in-centre haemodialysis (B) and patients in self-care HD (C). The autonomy preference index (API) is a tool developed and validated in general medical patients, consisting of two subscales: an eight-item information-seeking subscale and a six-item decision-making subscale. It was employed to study patient preferences for information seeking and decision-making. In the single variable analysis of the information-seeking subscale scores, the predictors at the 15% significance level of high information-seeking scores (linear regression with just the variable of interest in the model) were; age, education, study group and gender, marital status and existence of heart failure (Jayanti et al. 2015). Also, decision-making (DM) subscale scores were subdivided to identify variables associated with high DM scores ( $>70$ : empirically designated as autonomists) and low DM scores ( $<30$ : empirically designated as delegators). This shows an association of higher decision-making scores with lower age ( $p<0.001$ ), lower comorbidity index scoring ( $<0.001$ ), higher executive brain function, belonging to the self-caring cohort and being unemployed (Jayanti et al. 2015). Higher education emerged as a significant variable for information seeking but not for decision-making ( $p<0.05$ ). Retired individuals were more likely to assume a passive role in the decision-making ( $p<0.001$ ), and marital status appears to influence decision-making preferences ( $p<0.015$ ). This study provides evidence regarding the patients' role in the decision making process, yet it includes only patients on HD.

Other studies that include all treatment options in the decision making process would provide a wider view of the shared-decision making process.

Nevertheless, according to Jayanti et al. (2015) communicating information and determining patients' values and preferences must be culturally sensitive and should account for the cultural diversity of different regions. For example, the study findings showed that white patients were more likely to prefer to be involved in decision making ( $p<0.001$ ) compared to non-white. The population of the KSA tends to be more ethnically and culturally diverse than in western countries. From the literature review it appears that preferences regarding decision-making or information seeking in the KSA are not clear and had not been studied at the time of the current research.



Two prospective studies investigated patient changes of the preferred treatment method after information had been provided and dialysis initiated. In France, Maaroufi et al. (2013) undertook a prospective cohort study in a single centre to evaluate patients' preferred treatment modality after information delivery, as well as to evaluate their views on choice of treatment options. A total of 228 patients received information during the pre-dialysis care; 177 (78%) patients were not undergoing dialysis yet, and the other 51 (22%) had started HD less than 1 month before and had not received any pre-dialysis information. Of the 177 informed patients, 82(46%) expressed preference for PD and 49 (28%) preference for HD, while 34 (19%) were undecided and 12(7%) were reluctant to say. Patients who said they preferred PD had a significantly lower Body Mass Index (BMI), tended to be older ( $p=0.05$ ) and were more likely to have been informed before, rather than after, starting dialysis (OR 3.4, 95% CL 1.5-7.4). In addition, the findings identified a mismatch between patient preferences and therapeutic modality. In the PD group, a mismatch occurred in 53% of the patients who were informed before, and 66% of the patients who were informed after, starting dialysis ( $p<0.05$ ). However, the findings indicated that approximately 50% of PD mismatches were for medical reasons (Maaroufi et al. 2013). PD was preferred for reasons such as autonomy and convenience for travelling and employment; while choosing HD was for the social interaction and security that patients perceived came from inpatient treatment. These findings are similar to those of Harwood & Clark (2013), which were discussed in the previous section.

Similarly, in Spain, Prieto-Velasco et al. (2015) conducted an observational prospective multicentre study in 26 hospitals to determine the impact of a structured Education Process (EP) with patient decisions aid tools (PDAs) for RRT patients' choices. The EP process consists of four phases. The first phase (value phase) aims to identify the patient's values, preferences, life styles, and EP is based on respect of these values. The second phase (information phase) consists of providing patients and relatives with formal information about CKD and RRT modalities. The third is the deliberation and question-answer phase, whereby patients and relatives are guided to think about their choices; it comprises a number of visits until the final choice is made. The final phase is the decision-making phase, when patients confirm their treatment choice and sign the consent form with the nephrologist, who records the definitive

decision and starts RRT preparation. Out of 1044 people, 569 patients used PDAs and made a definitive choice by the end of the registration; 88.4% chose dialysis (43% HD and 45% PD), 3.2% pre-emptive living-donor transplant and 8.4% conservative treatment. The findings indicate that patients who followed the EP changed their mind significantly less often [ $\kappa$  value of 0.91 (95%CI, 0.86\_0.95)] than those who did not. Additionally, the findings identified that more of patients who participated in the ED process started PD than those who did not participate in an EP (47.8% vs. 6.5%, Chi-square test  $p < 0.001$ ) (Prieto-Velasco et al. 2015). Furthermore, when a chi-square test was used to determine if there are significant differences between the final choice and the definitive modality for each of the treatment options, statistically significant differences were found for PD ( $p = 0.03$ ), as well as for transplant and CT ( $p = 0.05$ ); no statistical significance was found for HD ( $p = 0.17$ ). In addition, 98.7% of the non-educated patients (those not participating in an ED process) started urgent unplanned dialysis. Also in the non-educated group (not participating in an ED process), the percentages of HD as the initial and definitive method were high (96.1% and 92.4%) ( $p < 0.001$ ) compared to the educated patients (who participated in ED). However, there were no records of patients' comorbidities, which might lead to the unplanned dialysis starting in the HD group.

The study findings show the benefits of including PDAs tools in the education process, as they can help patients understand their own personal values and preferences when making treatment choices. According to Prieto-Velasco et al. (2015), PDAs were designed to progressively provide information and to guide patients to identify their personal values and important lifestyle aspects and preferences, thus facilitating the deliberation about, and ultimately the choice of, treatment. This study used the model proposed by Elwyn et al. (2012) (see chapter 2, section 2.5.1) of how to initiate shared decision-making in clinical practice. The importance of the inclusion of PDAs tools to support the patients during the information and the deliberation phase of the education process was evident.

Patient involvement in the decision-making process can improve their satisfaction with the treatment. In this regard, results from a large European survey of 3867 patients from 36 European countries (previously discussed in

section 3.3.1) indicated that almost half of respondents (46.7%) had been 'very involved' in the process of selection of the RRT modality or 'somewhat involved' (28.2%), whereas 48.8% explicitly stated they did not know about the RRT options (Van Biesen et al. 2014). The findings showed that participants who felt they had been involved in the modality selection were more likely to be 'very satisfied' than those who had not been involved (OR 3.31 (95% CI 2.72-3.60). In addition, (Van Biesen et al. 2014) found a similar association between perceptions of having a choice of treatment and 'overall satisfaction with care' (OR 2.25 (95% CI: 1.97-2.56). On the other hand, 22.8% remembered that the medical practitioner suggested at some point that their social circumstances were a contraindication for certain RRT modalities.

In Germany, Robinski et al. (2016) published the baseline results of a multicentre study of 780 patients from 55-dialysis centres, aiming to show the impact of multiple patient characteristics on treatment satisfaction (TS) after the choice of RRT. The researchers in this very recent study focused on the multivariate associations between aspects such as patient autonomy, psychosocial, physical and cognitive conditions, and social support. To aid comparability of the ESRD patients with regards to age, comorbidity, education and employment, the data were matched by means of a linear propensity score (PS) (which is a tool for causal inference in non-randomized studies that allows for conditioning on large sets of covariates (Thoemmes 2012). And the resulting groups were compared with respect to the outcomes; thus PD patients were only compared with those HD patients who showed similar age, comorbidity, educational level and employment status. The selection of PS-matching variables was based on interviews with nephrology experts in educating patients about modality choice.

Robinski et al. (2016) showed that after propensity score matching (PSM), PD patients reported higher treatment satisfaction (TS) ( $P < 0.001$ ), more autonomy and an information-seeking personality ( $P = 0.04$ ), better cognitive functioning ( $P = 0.001$ ) and more successful shared decision-making (SDM) ( $P < 0.001$ ) compared with HD patients. In addition, the patient's psychological state and shared decision-making play important roles for treatment satisfaction in both dialysis groups. Robinski et al. (2016) suggested the involvement of psychological professionals, as well as nephrologists, and facilitating contact

with other ESRD patients before a treatment choice is made. It was recommended that personality screening of patients should take place; their possible role within the decision making process (passive or shared selection with nephrologist or autonomous choice) was also emphasised (Robinski et al. 2016).

As stated earlier, there have been no studies in the KSA regarding the involvement of patients with ESRD in the decision regarding dialysis treatment type. According to Harwood & Clark (2013), dialysis modality decision making is highly individual and contextually driven, and so is likely to be transferable to other health decisions that are contextually based, as well as to other life-sustaining health decisions. With regard to the KSA, there was one cross-sectional survey conducted in 2009 that sought to determine HD patients' preferences regarding being resuscitated. Although the aim of Al-Jahdali et al. (2009) was not to explore ESRD patient treatment decisions, the research does provide data about how Saudi Arabian patients are involved in making decisions about their health. For this reason, the paper was included in the literature review as it can provide the context of patients' involvement in shared decisions making in the KSA. In their study, Al-Jahdali et al. (2009) found that only 14% of the 100 patients on HD who participated in the study knew about their disease prognosis. Some 77% felt that the doctor should make the decision about resuscitation if their condition did not permit them to make the decision, while 79% agreed to undergo resuscitation if they were likely to recover completely and become independent.

The research provided evidence that, despite the Saudi patients' inadequate knowledge regarding resuscitation and their low educational levels (years of education: means  $\pm$  SD = 5.6  $\pm$  5.54), they were able to make decisions about end-of-life issues once they were provided with enough information about risks and clinical outcomes. The researchers concluded that the physicians/doctors should inform patients about the benefits and the adverse effects of different treatments, in addition to their prognoses, so that patients would be empowered to participate in discussions and make informed choices (Al-Jahdali et al. 2009). Although these findings are from only 100 patients, the study was multi-centred, conducted in the KSA, and examined a sensitive topic that considered patients' preferences for resuscitation. Another study in the KSA,

by Mobeireek et al. (2008), was a large survey to assess physicians' and patients' views in the KSA about involving the patients, versus the family, in the process of diagnosis disclosure and decision making. A total of 321 doctors and 264 patients were included. The questionnaire used for the survey was previously developed collaboratively to compare the attitude of US and Japanese physicians. A total of 67% of doctors and 51% of patients thought the patients should be told about a diagnosis of incurable illness in preference to telling the family (Mobeireek et al. 2008). Patient participants were more supportive of informing the family than doctor participants ( $p=0.001$ ). When the family is already aware of the diagnosis and does not wish to inform the patients, 56% of doctors would still inform the patients.

This study supports the need to conduct similar studies to understand patients' needs in the KSA for information about their treatment, as well as their willingness to discuss their treatment options with physicians, even though these decisions may mean life or death. In similar circumstances, patients with ESRD, who have a low education level, should be able to make decisions about their treatment options if they are offered adequate pre-dialysis education. However, it is necessary to examine what information or education patients in the KSA receive, prior to their dialysis treatment, and who makes the decision of the treatment choice. Then, recommendations for a planned pre-dialysis education programme can be made.

This section has reviewed evidence regarding patients' experiences of treatment and shared decision-making. Patients' preferences towards seeking information and decision-making were also discussed. The impact of pre-dialysis education with decision aids tools on patient's choices, and the influence of patient involvement in the decision making on treatment satisfaction, were explored. The lack of evidence regarding shared decision making for patients with ESRD in the KSA was explained, including consideration of the studies conducted in the KSA to explore decision making by patients. The following section will discuss the literature concerning pre-dialysis education about the selection of home dialysis (PD or home HD) and self-care dialysis.

### **3.4 Studies on pre-dialysis education and treatment choice of home dialysis (PD or home HD) and self-care dialysis**

Apart from in-centre HD, the majority of patients on dialysis can also be managed either by home dialysis or in self-care centres. The popularity of home dialysis varies and seems to relate to the financial status of institutional dialysis (Maher 2012). Home dialysis can place stress on family relationships, but it is often satisfactory when there is space and family support (Maher 2012). On the other hand, self-care dialysis is particularly appropriate for those patients for whom home dialysis is difficult or impossible. The aim for this type of dialysis is to provide a place where patients can dialyse themselves, without assistance or supervision (Maher 2012). Evidence indicates that when patients receive appropriate pre-dialysis education regarding the different choices of treatment modalities available to them, they may have an equal chance of choosing self-care dialysis and home dialysis (Wuerth et al. 2002; Goovaerts et al. 2005). Pre-dialysis education can correct and eliminate misconceptions regarding treatment modalities. This section will start by discussing those studies that provide evidence about the influence of pre-dialysis education on the choice of home dialysis (PD or home HD) and self-care dialysis. Then it will discuss other, sometimes contradictory, studies (Chanouzas et al. 2012; Liebman et al. 2012), showing that patients do also choose HD after attending pre-dialysis education. A summary of the five studies is shown in Table 3.11, while one study was described previously (Table 3.9)

**Table 3.11 Summary of studies on pre-dialysis education and the selection of dialysis modality**

<b>Authors/ Date</b>	<b>Aims</b>	<b>Design/Methods</b>	<b>Sample Characteristics</b>	<b>Results</b>	<b>Limitation/ Remarks</b>
Goovaerts et al. (2005)	To evaluate the influence of a pre-dialysis education programme on the mode of RRT chosen.	Retrospective study between 1994 and 2000.	185 patients starting RRT.	Patients' ages in all self-care therapies were lower than the ages of in-centre HD patients ( $p < 0.001$ ).	Old data (1994-2000).
Mehrotra et al. (2005)	To examine the effect of the ESRD process on the selection of RRT among ESRD patients.	Survey data collected from all patients admitted to 229 dialysis units between 1 April 2002 and 30 May 2002.	Newly incident ESRD patients and dialysis staff.	30% of patients reported that treatment options were not presented to them until dialysis had been started, and 48% reported that options were presented to them after either the first dialysis or less than one month before the need for dialysis.  There was a strong relationship between satisfaction and the amount	Low response rate (31%)

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Authors/ Date	Aims	Design/Methods	Sample Characteristics	Results	Limitation/ Remarks
				of time spent discussing treatment options.	
Manns et al. (2005)	To determine the impact of a patient-centred educational intervention on patients' intentions to initiate self-care dialysis.	Randomised controlled trial. Participants were randomised to receive standard care or standard care plus educational intervention.	70 patients with CKD.	Significant improvements in knowledge/attitudes towards self-care dialysis for intervention patients ( $p < 0.001$ ).	RCTs. Randomisation process was successful.
Ribitsch et al. (2013)	To evaluate the impact of a pre-dialysis education programme on the frequencies of dialysis modalities.	Retrospective single-centred cohort study comparing the annual incidence rate of PD and HD for patients receiving pre-dialysis education with rates for the standard-care group for a 4-year	Incident ESRD patients 2004–2008 $n=227$ .	The educated stage 5CKD patients started significantly more often with PD (54.3%) than patients in the CG did (28%). In the CG, of those who received no formal pre-dialysis education, 28% started PD and 113 (72%)	Elimination of all patients with CVC minimised the bias of late referral and emergency start.



<b>Authors/ Date</b>	<b>Aims</b>	<b>Design/Methods</b>	<b>Sample Characteristics</b>	<b>Results</b>	<b>Limitation/ Remarks</b>
		period (2004-2008).		started HD ( $p<0.001$ ).	
Liebman et al. (2012)	To determine predictor of mismatch between chosen and actual dialysis modality after education.	Retrospective cohort study.	217 patients who received modality education between 2004-2009.	124 chose PD, 52 were undecided and 41 chose haemodialysis.  More patients started HD ( $n=150$ ), compared with PD ( $n=67$ ).	

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In Belgium, Goovaerts et al. (2005) studied the influence of a pre-dialysis education programme on the type of RRT chosen by patients with ESRD. This retrospective observational study involved 242 patients, of which 57 (24%) were directed to in-centre HD based on medical judgment and therefore had no choice of treatment. Of the remaining 185 patients who attended the pre-dialysis education programme: 102 (55.1%) chose self-care RRT (55 opted for PD, 30 for self-care HD in a satellite unit and 17 for home HD); 75 (40.5%) chose to have HD in a centre, and the eight remaining patients (4.3%) received transplantation. The findings also indicated that self-care patients were younger than the in-centre HD patients ( $p < 0.001$ ); the younger the age group, the higher the probability of choosing a self-care modality ( $p < 0.01$  Mann-Whitney U-test).

A qualitative study in the US by Wuerth et al. (2002) involved interviewing 40 ESRD patients (20 on PD, 20 on HD) to examine the influences and factors that led to their treatment modality selection. Autonomy, control, flexibility of schedule, whether travel is possible, and whether it is easier to work, were among the reasons stated by patients. Also treatment-specific factors, such as duration of treatment, concern about infection, and body image, were among the factors influencing patient choices. Out of 40 patients, only 22 had pre-dialysis education. Eighteen of the 22 patients who attended pre-dialysis education opted for PD. All 20 of the PD patients reported that they chose that treatment modality, while 12 of the 20 HD patients reported that they had no choice in determining their modality. Seven stated that they were too ill to make the decision, while five stated that the decision was made by their doctor, and they were presented with PD as a treatment option. Thus, only a few patients chose in-centre HD when they were offered education and choices (Wuerth et al. 2002).

In Italy, Piccoli et al. (2000) designed a pre-dialysis education pathway to lead to a better comprehension of ESRD and its therapies through repetition of information in various forms, such as lessons, booklets, and stories. The programme was designed and tested by a small team working in an out-of-hospital centre. Choices of treatment for all 50 patients who started dialysis in the centre were analysed; it was revealed that only 18 had received an educational programme. Patients' opinions and views about the educational

lessons, books, and stories were gathered by questionnaires and by interview. Piccoli et al. (2000) found that 12 out of the 18 patients (66.6%) who took part in the education programme chose a treatment option that they could undertake themselves (self-care dialysis and home dialysis-PD or home HD). However, the authors mentioned possible referral bias may have occurred, as the group performing the education programme also followed home-dialysis patients.

In contrast, not all studies reported that pre-dialysis education led to a preference for self-care. For example, in a questionnaire survey, Chanouzas et al. (2012) noted that the majority of the 118 patients who replied to the questionnaire (n=82, 70% response rate) had chosen HD, while 20% (N=24) chose PD, with 10% (N=12) opting for CM. However, the potential contraindications to a particular RRT were not excluded from the initial study group, and this led to the low uptake of PD according to the authors. Similarly Liebman et al. (2012), in a retrospective study of dialysis patients who received pre-dialysis education before dialysis initiation, found that of the 217, 124 chose PD, 52 were undecided and 41 chose haemodialysis. The PD group were younger and received education earlier than those who chose HD. However, in terms of initial dialysis modality, more patients started HD (N=150), compared with PD (N=67). Also, almost all (40/41) choosing HD started with this modality, as did the majority of undecided patients (45/52) and more than half of those choosing PD (65/124). As previous reports highlighted, patients starting with PD were more likely to be employed. On the other hand, more of those starting HD were over 75 years old (20%) compared with PD (7%); furthermore being over 75 was a predictor of HD start even in patients choosing PD. In patients initially choosing PD there were 40 urgent dialysis treatments started at the hospital; most of them started HD (N=38), compared with PD (N=2,  $p<0.0001$ ) (Liebman et al. 2012). Duration of education or the number of nephrology visits were not significant factors for starting one modality over another (Liebman et al. 2012)

Two studies also indicated that the clinician's preference could lead the patient towards a particular modality (Goovaerts et al. 2005; Mehrotra et al. 2005). However, these studies presented data from western countries, and there is no

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evidence available yet from Saudi studies to examine the influence or the preferences of clinicians in the KSA regarding treatment modality.

A study from the USA identified a bias towards presenting HD as the only RRT option. Mehrotra et al. (2005) studied the effect of patient education and the access of ESRD patients to RRTs beyond in-centre HD, by using survey data collected from new ESRD patients and from dialysis staff. Respondents were asked to complete a facility survey for every eligible patient from 229 dialysis units in the USA. Dialysis staff completed facility surveys for 1,193 patients (87%), while 428 patients themselves returned the patient survey (31%). Of the 428 participants, 327 (76%) placed identifiers that permitted the linking of their data to the facility survey. Of the responding patients, 30% reported that treatment options were not presented to them until dialysis had been started; 48% reported that treatment options were only presented to them after the first dialysis session or less than one month before their need for the first dialysis treatment.

Mehrotra et al. (2005) found that RRTs other than HD were not offered to most new ESRD patients, and 70% of the HD patients reported that PD was not offered as an option for RRT. The findings also showed the prevalence of medical contraindication to PD in the study (23% to 24%) but were unable to demonstrate any relationship between the presence of medical contraindication to PD and the probability of the therapy being offered. Mehrotra et al. (2005) identified a significant relationship between the length of time patients had known about their kidney failure and the selection of PD (Cramer's  $V=0.20$ ,  $p<0.01$ ). There was a strong relationship between satisfaction with the information presented (Cramer's  $V=0.17$ ;  $p<0.05$ ) and the amount of time spent discussing treatment options (Cramer's  $V=0.29$ ;  $p<0.0001$ ) among those who selected PD. In contrast, no significant correlation was observed for satisfaction with information presented and time spent discussing HD. In contrast to research conducted outside the USA, Mehrotra et al. (2005) raised the question of why PD was not being offered to patients as an option. However, there was a significant limitation to this study due to the low patient response rate (31%). This could have affected the generalisability of the results, in that they only represented the views of less than a third of the sample.

Two studies have provided evidence that the structure of the pre-dialysis education programme can influence the choice of self-care dialysis treatment, such as patient-centred education or providing a pre-dialysis education programme via the multidisciplinary education team. The following study offered a unique approach to providing education, by combining the provision of both written manuals/video and group sessions. Such an approach was associated with an increased likelihood of patients choosing the self-care option. Manns et al. (2005) undertook a randomised controlled trial with pre-dialysis patients with CKD to determine the impact of a patient-centred educational intervention on patients' intentions to initiate treatment using self-care dialysis and home dialysis (i.e. PD or home HD). Thirty-five out of 70 patients were randomly assigned to standard care (basic information, no video or educational session) and 34 of them completed the study; one failed to complete (Manns et al. 2005). The other 35 patients were assigned to standard care plus an educational intervention. In the intervention group, 30 patients completed phase one, involving educational booklets and a 15 minute video on self-care dialysis. Twenty-eight of these 30 patients also completed phase two, which involved a 90-minute small group interactive educational session on self-care dialysis.

The findings confirmed that the impact of the educational intervention was clear among those patients who were uncertain about which modality to start or who were planning to start with in-centre HD at the study baseline. For example, of the 18 patients who were part of the control group, only three (16.7%) planned to start self-care dialysis at the study's completion, compared to nine out of 14 (64.2%) in the intervention group ( $p=0.01$ ). There were also significant improvements in the knowledge and attitudes towards self-care dialysis for intervention patients ( $p<0.001$ ). Although more participants in the intervention group completed the trial than did participants in the control group, with a dropout rate of 1/35 in control group and 7/35 in the intervention group (34 and 28 patients respectively), the findings were considered robust. The high rate of dropout in the intervention group could be related to the education process itself; yet the authors did not address this issue. The study was a randomised controlled clinical trial, and the analysis of baseline characteristics confirmed that the randomisation process was successful.

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Manns et al. (2005) highlighted the important elements of pre-dialysis education, especially the small group discussion session. This involved participants describing the advantages and disadvantages of self-care dialysis based on their knowledge. It was followed by a dialysis scenario, in relation to which they had to find solutions to overcome barriers to self-care dialysis. In phase two of the intervention group, the education included the patients, their relatives, and the nephrology team. No other studies have been found which have used such a combined-factor intervention of written manuals/video and group sessions.

In Australia, Ribitsch et al. (2013) evaluated the impact of multidisciplinary pre-dialysis information on a dialysis education programme, known as INDIAL. This initiative was presented by a multidisciplinary team including nurses, dieticians, and nephrologists and considers the patients' choice of dialysis modality. In their retrospective cohort study of 227 patients who started dialysis, the frequency distribution of dialysis modalities between participants attending an educational programme and participants not attending the programme was analysed. Some 70 patients (30.8%) took part in the educational programme, while the control group of 157 (69.2%) did not receive any structured pre-dialysis education. Of the patients in the INDIAL group, 54% started with PD compared to only 28% in the CG ( $p < 0.001$ ). The patients who received the pre-dialysis education programme (intervention group) also started more often with PD (54.3%), compared to those started with HD (45.7%). Additionally, the older patients chose PD significantly less often; the odds ratio for each 10 additional years of age was 0.73 (95% CI: 0.60 TO 0.89;  $p > 0.001$ ). These findings supported previously discussed studies that younger patients choose PD more often than do older patients (Chanouzas et al. 2012; Liebman et al. 2012). Moreover, the study highlighted the importance of multidisciplinary pre-dialysis education programmes involving nephrologists, nurses, and dieticians. According to Ribitsch et al. (2013), this kind of multidisciplinary programme provides patients with the opportunity to make informed decisions and increases the likelihood that they will start dialysis in a planned structured manner. The study concluded that the multidisciplinary team was able to manage small groups of patients and facilitate adequate education quality. However, the implementation of this approach would require significant financial resources, dedicated staff, and support from the hospitals

or dialysis centres. This observation applies especially to the KSA, as patients are accustomed to getting information from the nephrologist in most settings.

### **3.5 Optimal timing for dialysis education and late referral**

Dialysis education should begin prior to patients commencing dialysis. For patients to be involved in their treatment choices, they should receive education before their actual need for dialysis. No experimental studies have been found that identify the optimum time to introduce patients to a pre-dialysis education programme. However, according to Lo et al. (2008), patients and their families need time to digest the information provided to them. These authors suggested that it is reasonable to start pre-dialysis education at around 4–6 months before the estimated commencement of the treatment, or when patients have reached stage 4 CKD with a GFR of about 15 ml/min/1.37m<sup>2</sup>. Nevertheless, according to the Kidney Disease Outcomes Quality Initiative (KDOQI) guidelines, patients should be informed about the general principles of PD, HD, and transplantation when their estimated GFR reaches <30 ml/min/ 1.73 m<sup>2</sup> (CKD stage 4) (KDOQI 2006). The UK National Service Framework for Renal Services recommends a period of one year of preparation prior to starting dialysis treatment (UK Department of Health 2004). The latest recommendation from a consensus conference in Europe was that renal replacement therapy options education (RRTOE) should start at least 12 months before the predicted start of dialysis (Isnard Bagnis et al. 2015).

Determining the ideal time for referral to nephrology services is difficult to predict, with eGFR being a major trigger in the referral process and because the variations across nephrology settings are great (Heatley 2009). In the KSA there are no recommendations or guidelines concerning pre-dialysis education or the period of time required for preparing patients with ESRD before the initiation of dialysis. This could explain the limited number of renal-failure related studies performed to date in the KSA, as well as the need for studies to address these issues in order to improve the practice of renal care for patients with ESRD in the KSA.

#### **3.5.1 Late referral for dialysis**

Referral is considered 'late' when management could have been improved by

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earlier contact with nephrology services (Heatley 2009). When patients are referred to nephrologists during the late stages of CKD (5), they feel very unwell and are generally suffering from different symptoms than those who are referred during earlier stages of their illness. These symptoms include fluid and electrolyte disturbance, acid-base imbalances because homeostatic regulation of water and electrolyte no longer occurs, and the metabolic waste accumulated within the body, resulting in uraemia (i.e. elevated serum blood urea nitrogen (BUN) and creatinine) (Schumacher & Chertock 2009). In such cases, the initiation of dialysis is an urgent, life-saving treatment, especially if the patient has an elevated potassium level and shortness of breath due to oedema. In these circumstances, there is no opportunity for patients to receive information about all the available treatment options because they are ill and may be confused or because of the urgent requirement for treatment.

Many studies show that early provision of information facilitates an informed choice of RRT, while late referral is associated with a lack of treatment sources, as well as a greater likelihood of receiving in-centre HD (Golper 2001; Wuerth et al. 2002; Finkelstein et al. 2008). Goovaerts et al. (2005) suggested that when patients are referred early to nephrologists and pre-dialysis education, they choose self-care treatment more often than in a late referral situation. Goovaerts et al. (2005) indicated that of the 58 patients who were referred late to nephrologists (when the need for dialysis was urgent), 25 were directed to in-centre HD, while the remaining 33 entered the pre-dialysis education programme three months before dialysis or after the onset of dialysis. Of these 33 patients, 20 (61%) chose the self-care treatment modality, while 13 (39%) opted for in-centre HD. No statistical differences were found between patient who chose self-care and patient who opted for in-centre HD

However, usually patients are referred to nephrologists during the later stages (stage 5 CKD) of their disease. Therefore, they typically require urgent, in-centre dialysis (Golper 2001). Morton et al. (2010a) recruited 721 incident stage 5 CKD patients. In 66 out of the 73 renal units in Australia, they reported that a significantly lower proportion of patients were not receiving information before starting dialysis (95% CI 13.8–19.4,  $p < 0.001$ ) than patients who were receiving information before dialysis. This could have been because the median time between the initial information and first treatment was six



months. Morton et al. (2010a) also found that patients who commenced home dialysis were referred earlier to a nephrologist, and they received information and started dialysis with permanent access (i.e. IV Fistula, IV Graft and Permanent catheter) more often than centre-based HD patients.

Despite this, a late referral to a nephrologist is not always the reason for patients' limited knowledge of RRT or for them being directed to in-centre HD. Finkelstein et al. (2008) reported that, even if patients were referred to nephrologists, the level of perception and knowledge of ESRD and treatment options was still insufficient. The authors explained that perceived lack of knowledge does not reflect actual lack of knowledge, and such a perceived deficit may reflect difficulties in communication with patients. However, Finkelstein et al. (2008) also identified that patients' knowledge improved significantly with the number of visits to their nephrologists, suggesting that patients need frequent visits to a nephrologist, thereby allowing more discussion about treatment in order to help them understand types and choices. For instance, 64% of patients who had four or more visits in the preceding year reported having knowledge of HD, compared to only 40% of patients seen once during the past year ( $p < 0.001$ ). PD knowledge reportedly improved from 25% to 51% with increased visits ( $p < 0.001$ ) (Finkelstein et al. 2008). These data indicated the importance of pre-dialysis care for ESRD patients at nephrology clinics, as well as such care's impact on patients' knowledge of treatment options.

Buck et al. (2007) retrospectively surveyed patients ( $N=126$ ) starting RRT in 2003 in a large regional UK renal network, in order to identify risk factors contributing to starting dialysis. The participants had knowledge of the renal services for at least 4 months prior to starting RRT. Data from 109 patients were included because 17 patients did not consent to data collection (response rate= 86.5%). The authors sought to identify possible risk factors for patients starting unplanned RRT, despite having knowledge of renal services for more than four months. They found that patients who did not attend a pre-dialysis clinic had a 90% increase in the odds [odds ratio =0.111,  $P=0.001$  (0.029, 0.429 CI)] of requiring urgent dialysis initiation, when compared to those who had attended a clinic. The authors highlighted that, according to their results, the services were judged at least in part responsible for the urgent start. The

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results pointed out a number of factors which contributed to the urgent start, such as delayed initial discussions about RRT, late referral for RRT counselling, and late referral for access.

In the western region of KSA, Hassanien et al. (2013) conducted a cross-sectional study in two dialysis centres in that region to review pre-ESRD care and to investigate the primary cause of ESRD among HD. The findings from a total of 403 haemodialysis patients shows that in 67 case records, the reasons for referral were missing or not reported; referral from the emergency department for urgent dialysis was the main source for 50.6%. A further 27.8% of referrals were from out-patient clinics for renal care and 21.6% were from different healthcare centres for dialysis (Hassanien et al. 2013). The pre-ESRD care period ranged between 0 to >12 months with 113 missing records. A high proportion (47.6%) of HD patients had not received pre-ESRD nephrology care; 28.6% of patients had received care for less than 6 months; 6.9% received care between 6-12 months, and 16.9% received care for more than 12 months. There was also a significant association between pre-ESRD care period and referral source ( $p < 0.0001$ ), where patients with CKD who had not received pre-ESRD care were most likely to be referred from emergency departments (Hassanien et al. 2013). The majority of patients had not received pre-ESRD care or they had received less than six months of care; most were referred for urgent HD. According to the authors, this situation reflected delayed referral to nephrology care from other primary care centre (Hassanien et al. 2013). The data showed that, in those specific centres, patients were referred late to nephrology care, thereby offering a view of the status of late referral for dialysis and the need for urgent HD. As identified from previous reports, patients who referred late mainly opted for urgent HD. Therefore, according to Hassanien et al. (2013), this is the case in the KSA, at least in the two centres involved in the study. However, Hassanien et al. (2013) included only HD patients, so it does not reflect the practice of renal referral for all dialysis patients. There is a need for a study in the KSA that includes more than just two dialysis centres, in order to reflect the status of late referral more clearly. The present study was designed, therefore, to highlight the nature of late referral in the participating hospitals.

### 3.5.2 Early referral to the multidisciplinary team

The education of patients in the early course of CKD is associated with many potential benefits for patients including improved treatment outcomes, reduced anxiety and improved timing for the start of dialysis (Golper 2001). In a survey of the National Pre-ESRD Education Initiative in the USA, which involved 932 referring nephrologists and 28 educators throughout the country, patients attended standardised education sessions. Subsequent sessions were more customised to suit the patients and the family members who also attended. Patients then chose their dialysis modality after completing the programme, and they completed a questionnaire shortly after the start of dialysis (Golper 2001). The questionnaire was completed by 2580 patients. At the end of the educational programme, HD was chosen by 55% of patients, and PD by 45% of patients. The results suggested that choice of dialysis modality is influenced by the extent of education received by the patient (Golper 2001). There was a significant reduction in the incidence of urgent dialysis in the educated group compared with the control group (13% vs. 35%, respectively,  $p < 0.05$ ). There was also more outpatient training (76% vs. 43%,  $p < 0.05$ ) and fewer hospital days in the first month of dialysis (6.5 days in the educated group vs. 13.5 days in the control group,  $p < 0.05$ ) (Golper 2001). The author concluded that pre-dialysis education involving a multidisciplinary team can have positive outcomes, but essential elements, such as early referral to a nephrology centre, as well as resources such as dedicated pre-dialysis education staff, need to be available.

The late referral of patients with CKD is associated with increased mortality and morbidity, severe hypertension, high initial hospitalisation rates, and low prevalence of permanent dialysis access. The delay also decreases patients' choice of RRT modality (Heatley 2009). In the UK, Heatley (2009) surveyed 100 patients for an audit of a structured education programme, which involved of a multidisciplinary team that followed specific referral pathways (the criteria for referral were based on an eGFR of 20ml/min and declining). All referred patients attended a patient education event and education workshop based at the clinic, so education was combined with the pre-dialysis visit. The workshop had life-size mannequins with dialysis access inserted, providing patients with visual examples of dialysis equipment and dialysis access. Heatley (2009) indicated that 97% of the patients attended the workshop and found it

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extremely valuable; 98% found talking to 'experienced' patients to be reassuring and encouraging; 58% found the written information to be good; and 75% found that the workshop and the written information helped them to make a decision about dialysis modality. According to Heatley (2009), early referral to a pre-dialysis service and a multidisciplinary team enhanced the intensive education programme that can lead to a delay in the start of RRT, better clinical variables at the start of dialysis, and a reduced likelihood of emergency dialysis or inpatient dialysis.

Results from a recent cohort study in Taiwan by Chen et al. (2015) provided new evidence to support the use of multidisciplinary care. A retrospective single-centre analysis was conducted of 1,382 patients with CKD (stage 3-5), which aimed to evaluate the effect of multidisciplinary care on renal outcome and survival. Of the total, 592 were multidisciplinary care programme participants and 614 patients were not part of any multidisciplinary care programme. The findings indicated that the multidisciplinary care group was better prepared, with fewer patients requiring an emergency start of dialysis (39.6% vs 54.5%,  $p=0.001$ ). Furthermore, the multidisciplinary care group had a better renal survival profile (hazard ratio 0.640; 95% confidence interval, 0.484-0.847;  $p=0.002$ ) (Chen et al. 2015). These results provided further support for the advantages of the provision of multidisciplinary care to patients with ESRD.

In this regards, Goovaerts et al. (2015) presented recommendations from discussions involving experts in renal replacement therapy options education (RRTOE) from six European countries, designed to provide nurses with advice and guidance on running RRTOE. The researchers concluded that enrolment to RRTOE should take place at stage 4 CKD (15-29mls/min/1.73m<sup>2</sup>) or 12 months before the predicted start of dialysis. It was argued that nurses are the case managers who are responsible for scheduling appointments, providing educational sessions, and communicating with other team members. These nurses must have substantial experience of all treatment modalities, in order to provide unbiased information (Goovaerts et al. 2015)

Another important aspect of education, highlighted by Goovaerts et al. (2015), was that educators need to elicit a patient's knowledge of RRT options and their current concerns, rather than work through lists of pre-prepared topics.

This, in turn, helps to determine what information should be provided and the most effective form for any particular patient. The authors recommended that the content should be ordered according to whether or not the patient had made a decision on treatment (Goovaerts et al. 2015). The use of group sessions was not possible for some units. One-to-one sessions were common, and all units reported variations regarding the number of sessions required, but 3-6 sessions were commonly recommended. Other methods, such as a visit to the dialysis unit and meeting with patients, were suggested, depending upon the unit's resources, as a means of adding variety to the provision of the information.

In Canada, Brown et al. (2015) performed a retrospective cohort study to identify risk factors for unplanned dialysis starts in patients, who were being followed in a multidisciplinary CKD clinic from January 2010 to April 2013. Out of 649 advanced CKD patients, 184 (28.4%) initiated dialysis, of which 76 patients (41.3%) initiated dialysis in an unplanned fashion, and 108 (58.7%) started electively. 98.7% of patients who had unplanned dialysis initiation started on HD, with only one starting PD. The findings showed significant differences between the groups; patients who initiated unplanned dialysis had a higher rate of coronary artery disease (CAD) (42.1%VS 24.1%;  $p=0.02$ ), diabetes (68.4% vs. 51.9%;  $P=0.04$ ), and congestive heart failure (CHF) (36.8% VS. 17.6%;  $p=0.01$ ) compared to patients who initiated dialysis electively (Brown et al. 2015).

Patients in the unplanned group were also much less likely to have received formal education about the different options for renal replacement therapies before they started dialysis (52.6% vs. 14%;  $p<0.01$ ). The multivariable analysis using logistic regression indicated that higher body mass index (BMI) (or 1.07 per unit change, 95% CI 1.02, 1.13;  $p=0.006$ ) and history of CHF (or 2.41, 95% CI 1.09, 5.41;  $p=0.04$ ) were associated with an unplanned start. It was noted that the presence of hypertension (or 0.08, 95% CI 0.004, 0.51;  $p=0.02$ ) was associated with an elective start (Brown et al. 2015).

The findings highlighted that late referral to a nephrologist is not always the cause of unplanned dialysis. Other factors, such as comorbidity, can lead to an unplanned start of dialysis in such patients with CAD, CHF, and diabetes. The findings present up-to-date evidence, which could explain the urgent

## Literature Review

unplanned dialysis start among patients who were known, and were followed, whilst under the supervision of a multidisciplinary team. The type of dialysis start (unplanned versus elective) was ascertained by a comprehensive chart review of the electronic health record systems by two authors independently. Patients were defined as having an unplanned start only if they started dialysis as inpatients in the hospital and had acute clinical indications, such as hyperkalaemia (Serum K of  $>5.5\text{mEq/L}$ ) volume overload and uraemia, which meant that assignment of both types of dialysis start was done appropriately. The efficiency of multidisciplinary clinics, where the main goal is to transition patients smoothly into dialysis, has not been well studied, but the findings of (Brown et al. 2015) indicate that other factors, such as some comorbidity, can still lead to an unplanned start of dialysis among patients with advanced CKD. However, the research by Brown et al. (2015) was only published after the present study was completed and, whilst it can inform the discussion of findings, the information was not available when planning the research.

### **3.6 Content of pre-dialysis education**

Two studies and two systematic reviews have reported differences in terms of the content and form of delivery by which pre-dialysis education can be presented to patients. The following section focuses on the literature that describes the content of pre-dialysis education and recommendations for the type of information to include in these education programmes.

In the UK, Ormandy et al. (2007) conducted a mixed methods study. First, semi-structured interviews were undertaken with CKD patients ( $n=20$ ) to elicit core patients' information need themes. The authors then conducted a cross-sectional survey using face-to-face structured interviews to validate/test the renal-specific information needs questionnaire (INQ) with 89 CKD patients. Stratified sampling was used to include patients in groups of HD, PD, and pre-dialysis patients. Nine points of core information were identified from the initial interviews, such as information about the cause, progression, and future expectations of the disease, followed by explanations of the different treatment options and the practical aspects of these options.

In other research, Lewis et al. (2010) studied 30 patients with CKD stage 4, from one clinic in the USA, in order to identify the informational needs,

problems and concerns perceived by patients, as well as to explore what to include in the educational programme. Using structured interviews, Lewis et al. (2010) found that the problems and concerns experienced by patients were not always consistent with the information perceived as 'needed' by the healthcare providers in an educational programme. For example, patients wanted more information about kidney disease, vascular access, treatment options and medication included in the educational programme. Furthermore, three patients responded regarding end of life decisions and care, indicating that they would not like to start dialysis. Therefore, according to the authors, patients do need information regarding end of life and withdrawal issues to be available in the educational programme for patients with CKD stage 4. This, in particular, is an important issue in relation to patients in the KSA; usually this information is not offered and, if patients wish to withdraw or refuse dialysis, they would lose contact with their nephrologist and health care support.

Furthermore, a systematic review of 25 articles was conducted by Ormandy (2008) to identify the information needs and topics considered important to CKD patients. The author found that the majority of studies indicated that participants wanted information about the disease itself. However, they also wanted unbiased information about the RRT, including information about the impact of the treatment on their physical appearance, as well as on their social and family lives. Further information regarding the flexibility of the treatment schedule and the need to travel to the hospital, compared with having the treatment at home, was also desired. Additionally, the patients wanted information about any complications they could expect and how to deal with them, as well as how to manage their diet, fluid restriction, and medication. According to Ormandy (2008), patients' preferences and priorities for information change over time, as their disease progresses. The Ormandy (2008) review illustrates the information/topics that should be considered essential in the development of pre-dialysis programmes. In addition, a systematic review of ten studies by Murray et al. (2009) focused on decision making and information needs, and this identified similar patient requirements for information to those highlighted by Ormandy (2008). The most common information need identified by Murray et al. (2009), related to the severity and potential side effects of the disease.

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Pre-dialysis education programmes should also provide a realistic picture of PD and HD with regard to vascular access creation, peritoneal catheter insertion, and long-term care, so as to identify and correct misconceptions about dialysis (Covic et al. 2010). The European Renal Best Practice (ERBP) Advisory Board on RRT modality selection for ESRD, advised that well-balanced information should also apply to all new patients, including late-referral patients, once their conditions stabilise, and that patients' preferences should be the leading criterion for modality selection (Covic et al. 2010).

In Europe, results from a consensus conference about the quality standard of pre-dialysis education by Isnard Bagnis et al. (2015) provided a clear recommendation for Renal Replacement Therapy Option Education (RRTOE), based on current evidence and pre-existing guidelines. According to Isnard Bagnis et al. (2015), a RRTOE team should consist of nephrologists and a CKD nurse and that she/he should have hands-on experience of all treatment modalities at a minimum and, optimally, the team should have training regarding principles of adult education and communication skills. Topics to include in a RRTOE programme should be those requested by the patients, thereby offering unbiased information about the treatment options that are in line with the patients' beliefs and values. On the other hand, Murphy et al. (2008) added that it must be recognised that not every option is suitable for every patient; hence this point needs to be considered when providing information. Additionally, patients who are not suitable for dialysis because of multiple co-morbid factors, or who choose not to have dialysis, should be provided with the management of physical symptoms and liaison with other services, such as end of life care. This matter is important, because in the KSA, as mentioned in the previous section, patients are not offered conservative treatment or the choice not to have dialysis. The current study addresses this issue.

Van den Bosch et al. (2015) conducted a review to compile evidence on the effective components of pre-dialysis education programmes in respect of modality choices and outcomes. Out of the 1,005 articles identified from the initial search, 110 were given full text reviews; only 29 out of the 110 studies met the inclusion criteria. Ten out of 13 studies used a comparative design, nineteen had a type of quasi-experimental design and ten were narrative



reviews. Four of 19 quasi-experimental studies reported high levels of knowledge about ESRD and different options for patients attending pre-dialysis education. Seven studies described multidisciplinary education programmes, whereby patients attend multiple education sessions with three or more health care professionals, and where there was a mixture of one-to-one and group sessions. According to the authors, the findings were not based on strong evidence; most experimental studies lacked a control and pre- and post-intervention measures, and there was a lack of studies comparing detailed components of educational programmes. There was little standardisation in the description of educational content. Many papers did not use educational theory to describe the selection or design of the educational programmes. This review pointed out the need for standardisation of pre-dialysis programmes, and that there is a lack of evidence considering the most effective methods to develop the education initiatives/programmes.

### **3.7 Styles and approach of pre-dialysis education**

Five studies have investigated the different ways in which pre-dialysis education can be provided to ESRD patients (Gomez et al. 1999; Manns et al. 2005; Winterbottom et al. 2007; Morton et al. 2010a); these studies have been described in previous sections. Three of the studies showed that the most common methods of education were written materials, such as educational booklets, as well as videos and discussions between patients/families and nephrologists or renal nurses (Manns et al. 2005; Winterbottom et al. 2007; Morton et al. 2010a).

In addition, two studies have assessed the effectiveness of the different ways education has been provided. A multi-centred controlled study conducted in Spain by Gomez et al. (1999) evaluated the effectiveness of a standard information package for ESRD patients in a pre-dialysis programme. All patients attending the centres between 1 June 1996 and 30 June 1997 (n=304) were included from 14 hospitals. The patients received two sets of questionnaires: pre-information knowledge (questionnaire 1) and post-information package (questionnaire 2). A total of 216 patients completed questionnaire 1 (response rate=71%) and 158 patient completed questionnaire 2 (response rate =51.9%). During the study period 147 patients started

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treatment; of these, 86 (49.4%) received information according to the study protocols (informed patients). The remaining 88 patients did not follow the standard information study protocol (and were classified as 'uninformed' patients). The results indicated a significant increase ( $p < 0.0001$ ) in patients' knowledge regarding all treatment options assessed. They also showed that patients who received information during the pre-dialysis phase obtained adequate knowledge to identify treatment options. The results further indicated that PD was the least known treatment option ( $p < 0.0001$ ), and that older patients knew significantly less than younger patients did, even after information provision ( $p = 0.018$ ).

In the UK, Iles-Smith (2005) conducted a qualitative study by interviewing ten pre-dialysis patients who had attended a pre-dialysis clinic for an average of 13 months to explore their perceptions, expectations, and experiences of ESRD prior to starting dialysis. The interviews covered topics relating to the patients' expectations of treatment, knowledge of treatment, and options. The analysis identified one main theme: patients experienced difficulty interpreting the information and lacked an understanding of the techniques of performing dialysis. Due to this problem, the patients were actively seeking out information from other sources. Additionally, the patients received different amounts of information. Iles-Smith's (2005) study elicited the experience and expectations of the patients in the pre-dialysis phase and showed how 13 months spent attending the dialysis clinic did not improve their understanding. The study findings highlighted related issues, such as difficulties in receiving information in a clinic setting. Patients referred to the limited time available in the clinic to discuss dialysis. Iles-Smith (2005) also demonstrated that patients received different amounts of information. According to the author, the study demonstrated the need for the use of different educational materials, plus the reinforcement of the information on various occasions.

The study of Manns et al. (2005) showed that the combination of an educational booklet describing the types of dialysis, as well as the advantages and disadvantages of each dialysis modality, combined with videos and a small interactive session involving 2–6 patients, led to more effective educational outcomes when compared to the standard method. However, the study by Ormandy et al. (2007), that aimed to describe the information needs of CKD

patients in the UK, found that the majority of patients (85.4%) preferred to receive information verbally, face-to-face and alone, followed by verbal, face-to-face, with the family present (70.8%), and written information (2.9%). A higher proportion of participants felt strongly that they “would never like” information provided using an audiotape (61.8%), face-to-face with a group (42.2%), or using a DVD (32.6%) or video (32.6%) (Ormandy et al. 2007).

Some advantages of group discussions are that patients feel less alone in their situation, and some patients may ask questions which are useful for others in the group. However, points raised may bias other people and there can be logistical challenges in arranging times and places to suit a group (Isnard Bagnis et al. 2015). With regard to pre-dialysis education in the KSA, the nature and the culture of the population is conservative, and there are no studies of patients’ preferences regarding discussion sessions in a group versus individually.

### **3.8 Conclusions from the literature review**

This chapter has reviewed the existing literature on pre-dialysis education, including its influence on patients’ selection of dialysis modalities. It should be noted that the literature available up to 2012 informed the design of the study as fieldwork commenced in 2013. Reviews of literature published between 2013 to 2015 were undertaken, and this ‘disconnect’ was taken into account when discussing the findings of the study and their implications.

Previous studies have suggested that patients with ESRD should be told about different treatment options so that they can make informed decisions regarding dialysis treatment (Gomez et al. 1999; Klang et al. 1999; Lee et al. 2008). Other studies have suggested that being informed opens patients to more options that they can consider, depending on their clinical needs and personal circumstances (Wuerth et al. 2002; Goovaerts et al. 2005; Mehrotra et al. 2005; Liebman et al. 2012). The research studies concluded that patients who participate in education programmes are more confident that they are making the right treatment choices.

Improving dialysis-related education for patients with ESRD in the KSA is important in order to optimise clinical practice since patients in the KSA have

only two treatment options, HD in hospital or PD at home, as home HD is not a service that is available from government hospitals. This raises questions regarding the level, type, and format of the RRT education that should be provided to patients in the KSA, as well as about the impact of this education on the treatment that patients receive. No studies were found which investigated this issue for dialysis patients in the KSA and therefore details regarding the current level, type of information provided and its mode of delivery to patients in the KSA were unclear, prior to the start of the present study. Furthermore, the influence of information on patients' treatment choices and outcomes, where it was available, had not been studied; thus the present research sought to rectify this situation.

### **3.9 Research aims and research questions**

The literature review was conducted to identify the evidence regarding pre-dialysis education and the factors that had been identified in the literature as being influential in relation to patients' choices and decisions about treatment type. Whilst there was substantial literature, most of the studies were conducted in western countries. Therefore, there was a lack of reports or research from the Middle East in general, and from the KSA in particular, regarding how information and education were provided to patients with ESRD, and how the decision about the type of dialysis is made.

This study underlines the need to identify how information and education on dialysis treatment options was given to ESRD patients and to analyse the factors that influence the patients' treatment decisions. The research questions that guided this study were partially developed based on the Health Belief Model (Rosenstock 1966), where the patient's belief of his health condition is an important variable influencing the decision to take action. Also, based on the theoretical framework of the model from Elwyn et al. (2012), which was designed to achieve shared decision-making, and which includes the three steps of 1) 'choice talk', 2) 'options talk' and 3) 'decision talk', it was determined that there was a need to provide a structured pre-dialysis education programme to inform patients of their condition and treatment options. This is particularly important within the context of Saudi Arabia since there is no evidence of any structured pre-dialysis educational programmes in place.

Hence, based on the critical appraisal of the published work, the following research questions were developed for this research:

1. What pre-dialysis education or information is provided to ESRD patients in the KSA?
2. What factors do patients perceive as influential regarding their dialysis treatment modality decisions?

The aim of this current research has been to examine the dialysis education provided to ESRD patients in the KSA and to ascertain the factors that patients perceive as influencing their treatment decisions. In order to achieve these objectives, a cross-sectional questionnaire survey was undertaken to address the following objectives:

- a) To find out what information new dialysis patients receive about dialysis modalities in the KSA.
- b) To ascertain the factors that patients perceive as being influential in their dialysis treatment decisions.
- c) To develop recommendations for the preparation of pre-dialysis education programmes for patients in the KSA.

This study used an extended version of the patient questionnaire survey used by Mehrotra et al. (2005) in the USA, with additional questions related to the KSA and patients' views and recommendations to improve education being included.



## **4. Chapter 4 Methodology, Research Design and Methods**

This chapter is divided into four sections. Section one discusses the chosen research approach and design, along with the research methods used and their justification. It includes the questionnaire that was the data collection tool, together with an explanation of its validity and reliability. Section two outlines the pilot study, its aims, and the recruitment procedure. Section three presents the main study and includes the selection of the sample and participant recruitment. It also involves a consideration of the ethical issues, and an explanation of how the research was carried out in practice, together with a description of methods used in analysing the data. Section four includes the aims and methods of the national audit of hospitals with a dialysis centre in the KSA.

### **4.1 Section one: research approach**

#### **4.1.1 Introduction**

In order to conduct this study, it was necessary to select an appropriate research approach to gather data that would meet the study's objectives. These were:

- To identify what information new dialysis patients receive about dialysis modalities in the KSA;
- To ascertain which factors patients perceived as being influential in their dialysis treatment decisions; and
- To develop recommendations for the preparation of pre-dialysis education programmes for patients in the KSA.

According to Punch (2014) there are two main ways to approach the planning of a research process: a paradigm-driven approach, where the researcher begins with a paradigm, articulates it, and develops research questions and methods from it. Alternatively, there is a pragmatic approach, where the researcher begins with research questions that need answers and then chooses a design and methods to answer those questions.

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The concept of a paradigm was proposed by Thomas Kuhn in 1970, and it has been defined “*as a whole system of thinking. It includes assumptions, the questions to be answered and research techniques to be used*” (Neuman 2006, p. 81). According to Punch (2014, p. 14), a paradigm is “*a set of assumptions about the world, and what constitute proper topics and techniques for inquiring into that world.*” Topping (2015), among many other authors, refers to these paradigms as being on a quantitative / qualitative continuum. Philosophically, quantitative research is underpinned by the belief that scientific truths exist, and this is called positivism. Positivism predicates knowledge solely on observable facts and rejects speculation about the ultimate origins of that knowledge (Creswell & Plano Clark 2008). Positivism explains human behaviour in terms of cause and effect (May 2001).

Conversely, qualitative research fits into an interpretivist tradition, whereby the researcher tries to make sense of human behaviour by taking account of the interaction between people (Topping 2015). If the researcher is starting with a pragmatic approach, the perspective is not that of a paradigm but rather a problem or a question that needs an answer. This question comes from literature, an existing theory, or from personal experience, but especially in the professional fields of education or nursing, it comes from practical and professional issues and problems associated with the workplace (Punch 2014). The following sections provide an explanation of both quantitative and qualitative research approaches, in general, and how these relate to the current research questions and objectives.

### 4.1.2 Quantitative research

Quantitative research adopts a deductive hypothesis testing approach towards data collection, data analysis, and data interpretation. It derives primarily from the epistemological tradition based on prediction, i.e. on the notion of causal analysis (Reed & Procter 1995). According to Creswell & Plano Clark (2008, p.11) “*deductive logic’s emphasis is on arguing from the general to the particular or on prior hypotheses or theory.*” The strength of this approach is that it builds upon the results of previous research; it requires specialist knowledge of the area, and it facilitates the development of research around the improvement of knowledge (Reed & Procter 1995). Quantitative research is



directed at theory verification, and usually hypotheses are present.

Quantitative approaches are widely employed in scientific research, healthcare, and social research (Curtis & Drennan 2013).

There are two main types of hypothesis-driven research design that use random selection:

i) Experimental research: this type is sometimes referred to as a randomised experiment or randomised controlled trials (RCTs). It is considered the most robust research design in determining causation among variables (Edmonds & Kennedy 2013). In this type of research, an experiment is set up to confirm or refute a hypothesis or hypotheses, and it is necessary to control the independent variables. Randomisation is also important, whereby participants have an equal chance of being selected or assigned to an experimental or control group. The experimental group receives the intervention, and the control group does not (Curtis & Drennan 2013). Such an experimental approach was not appropriate for the current study, since it was arguably the first study in the KSA that investigated pre-dialysis education and information provided to patients before starting dialysis. No previous research on pre-dialysis education and information for ESRD in the KSA existed that could inform this design, and an RCT would not have answered the research questions.

ii) Non-experimental research: This research design is conducted when the independent variables are not controlled by means of manipulation, such as inclusion, exclusion, or group assignment (Edmonds & Kennedy 2013). The two common approaches to non-experimental research are observational studies and randomly selected correlational and comparative surveys. Observational study designs are correlational and are employed when researchers are interested in measuring the degree of association between variables or seek to predict an outcome (Edmonds & Kennedy 2013). The current study is not attempting to explain the degree of association between variables or make causal inferences. The aim of this current study was to identify what education and information patients receive before starting dialysis in the KSA; as well as to ascertain recommendations for increased education and information giving in the future. Therefore, observational design was not selected for this study. Another variant of non-experimental research

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is the descriptive (non-correlational) survey. This would have merit when the aim of the study (as in this case) is to obtain information on the current status, so as to describe 'what exists' with respect to variables or conditions (Sim & Wright 2000). Surveys are used to observe trends, attitudes, or opinions of the population of interest (Edmonds & Kennedy 2013). It aims to show causal relationships, but surveys only indicate the strength of statistical association between variables and not the direction of any association identified.

There are two main types of surveys: cross-sectional surveys and longitudinal surveys. Cross-sectional or descriptive surveys are carried out at one single point in time, and they aim to collect information about past, current, or prospective attributes. They explore associations between variables at one point in time, but do not describe changes over time (Bowling & Ebrahim 2005). Cross-sectional studies offer economies in terms of time and resource utilisation (Curtis & Drennan 2013). In contrast, longitudinal surveys are conducted at more than one point in time, either prospectively or retrospectively, with the aim to explore cause-and-effect relationships; they are sometimes referred to as analytical surveys (Bowling & Ebrahim 2005). My study followed a cross sectional rather than longitudinal design.

Survey design tends to emphasise common features in relation to the population of interest, the purpose of investigation, and testing relationship between variables (Curtis & Drennan 2013). Surveys are commonly used in the KSA, not only in health science research, but also in other fields such as education and economics. People in the KSA would be familiar with questionnaire-based surveys and therefore surveys are likely to be culturally acceptable. Also, cross-sectional survey were utilised by previous Saudi studies (Hijaili et al. 2007; Al-Jahdali et al. 2009 and Hassanien et al. 2013). However, one possible issue to consider is that some patients may not be able to fill out the questionnaire by themselves because of their educational level or other reasons. In this instance, it is common for the principle investigator to be available to help them to fill out the questionnaire if some patients are not able to do so themselves. While pragmatically this offered the best design for my study, a more qualitative approach could have been considered. The following section will discuss whether this may have been appropriate.

### 4.1.3 Qualitative research

Qualitative research adopts an inductive approach, which aims to develop a theoretical explanation about the social world under examination (Reed & Procter 1995). In inductive logic, there is an emphasis on arguing from the particular to the general or an emphasis on theory development rather than theory testing (Creswell & Plano Clark 2008). Qualitative research is concerned with the meanings people attach to their experiences of the social world (Pope & Mays 2006). The aim of qualitative research is to reveal and understand phenomena within a particular context, without attempting to infer any type of causation (Edmonds & Kennedy 2013). As such, qualitative investigations can offer rich, deep understanding of the perspectives of the participants and can study individuals' beliefs about health or illness, and how this might influence behaviours (Bowling & Ebrahim 2005).

Qualitative research tries to interpret social phenomena, such as interactions and behaviour, and is interpretive in nature. This approach means that the researcher has to question common sense assumptions or ideas that are taken for granted (Pope & Mays 2006). There are several approaches, including grounded theory, ethnography, narrative, phenomenology, and case studies (May 2001). Grounded theory is inductive, and theory is facilitated to emerge from the data that are being collected (Edmonds & Kennedy 2013).

Ethnography is an approach that was developed to describe cultures; the researcher is embedded within the culture and takes account of the beliefs, motivations, and behaviours of the individuals being studied (Edmonds & Kennedy 2013). Methods for data collection commonly include in-depth interviews and observations.

Research in the KSA is not usual, and therefore patients may be uncomfortable taking part in interviews and being audio recorded, the latter being important for gaining an accurate record of the interview. From personal professional knowledge of the context, it was anticipated that that many women would be reluctant to be audio recorded for religious or cultural reasons. This was vindicated in reality with the high percentage of woman who declined to be recorded (see section 4.3.8.2). Also, as a female researcher, it was difficult for me to have in-depth interviews with male participants because of the same cultural issues. For instance, an interview would need a private setting between

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the researcher and the participant, and it requires continuous eye contact between them. This would be unacceptable if the participant were a male.

Furthermore, as mentioned earlier, the KSA adopts a strict code of conduct, so gender segregation is mandatory in almost all service settings, including health services. Male and female patients are treated separately and are allocated, according to their gender, to either the male or the female unit.

In addition to these practical and cultural considerations, a purely qualitative approach was ruled out for the current study, as the aim was not to derive a theory or hypothesis from the data, but rather to try to identify what dialysis education and information was provided to participants and what influenced the dialysis treatment choices (Gelling 2015). Additionally, the purpose of the study was not to study the culture of its participants.

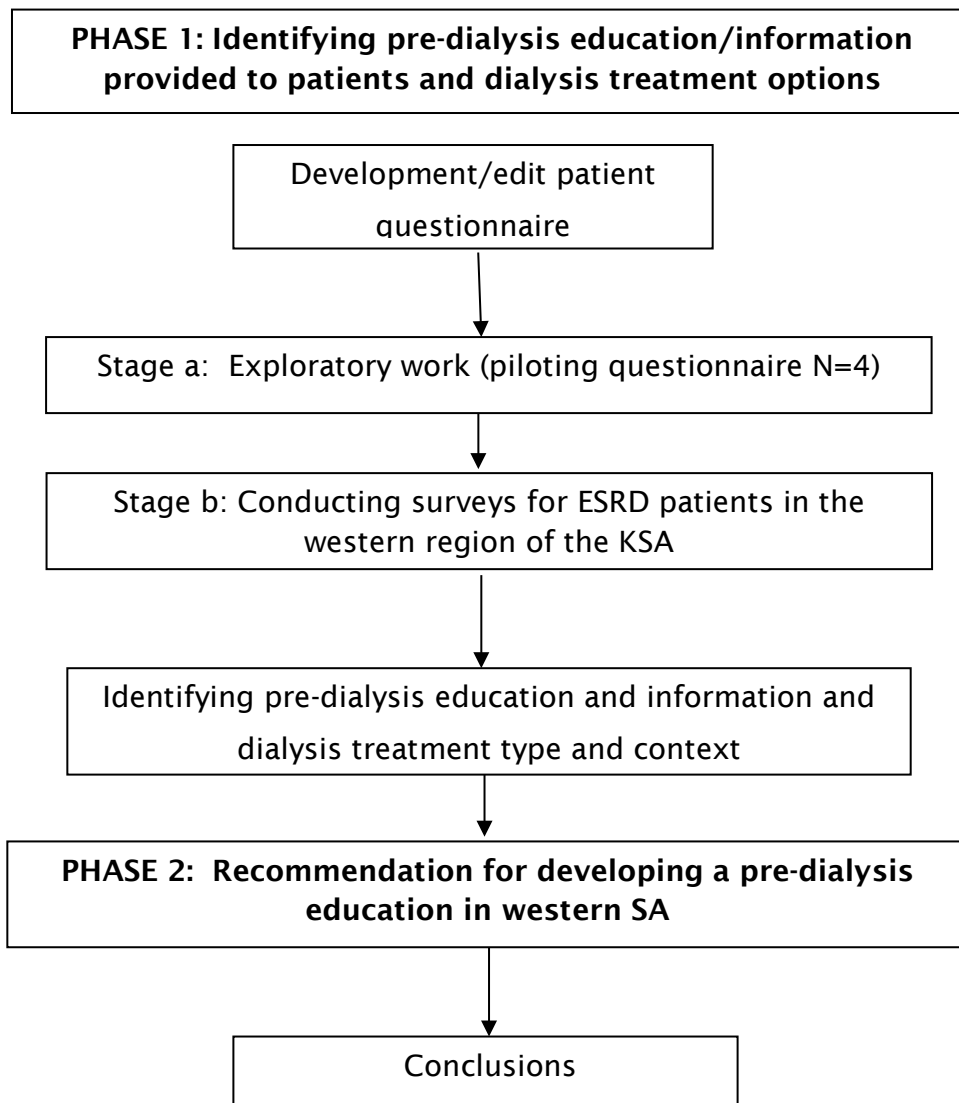
Although a purely qualitative methodology was not deemed appropriate for my study, an opportunity for participants to give their views, unconstrained by a very structured design, was considered. Thus, participants had the chance to add extra comments in free-text at the end of the questionnaire. This meant that, by the use of open-ended questions, participants were able to express their views and recommendations, albeit to a limited extent.

### 4.1.4 Study design

In order to select the best research design for this study, the above methodological and pragmatic considerations were taken into account. A descriptive survey design was selected because it enabled the identification of patterns while involving a reasonable number of participants, also making it possible to establish a link between pre-dialysis education/ information and treatment options. This study made use of a descriptive approach that aims to depict participants and/or the central idea of the research in an accurate way. Descriptive research typically describes the current status of a variable under consideration, using descriptive statistics such as frequencies and percentages with the aid of graphs. It does not answer questions about “how” or “why” but rather it addresses “what” questions, which were consistent with the research questions aforementioned.

The use of a survey was also beneficial in this study, because this was the first study in the KSA (western region) to identify pre-dialysis education and information provision and treatment options in patients with ESRD. Surveying a relatively large number of patients from different hospitals had the potential to provide an overview of pre-dialysis education and information in general, which would not be possible with a purely qualitative design. Nevertheless, the chance for participants to offer additional perspectives was incorporated into the questionnaire. This option was created by the inclusion of three open-ended questions regarding what influenced their treatment choice, their recommendations for the improvement of practice, and any other additional information they wished to add.

This research was undertaken in two phases, as shown in Figure 4.1. The survey was conducted using an existing questionnaire that specifically addressed pre-dialysis education (Mehrotra et al. 2005) in the context of the USA. The reason for using this questionnaire was that it offered a template that covered the relevant areas, and thereby addressed the research questions. It allowed benchmarking and comparison of my findings against an existing study, conducted within a western system (USA) and on the topic of pre-dialysis education. For the purposes of my study, the questionnaire was extended to explore other pertinent questions relevant to the research aims that were not covered in the existing questionnaire. For example, open-ended questions were added to provide the opportunity to gain patients' views and recommendations to improve education, as well as information about the factors that influenced their choices. These questions were aimed at overcoming the limitations of using questionnaires; by adding those open-ended questions, it was anticipated that the patients would have an opportunity to add important details. The additional questions were informed by the research literature and clinical experience, and they were piloted before use (see point 4.1.6.1).



**Figure 4.1 Diagrammatic representation of the study**

The questionnaire survey needed to be understood and completed easily, so it required questions that were short and simple enough to be comprehended fully (Foddy & Foddy 1994). It was also suitable, taking into account the resources and the timeframe of a doctoral study.

However, there are disadvantages of using a questionnaire, especially if it is administered by post. These include the possibility of a low response rate and the inability of some people to complete the questionnaire because of illiteracy, visual impairment, and/or the inability to understand the questions. The lack of contact between respondent and researcher also means that there

is no opportunity to clarify any of the questions (Oppenheim 1992). Therefore, to increase the response rate and address issues of illiteracy, in the context of this survey it was decided that the researcher would be present with the participants when they completed the questionnaire. This approach decreased the chances of participants misunderstanding questions, and the presence of the researcher allowed for clarification of unclear questions or concerns that the participants might have had. However, certain issues were considered when collecting data from male patients such as minimising the time spent, the interaction and eye contact with the participants.

Nevertheless, such an approach can increase the risk of bias because patients might feel that their treatment will be affected by their answers or the researcher may unwittingly guide the participants to respond in a particular way. Patients were informed that this was an independent study for a doctorate degree in the United Kingdom (UK), that the hospital and individuals would not be identified, and that the patients' responses would not be revealed.

#### **4.1.5 Validity and reliability**

The current study used the Mehrotra et al. (2005) questionnaire as a framework, which allowed the exploration of the differences between the KSA and western countries. It is important to determine the degree of validity of a measure, rather than whether validity exists in totality (Burns & Grove 2005). The validity of the questionnaire is the extent to which it addresses the research question and objectives set by the researcher (Parahoo 1997). Validity is reported in terms of both internal and external validity. The focus on validity in this study was to ensure that the questionnaire was internally valid, i.e. in terms of its face and content validity; the research did not seek to address external validity.

##### **4.1.5.1 Internal validity**

Face and content validity are legitimate ways of assessing validity in order to determine if the measure seems to be achieving the desired results (Nardi 2006). Face validity indicates that the items that are supposed to measure a concept, on the face of it, do look like they are measuring the concept (Neuman 2006; Krishnaswamy & Sivakumar 2009). Testing of the additional questions, by ascertaining patients' views and comments regarding the

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questionnaire, was conducted prior to the main study, as discussed in section two in this chapter.

Content validity of a measuring instrument is the extent to which it provides adequate coverage of the topic under study. Talbot (1995) suggested that for a researcher to test a questionnaire for its content validity, the instrument should be given to an expert for review, based on his/her practical or academic knowledge. Any changes should be made according to the expert's comments and recommendations. As such, the added questions were designed and reviewed with the guidance of academic supervisors. Furthermore, before the questionnaires were distributed to participants, a copy of the questionnaire was piloted with patients in the KSA to test its face and content validity and to ensure that the questions indeed asked what they intended to ask. Internal validity has to do with causal inferences, and hence it does not apply to non-experimental research (Edmonds & Kennedy 2013)

### **4.1.5.2 External validity**

External validity is the extent to which the research findings can be generalised to the wider population of interest and applied to different settings (Bowling 2002). In this study, the population was confined to including all patients with ESRD who received dialysis treatment in a sample of hospitals in the western region of the KSA. However, there are similarities between dialysis services in different regions of the KSA. In addition, this study repeated the use of instrument albeit one that was applied in a different setting of outpatients in the United States. However, as mentioned earlier, the focus of this study was not to seek external validity; hence the inability for generalisation of the findings is acknowledged as a limitation in the final chapter.

### **4.1.5.3 Reliability**

Reliability refers to the stability, repeatability, and consistency of a data collection instrument (Burns & Grove 2005). There are specific tests to determine the reliability of research instruments, including a test for stability, a test for equivalence, and a test for internal consistency (Brink & Wood 1998).

Stability can be defined as the extent to which an instrument can establish the same result with repeated administration (Polit & Hungler 1997). Repeatability, or equivalence, can be used to determine whether two observers using the



same instrument can measure the same event, at the same time, and obtain similar results (Burns & Grove 2005). Internal consistency refers to the extent to which all parts of the measurement technique are measuring the same concept (Brink & Wood 1998).

In this study, it was not possible to measure two of these components of internal reliability. The variable being measured, i.e. pre-dialysis education/information for ESRD patients in the KSA, is changeable and would not remain constant over time; therefore, assessing for stability is inappropriate. In addition, it was not appropriate to measure equivalence in this study. The questionnaire is lengthy, and it would be inappropriate to ask patients to complete it twice for different observers. Therefore, in this study, only internal consistency could be assessed, which is appropriate given the aims of the study. This is usually achieved using Cronbach's alpha coefficient, which can be used to test the internal consistency of questions that have a Likert scale measurement. Cronbach's coefficient is a measure of internal consistency regarding how closely related a set of items are as a group. However, after discussion with a statistician, it was advised that this test is only appropriate for a set of questions measuring one topic; therefore it was not appropriate for this survey. However, this study employed a previously used questionnaire, which had been piloted in the research undertaken by Mehrotra et al. (2005).

#### **4.1.6 Developing the survey questionnaire**

In order to answer the research questions, certain data were required. This included demographic information, what pre-dialysis education and information participants had received prior to starting dialysis treatment, and from where they obtained this information. It was also necessary to ascertain how the decision regarding the dialysis treatment they received was made, what factors affected the type of dialysis treatment choice and, finally, what dialysis treatment participants were currently receiving (haemodialysis or peritoneal dialysis). The questionnaire employed by Mehrotra et al. (2005) in the USA included questions about pre-dialysis education and information patients received before starting dialysis. While some focused on pre-dialysis education programmes, many of the questions were more generic and aimed to elucidate what information patients received, rather than specially exploring

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pre-dialysis education programmes. This questionnaire was therefore also appropriate for those patients who did not have access to a pre-dialysis education programme, as such. Permission was sought, by email, from the Mehrotra team to employ their questionnaire in this current study; permission was granted on 8 September 2011 (See Appendix 1).

### 4.1.6.1 Additional sections

The Mehrotra questionnaire was about pre-dialysis education; however, additional information was required for this study. The questionnaire needed to address the context of the KSA with regard to education levels, and some patients would not have any educational background or literacy. Therefore, the option of 'illiterate' was added to the question about educational levels.

However, apart from the addition of one category as above, there were no changes made to the wording of the original questionnaire. There were, however, additional sections added in order to address the research questions.

Further questionnaire sections were developed to collect data as follows. A section about participants' demographic data was added. In addition, the original questionnaire did not address other key aspects that this study wished to explore (e.g. information regarding patients' descriptions of the advantages and disadvantages of each treatment modality, and how pre-dialysis education could be improved). In previous studies, sections regarding patients' descriptions of the advantages and disadvantages of their treatment were shown to affect patients' preferences, and hence their selection of treatment modality (Wuerth et al. 2002; Goovaerts et al. 2005; Lee et al. 2008; Chanouzas et al. 2012; Liebman et al. 2012). Studies regarding patients' descriptions of the factors influencing their decision of dialysis treatment options, and the effects of dialysis education on their choices, have provided key information about patients' views (Wuerth et al. 2002; Morton et al. 2010b); therefore, these questions were added to the Mehrotra et al. (2005) questionnaire.

Furthermore, a section to develop recommendations for a patient education programme was necessary. Most of the previous studies explored pre-dialysis education and patients' choices and provided evidence that some of the

educational materials were not sufficient or were too short and inadequate to enable patients to make a choice (Piccoli et al. 2000; Winterbottom et al. 2007; Lee et al. 2008). Although these previous studies pointed out issues regarding the quality of pre-dialysis education, they did not provide suggestions for improving pre-dialysis education, nor did they ask patients for their personal recommendations for doing so. Therefore, to learn more about pre-dialysis education, and to enhance the understanding from the survey questions, open-ended questions were included in the last section of the questionnaire. These open-ended questions asked patients about their own views and recommendations for improving pre-dialysis education in future practice. This took the study a step further and provided the basis for stage two of the study, which was developing recommendations for an improved pre-dialysis education programme in the KSA.

In summary, the additional questionnaire sections were designed by myself and were further refined according to my supervisors' suggestions before testing with dialysis patients in the KSA. Feedback from the patients was considered, and the questions were amended accordingly. Once this was completed, the additional sections were added to the end of the questionnaire for the main study. Details of the additional sections, added after the completion of the pilot study, are described in the next section (section 4.2.7.3).

#### **4.1.6.2 Questionnaire translation**

The Mehrotra et al. (2005) questionnaire survey was written in English and used with ESRD patients in the USA. Therefore, it had to be translated from English into Arabic, as follows. Two professional translators who are native Arabic speakers independently translated the questionnaire, and two other native Arabic/English speakers then reviewed the translation.

## 4.2 Section two: pilot study

### 4.2.1 Introduction

As mentioned in the previous section, some of the issues relating to dialysis in the KSA were not addressed in the Mehrotra et al. (2005) questionnaire, but they were considered worth highlighting in this study; for example, the views and recommendations from patients to improve pre-dialysis education. These questions were added to serve the study's main objectives. The added questions needed to be piloted with a small sample of patients selected from one hospital in the KSA. The aims of this pilot study were to test the face validity of the questions, to inform the feasibility of the main study, and to test the process of recruitment. This section discusses the pilot study process and results.

### 4.2.2 Local ethical and research governance approval

Ethical approval was applied for from the chosen hospital in December 2010. The ethics committee requested that the patient pilot questionnaire (Appendix 2) and the information sheet (Appendix 3) be translated into the Arabic language, and that a hospital contact number be included for patients to refer to, in case of comments or complaints. Approval was obtained on 4 January 2011 (Appendix 4), enabling the study to commence early that month. It was not necessary to obtain written informed consent from the participants; agreement to take part and completion of the questionnaire was seen by the ethics committee and hospital as providing informed consent.

### 4.2.3 Inclusion and exclusion criteria

Patients were **included** if they were:

- Aged over 18;
- Had ESRD and were under medical care; and
- Receiving either haemodialysis or peritoneal dialysis as the first treatment option for at least three months (so they had experience with the therapy), but no more than one year (3-12 months).

Patients were **excluded** if:

- They were unable to comply with the study conduct (e.g. patients with mental impairment/unable to make informed decisions).

#### 4.2.4 Recruitment of participants

The hospital where the pilot was conducted was chosen for pragmatic reasons. I worked there previously and was therefore familiar with the procedures for research governance in the hospital, which helped in obtaining approval for the study in a relatively short time. After the hospital ethics committee's approval was obtained, recruitment of patients was conducted as follows. The head nurse of the dialysis unit identified new dialysis patients who would be eligible to participate in the study. According to the selection criterion, these were patients who had been on dialysis for a period from three months to one year. I approached the patients after the head nurse identified them.

The timeframe to conduct this pilot study was 16 days, which had to include gaining ethical approval and patient recruitment, and only patients who had started dialysis recently were available in the unit at the time; two were on haemodialysis and one was on peritoneal dialysis. One additional patient, who was on peritoneal dialysis, had to be contacted by phone. Therefore, a total of four patients agreed to take part in the pilot study.

Although this number was small, it was not critical for the pilot work, as the aim was to ensure the face validity of the proposed questionnaire rather than to look for statistical significance. Three patients were available in the dialysis unit on the day of recruitment; two patients were receiving haemodialysis sessions, and one patient was on peritoneal dialysis and was in the unit for an appointment. They were approached by myself and given the information sheet. However, the patients on haemodialysis preferred assistance to complete the questionnaire; therefore, the questionnaires were filled out with my help. Another peritoneal dialysis patient was contacted by the dialysis nurse, to whom I offered an explanation of the study over the phone. The patient agreed to participate, and the questionnaire was completed over the phone. Recruitment of the four patients, two receiving haemodialysis and two receiving peritoneal dialysis, took place during a period of two days.

Data collection consisted of two stages: first, the participants completed the questionnaire. Second, I reviewed the questionnaire with the participants and encouraged comments and feedback by asking questions regarding: the information sheet, the introduction page, the length of the questionnaire, the structure of the questions, possible options for answers, the scales used to

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answer some questions, and, finally, how easy or difficult the questionnaire was to complete.

### **4.2.5 The pilot questionnaire**

The pilot questionnaire (Appendix 2) was divided into five sections, as follows:

- Section 1 requested general information about the patient.
- Section 2 asked about information the patient received before starting dialysis treatment, and where the patient received this information.
- Section 3 asked about how the decision about dialysis treatment was made.
- Section 4 asked about the factors that might have affected the choice of dialysis treatment.
- Section 5 asked about current dialysis treatment (haemodialysis or peritoneal).

### **4.2.6 Results of pilot study**

#### **4.2.6.1 Demographic data and perception of disease and dialysis options**

Three of the four patients participating in the pilot study were female. Two were aged 20–29 years, and two were aged 40–49 years. Regarding their levels of education, two had elementary/primary school education, one was unable to read and write, and one had a Baccalaureate degree, thereby providing a range of different education backgrounds. Of the four participants, three were unemployed, and one was employed full-time. Two patients were receiving haemodialysis, and two patients were on peritoneal dialysis. Three of the patients said that they lived with their spouses, while one said she lived with her parents. These show quite a variety in patient characteristics with regard to their educational backgrounds and employment.

#### **4.2.6.2 Time since being diagnosed with kidney problems and dialysis therapy**

All participants had been diagnosed with kidney problems, and they had been receiving dialysis for different periods of time. One participant had been diagnosed for less than 6 months, one for 6–12 months, and another for about 12 months. One participant did not answer this question. Both of the two

participants who responded to the question about length of time on dialysis reported that it was for a period of 6–12 months.

#### **4.2.6.3 Perceptions about the cause of kidney failure**

Two patients reported that hypertension was the cause of their kidney failure. One reported chronic headache, and one patient did not know the cause of his/her kidney failure. Three of the four patients felt they knew nothing about kidney failure.

#### **4.2.6.4 Information received before starting dialysis treatment**

Three of the four patients reported that a doctor and/or nurse had discussed treatment with them. However, one patient reported that no one talked to her about her condition/dialysis options. Three of the four patients reported that they had an opportunity to talk to a dietician about their diet; the fourth patient reported that it was a nurse who had discussed diet.

Three of the four patients said that they had been told about home dialysis options, and that it was a nurse who had talked to them about it in a one-on-one session. Two patients indicated that they had been spoken to only once about their treatment options, for less than 15 minutes. However, the others had had conversations on more than one occasion; two had three conversations, and the fourth said more than four discussions. Three of the patients said the conversation was in the dialysis unit, and one said it occurred in the nephrology clinic.

Of the four patients, three said that a family member was present during the information sessions, and all of the patients indicated that they were given education. Two patients said the materials were brochures /booklets, while the other two said they had talks/discussions. Two rated the information as excellent, while one said it was good, and one said it was totally inadequate. However, when asked for the reasons behind their ratings, only two responded: one saying because it was not enough information, while the other said that the information helped her to understand the dialysis treatment and how to deal with it. The two patients who gave an excellent rating were on peritoneal dialysis. Three patients said they were very confident that they understood the information provided to them. Two of them indicated that the pre-dialysis education did not influence their decisions about the type of

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dialysis. One said it did influence the decision because of the way the two different types of dialysis were explained.

Three out of the four patients said that the information was very useful in helping them make the decision about which type of dialysis to have. In response to whether they would like any additional information, three out of the four said yes; two of the patients indicated that they would like to have more information about how dialysis works. Two patients said that they did not have to find information elsewhere, and one said that she had looked for information elsewhere, specifying spouse/significant other and the Internet as the places where she sought additional information.

### 4.2.6.5 Decisions regarding dialysis treatment

This part of the questionnaire asked patients to indicate their level of agreement or disagreement with lists of different statements. Participants reported their responses as either 'strongly agreed' or 'strongly disagreed' with all these statements. (See Table 4.1)

**Table 4.1 Decisions regarding dialysis modality**

<b>Statement</b>	<b>Strongly agree (Participant #)</b>	<b>Strongly disagree (Participant #)</b>
This decision on what type of dialysis to have was hard for me to make	3	1
It was clear what choice was best for me	3	1
I am aware of the choices I have to make for a decision about dialysis	3	1
I feel I know the risks and side effects of dialysis treatment	2	2
I need more advice and information about the choices	4	0
I know how important the benefits of dialysis treatment are to me in this decision	3	1
I know how important the risks and side effects of dialysis treatment are to me in	2	1



this decision		
I feel pressure from others in making this decision	2	2
I have the right amount of support from others in making this choice	3	1
I feel I have made an informed choice	4	0
I am satisfied with the decision about which treatment I receive	4	0

In response to the question about who made the decision about the type of dialysis the patient received, two patients indicated that their doctors made the decision, while the other two said it was their own decision.

#### **4.2.6.6 Factors affecting choice of dialysis**

Two patients said that they were unaware of other illnesses that affect the type of dialysis therapy they receive, and one reported asthma. Three respondents indicated that the supply of electricity was never a problem, and one said it is rarely a problem in the house. All four indicated that the water supply at their homes was regularly available. All patients said that family support, electricity, and water supply affected their choice of dialysis treatment. Patients were asked how they usually got to the dialysis unit; three out of four said that a friend or relative drove them; one said that he drove himself. All four patients indicated that it took them 15–30 minutes to arrive at the dialysis unit.

#### **4.2.6.7 Current dialysis treatment**

When patients were asked about the advantages of the treatment they were receiving, the patients on haemodialysis (N=2) indicated that they preferred treatment in dialysis centres and preferred nurses/others to take care of them. On the other hand, the patients on peritoneal dialysis (N=2) indicated that they preferred doing it themselves in the privacy of their homes; flexibility of schedule was the most common advantage of the treatment.

In response to questions regarding the disadvantages of the treatment they were receiving, the patients on haemodialysis provided a list of disadvantages. They did not like the blood and being pricked with needles, nor the

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transportation and fluid/diet restrictions. On the other hand, the patients on peritoneal dialysis indicated concerns about infection and the duration of the treatment (7 days per week) as the main disadvantages.

Two participants responded 'yes', one said 'no', and one said 'not sure' to the question about the willingness of family members to help with treatment at home. All patients said that they were satisfied with the treatment they were receiving; only the two patients on peritoneal dialysis answered the question about the three most important things that influenced their dialysis treatment choices. They indicated that family support, suitability for their lifestyle, and 'no need for needle pricks' as the main factors. Patients agreed that dialysis limits their social lives and their partners'/carers' social lives.

### 4.2.7 Patients comments regarding the questionnaire

The following section will discuss the results regarding the study aims to test the face validity of the questionnaire, as well as discussing the feedback from the patients who completed the questionnaire, related to both general aspects and specific content of the questionnaire.

#### 4.2.7.1 General issues with the questionnaire

The following issues were raised in respect of the general format of the questionnaire:

- a. Approach to answering questions:  
Not all of the participants were familiar with, or understood, how to score a visual analogue scale (VAS), which was employed in section three. According to all the participants, tick boxes and Likert scales were easier to understand and follow. In response to this, tick boxes and Likert scales were then used in the questionnaire in the main study.
- b. Questions requiring writing:  
Most questions that required writing or explanation were not answered. Therefore, in the main study, the requirement to provide additional information was reduced considerably.
- c. Length of the questionnaire:  
Most participants indicated that the questionnaire and the introduction page were too long. One participant did not want to complete it because he thought that there were too many questions. As a result, both the introduction page and questionnaire were made shorter, as explained in

the next section, while still ensuring that all questions were included for the main study.

One key finding from this pilot was that it was apparent that I, as the principal investigator, needed to be with the participants because they were undergoing dialysis at the time, to help them complete the questionnaire. This finding had an impact on the number of participants that could be recruited for the main study.

#### 4.2.7.2 Specific issues regarding some questions

There were also some additional points to consider.

a. Repeated questions on pilot questionnaire (Appendix 2). There were three occasions where participants felt questions were repeated. These were:

- length of time on dialysis, reported in both questions 7 and 8
- awareness of risks associated with treatment, reported in both questions 27 and 30
- how satisfied they were with treatment, reported in both questions 35 and 45

After reviewing the questions and the patients' comments, I decided to keep the clearer questions 7 and 45 and deleted questions 8, 27, 30, and 35 from the questionnaire (Appendix 5.A).

b. Too many options or inadequate explanations for some questions.

Participants reported that

- Two questions did not have all possible options needed. For example, question 4 should include "illiterate".
- Question 19 Part A (Appendix 2), however, had too many options that patients felt had the same meaning. The decision was made to keep the clearer option.
- There were inadequate explanations for some questions. There were four questions that patients did not understand and for which they needed more explanation: questions 25, 26, 31, and 46 (Appendix 2).

After reviewing the questions, questions 25 and 31 (Appendix 2) were excluded from the questionnaire, as they were somewhat confusing. It was decided to keep questions 16, 20, 43, 44 and 46, as they were important to the research questions (Appendix 5.A).

c. Questions that could be deleted. Participants felt that the following questions could be omitted:

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- Two patients thought that six questions were unrelated to the study question: 11, 37, 38, 39, 41, and 42 (Appendix 2); after review, these questions were removed from the revised questionnaire, as they were judged to be irrelevant to the study's main objectives and did not add key data.

### 4.2.7.3 Extra sections

The pilot study highlighted some additional issues, such as the length and structure of the questions. Piloting improved the content and structure of the questionnaire by giving opportunity to revise the questions, to remove duplicate questions, to keep relevant questions, and to exclude unclear and unrelated questions. It helped to make the questionnaire more focused on the aims and objectives of the study. The result of the pilot study revealed that one question should not be included in the final form of the questionnaire and this was: What sort of information the patients actually received prior to starting their treatment regime? All comments from patients were taken into consideration when revising the questionnaire, and after comparing it to the Mehrotra et al. (2005) questionnaire, the following changes were made to the final questionnaire to be used in the main study:

- An additional section one (demographic data) was added to the Mehrotra et al. (2005) questionnaire; the Mehrotra et al. (2005) question regarding level of education was moved to this section (Appendix 5.A, questions 1–5).
- Section two now includes all the questions from Mehrotra et al. (2005) regarding the pre-dialysis education patients received before starting dialysis treatment (Appendix 5.A, questions 6–18).
- An additional section three was added, which includes questions asking patients how they would like their pre-dialysis education to be (Appendix 5.A, questions 19–26).
- An additional section four was added, which includes information about the patients' current treatment, describing the advantages and disadvantages of each modality (Appendix 5.A, questions 27a, 27b, 28a, 28b and 29). Duplicate questions and unrelated questions were removed.

- Most questions were made easy to understand and easy to complete (using tick boxes).
- The questionnaire was shortened.

The questionnaire was therefore revised for use in the main study (Appendix 5: A).

#### **4.2.8 Recruitment issues**

Despite the small number of participants recruited in the pilot study due to time limitations, the pilot study was successful and achieved its aim of determining how to recruit for, as well as conduct, the main study. For instance, the need for the researcher to help the participants complete the questionnaire was a very important issue that had been considered previously. This influenced the number of hospitals involved, as I had to carry out advanced planning of the hospital visits to ensure I had enough time to travel and sit with patients. The main study included only hospitals from the western region of the KSA because the researcher primarily resides in the western region. Therefore, no travelling or accommodation budget was needed. I was able to contact and recruit the hospital and to be with the patients to help them complete the questionnaire. In addition, the time required to obtain ethical approval from the hospital was an indication that recruiting hospitals from different regions in the KSA would take a long time. This arrangement would not have been feasible within the timeframe for the main study; therefore, only hospitals in the western region were approached for the main study.

In the main study, the dialysis head nurse undertook recruitment of patients, as that method worked well in the pilot study and was efficient because this process saved time. This saving was possible because the head nurse had a list of newly admitted patients and all new dialysis cases for the unit records, and I was then able to approach the patients and provide the information sheet to them. This way was more practical than asking other nursing staff to contact the patients.

Finally, with regard to feasibility, the strengths of this pilot study are that it achieved its aims, i.e. to assess face and content validity, and that data were

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collected from both haemodialysis and peritoneal dialysis patients. Its results helped in the recruitment, planning, and questionnaire improvement that were implemented prior to the main study.

### **4.3 Section three: main study**

This section describes the main study and starts by explaining the sampling strategy and rationale, along with the inclusion and exclusion criteria. It describes the process of hospital recruitment and rationale. Ethical considerations, such as confidentiality, gaining permission, and informed consent, are also discussed. Finally, there is an explanation of the method of data analysis.

#### **4.3.1 Sampling strategy**

There are two types of sampling: probability sampling and non-probability sampling. In probability sampling, it is important that each person in the population has an equal chance of being selected, but it is vital for a probability sample that a complete list of the population exists (the sampling frame) and that a random sample is selected from the list (May 2001). A number of sampling approaches can be employed for survey questionnaires, as discussed below.

De Vaus (2002) suggested that simple random sampling is useful when the population is geographically concentrated and no travel is required; however, it would have been difficult to use in this study. The large geographical spread would have caused practical issues for recruitment, as travelling is difficult for women in the KSA, and the additional cost and time would be significant issues. These considerations all affected the sampling strategy. It would be ideal to sample patients from each of the 24 hospitals in the KSA, but the expense and time needed to recruit would be too high for the purposes of this study. Therefore, simple random sampling was not used.

Stratified sampling is another sampling approach whereby representative hospitals from each region would be randomly sampled. However, practically, this would pose problems, as it would still mean travelling to each region in the KSA to distribute the questionnaires to patients (there is no prepaid mail service in the KSA). That would be too resource-intensive and costly, and there

is also the issue of the researcher needing to be present during completion of the questionnaire.

Non-probability sampling is used when there is no sampling frame (May 2001). Purposive sampling is useful when the sample needs to be reached quickly, but the results of the study usually overweigh the subgroup of the population that is more accessible (Trochim 2006). In purposive sampling, a selection of those to be surveyed is made according to known characteristics (May 2001). However, purposive sampling is usually used to obtain qualitative data; it involves selection of participants according to specific characteristics but was not used for this study.

With regard to the current study, there is no clear number regarding the population because the number of new patients starting dialysis treatment in the KSA continues to change; thus, probability sampling was not possible. In addition, as this was the first study of new dialysis patients in the western region of the KSA, it was proposed to include all identified new dialysis patients. Therefore, a consecutive sample of ESRD patients undergoing dialysis treatment, who met the inclusion criteria, were included and were surveyed over the period of data collection (December 2012-April 2013). Consecutive sampling is a non-probability sampling technique that involves all subjects from an accessible population over a specific time interval (Polit & Beck 2013). Also, as I am a female researcher, it would have been difficult for me to travel to the different regions of the KSA. Therefore, as stated above, for practical reasons recruitment of patients was only from hospitals in the western region of the KSA. This area is more accessible to me, as I am a resident of this region. It was proposed that all eight of the hospitals in the western region would be targeted for inclusion in the study. Although there were some limitations to this approach, they are mitigated by the fact that government hospitals in the different regions provide similar clinical renal services for their dialysis patients. In addition, the cultural backgrounds of the people in the different regions are similar. According to Bowling (2002), it is the responsibility of the investigator to indicate the extent to which the accessible population deviates from the excluded population. Therefore, although generalisation of the findings of the study was not feasible, this is the first study of its kind and it will provide information to inform a wider national study.

### 4.3.2 Recruitment of hospitals for data collection

In order to address the research questions, it was necessary to survey patients from hospitals that offered both HD and PD treatment options. Twenty four hospitals provide both haemodialysis and peritoneal dialysis services in the KSA (SCOT 2010) and these hospitals are located in 15 cities across all regions of the KSA:

- central region (8)
- western region (8)
- eastern region (6)
- north (1)
- south (1)

Prior to a decision being made to focus on the western region (for reasons indicated above and because it comprises the largest number of hospitals, in line with the central region), an attempt was made to contact all 24 hospitals across the KSA by phone. This was to identify if they gave pre-dialysis education to ESRD patients, what was provided and who was involved. This attempt was not particularly fruitful, and did not yield comprehensive information, though this exercise was repeated, and a much more successful audit of hospitals was undertaken, following completion of the study (see section four of this chapter).

The eight hospitals from the western region were contacted and they are identified in Table 4.2. This shows the hospitals that provided HD and PD and were included in the study, as well as the recent number of new dialysis patients in the western region. These hospitals are divided into Ministry of Health (MoH) hospitals or Governmental Non-Ministry of Health (GOV Non-MoH) hospitals. I contacted all eight hospitals in the western region to identify if the renal units at these hospitals would be interested in participating in the study. Of the eight hospitals, two military hospitals were not prepared to participate in a study with an external researcher, one declined to participate, and one did not respond despite repeated attempts to recruit. Therefore, a total of four hospitals were willing to be approached and were recruited, pending approvals, for data collection. Hospitals 1, 2, 3, and 4 were therefore selected for this study.



**Table 4.2 List of four hospitals participating in the study**

Hospital	Hospitals that provide both HD and PD in the western region	New HD patients	New PD patients	Included in study	Hospital's utilisation of PD
1	GOV Non-MoH Hospital	20	9	√	Low
2	MoH Hospital	170	34	√	Low
3	GOV Non-MoH Hospital	60	34	√	High
4	MoH Hospital	0	10	√	High
5	GOV Non-MoH Hospital	11	8	Declined	
6	MoH Hospital	61	3	Declined	
7	MoH Hospital	No information	No information	No response	
8	GOV Non-MoH Hospital	10	18	Declined	

The four hospitals which agreed to provide information about the number of patients on dialysis treatment, and to take part in the study, were included in the study. The research aimed to identify what pre-dialysis education and information that patients received before initiation of dialysis and to identify the patient's perspectives on factors influencing the treatment they receive. Other studies, e.g. Mehrotra et al. (2005), have made links between the amount of time spent on patient education and the choice of dialysis treatment. No previous study in the KSA had investigated pre-dialysis education and how the patients' perceptions influence the treatment they receive. By investigating hospitals with high and low numbers of patients on PD/HD, this study highlighted the issues regarding patients' treatment in the western region of the KSA. In addition, it identified the availability and quality of pre-dialysis education and information in these hospitals.

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### 4.3.3 Sample size

The ESRD patients from the four hospitals comprised the sample for this study. The maximum anticipated number of respondents that could be involved in the study was the whole sample population.

#### 4.3.3.1 Inclusion criteria and exclusion criteria

Criteria for patient inclusion were participants who:

- Were aged over 18;
- Had ESRD and were under medical care at one of the four hospitals; and
- Were receiving either HD or PD for at least three months (so they had experience with the therapy), but no more than one year (3-12 months).

Patients were excluded if they were unable to comply with the study conduct (e.g. patients with mental impairment/unable to make informed decisions).

### 4.3.4 Recruitment process

At each of the participating hospitals, the study was explained to the head nurses, who were provided with a list of inclusion/exclusion criteria to identify patients. The head nurses were asked to identify the ESRD patients receiving both HD and PD, who had commenced dialysis treatment in the previous three months up to a maximum of one year prior to contact about participation. Then I approached the patients in the dialysis unit via the head nurse, offering each potential candidate an introductory letter (Appendix 6.A).

### 4.3.5 Ethical issues

#### 4.3.5.1 Voluntary participation

The intended participants received the questionnaire, together with an information sheet (Appendix 7. A) to explain, in clear lay language, the purpose of the study, the benefits, and any potential risks. It was made clear that participation was voluntary, with no influence on their future treatment; that the information they provided would not be recorded in their hospital notes; and that the clinical staff would not know if they agreed to take part or not, as the study was independent of their treatment. Their right to withdraw

from the study at any time, with no consequence, was also indicated. Contact details for the investigator and the supervisor were included in the information sheet for any questions or inquiries. Patient participation and completion of the questionnaire was considered as providing consent that the patient agreed to participate, and this was declared in the information sheet and the questionnaire. However, hospital 2 and hospital 4 requested to use their own consent form for participants (Appendix 8).

#### **4.3.5.2 Setting**

The questionnaires were completed in the hospital, so there was no need for formal procedures, and the lone worker forms were not applicable. In addition, if a patient was to become unwell or distressed during completion of the questionnaire, the process would have been stopped, and the patient referred to the unit head nurse. The participant would then be withdrawn from the study. However, no such incidents occurred during data collection.

#### **4.3.5.3 Confidentiality**

All gathered data were treated as confidential and anonymous, and it was made clear to the participants that no identifiable information would be published. Assurance of anonymity was given to all participants, which was emphasised in the participants' information sheet, and verbally reconfirmed prior to the start of data collection. Furthermore, to ensure anonymity and to protect participants' identities, the questionnaire did not ask for names or initials. Instead, each questionnaire was given an ID number. Participants were also assured that all information collected would be kept confidential and only used for the purpose of the study. All information, from which identities could be inferred, such as locations, was removed. Participants were made aware that they were entitled to reject particular forms of data collection, such as tape-recorders. During the course of the study, data were kept in a locked filing cabinet, and access to personal and university computer files were password protected. After the study, in accordance with governance procedures at the University of Southampton, all data were to be kept in a locked storage cabinet for ten years in the Faculty of Health Sciences, University of Southampton.

### 4.3.5.4 Permission from participating hospitals

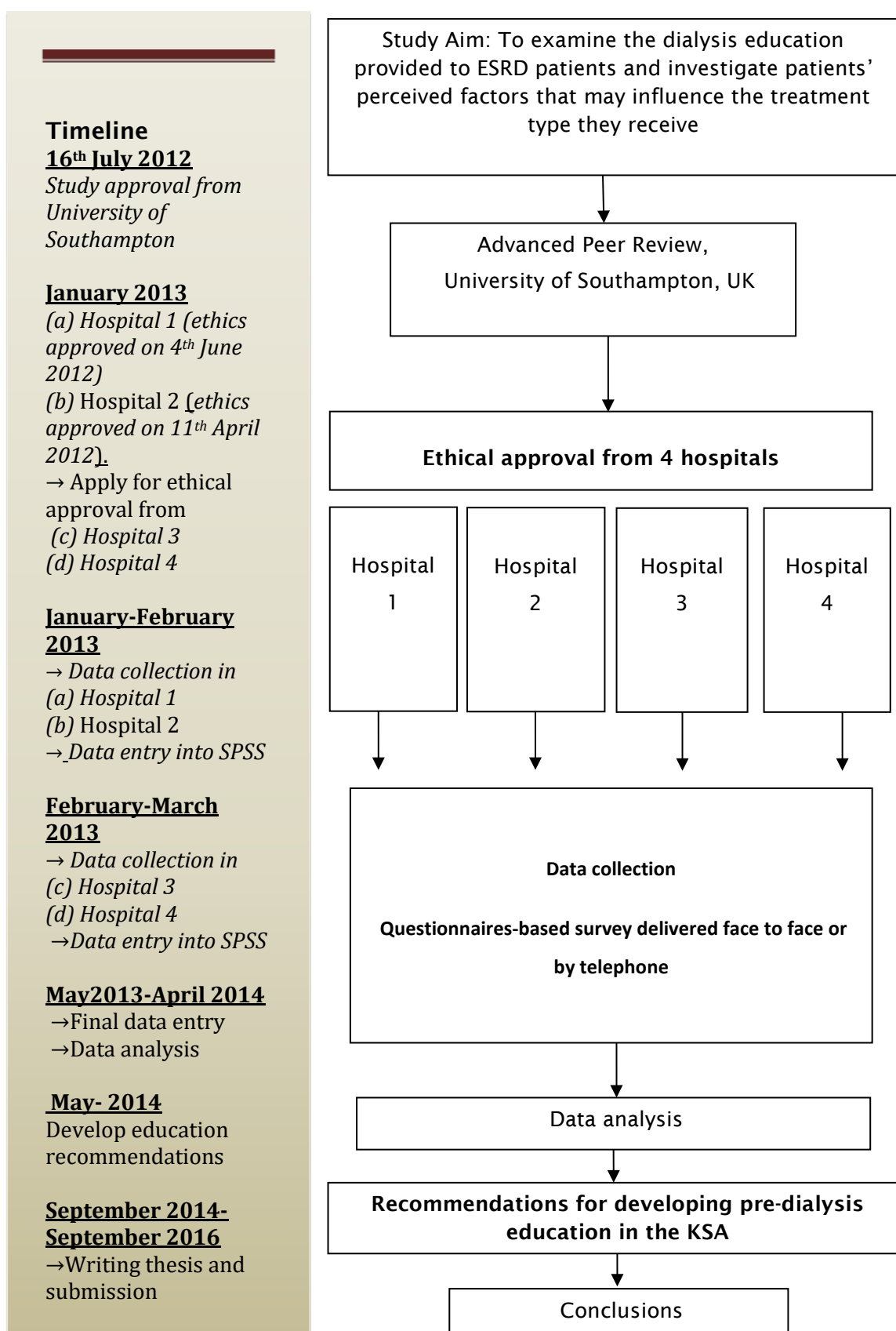
After approval from the advanced peer review at the University of Southampton (Appendix 9), permission to carry out the study was obtained from the hospitals involved. Each hospital had its own research committee to review the proposed study in order for ethical approval to be granted. (See Appendices for confirmation of approvals from hospitals in the MoH, (hospital 2 and hospital 4)(Appendix 11), other two non-MoH hospitals (1 and 3) had identify the hospital so it was not included in the appendices.

### 4.3.6 The main study questionnaire

The final questionnaire used to collect data for the main study was divided into four sections, details of which can be found in Appendix 5.A. Section one asks general information about participants. Section two asks what information participants received before starting dialysis treatment and from where they got this information, as well as how a decision about their dialysis treatment was made. Section three asks about factors affecting their choice of dialysis treatment, and section four asks about their current dialysis treatment (haemodialysis or peritoneal dialysis) (Appendix 5.A).

### 4.3.7 Data collection

Data collection took place from mid-December 2012 to mid-April 2013 in the KSA; see Figure 4.2 for study plan and timeline. The principal investigator helped the patients to complete the questionnaire. However, to increase the response rate, and to reach the maximum number of patients who were having dialysis on the late night shift, the unit head nurses distributed questionnaires to these patients who then completed it themselves. Also, for patients who were on PD and were living in areas distant from their hospital, the questionnaires were completed over the phone with the principal investigator. The limitations of this approach will be discussed in the final chapter.



**Figure 4.2 Diagrammatic representation of data collection plan**

### 4.3.8 Data analysis

#### 4.3.8.1 Quantitative data analysis

Analysis of quantitative data was performed using the Statistical Package for Social Sciences (SPSS) v.20 software. All data were analysed using descriptive statistics. Frequency distribution and basic statistics were used to describe the data with mean and standard deviation, as well as confidence intervals if appropriate, or median values for non-normal distributed variables. Numeric codes were used to identify data categories, such as (1, 2) for nominal and interval data. Missing values were coded as (-1).

Pearson's chi-square test was used to compare the frequency data. Association between nominal variables was assessed using Cramer's V (a type of correlation coefficient suitable for categorical data). Factors associated with the likelihood of using PD versus HD were determined using logistic or linear regressions as appropriate. In all cases, a *P* value <0.05 was considered statistically significant.

#### 4.3.8.2 Analysis of open-ended questions

This study contained open-ended questions to enhance the understanding of issues. Those open-ended questions were analysed and summarised using content analysis. This form of analysis was used because it was the most appropriate given the type of data obtained from the open-ended questions, which were short answers and sentences limited to a single word or short listing of factors influencing treatment decisions. Content analysis is a technique for examining the content, or information contained in a written document (Neuman 2006). It involves the systematic reduction or simplification of recoded text into a set of categories that represent the frequency and intensity of selected characteristics (Waltz et al. 2010). The main advantage of such analysis is that it is applied to recorded or written information, which allows for exact replay of the original communication (Waltz et al. 2010). Content analysis is used to study themes or trends in some topics or in answer to open-ended survey questions (Neuman 2006), and can be both quantitative and qualitative. Quantitative approaches were appropriate

for analysis within this study, because the open-ended questions provided short answers rather than in-depth data. In addition, the point of adding open-ended questions was to let patients provide their recommendations to improve education. Also, it was found that the majority (91.3%) of the patients declined the use of an audio-recorder and did not provide detailed information on the series of open-ended questions. Instead, patients answered with brief responses using a few words and this needed to be analysed using content analysis (i.e. it was the best choice of analysis given the type of data provided by the patients).

## **4.4 Section four: national audit**

### **4.4.1 Introduction**

This section describes the national audit of dialysis units in the KSA. This was conducted after the completion of the main study to contextualise the results. Also, the audit aimed to identify what pre-dialysis information or structured pre-dialysis education programmes were available for patients and to determine the information provided at the national level. This audit was anticipated to facilitate a recommendation to improve the pre-dialysis education practice nationally. A total of 24 hospitals were identified to have dialysis units, which provide different RRT (including HD and PD) (SCOT 2010).

### **4.4.2 Method**

Telephone interviews using a questionnaire was the method chosen to gather the information from the hospitals from the different regions of the KSA since phone calls did not require travel and are cost effective. The telephone interviews were conducted with the head nurses of the dialysis units from 21 hospitals that provide RRT in the KSA. There were three other hospitals but they had to be excluded from the audit due to the difficulty of soliciting responses despite several attempts to contact them. The researcher produced the audit tool (see Appendix 11): a three-page questionnaire. This was reviewed with a supervisor, resulting in a simple and clear method to elicit information from across country; the findings of the study could be viewed in the light of the national picture. The results of the audit are presented in chapter 5, section 5.9.

## 4.5 Conclusions

Section one stated the aims of the study and discussed the two most common research approaches, of qualitative and quantitative approaches. It explained the epistemology underlining both. As it was the first study to examine pre-dialysis education and information, a quantitative design was considered to be the most suitable option. A survey was chosen and the rationale was explained. The questionnaire used by Mehrotra et al. (2005) was selected to be used, with the addition of some extra questions. The development of the survey questionnaire was explained with discussion of the validity and reliability of the questionnaire. The additional questions were piloted as described in section two.

Section two described the pilot study, with regard to feasibility and outcomes. The process of gaining ethical approval and recruitment of participants was discussed. The strengths of this pilot study were that it achieved its aims, i.e. to assess face and content validity, and that data were collected from both haemodialysis and peritoneal dialysis patients. Patients' comments regarding the questionnaires were vital for the revision of the questions to be used in the main study. In addition, the pilot study results, with regard to the recruitment process, helped in recruitment planning for the main study. This was undertaken via the head nurses of the dialysis units, with the need for the researcher to help patients to complete the questionnaire, especially those on HD being acknowledged. Changes to the questionnaire were made according to patients' comments in order to develop the main study, which was explained in section three.

Section three discussed the main study including the sampling strategy and the rationale for recruiting the hospitals from the western region of the KSA. This study aimed to include the maximum number of participants from the four hospitals who agreed to take part in the study. Ethical issues were explained to participants in the information sheet, such as their voluntary participation and the right to withdraw from the study at any time. Confidentiality of the information provided, and ethical approval from the hospitals, were also considered. Presentation of the data collection plan, together with the timeline frame, were described in figure 4.2. SPSS (v.20) was used to analyse the quantitative data from the survey questions, and content



analysis was used to analyse the open-ended questions. The next chapter will present the results of the main study. Section four discussed the aims and method used to conduct a national audit, in the KSA, of hospitals which provided renal options to patients with ESRD, in order to place the study hospitals in a national context.



## **5. Chapter Five. Results of the main study and national audit**

### **5.1 Introduction**

The data analysis and findings of the main study are presented in this section. The first part of this chapter provides descriptive data reporting the findings relating to the education/information patients received before starting dialysis. Results exploring the relationship between the types of dialysis patients received, HD or PD, and the level of education/information received by these two groups, are also presented. The chapter then provides the findings from a sub-analysis, comparing pre-dialysis education/information across the four hospitals. The results of statistical tests, such as correlational analysis, were used to determine any significant associations between relevant variables; a regression analysis was employed to identify the predictors of treatment allocation or satisfaction with treatment. The second part of this chapter presents the results from the national audit that was undertaken after the main study and which provided information about the provision of pre-dialysis education across the country.

### **5.2 General overview**

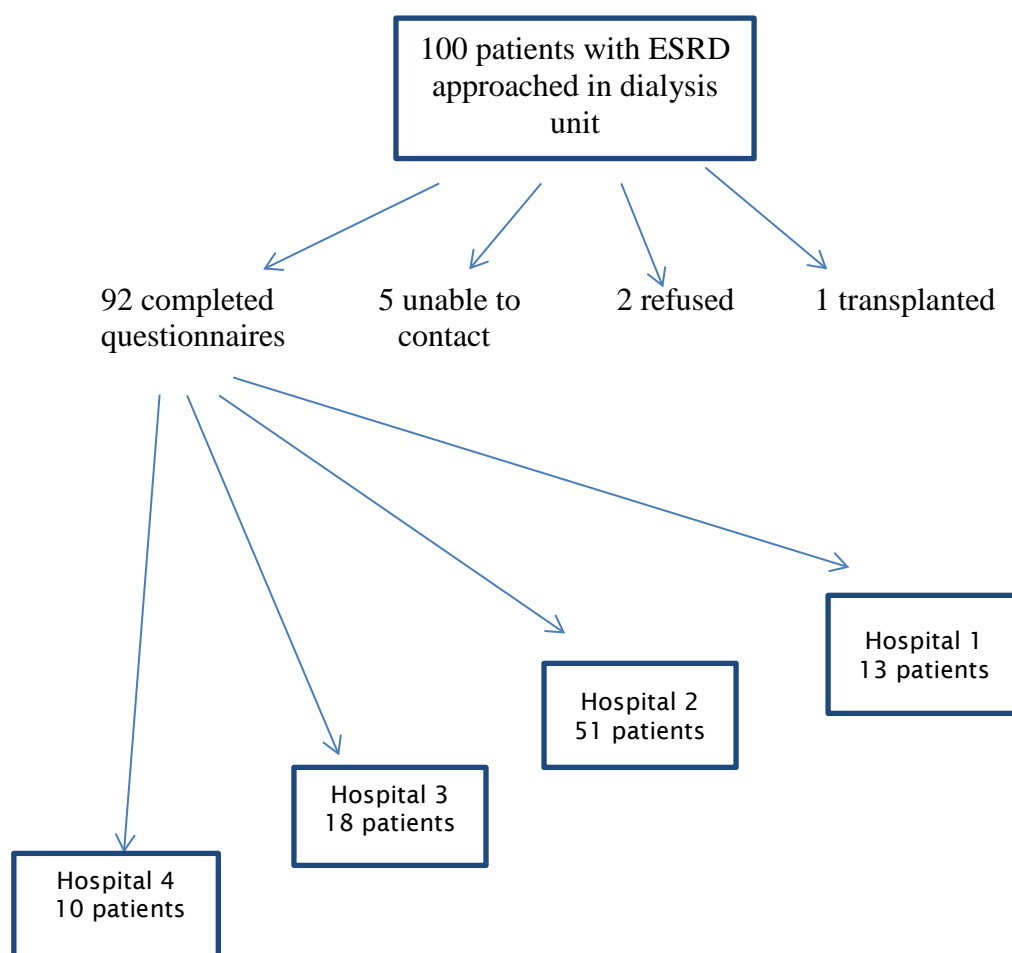
#### **5.2.1 Patient recruitment and response rate**

As described in chapter 4 (section 4.3.2), patients were recruited from four hospitals in western Saudi Arabia. These participants were approached by each hospital unit's head nurse, on behalf of the principal investigator. It was difficult to calculate the exact response rate, as one of the hospitals (# 2) did not have a patient census that counted the total number of new dialysis patients admitted to the centre. However, the other hospitals did provide the total number of their new dialysis patients. One hundred patients were contacted and 92 questionnaires were completed, giving a response rate of 92%. During data collection, all available patients in the hospitals were recruited and every effort was made to increase the number of participants. This included different methods of questionnaire completion to suit the

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circumstances of participants, such as face-to-face questionnaires, assisted by the researcher, self-completion of questionnaires by patients who had midnight dialysis sessions and questionnaires completed over the phone for patients who lived at a distance from their hospital centre.

The number of patients approached and recruited is illustrated in Figure 5.1.

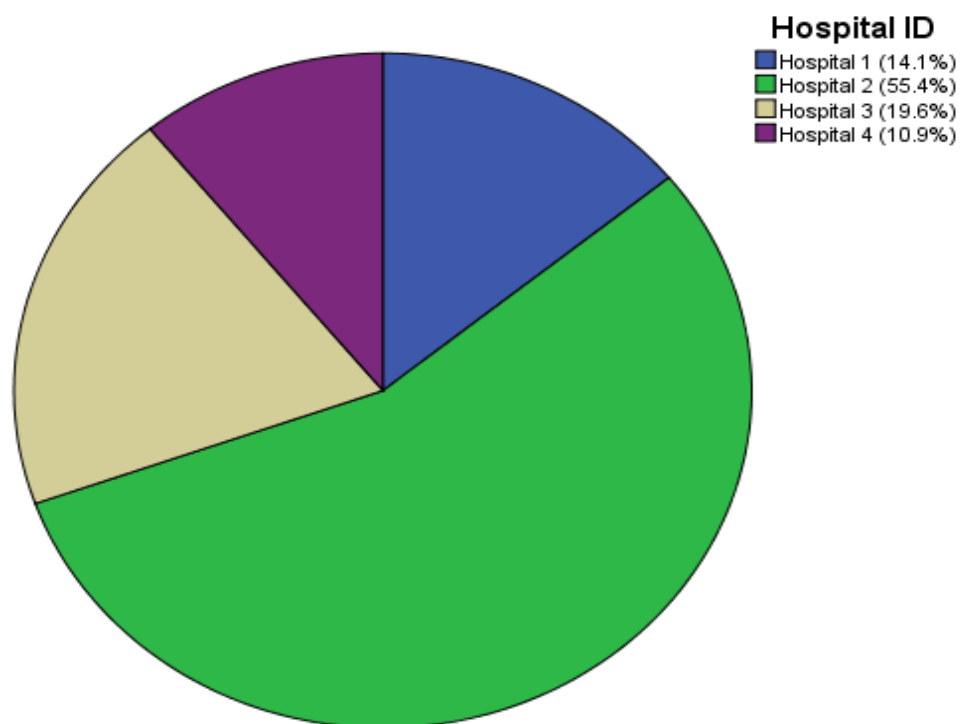


**Figure 5.1 Patient recruitment**

The total number of targeted patients meeting the inclusion criteria for this study (i.e. 100), the number recruited (92) and the response rate of 92% were considered to be acceptable. This was concluded since all of the available patients in the centres were included, there were time constraints on the data collection, and this was being undertaken for a practice oriented doctoral study. Also, this number yielded statistically significant results.

A total of 92 questionnaires were completed during a four-month period from mid-December 2012 to mid-April 2013 at the four hospitals. Forty-five (48.9%) were read to patients and completed by myself (as PI). Twenty-four (26.1%) were read and completed by participants themselves on site, and 23 (25.0%) were read to participants over the phone and completed by myself. In total, 62% of participants were receiving HD, and 38% were receiving PD.

The majority (55.4%) of completed questionnaires was obtained from patients at Hospital 2, followed by patients at Hospital 3, Hospital 1, and Hospital 4 respectively (19.6%, 14.1% and 10.9%) (Figure 5.2).



**Figure 5.2 Patient distribution across the four hospitals**

### 5.2.2 Treatment type and hospital

All hospitals provided both HD and PD treatments for patients. However, the distribution of dialysis treatment type varied across the different hospitals. As seen in Table 5.1, patients at two other hospitals (Hospitals 1 and 3) had approximately equal proportions receiving both treatment options.

Nevertheless, the majority of patients at Hospital 2 were receiving HD (71.9%). This hospital (Hospital 2) is one of the biggest dialysis centres in western SA, which provides dialysis to patients from different areas of the KSA. Thus, the

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participating hospitals consisted of one with high PD/low HD utilisation (Hospital 4), one with low PD/high HD utilisation (Hospital 2), and two with almost equal PD/HD utilisation (Hospital 1 and Hospital 3).

**Table 5.1 Treatment type and hospital**

	<b>Number of patients (% of total participants in study)</b>	<b>Number of patients on HD N(%within hospital)</b>	<b>Number of patients on PD N(% within hospital)</b>
Hospital 1	13 (14.1%)	7 (53.8%)	6(46.1%)
Hospital 2	51 (55.4%)	41(80.3%)	10(19.6%)
Hospital 3	18 (19.6%)	9(50%)	9(50%)
Hospital 4	10 (10.9%)	0 (0.0%)	10(100%)
Total	92 (100%)	57(61.9%)	35(38%)

### 5.2.3 Demographic data

The majority of participants were female (N=55, 59.7 %) and aged 50 years or older (N=49, 53.2%), with 43 (46.7%) participants aged below 50. The majority were unemployed (N=60, 65.2%). Thirteen (14.1%) were employed full-time, and 2 (2.1%) were employed part-time. Four participants were self-employed, one was a housewife, and one was in the military.

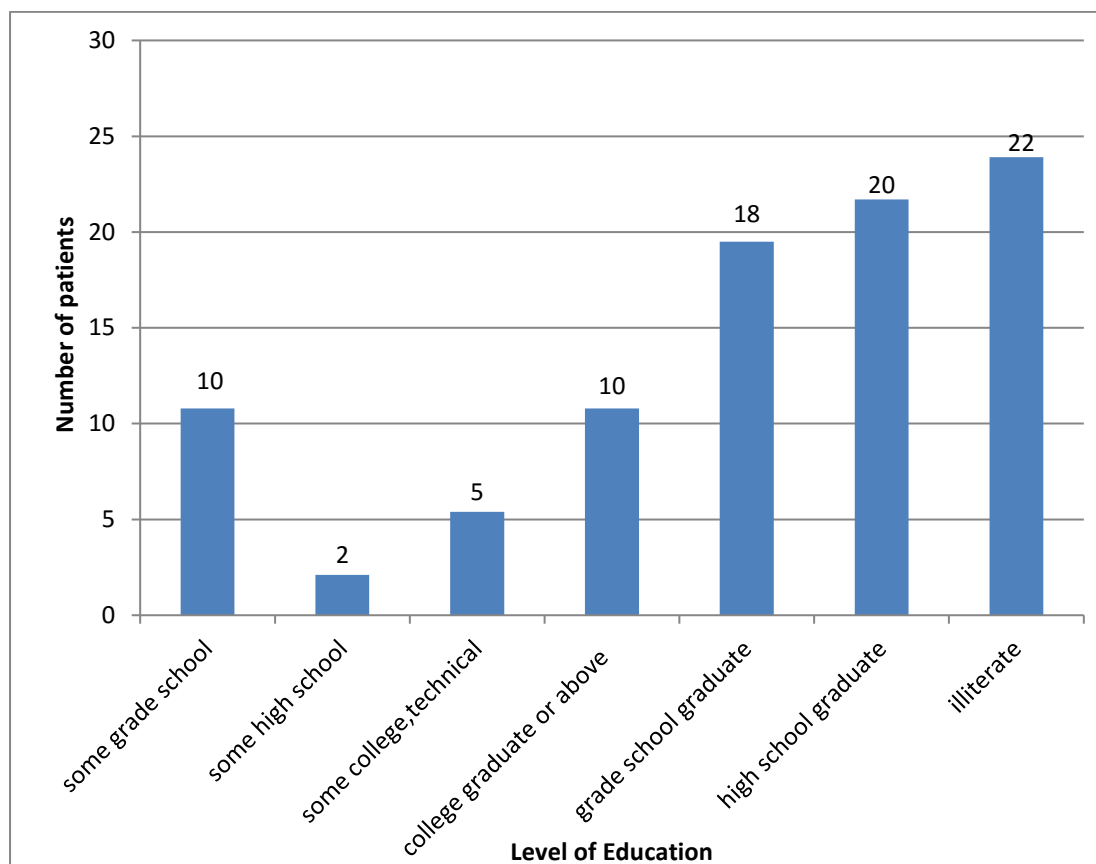
**Table 5.2 Characteristics of patients undergoing HD and PD**

<b>Patient characteristics</b>	<b>HD patients N (% of total HD)</b>	<b>PD patients N (% of total PD)</b>	<b>Number of patients N (% of total)</b>
Number of patients	57 (61.9%)	35 (38%)	92 (100.0%)
Age n (%)			
Below 50 years old	24 (55.8%)	19 (44.1%)	43(46.7%)

<b>Patient characteristics</b>	<b>HD patients N (% of total HD)</b>	<b>PD patients N (% of total PD)</b>	<b>Number of patients N (% of total)</b>
Above 50 years old	33 (67.3%)	16 (67.3%)	49(53.2%)
<b>Gender n (%)</b>			
Male	20 (35%)	17 (48.5%)	37 (40.2%)
Female	37 (64.9%)	18 (51.4%)	55 (59.7%)
<b>Level of education n (%)</b>			
Some grade school	6 (10.5)	4 (11.4%)	10 (10.8%)
Grade school graduate	13(22.8)	5 (14.2%)	18(19.5)
Some high school	2 (19.2)	0 (31.4)	2 (2.1 %)
High school graduate	9(15.7)	11(31.4%)	20(21.7%)
Some college/technical school education	4 (7%)	1 (2.8%)	5 (5.4%)
College or above	5 (8.7)	5 (14.2%)	10 (10.8%)
Illiterate	16 (28)	6 (17.1%)	22 (23.9%)
Other	2 (3.5)	3 (8.5%)	5 (5.4%)
<b>Employment status n (%)</b>			
Employed full time	5 (8.7%)	8(22.8%)	13 (14.1%)
Employed part time	2 (3.5)	0 (0.0%)	2 (2.1%)
In education	0(0.0%)	2 (5.7%)	2 (2.1%)
Retired	8 (14%)	2 (5.7%)	10 (10.8%)
Unemployed	40 (70.1%)	20 (57.1%)	60 (65.2%)
Other	4 (7%)	2 (5.7%)	6 (6.5%)

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Regarding the education level of the patients, the majority had some formal education beyond grade school. Twenty participants (21.7 %) were high school graduates, 18 were grade school graduates (19.5%), and five (5.4%) had degrees (2 BS, 2 MSc, and 1 PhD). However, nearly 24% of the participants were illiterate (n=22, 23.9 %) (Figure.5.3).



**Figure 5.3 Participants' educational level**

Pearson's chi-square test showed that gender, age, and education level were not statistically associated with the type of dialysis treatment ( $P=0.20$ ,  $P=0.40$ ,  $P=0.27$ ). However, employment status was statistically associated with the type of treatment (chi-squared=13.05,  $df=4$ ,  $P=.011$ ). A higher proportion (Table. 5.2) of unemployed participants were receiving HD, suggesting patients are more likely to be unemployed if receiving HD compared to PD.



## 5.3 Dialysis education

### 5.3.1 Information received before starting dialysis

A relatively high proportion (N=60, 65.2%) of participants knew very little or nothing about their kidney disease before they started their first dialysis treatment. Of the 92 participants, 38 (41.3%) knew they had kidney failure for at least one year before their first dialysis treatment. Of these, 22 (23.9%) knew they had kidney failure for one to three years before they started dialysis. However, 29 (31.5%) were only aware that they had kidney failure less than three months before their dialysis started.

Approximately half of the sample (N=53, 57.5%) had seen a nephrologist in the 12 months preceding starting dialysis; of these, 34 (36.9%) did not see their nephrologist any sooner than four months before they started dialysis treatment. However, some had had longer contact with their nephrologists, reporting that they had had consultations over one to three years, or even more than three years before starting dialysis (20.6%, 17.4% respectively) (see Table. 5.3).

**Table 5.3 Length of time patients knew they had kidney failure and the duration of pre-dialysis nephrology care**

	How long have you known you have kidney failure? N (%)	How long were you seeing a nephrologist for, before you started dialysis? N (%)
< 4 months	29(31.5%)	34(36.9%)
4 to 12 months	24(26%)	19(20.6%)
1 to 3 years	22(23.9%)	18(20.6%)
> 3 years	16(17.3%)	16(17.4%)
Don't know/ don't remember	1(1.1%)	5(5.4%)

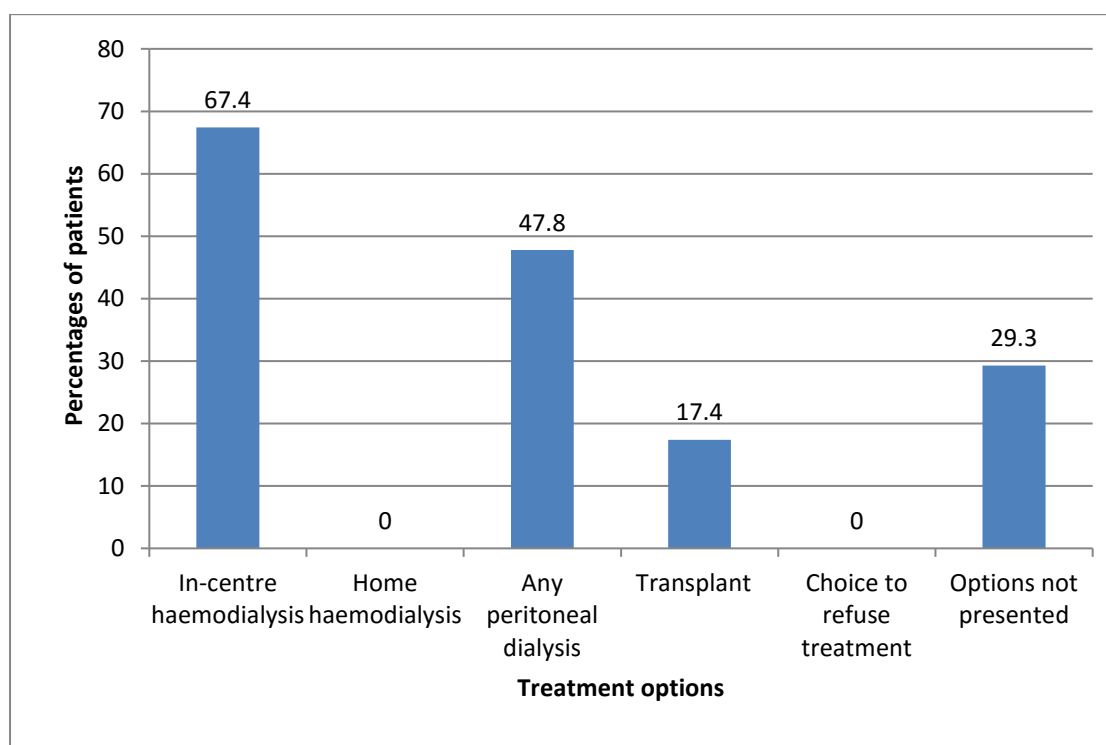
### 5.3.2 Presentation of treatment options

For the majority of participants, (N=54, 58.6 %), treatment options were given very late i.e. less than one month before dialysis. Forty (44%) of the participants were given options either after they had started dialysis or less

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than one month before their first dialysis treatment (N=14, 15.4%). Only a small proportion had more than one month to consider the treatment options presented (N=17, 18%). A high proportion (N= 41, 73.2%) indicated the medical team took the lead in deciding the treatment type.

Participants were given treatment options as follows: HD was offered as one of the options to 67.4% of participants (N=62); forty-four participants (47.8%) were offered any type of PD as one of the treatment options and transplantation was offered to 17.4 % (N=16) (Table 5.4: please note participants can tick more than one choice of treatments). No participants were given the option to refuse treatment.



**Figure 5.4 Distribution of treatment options initially offered to patients**

However, of the 92 participants, 27 (29.3%) reported not being offered treatment options and were told they had to receive a specific type of treatment. Most of these 27 patients were from Hospital 2 (N=17); five were from Hospital 3; three were from Hospital 1; and two were from Hospital 4. Further analyses revealed that of these 27 participants, only 11 (11.9%) were

told they had to use one type of dialysis only, either HD or PD. The other 16 (17.3%) participants reported that they were presented with treatment options but perceived that, in reality, they were not really given any treatment option. Table 5.4 reports the range of treatment options that were initially offered to those 16 participants and what they perceived.

A chi-square test showed significant association between patients saying treatment options were not offered and receiving HD ( $N=92, P=.0013, df=1$ ); as such, the majority of patients receiving HD did not perceive they were given an option about their treatment.

**Table 5.4 Treatment options presented initially to participants**

<b>Treatment options offered</b>	<b>Number of participants perceived no treatment options offered</b>
In-centre HD only	11
Any PD only	2
HD+PD	1
HD +PD+ Transplant	1
HD+ Transplant	-
PD+ Transplant	-
Transplant only	1
No options given	-
Total	16

### **5.3.3 Discussion of treatment options**

Of those who reported discussing treatment options, most ( $N=66, 71.7\%$ ) had discussed their treatment options with their nephrologists. Three of these 66 participants said that nurses from the dialysis centre were also present during these discussions. Twenty-two (23.9%) reported they had not discussed treatment options with anyone, while the remaining participants ( $N=3$ ) reported discussing treatment options with other health care professionals, i.e.

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a nurse from a dialysis centre (N=1); their family doctor (N=1); and their social worker (N=1). One patient did not answer this question.

### 5.3.4 Materials used to explain treatment options

The participants who were given treatment options reported that the most common tools used to explain treatment options were: face-to-face discussions with doctors or nurses (N=64, 69.5%); printed materials such as pamphlets or brochures (N=32, 35%); discussions with other patients on HD (N=10, 11%); and visits to dialysis units (N=8, 9%). The use of education resources was as follows: videos (N=5), CD-rom (N=5), classes (N=5), and seminars (N=4) (Table 5.5); none of participants experienced the use of cassette audiotape. (Patients were permitted to tick more than one option if appropriate). It is noteworthy that 34 patients indicated that treatment options were never given to them. This is different from what was previously reported (27 in Figure 5.4). Further analysis of these 34 cases shows that 11 participants perceived that they were not given any treatment option, despite being offered some information. These participants selected at least one of the options reporting which materials were used to explain the treatment they were to receive but, in addition, they also selected the option stating that treatment options were never given to them.

**Table 5.5 Materials used to explain treatment**

<b>Materials used to explain your treatment</b>	<b>Haemodialysis N (% of cases)</b>	<b>Peritoneal dialysis N(% of cases)</b>	<b>Number of total (% of total 92)</b>
Face-to-face discussion with doctors or nurses	34 (53.1%)	30(46.8%)	64(69.5%)
Classes or seminars	1(25%)	3(75%)	4 (4.3%)
Discussions with other patients on HD	8(80%)	2(20%)	10(10.8%)
Discussions with other patients on PD	1(20%)	4(80%)	5 (5.4%)
Visits to dialysis centres	5(62.5%)	3(37.5%)	8 (8.6%)
Printed materials such as pamphlets or brochures	10(31.25%)	22(68.75%)	32(35%)

<b>Materials used to explain your treatment</b>	<b>Haemodialysis N (% of cases)</b>	<b>Peritoneal dialysis N(% of cases)</b>	<b>Number of total (% of total 92)</b>
Educational CD-rom	1(20%)	4(80%)	5(5.4%)
Video	3(60%)	2(40%)	5 (5.4%)
Kidney website on the Internet	3(42.8%)	4(57.1%)	7(7.6%)
Don't know/don't remember	1(100%)	0	1(1.08%)
Treatment options were never given to me	25(73.5%)	9(26.4%)	34(36.9%)
Total may exceed 100% as participants could tick more than one option	92	83	175

### **5.3.5 Hospital differences regarding materials used to explain treatment**

Overall, there were not many differences between hospitals in terms of the types of materials used. Face-to-face discussions between clinicians and patients, and printed educational materials, were the most common approaches and were employed in all of the hospitals. The use of other types of educational tools varied, depending upon the hospital.

Hospital 1 and Hospital 2 referred patients to kidney websites and arranged for them to talk to patients already receiving HD or PD. Hospital 3 used an educational CD-rom, classes and seminars, visits to the dialysis centre, and videos. Hospital 4 used an educational CD-rom, discussion with patients about PD and videos.

However, not all patients at the same hospital received the same dialysis information; a point highlighting a lack of consistency in dialysis education presented within, as well as between, the hospitals. For example, in one hospital (Hospital 4), one patient reported having face-to-face discussions with

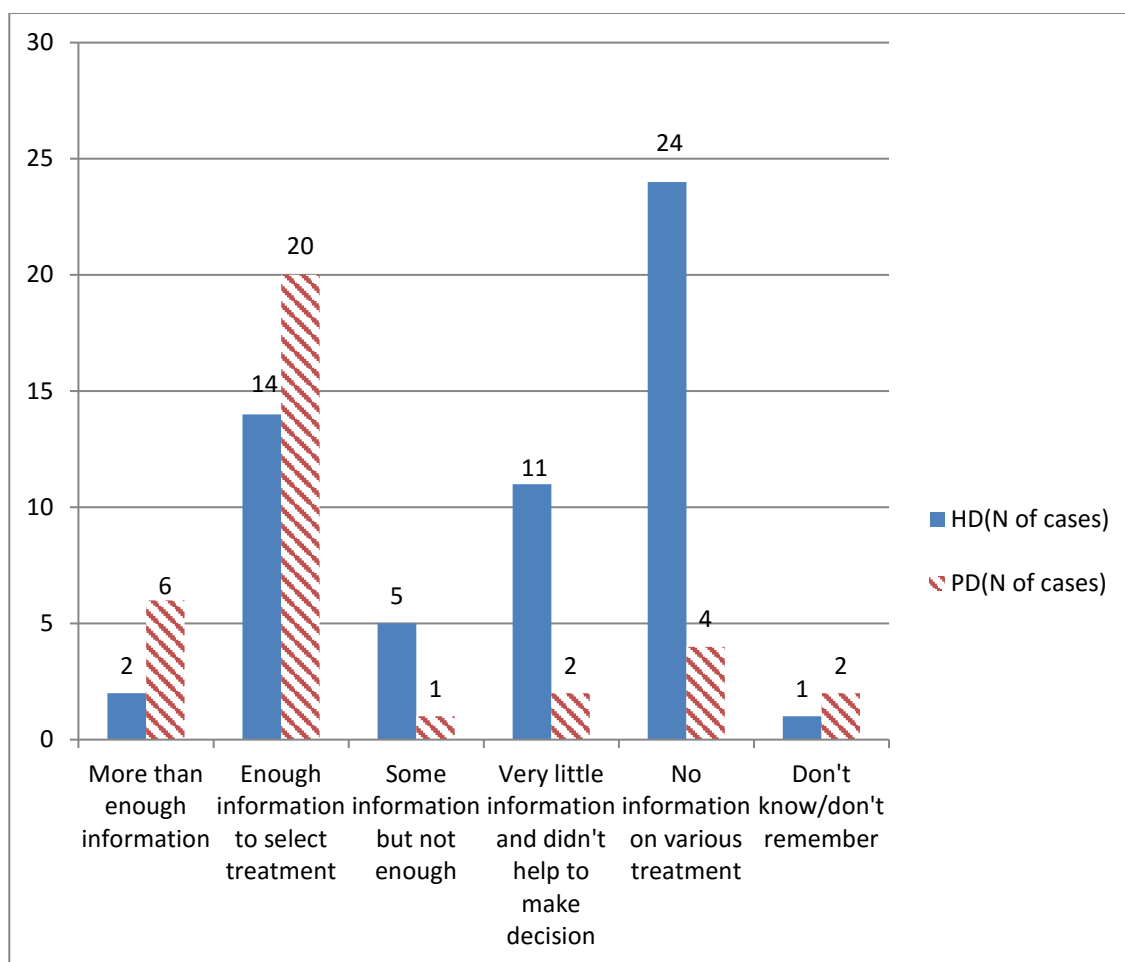
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his/her medical team and visiting the dialysis centre, while another participant reported being given printed materials and being shown a video.

### **5.3.6 Do you feel you were provided with enough information about your treatment option?**

With regard to this question, participants provided a variety of responses. Eight participants (8.7%) considered they had more than enough information to select a treatment; 34 (36.9%) considered they had enough information to select a treatment option. However, 47 of the 92 patients (51.0%) considered they had inadequate information to make a decision about their treatment. Specifically, six (6.5%) reported that although they had some information, it was not enough to help them decide upon a treatment. Thirteen (14.1%) said they had very little information and did not have enough information to help to make a decision. 28 patients (30.4%) said that no information was given about the various treatment options. Three participants (3.3%) did not know or did not remember what information was provided.

When comparing participants' answers to this question with respect to the treatment type they ultimately received, of the total of 57 participants on HD, 24 (42.1 %) indicated that no information was given to them about the various treatment options or that they received very little information, and what they did get was not helpful (N=11, 19.2%). On the other hand, of the 35 participants on PD, only 4 (11.4%) indicated that no information was given to them to select a treatment type, or that they did not receive enough information (i.e. very little information) to select which treatment they felt was best for them (N=2, 5.7%) (Figure 5.5).

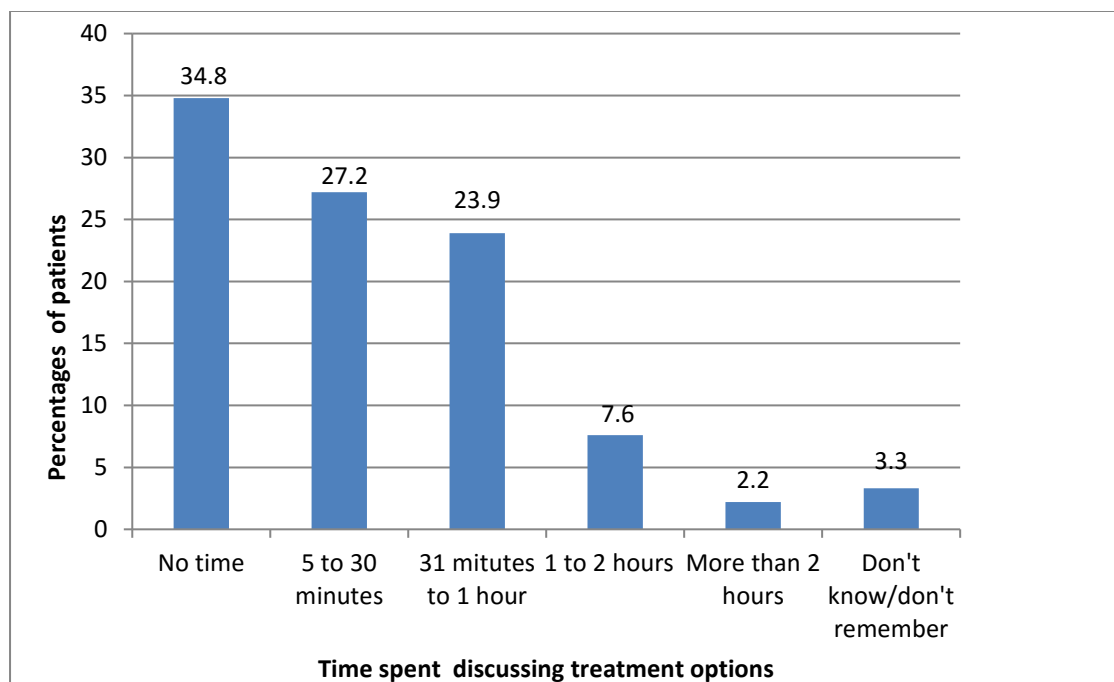


**Figure 5.5 Comparison between levels of information provided to both HD and PD patients**

### 5.3.7 Time spent discussing treatment options

The most common response (N=32, 34.8%) indicated that no time was spent discussing treatment options. Of those who did discuss their options with medical staff, 25 (27.2%) reported spending between 5 and 30 minutes, and 22 (23.9%) reporting spending between 31 minutes and 1 hour (see Figure 5.6). The results showed that the majority receiving HD spent either no time, or between 5 to 30 minutes, discussing their treatment options (N=25, 44% or N=20, 35%, respectively). Participants (N=13, 38%) receiving PD spent 31 minutes to 1 hour discussing treatment options. Pearson's chi-square test identified significant statistical associations between any time spent discussing treatment options and treatment type (N=88, df=1, P=0.015), which meant that any time spent discussing treatment options was associated with the choice of PD.

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**Figure 5.6 Time spent discussing treatment options**

## 5.4 The decision regarding dialysis modality

### 5.4.1 The choices of treatment type

As mentioned previously, most participants (N=57, 61.9%) were receiving HD at the dialysis centre. Seventeen (18.5%) were receiving automated peritoneal dialysis (APD) using a machine at home, and 17(18.5%) were receiving continuous ambulatory peritoneal dialysis (CAPD). As home HD is not yet available in the KSA, no patients reported this option, although it was asked as part of the questionnaire. A total of 91 participants responded to the question 'Did you choose this type of therapy?' As shown in Table 5.6, just over half (N=49, 53.3%) reported that they did not choose the type of dialysis they received. This result was regardless of the previously different results on the number of patients who indicated that treatment options were never given to them (27 in figure 5.4; 34 in table 5.5). It shows that 53.3% of patients still did not choose their dialysis type. However, when looking at the answers to this question and the treatment modality, the majority (63.1%) of participants who answered 'No' (36 of 57) were on HD, compared to 38.2% (13 of 34) of participants on PD who answered 'No' (Table 5.6).



**Table 5.6 Choices of treatment type**

Treatment type	Number of patients (% of total)	Did you choose this type of therapy?	
		Yes	No
Haemodialysis	57(62.6%)	21 (36.8%)	36 (63.1%)
Peritoneal dialysis	34(37.3%)	21 (61.7%)	13 (38.2%)
Total	91(100%)	42 (46.1%)	49 (53.3%)

#### 5.4.2 Reasons for treatment choices

Of the 42 participants who reported choosing their treatment type, 37 provided the reason(s) for their choice. These reasons were quite varied and related to lifestyle, practical concerns, medical and other reasons; the most common explanation being that it was comfortable for them, either at home or at the hospital. Table 5.7 summarises the most common responses from both the HD and PD patients.

**Table 5.7 List of the most common reasons for treatment selection**

Type of Reason	HD (N = number of people providing this response)	PD (N = number of people providing this response)
Lifestyle	<ul style="list-style-type: none"> <li>• 4 Better at the centre/hospital</li> <li>• 2 Easier at the centre</li> <li>• 3 Better for me</li> </ul>	<ul style="list-style-type: none"> <li>• 2 It is suitable for lifestyle</li> <li>• 3 It is suitable for job and working time</li> <li>• 3 Better for me</li> </ul>
Practical reasons	<ul style="list-style-type: none"> <li>• 4 Don't have someone at home to help (so PD is not possible)</li> <li>• 1 Because patient lives outside a city (PD not possible)</li> </ul>	<ul style="list-style-type: none"> <li>• 8 Can do it at home</li> <li>• 2 It is easy to do</li> <li>• 6 It is comfortable, flexible and safer</li> <li>• 1 There is more freedom at home</li> </ul>
Medical reasons	<ul style="list-style-type: none"> <li>• 1 Heart problems</li> <li>• 1 Multiple abdominal operations</li> <li>• 1 Caesarean/section operation</li> <li>• 1 Hernia</li> </ul>	
Other	<ul style="list-style-type: none"> <li>• 2 Heard that PD had too many problems/not good</li> </ul>	<ul style="list-style-type: none"> <li>• 1 Worried about HD complications</li> </ul>

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### 5.4.3 Arrangement of treatment types

Of the 92 participants asked about who arranged their treatment, 56 answered. It was expected that only the 49 who answered 'No', (they did not choose their treatment type), would complete this question. However, despite this, a further seven also answered.

The majority of the 46 'No' patients (N=41, 73.2%) stated that their medical team took the lead in making the decision; 14 (25%) said it was a joint decision between the participant, family and medical team members, and one (1.8%) replied that he/she did not know/did not remember. Of the seven participants who reported choosing their treatment modality, six said it was a joint decision with their doctors, and one said that his/her medical team made the decision. The results indicate that most of the participants who said the medical team took the lead in making the decision were on HD, compared to PD (N=31, 75.6%; N=10, 66.6%, respectively) (Table 5.8). The data are complex regarding patients' choices. Some patients seemed reluctant to report if it was their choice or if it was actually an arrangement of joint decision by patients, family, and the medical team.

**Table 5.8 Arrangement of treatment type**

Treatment type	Number of patients (% of total patients)	Who chose/arranged treatment type?		
		Medical team (doctors, nurses, social worker) N (% of total)	Joint decision by patients, family and medical team N (% of total)	Don't know/don't remember N (%)
Haemodialysis	41 (73.2%)	31 (75.6%)	9 (21.9%)	1 (2.4%)
Peritoneal dialysis	15 (26.8%)	10 (66.6%)	5 (33.3%)	0
Total	56 (100%)	41 (73.2%)	14 (25%)	1 (1.7%)

The majority (N=69, 75%) of participants received the same treatment they started with. However, 23 (25%) subsequently changed their treatment. When asked why the type of treatment was changed, just over half of those participants (N=13, 56%) stated that they had to start urgent HD first before switching to PD. Other medically related reasons were also offered, such as PD

catheter-related issues (2); they were uncomfortable on HD (N=1) or PD (N=1); due to Heparin-related issues (1); and because of heart catheterisation (1). Only two participants stated the change was at their request, and two did not give reasons.

#### 5.4.4 Hospital differences in regards to the decision of treatment choices

With regard to participants' decisions about treatment choices according to their hospitals, the results identified that Hospital 1 had the highest percentage of participants choosing their treatment type (69.2%), followed by Hospital 4 (60%). Hospital 2 had the lowest percentage, with only 36% of participants choosing their treatment type. Half of participants chose their treatment in Hospital 3 (50%) (Table 5.9)

**Table 5.9 Comparison of hospital results regarding the choice of treatment**

Hospital ID	Number of patients (% of total)	Did you choose this type of therapy?	
		Yes	No
Hospital 1	13(14.2%)	9(69.2%)	4 (30.7%)
Hospital 2	50(54.9%)	18 (36%)	32 (64%)
Hospital 3	18(19.7%)	9 (50%)	9 (50%)
Hospital 4	10(10.9%)	6 (60%)	4 (40%)
Total	91	42 (46.1%)	49(53.8%)

### 5.5 Patients' perceptions of the dialysis information

#### 5.5.1 Satisfaction with the treatment

Despite the fact that the majority of patients were not given an option about their treatment, most reported being either 'somewhat satisfied' (50%) or 'very satisfied' (35.9 %) with the treatment they were receiving (HD or PD). Only 5.4%

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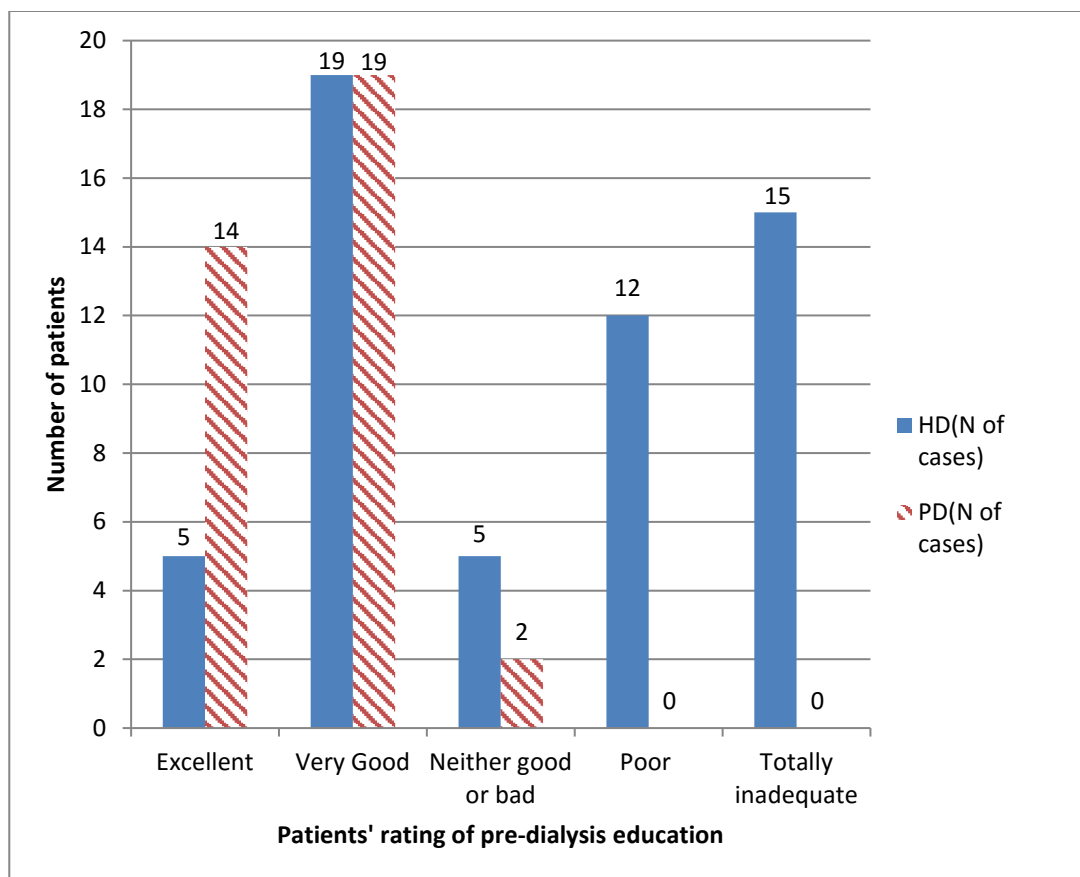
of patients were 'somewhat dissatisfied', and 5.4% were 'very dissatisfied' (Table 5.10).

**Table 5.10 Patients' satisfaction with treatment**

<b>Patients' rating of their treatment</b>	<b>Number of patients (%)</b>
Very satisfied	33(35.9%)
Somewhat satisfied	46(50%)
Neither satisfied nor dissatisfied	3(3.3%)
Somewhat dissatisfied	5(5.4%)
Very dissatisfied	5(5.4%)
<b>Total</b>	<b>92(100%)</b>

### **5.5.2 Patients' ratings of the pre-dialysis education**

When patients were asked to rate the pre-dialysis education they received, all 92 patients answered this. Most rated it as 'very good' (N=38, 41.3%) or 'excellent' (N=19, 20.7 %). Thirteen percent (N=12) rated it as 'poor', and 16.3% (N=15) as 'totally inadequate'. Further analysis revealed that the 27 participants who rated the pre-dialysis education as 'poor' or 'totally inadequate' were receiving HD (Figure 5.7). A Cramer's V statistical test confirmed a significant association between treatment type and rating the pre-dialysis education as 'poor' or 'totally inadequate' (N=91,  $k = 0.537$ ,  $P=0.000$ ). However, as demonstrated in Figure 5.8, it is notable that none of the PD participants rated their pre-dialysis education as 'poor' or 'totally inadequate', confirming that the significant association was specifically related to those receiving HD treatment only.



**Figure 5.7 Comparison between HD and PD patients' ratings of pre-dialysis education**

### 5.5.3 Comparing the four hospitals and patients' ratings of the pre-dialysis education

Most of the 27 patients who rated their pre-dialysis education as 'poor' or 'totally inadequate' were from two hospitals, Hospital 2, 44 % (22 of 50) and Hospital 1, 30.7 % (4 of 13). Only one patient from Hospital 3 and none from Hospital 4 gave a 'poor' rating. As previously mentioned, the majority of participants were from Hospital 2, because it is the biggest kidney centre in the region (Table 5.11).

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**Table 5.11 Patients' ratings of the pre-dialysis education in the four hospitals**

Hospital	Total N (% of total)	Excellent N (%)	Very good N (%)	Neither good nor bad	Poor	Totally inadequate
Hospital 1	13(14.2%)	3(23.0%)	6(46.1%)	0	1(7.6%)	3(23.0%)
Hospital 2	50(54.9%)	4(8%)	20(40%)	4(8%)	10(20%)	12(24%)
Hospital 3	18(19.7%)	9(50%)	6(33.3%)	2(11.1%)	1(5.5%)	0
Hospital 4	10(10.9%)	3(30%)	6(60%)	1(10%)	0	0
Total	91(100%)	19(20.8%)	38(41%)	7(7.6%)	12(13%)	15(16.4%)

### **5.5.4 Patients' preferences regarding the conduct of information sessions**

Just over half (N=49, 52%) of the participants indicated they would like information sessions to be conducted privately at the hospital. Others (N=18, 19%) preferred group sessions at the hospital or a combination of both private and group sessions (accompanied sessions) (N=27, 29%). Only 5.5 % (N=5) chose internet-based sessions.

### **5.5.5 The need for additional information to help patients make decisions about their treatment**

Of the 90 participants who responded to this question, the majority (N=57, 63.3%) said they would like additional information to help them make a decision about their treatment choices. Most of these 57 participants were receiving HD (N=44, 77.1%), with only 13 (22.8%) participants receiving PD, suggesting that patients receiving HD were given inadequate information regarding treatment options. Pearson's chi-square test confirmed a highly significant statistical association between the participants' need for additional information and their treatment type (N=90,df=1,P=0.000). Regarding the participants' need for additional information, most participants wanting

additional information were from Hospitals 2 and 1 (72.5% and 69.2% respectively) (Table 5.12).

**Table 5.12 Participants' needs for additional information in the four hospitals**

Hospitals	Would you like any additional information to help you make a decision?		Total N (%)
	Yes N (%)	No N (%)	
Hospital 1	9(69.2%)	4(30.7%)	13(14.4%)
Hospital 2	37(72.5%)	14(27.4%)	51(56.6%)
Hospital 3	8(50%)	8(50%)	16(17.7%)
Hospital 4	3(30%)	7(70%)	10(11.1%)
Total	57(63.3%)	33(36.6%)	90

Cramer's V test confirmed a significant association between patients' needs for additional information and which hospital they attended ( $P=0.045$ ,  $N=90$ ). This means that the patients' need for additional information, as shown in Table 5.12, indicated that most patients asking for more information were from Hospital 2. However, it should be noted that the majority of participating patients in this survey (55.4 %) were also from Hospital 2.

#### **5.5.6 What sort of additional information would patients like to receive?**

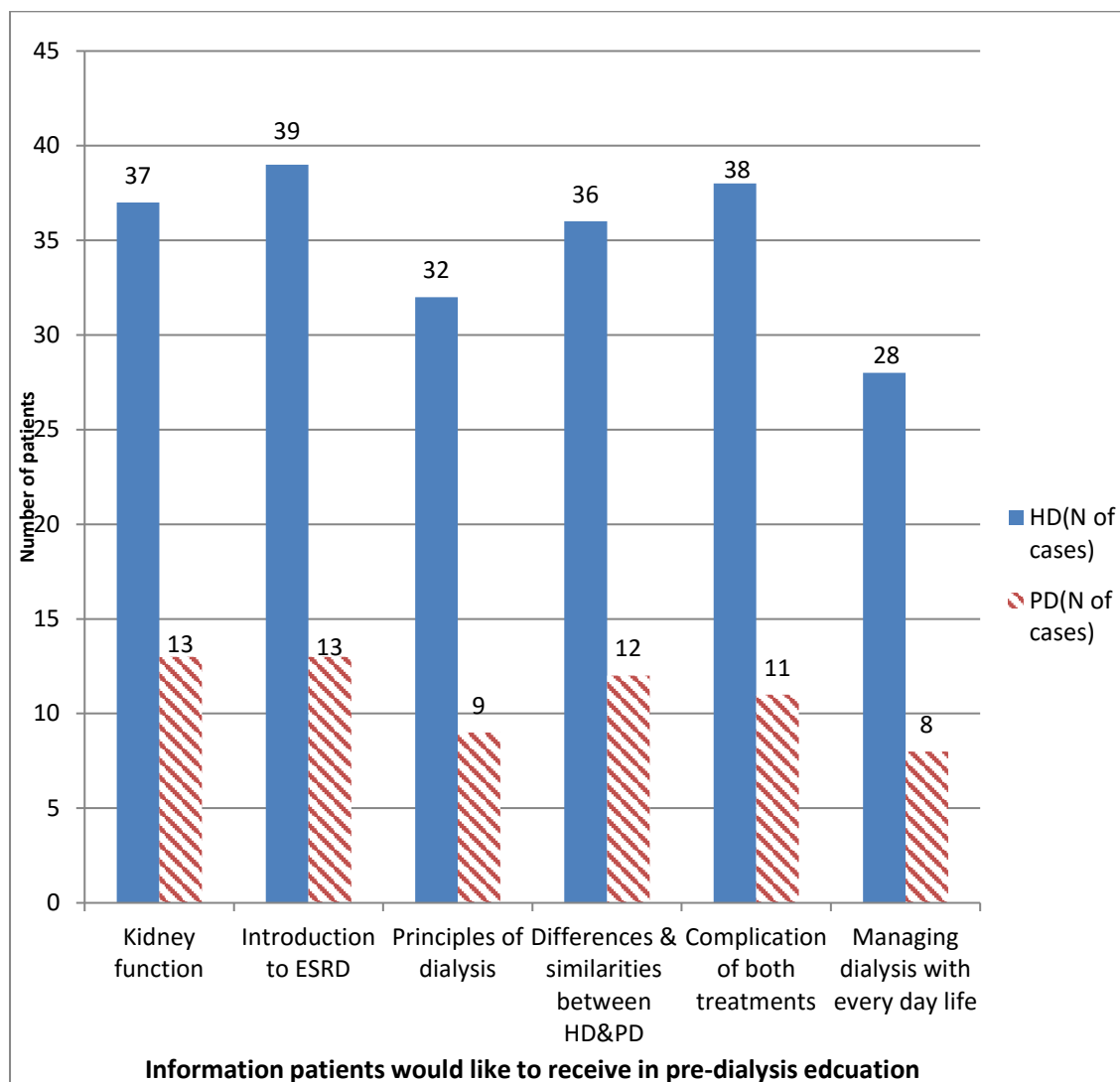
Those patients ( $N=57$ , 62%) who said they would like more information were asked to tick the kind of information they would like to receive in pre-dialysis education.

##### **5.5.6.1 Theoretical knowledge**

The majority of patients ( $N=52$ , 56.5%) asked for a basic introduction to ESRD. Fifty patients (54.3%) asked for information about kidney function, followed by information about the complications of both treatment and the differences and

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similarities between the treatment types. Figure 5.8 describes differences between both treatment types.



**Figure 5.8 Distribution of the information patients would like to receive in pre-dialysis education**

Although it seemed that most of the participants who requested more information were receiving HD (Figure 5.8), when the differences were assessed using Cramer's V test, no statistical differences were identified with regard to request for types of information; either across treatment groups (HD or PD) or across the four different hospitals (Table 5.13).



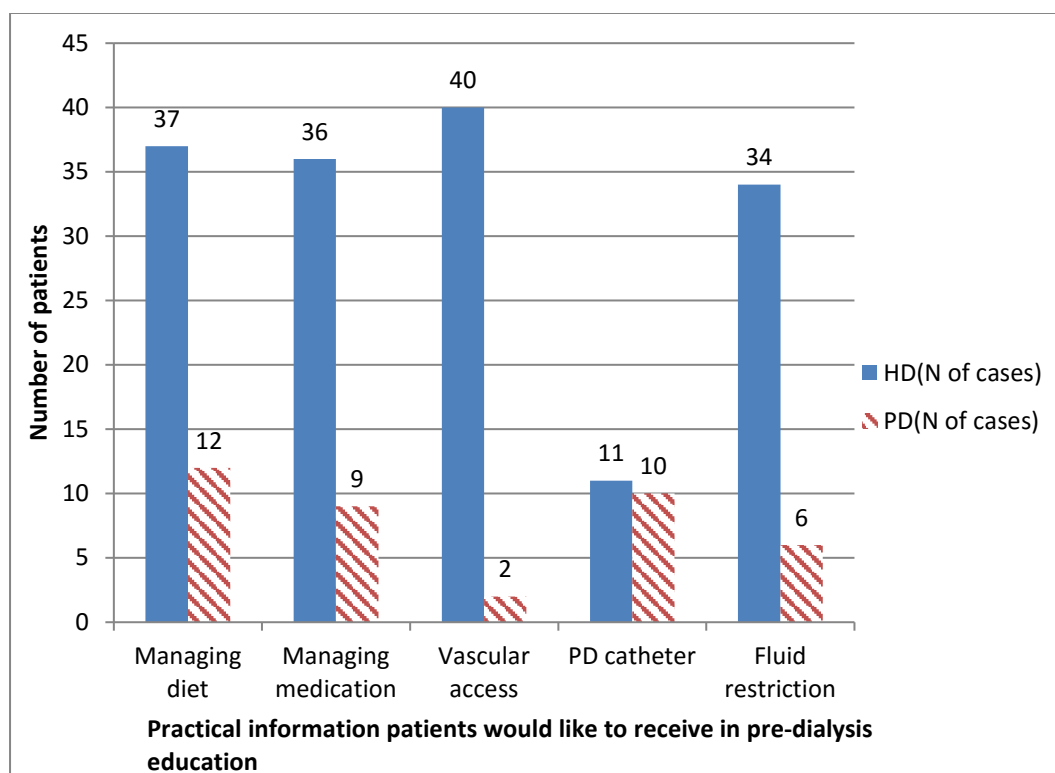
**Table 5.13 Statistical tests for association between knowledge requested and treatment type and hospitals**

<b>Requested knowledge</b>	<b>Cramer's V test (P value)for association with treatment type</b>	<b>Cramer's V test (P value) for association with hospitals</b>	<b>Number of valid cases</b>
1. Kidney function	0.407	0.866	58
2. Introduction to ESRD	0.652	0.687	58
3. Principles of dialysis	0.517	0.847	54
4. Differences and similarities between HD and PD	0.301	0.331	58
5. Complications of both treatments	0.609	0.111	59
6. Managing dialysis with everyday life	0.529	0.389	50

#### **5.5.6.2 Practical aspects**

Regarding the practical aspects of dialysis, 49 of the 92 participants stated they wanted information about managing their diet (N=49, 53.3%), followed by managing their medication 45(48.9%), then information about vascular access and fluid restriction. Figure.5.9 describes differences between treatment types.

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**Figure 5.9 Distribution of practical information patients would like to receive in pre-dialysis education among treatment types**

Although most participants requesting more practical information were receiving HD (Figure 5.9), Cramer's V test identified no significant association between participants' treatment type and wanting more information about either managing diet or managing medication and fluid restriction. However, significant associations were identified between requesting information about vascular access (fistula or catheter) and both the treatment type ( $P=.000$ ,  $N=55$ ), as well across the four hospitals ( $P=0.005$ ,  $N=55$ ). In addition, a significant association was also recognised between information on PD catheter and the treatment type ( $P=0.000$ ,  $N=53$ ) (Table 5.14). However, the number of cases with regard to this was only 53; however it could be that mainly patients on PD selected this option because it related to their treatment type.

**Table 5.14 Statistical test for association between practical aspect and treatment type and hospitals**

Practical aspect	Cramer's V test (P value) for association with treatment type	Cramer's V test (P value) for association with hospitals	Number of cases
1. Managing diet	0.454	0.464	57
2. Managing medication	0.598	0.332	56
3. Vascular access	0.000	0.005	55
4. PD catheter	0.000	0.368	53
5. Fluid restriction	0.070	0.259	53

### 5.5.7 Factors influencing patients' choice of dialysis treatment

Participants were asked to choose factors that influenced their choice of dialysis treatment. The most common factors in descending order of response were:

- 'my doctors opinion' (N=69, 75%),
- 'the opinion of my spouse/significant other' (N=30, 32.6%),
- 'having someone at home to help me manage my treatment' (N=26, 28.3%),
- 'having a dependent at home' (N=15, 16.3%),
- 'talking to someone already on dialysis' (N=15, 16.3%), and
- 'I don't have someone at home to help me manage my treatment' (N=13, 14.1%).

Interestingly, the least common factors that influenced treatment choices were 'having more written information' (N=3, 3.3%), followed by 'the opinion of my friends' and 'the opinions of my nurse' (N=7, 7.6%; N=9, 9.8%, respectively).

No statistical associations were found between the most common factors (my doctor's opinion; the opinion of my spouse/significant others, and talking to someone about dialysis) and the treatment type (Chi-square test,  $P=0.385$ ,  $P=0.100$ ,  $P=0.865$ , respectively,  $N=92$ ).

Statistically significant associations were found between factors that relate to treatment type and the participants' family and home environment.

Associations between treatment types were identified with having a dependent

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at home ( $P=0.056$ ); having someone at home to help me manage dialysis ( $P=0.000$ ); and not having someone at home to help to manage dialysis ( $P=0.002$ ). In addition, Cramer's V test shows association between treatment type with both having more written information ( $P=0.02$ ,  $N=92$ ), as well as the opinion of the nurse, ( $P=0.01$ ,  $N=92$ )(Table. 5.15). Cramer's V test was used when a Chi-square test was not appropriate.

**Table 5.15 Statistical test for association between factors influencing treatment choices and treatment types/hospitals**

Factors influencing treatment choices	Chi-square test( P value) for association with treatment type	Cramer's V test( P value) for association with hospital	Number of cases
1. My doctor's opinion	0.385	0.507	92
2. The opinion of my spouse/significant other	0.100	0.582	92
3. Having dependents at home	0.056	0.696	92
4. Having someone at home to help to manage treatment	0.000	0.006	92
5. Don't have someone at home to help to manage treatment	(Cramer's V) $P=0.002$	0.138	92
6. Talking to someone about dialysis	0.865	0.094	92
7. More written information	Cramer's V $P=0.025$	0.064	92
8. Nurse's opinion	Cramer's V $P=0.010$	0.022	92
9. Friend's opinion	Cramer's V $P=0.785$	0.134	92

The most important factors that influenced treatment choices were the doctor's advice and family members ( $N=37$ , 49.3 %). In eleven cases, the

doctor's advice was based on the participants' medical conditions (hernia (3); heart problem (1); heart catheterisation (1); history of Caesarean section (1); multiple abdominal surgery (1); water in lung (1); over 70 years old and cannot tolerate HD (1); Heparin reaction (1); and patient was planned for transplantation (1). Others factors such as concern about infections (N=7, 7%), transportation (N=6, 6%), dialysis time (N=6, 6%) and having no one at home to help (N=3, 3%), were also reported as influencing factors for treatment choices. Seventeen participants (18.4%) did not answer this question. Sixteen patients gave detailed answers in the open-ended questions shown in Table 5.16

**Table 5.16 The most important factors influencing treatment choices**

<b>Most important influences on treatment choices</b>	<b>Patients' quotes</b>
1. Doctors' advice and family members	<p><i>"Doctors convinced me of PD" participant #69 on PD</i></p> <p><i>"Doctors opinion, options were not given to me"</i></p> <p>Participant# 46 on HD</p> <p><i>"Doctor's explanation, family advice, better at home"</i></p> <p>Participant# 73 on PD</p>
2. Safer at hospital	<p><i>"Safer at hospital, nurses and doctors around"</i></p> <p>Participant # 2on HD</p> <p><i>"Better at hospital with doctors, every two days you see doctors, if there is problem or complication doctor will be available"</i> Participant #33 on HD</p> <p><i>"Afraid of machine, family and kids at home"</i></p> <p>Participant # 4 on HD</p> <p><i>"Afraid to do dialysis at home alone"</i> Participant# 87 on HD</p>
3. Transportation	<p><i>"No need for transportation, have someone to help me at home, can carry it with me when and where I go"</i> Participant # 72 on PD</p>
4. Employment	<p><i>"My job, doctors' advice, talking to patients on dialysis"</i> Participant# 67 on PD</p>

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Most important influences on treatment choices	Patients' quotes
	<p><i>"Flexible, comfortable for working"</i> Participant# 62 on PD</p> <p><i>"To be able to work, easy to do"</i> Participant# 45 on PD</p>
<ul style="list-style-type: none"> <li>Other influence</li> </ul>	<p><i>"Friend's advice, comfortable, don't have symptoms like HD such as headache, pain and hypotension, does not take longer time to do it"</i> Participant #51 on PD</p> <p><i>"Because the majority of patients are on HD"</i> Participant# 48 on HD</p>
<ul style="list-style-type: none"> <li>Personal preferences</li> </ul>	<p><i>"Don't like HD because worried about infection, blood loss in HD and have someone at home to help me to do PD"</i> Participant#56 on PD</p> <p><i>"Don't like PD, worried about infection and time consuming, doctors' explanation"</i> Participant #42 on HD</p> <p><i>"At home with family, comfortable, easy, no need for transportation and I didn't like HD"</i> Participant # 26 on PD</p>

Nearly all of the participants considered it important to be involved in their treatment choice. Eighty-three participants (90%) felt it is 'very important', and seven (8%) considered it is 'somewhat important'. Of these 83 participants, 50 (60%) were receiving HD, and 33 (40%) were receiving PD. There were no treatment differences in perceived importance of being involved in making their treatment decision.

### 5.5.8 Patients' views and recommendations about improving dialysis information

A total of 47 participants (51.0%) did not record any need for improvements. One participant (2.2%) said information was 'excellent', 9 (10 %) said it was 'good', 9 (10%) said they had 'nothing to add', and data were missing for 28 (30%) participants. Therefore, only 45 participants (48.9%) made recommendations about improving pre-dialysis education. In addition, only eight participants agreed for audio recording. The most commonly reported views are described in Table 5.17.

**Table 5.17 Patients' recommendations for improving pre-dialysis education**

Recommendations for improving pre-dialysis educations	Patients' quotes
<ul style="list-style-type: none"> <li>• More information about the advantages and disadvantages of both treatment types (N=17, 37.7%);</li> <li>• More explanation regarding treatment types (N=1, 2.2%)</li> </ul>	<p><i>"To explain the advantages and disadvantages of both type of dialysis"</i> Participant #57</p> <p><i>"There is a need to educate the community about dialysis, to do home visits to patients on dialysis, to review and discuss problems with patients"</i> Participant #52</p>
<ul style="list-style-type: none"> <li>• The opportunity to visit the dialysis centre or speak to patients currently on dialysis (N=8, 18%)</li> </ul>	<p><i>"Before dialysis I was scared and not accepting the idea of dialysis, it is better if patients get to see dialysis centre and the chance to speak to patients on dialysis"</i> Participant #33</p>
<ul style="list-style-type: none"> <li>• Explanation to be given as early as possible (N=5, 11.1%)</li> </ul>	<p><i>"Early education, education should have been long before my need for urgent dialysis, I knew I had kidney problems for 7 years but was never told anything about dialysis,, I</i></p>

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	<p><i>thought I will recover</i>" Participant #47</p> <p><i>"It would be better if education was given at an early stage"</i> Participant #73</p> <p><i>"Explanation should be provided from the start not at late stage"</i> Participant #67</p>
<ul style="list-style-type: none"> <li>To provide more time for non-educated patients (N=5, 11.1%).</li> </ul>	<p><i>"Educated patients would understand better, should more explanation be provided to non-educated patients"</i> Participant #81</p> <p><i>"Some patients need more time for education than others"</i> Participant #26</p> <p><i>"An hour of education to patient about both type of dialysis would be acceptable"</i> Participant #41</p>
<ul style="list-style-type: none"> <li>To explain things in laymen's terms (N=5, 11.1%)</li> </ul>	<p><i>"Education should be adjusted to patient's level of understanding, in non-medical words"</i> Participant #42</p>
<ul style="list-style-type: none"> <li>To be presented and provided with all the options (N=2, 4.4%):</li> </ul>	<p><i>"Explanation should include both types of treatment not only one, I received explanation about PD only because there was no place on HD"</i> Participant #4</p> <p><i>"Patient need to be informed about the dialysis types"</i> Participant #17</p>
<ul style="list-style-type: none"> <li>The families should also be provided with dialysis education and treatment options (N=2, 4.4%)</li> </ul>	<p><i>"To improve and provide education to patients as well as families about the treatment options"</i> Participant # 82</p>



	<i>"To give education to patients as well as their caregiver"</i> Participant #19
<ul style="list-style-type: none"> <li>To use different educational tools, such as pictures, audio-visual materials or a demonstration of the treatment (N=1, 2.2%);</li> <li>The educational materials should be reviewed by patients and medical staff together (N=2, 4.4%).</li> </ul>	<p><i>"Explanation and education should be in different ways to explain, such as use of pictures, video, audio-visual materials"</i> Participant #46</p> <p><i>"To use more materials for education and demonstration of PD and how to look after the patient in the home"</i> Participant #83</p> <p><i>"Some people cannot understand and need more explanation and to use different ways to explain such as videos and pictures".</i> Participant #75</p>

It is worth noting that some participants' answers to this question were different, reflecting the diversity of education provided and patients' responses. One indicated that he did not receive education: *"there was no pre-dialysis education"* (Participant #65). Another described education as, *"It was very old"* (Participant # 72), and another patient considered that the education was not sufficient.

## 5.6 Advantages and disadvantages of treatment types

### 5.6.1 Advantages and disadvantages of HD

Of the 59 participants receiving HD, the vast majority (N=53, 89.8 %) stated they preferred treatment in a dialysis centre, and 50 (85%) stated they would like the nurse, or others, to take care of them. Thirty-nine (66.1%) preferred a planned schedule (HD 3 times per week), and 31 (52.5%) preferred regular contact with other patients on dialysis. Dietary restrictions were found to be the most common disadvantage of HD (N=43, 75.4%), followed by fluid restrictions (68%) (Table 5.18).

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**Table 5.18 Advantages and disadvantages of HD**

Advantages	Number, %	Disadvantages	Number, %
1. Prefer treatment in dialysis centre	(N=53, 89.8%)	1. Dietary restrictions	(N=43, 75.4%)
2. Let nurse/other take care of me	(N=50, 84.7%)	2. Fluid restrictions	(N=39, 68.4%)
3. Prefer planned schedule	(N=39, 66.1%)	3. Don't want to be pricked with needle	(N=38, 66.7%)
4. Prefer regular contact with others	(N=31, 52.5%)	4. Transportation to dialysis centre	(N=37, 64.9%)
-	-	5. Duration of treatment (3x/week)	(N=34, 60.7%)
-	-	6. Don't like the blood	(N=21, 36.8%,)

### 5.6.2 Advantages and disadvantages of PD

Among the 34 participants receiving PD, the most common (N=30, 88%) advantage was that travelling was easier because patients were able to take their dialysis fluid with them, followed by preferring to self-manage their condition (N=29, 85%), and preferring the privacy of home treatment (N=28, 82%). The most common disadvantage of PD was the concern about infection (N=24, 71%), followed by the duration of treatment (N=23, 68%) (Table 5.19).

**Table 5.19 Advantages and disadvantages of PD**

Advantages	Per cent (%)	Disadvantages	Number (%)
1. Travelling is easier	(N=30, 88.2%)	1. Concerned about infection	(N=24, 70.6%)

2. Rather do it myself	(N=29, 85.3%)	2. Duration of treatment (7x/week)	(N=23, 67.6%)
3. Prefer privacy at home	N=28 (82.4%)	3. Don't like tube in my abdomen	(N=21, 61.8%)
4. Easier to work	(N=27, 79.4%)	4. Ordering, delivery and storage of supplies	(N=15, 44.1%)
5. Flexibility of schedules	(N=24, 70.6%)	5. Body image (personal appearance)	(N=12, 35.3%)
6. Could be done at home while sleeping	(N=22, 64.7%)		

## 5.7 Regression analysis

Following the initial analysis, a second set of binary logistic regression models was carried out to determine if relevant factors (gender, age, education, employment status, having dependent at home, and having someone at home to help with treatment) were associated with what treatment they received. The results from these models identified that 'having someone at home to help with the treatment' was significantly associated with participants' choice of treatment modality ( $P=0.000$ ,  $CI=0.002-0.107$ ) (Table 5.20).

**Table 5.20 Binary logistic regression analysis to determine the predictors of modality selection**

Factors	Comparisons	Odds ratio	Lower 95% CI	Upper 95% CI	Overall P value
Gender	Male vs. female	1.399	0.240	8.145	0.709
Age	<50 y/old vs. >50 y/old	1.020	0.169	6.156	0.982
Education	Educated vs. illiterate	0.376	0.050	2.847	0.344
Employment status	Employed vs. unemployed	0.170	0.021	1.384	0.098
Having dependent at home	Yes vs. no	0.702	0.068	7.272	0.767
Having	Yes vs. no	0.016	0.002	0.107	0.000

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Factors	Comparisons	Odds ratio	Lower 95% CI	Upper 95% CI	Overall P value
someone at home to help with treatment					

Additionally, binary logistic regression analysis was performed to determine if the factors of age, educational level, patients choose their treatment options, and time spent on treatment discussion were associated with patients' satisfaction with treatment. The results were not significant because there was an insufficient number of dissatisfied patients, as most participants were satisfied with their treatment (Table 5.21).

**Table 5.21 Binary logistic regression analysis to determine the predictors of patient's satisfaction**

Factor	Comparisons	Odds ratio	Lower 95% CI	Upper 95% CI	Overall P value
Age	<50 y/old vs. >50 y/old	3.156	0.515	19.322	0.214
Education level	Any education vs. illiterate	1.127	0.232	5.474	0.882
Patients choose their treatment	Yes vs. no	5.817	0.636	53.234	0.119
Time spent on treatment discussion	No time vs. anytime >1	0.610	0.130	2.865	0.531

## 5.8 Conclusions of the main study

This chapter reports the findings from the survey of 92 patients with ESRD, who were receiving HD or PD across four hospitals in the western region of the KSA. This is the first time data have been presented reporting the opinions of patients with ESRD in the KSA. The study identified similar findings across the four hospitals involved in this research, with regard to their pre-dialysis education. The findings suggest there was a lack of standardised dialysis information provided to new dialysis patients within all four hospitals. This was emphasised by the fact that only 2 of the 4 hospitals had some educational information available for patients. This study has provided insights about the information patients receive before starting dialysis, the factors that influence

patients when considering their treatment type, and the level of patient involvement in the selection of treatment type. The overall findings were as follows:

- The majority of patients received HD (61.9%), but comparatively this level is lower than found in other countries. On the other hand, 38.1% of patients received PD; this level is higher than that found in other countries (Mehrotra et al. 2005).
- The findings indicate that over half of the patients (N=54, 58.6 %) were not offered information on dialysis until after they had already started dialysis; or they received information less than one month before dialysis started.
- The findings suggest that while some patients were offered a choice of treatment, they did not perceive they were offered a 'real' choice.
- The findings indicate that most patients were either 'somewhat satisfied' (50%) or 'very satisfied' (35.9 %) with their treatment.
- The survey found that half of the participants did not suggest ways to improve current education/information (50%).
- HD was initially offered as a treatment option to 67.4% of the participants. However, only 61% of the participants elected to receive HD.
- The majority (79%) of participants who received HD spent either "no time" or "between 5 to 30 minutes" discussing their treatment options with medical staff before they started HD (N=25, 44% vs. N=20, 35%, respectively).
- There was a statistical association between the time spent discussing dialysis options and the treatment type they received ( $P=0.015$ ).
- There was a significant association between participants rating the dialysis education as 'poor' or 'totally inadequate' and the treatment type they were receiving (HD) ( $P=0.000$ ), because only patients on HD rated pre-dialysis education as 'poor' or 'totally inadequate'.
- There was a significant association between patients' needs for additional information and treatment type (HD) ( $P=0.000$ ).
- Binary logistic regression determined that having someone at home to help with treatment was a predictor for participants receiving PD ( $P=0.000$ ).

### **5.9 Results of the national audit of dialysis centres in the KSA**

#### **5.9.1 General characteristics of dialysis units**

It should be noted that this audit was undertaken after the completion of the main study (see chapter 4, section 4.4.1). Thus in 2016, twenty-four hospitals were identified as providing different options of RRT in the KSA. One provided paediatric dialysis, so it was not included in the audit. Fourteen of the hospitals were under the Government non-Ministry of Health sector, while 10 hospitals were under the Ministry of Health sector. Out of the 24 hospitals, three have a dialysis centre which is located in a building attached to the hospital (one in central region, one in western region and one in eastern region). Twenty-one (out of 24) dialysis units were contacted, three units were not possible to contact after several attempts. Nineteen out of the twenty-one units agreed to participate in the audit and two units only stated that they do not provide pre-dialysis education programmes and declined to provide any more information for the audit. Geographically, six of the hospitals were from the central region, seven were from western region and six were from the eastern region. Additionally, one hospital was from the northern border while another one was from the southern region of the KSA.

All 21 responding units provided HD, CAPD and APD. Six undertook renal transplants as well. One unit in the eastern region indicated that they did pre-emptive-transplants as the first option for patients. No unit gave information about conservative management or having a 'no dialysis' choice. One unit indicated that they had two types of patients: those who were 'regular' and those who were 'visitors' who came to visit the holy city and needed urgent dialysis before travelling back to their home land. One centre in the central region indicated that it did not receive emergency cases but only transfers from the main hospital. One centre said that since 2014, they had started referring patients to a private hospital for home HD, but not enough information was given regarding this aspect.

Patient referral to dialysis varied. In eight units patients were referred to dialysis treatment through nephrology clinics and/or emergency departments; through the nephrology clinic (N=3); through primary healthcare centre and

inpatient departmental referral (N=3); two units provided emergency dialysis, and then transferred those patients to different hospitals. One unit indicated it did not have an emergency department, and therefore patients needing an emergency start would be transferred to the main hospital. Two units were not sure how patients were referred to dialysis.

## **5.9.2 The provision of education and information to patients with ESRD**

### **5.9.2.1 How and where is information provided?**

All of the 21 dialysis units stated that they did not have a structured pre-dialysis education programme. Two of these units declined to provide more expanded information, merely confirming that they did not provide such a programme. However, 19 dialysis units described how they gave information to patients in the form of face-to face discussions with a nephrologist, as well as via the provision of leaflets or booklets about treatment options in the clinics. The combination of these two practices was the main method used to provide information to ESRD patients. In addition, three units indicated the use of video tapes, two said they used a dummy with a catheter to illustrate dialysis techniques, three referred patients to kidney websites and five units indicated they provided a visit to the dialysis centre.

Overall, there was a difference regarding the provision of information about treatment options to patients amongst units. In four units, information was provided after dialysis had started. In three units, this was less than one month before the start of dialysis. In seven units, it was four to six months before the beginning of dialysis and more than four months before beginning dialysis in five units. Also, the time spent on providing information to patients was very varied. One unit indicated it took between five and 30 minutes. Two units suggested the time was between 30 minutes and one hour. Two units indicated they provided one session, three units gave 1-2 sessions and one unit identified 3-4 sessions. Other units were not able to say, as it was not clear to them how many sessions were provided and how long such sessions took.

In terms of the practicalities of giving information, 21 units had a nephrology clinic where patients could be treated as early as stage 4 CKD, with the

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exception of some extreme or emergency cases. These extreme cases were belatedly referred to the nephrologists through the ER or another department. This is similar to a previous Saudi report which identified an association between the pre-ESRD care and referral source ( $p < 0.0001$ ) (Hassanien et al. 2013). However, data from the current study show that 57.5% of patients did see the nephrologist in the 12 months preceding the start of dialysis. This setting suggests that a 12-month pre-dialysis education programme may be possible, since Goovaerts et al. (2015) presents findings that enrolment to RRTOE should take place at stage 4 CKD (15-29mls/min/1.73m<sup>2</sup>) or 12 months before the predicted start of dialysis.

### 5.9.2.2 Who provides the information?

In 12 centres, the nephrologists introduced treatment options to patients in the nephrology clinic, while in another six centres both nephrologists and nurses from the dialysis unit provided the information to patients at the clinic. In four out of the six units, doctors present the initial information about treatment options and, if the patient chooses PD, they will be referred to the PD nurse for education (N=2 units); and referred to a PD centre for PD education (N=2 units). Four units had a health educator with a nephrology background who provided information about treatment options to patients. These health educators have experience in RRT options and give information before a patient commences dialysis. However, this process was conducted in an unstructured manner, and inconsistency of presentation and content may be a concern. Prior to discussing treatment options, the nephrologist endorses the patients who are fit for education, while in two other centres the doctor decides if the patient is fit for PD.

### 5.9.2.3 Type of information provided.

In 19 units, information about the treatment options was always discussed with the patient, with a relative present. The discussion included topics such as kidney function, differences and similarities between HD and PD, managing diet and medication. Eight units talked about pre-emptive transplantation and transplantation to patients with other dialysis options. One unit described pre-emptive transplant as the first option for patients and also included the



options of home-HD but in a different private setting, where the patient could be referred if he or she chose it.

### **5.9.3 Barriers to education**

The main barrier to an education programme was that of communication. A language barrier was identified in five units, because many nurses, for example, did not speak the same language as the patients, though a translator was used in one unit. Patients' denial as to the need for dialysis treatment was considered an obstacle to providing information about treatment (N=3 units). A further point was raised by one unit, in that patients do not like to change between modalities. If patients started an urgent HD, then if offered PD as a treatment option, they tend to be reluctant to change dialysis treatment type. Such hesitation is because they are used to being dialysed 'in-centre' with no responsibility for treatment, compared to PD, which is conducted at home by themselves. Late referral to a nephrologist was described as an obstacle (N=5 units). A patient's level of education was also considered as a potential barrier to providing information to patients (N=4 units), if that level was low.

### **5.9.4 Conclusions**

The data collected from this national audit provides evidence that a structured pre-dialysis education programme for patients with ESRD is not available throughout the KSA. This finding therefore indicates that the situation identified in the four hospitals sampled in the main study was mirrored across other units; the four hospitals can therefore be thought of as typical to other hospitals in the KSA. Although it was apparent that there are efforts to provide education and information to patients in the nephrology clinics included in the audit, such efforts are neither consistent nor clear.

International guidelines recommend that pre-dialysis education should best be provided in a structured programme, which includes nephrologists, dialysis nurses and dieticians (Isnard Bagnis et al. 2015; Coovaert et al. 2015) and even with a psychologist's referral (Robinski 2016). A case can therefore be made that recommendations from this study could be applied to the different regions of the KSA, in order to improve the pre-dialysis education offered.

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## **6. Chapter 6. Discussion**

### **6.1 Introduction**

The aim of this study was to examine the pre-dialysis education and information provided to ESRD patients in the KSA and the factors that patients perceived as having influence over their treatment decisions. These goals were formulated in line with the intention to develop recommendations to optimise dialysis education in the KSA. This chapter will start with an overview of the main results and discuss them in the light of previous literature, to address the study aims. However, most of the existing literature was from the western world, with a lack of studies from the Middle East. Therefore, there are likely to be differences in terms of the impact of education and information, regardless of the health issues themselves. Subsequently, this chapter will focus on the three major factors perceived as influencing dialysis treatment type in the KSA i.e. perceptions of pre-dialysis education, clinical factors, and cultural factors. Patients' views and recommendations will also be discussed. Finally, the chapter finishes by indicating the new knowledge that the study has provided.

### **6.2 Overview**

A key finding from this study was that none of the four hospitals provided a structured pre-dialysis education programme for patients with ESRD. Hospitals provided dialysis education and information in an unstructured manner. Ninety-two participants from four hospitals in the western region of the KSA completed the survey. Most were receiving HD (61.9%), and most had limited knowledge or understanding of their disease. Similar to previous reports in western countries (Finkelstein et al. 2008; Lee et al. 2008; Mehrotra et al. 2005), the majority of patients in this study (65.2%) did not receive early pre-dialysis education. Similar to previous reports, such as Mehrotra et al. (2005), the use of HD in the KSA was more prevalent than PD, although the survey identified the unexpected high result of 38% of participants who were receiving PD compared to a previous Saudi report (SCOT 2010).

### **6.3 Prevalence of dialysis treatment type**

As previous literature reports (Goovaerts et al. 2005; Mehrotra et al. 2005; Chaudhary et al. 2011), average PD usage is variable between countries. In this study, the relatively high prevalence of PD usage (38%) may, in part, be explained because only four hospitals were included in the sample; the results may represent only these four hospitals, but not the whole of the renal patient population in the KSA. In contrast, the US study (Mehrotra et al. 2005) showed a much lower PD usage of 24 (6%) participants compared to 392 (94%) on HD. Those survey results reflected a large scale study of 229 dialysis units around the United States, while the study by Goovaerts et al. (2005) was based upon only one centre's reports.

Unlike previous studies, in which younger patients opted for PD (Wuerth et al. 2002; Goovaerts et al. 2005; Chanouzas et al. 2012; Liebman et al. 2012; Ribitsch et al. 2013), this study shows that although there was a slightly higher distribution of older people in the sample, there was no significant difference in treatment received due to age. The findings of this study indicated that the timeliness of receiving education and information about treatment types, and the choice of treatment, was influenced not only by pre-dialysis education but also by other factors such as clinical and cultural factors, which will be discussed in the latter part of this chapter. Moreover, it was clear from the findings that patients value information, and they believe that having more information might help them make better choices. The findings also indicated that different educational materials should be utilised more in patients' education.

### **6.4 Pre-dialysis education and treatment decisions**

#### **6.4.1 Presentation of treatment options**

The data suggest that pre-dialysis education in the participating hospitals is currently unbalanced, as most of the HD patients, when compared to those receiving PD, perceived they were either not provided with information or were provided with too little information to make a decision about treatment choice.

However, the PD patients reported that they had enough, or more than enough information to select treatment (chapter 5, figure 5.5). Therefore, this suggests that PD education is more acceptable to patients; the focus should be on early education so that patients can make informed choices, as well as on improving HD education. Previous evidence has shown that patients who were involved in pre-dialysis education started PD more often than patients who did not receive education (47.8% vs 6.5% Chi square-test  $p < 0.001$ ). Additionally, it was also found that uneducated patients start with unplanned HD as the initial and definitive treatment method, compared to the educated patients (Prieto-Velasco et al. 2015). HD and PD patients have some similar but also divergent needs. These issues will be taken into account in the recommendations to improve the practice of pre-dialysis education in the KSA, since the main objective of these study results has been to investigate pre-dialysis education information from the patient's point of view. Although the findings only relate to the practices in the four hospitals participating in the study, they can still provide an understanding of the wider practice within the KSA, especially with the results from the national audit. This provides data which can be used as a starting point to improve patient education in future studies and on a nationwide scale in the kingdom of Saudi Arabia.

It was very clear from the study's findings that the patients who rated their pre-dialysis education as 'poor' or 'totally inadequate' were solely from the group of patients on HD. This was confirmed by a statistical association between the poor rating and the HD treatment type ( $p = 0.000$ ). As noted earlier, most of the HD patients were not presented with treatment options, which appears to explain why they rated their pre-dialysis education so poorly. These results were similar to the previous reports that patients on HD rated their pre-dialysis education lower than those on PD (Rubin et al. 2004; Mehrotra et al. 2011). However, it is noteworthy that some patients who received HD (11 cases) had no other option; a situation informed by clinical reasons such as multiple abdominal surgery, S/C or abdominal hernia, heart disease, and age. Those patients were advised by nephrologists to opt for a specific treatment type, based on their medical histories.

These results were similar to a previous report from Belgium by Goovaerts et al. (2005) that showed 50 patients were directed by their nephrologists to in-

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centre HD for either psycho-social or medical reasons. Likewise, in the US, a prospective cohort study was conducted by Mendelssohn et al. (2009), where 1,303 patients with CKD (stages 3-5) were evaluated for medical or psychosocial eligibility for RRT. Mendelssohn et al. (2009) found that that 98% [95% confident interval (CI):97.4-98.8%] were eligible for HD, while 87% [95%CI: 85.0-88.6%] of patients were assessed as medically eligible for PD. Causes for non-eligibility for HD included advanced age (mean=82, range 76-86 years), terminal illness, cardiovascular instability, and vascular disease. With regards to PD, the leading cause for non-eligibility was age, with ineligible patients being significantly older than eligible patients ( $78.7 \pm 0.8$  versus  $65.5 \pm 0.4$  years, respectively,  $p < 0.0001$ ). The stages of CKD did affect patients' medical eligibility for HD or PD. It is therefore important to acknowledge that medical decisions of dialysis treatment type could be based on patients' medical contraindication or patients' medical histories. The focus of this study is to provide recommendations to improve pre-dialysis education for patients who could have options for treatment but are not offered any.

Furthermore, aside from HD and PD as treatment options for RRT, there are other options that can be considered. For instance, one may opt to use pre-emptive transplantation, which is a form of transplantation that occurs prior to commencement of dialysis. According to (Laskin et al. 2015) the use of pre-emptive transplantation is associated with a 21% improvement in patient survival compared to transplant recipients who did not receive pre-emptive transplantation. Patients who undergo pre-emptive transplantation also experience other advantages of dialysis avoidance, such as improved physical growth, better quality of life, and freedom from dialysis, diet and fluid restrictions (Grams et al. 2011). However, religious beliefs must be considered when renal transplantation is sought within the KSA. There has been evidence that patients may show uncertainty in accepting donor organs, especially from deceased donors despite acceptance of most Muslim jurists (Oliver et al. 2011). Another option that is available is home haemodialysis where haemodialysis is primarily performed at home. Though it was first introduced during the 1960s, it is only in the past decade that home haemodialysis has undergone global resurgence as a form of RRT (Tennankore et al. 2012). This resurgence is related to a growing appreciation of its benefits, including improved patient survival and quality of life, as well as its reduced costs,

compared with in-centre conventional haemodialysis (Nitsch et al. 2011). The immediate health benefits of home haemodialysis are derived from both increased dialysis intensity and the performance of dialysis in the home environment. In the KSA, home HD is not presently an option in government hospitals. However, the audit data from one unit in the western region of the KSA indicates that patients are offered transfer to a private hospital for home HD. This option was only initiated in 2014 and is uncommon or poorly implemented. Nevertheless, if it is introduced as part of the free dialysis services in governmental hospitals, it would be a new choice that can be offered to ESRD patients. Home haemodialysis can offer an alternative choice to patients who have contraindications to PD, other difficulties or transportation issues for in-centre HD.

#### **6.4.2 Materials used for education**

This study's findings and data from the national audit show that face-to-face discussion with doctors and printed materials were the most common methods used to explain treatment options to participants. Previous studies in western contexts have also found that a treatment discussion with a nephrologist, with the provision of printed materials explaining treatment types, was among the most common educational methods (Manns et al. 2005; Winterbottom et al. 2007; Morton et al. 2010a). Thus, when considering the different contexts between the KSA and these western reports, the use of printed materials was also common in the KSA. The nephrologist made the initial discussion on the need for dialysis, and therefore, he/she would be expected to explain the treatment and dialysis options to their patients. However, the time that nephrologists spend on discussing information with each individual patient in a busy clinic varies, and it is constrained by the time limits for the clinic itself (Iles-Smith 2005). The provision of printed materials is used for a more detailed explanation regarding the treatment types, but if a high proportion of the patients are illiterate (as in this current study), this method would be relatively ineffective.

Therefore, other media for providing information should be utilised, such as video tapes or classes, visits to the dialysis centre, or arranging talks with patients who are already on dialysis (HD or PD). These alternate forms of

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communication would enable appropriate access to information for those with reading difficulties. Accordingly, these findings emphasised the effectiveness of the combination of an educational booklet with small interactive sessions with patients; a model which has been studied in the past and has been proven to be effective (Manns et al. 2005). Moreover, a recent experimental study showed that using patients' stories about their dialysis experiences influences other patients' choices, especially when the information is presented by the patients on dialysis, rather than by the doctor (Winterbottom et al. 2012). The results of the current study showed that the participants would prefer to have more information and different materials explaining treatment, and that talking to patients already on dialysis was among the patients' recommendations to improve pre-dialysis education. The current study revealed that patients accept and prefer group discussions about treatment options. This particular result is interesting because, regardless of the conservative cultural nature of people in the KSA, some patients would like to have group discussions with other patients regarding their treatment options. Therefore, the inclusion of some group sessions, as well as private sessions, to explain the treatment options to the patients might prove useful, considering the hospitals' limited resources, such as time constraints and staffing issues. Such group discussions may also be a cost effective way of delivering pre-dialysis education. Some of these obstacles can result in reducing the time and the quality of pre-dialysis education. Therefore, these results provide evidence that can help to expand the practice of pre-dialysis education and introduce new and different ways to provide patients with the education and information they need before starting dialysis treatment.

While some of the hospitals participating in this study did use a variety of educational tools, a key finding was the lack of consistency in pre-dialysis education within, as well as between, the hospitals; a situation reflecting the lack of a standardised pre-dialysis educational programme in the KSA. These findings are similar to previous reports from a dialysis centre in the UK. Iles-Smith's (2005) findings from a qualitative study of ten dialysis patients showed that participants received differing amounts of information; some individuals stated they had been well informed, while others stated they had received nothing or not enough, and had to seek information from other sources.



Therefore, consistency and standardised pre-dialysis education in the KSA is a key point in the recommendation to improving the practice in the KSA.

#### **6.4.3 Time spent on pre-dialysis education**

Discussing treatment options with patients is an important element of pre-dialysis education, yet there are no guidelines suggesting the optimal time for discussing kidney disease and treatment options. The amount and quality of the time spent discussing and explaining those options is vital, and the success of such education is closely related to the time spent with patients during such education programmes (Ribitsch et al. 2013). The current findings indicate that 27.2% of the patients were given 5-30 minutes of discussion about treatment options, while 23.9% reported discussions lasting from 30 minutes to one hour. Additionally, the findings highlighted that most of the HD patients spent no time (44%) or five to 30 minutes (35%) in discussion. The findings show differing and non-standardised provision of education, especially for patients on HD.

This study demonstrates a high proportion of participants who did not know about kidney disease. There was also a high percentage (23.9%) of illiterate patients, which is similar to previous reports from the KSA (Hijaili et al. 2007). Therefore, the time spent discussing treatment options should be increased, especially for illiterate patients, because they would need more time spent on explanations than would literate patients. Hospitals should also arrange to review the information provided to their patients to make sure that they understand their options and the differences between each treatment. A previous study from the west found that a lack of time spent with patients results in doctors and nurses relying on written words, leaving those patients with poor health literacy at a substantial disadvantage to more literate patients (Gazmararian et al. 2003).

A study in the KSA by Al-Khaldi and Khan (2000) of a diabetic education programme found that 27% of diabetic patients did not receive any health education. The researchers indicated that the poor educational status of the patients was one of the reasons for this. Physicians can communicate effectively with educated patients because such patients can read and understand the written material provided during the education session.

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Statistical association reveals that educated male patients are offered more topics than illiterate and female patients ( $P < 0.000$ ) (Al-Khaldi & Khan 2000). This report is of key importance because it was conducted in the KSA and was about an education programme. Although it was focused on diabetic education, it had a similar context to this current study. Patients with a low level of education can be left out or miss the opportunity for an equal chance to be provided with education regarding their disease requirements. A previous study also measured health literacy using a validated Arabic version of the S-TOFHLT in the KSA, which identified an association between a health literacy score and both the participant's level of education ( $p = 0.000$ ) and gender ( $0.010$ ) (Alamari 2012). Those results provided evidence of the relationship between patients' gender and levels of education and patients' health literacy in the KSA, although no details of the type of association were reported in the paper. The majority of the participants in the current survey were female ( $N = 55$ , 59.7%), which could be linked to the illiteracy rate factor. Given the context of life in the KSA, future efforts on patient education should consider the patient's literacy rate and health literacy. However, unlike previous studies, the current study's results show no association between lack of knowledge and level of education (Hijaili et al. 2007; Finkelstein et al. 2008; Lee et al. 2008).

### 6.4.4 Patients' request for more information

In this study, the HD patients made up the majority of the patients requesting more information ( $p = 0.000$ ). This was in agreement with the previous report from the KSA by Hijaili et al. (2007), which showed that patients on HD had a significantly lower score on levels of awareness of their disease and treatment options when compared to patients on PD ( $p = 0.005$ ). Moreover, most of the participants who asked for more information were from Hospital 1 and Hospital 2. These results were highlighted in the recommendations for improving pre-dialysis education practices in these specific hospitals. The results can also provide the basis to investigate the hospitals' practices in-depth, as these hospitals have large dialysis units and are providing services to a large proportion of the population.

Participants also requested information on some technical aspects of dialysis, and there were significant associations between the request for information on vascular access and treatment type (HD) ( $p=0.000$ ) across the four hospitals ( $P=0.005$ ). Those requests suggest most of the HD patients did not even know about the vascular access used for dialysis (fistula or catheter), a phenomenon observed in all four hospitals. Similarly, previous studies have emphasised education with regard to fistula creation or PD catheter insertion and long-term care (Goovaerts et al. 2005). However, there were no previous studies showing any link between the knowledge of vascular access and the treatment choice.

## **6.5 Factors influencing treatment decisions**

This section will discuss the factors that were identified from the study results that also appear to have influence on dialysis treatment decisions, either directly or indirectly. The section is divided into two sections: clinical factors and cultural factors.

### **6.5.1 Clinical factors**

#### **6.5.1.1 Late referral to nephrologist**

The majority (63.1%) of participants who did not choose their dialysis treatment type were on HD. These results were expected, given the information from the previous section's findings regarding the unequal presentation of treatment options between HD and PD. On the other hand, 25% of patients had changed their treatment type. Also 56% had to begin with urgent HD first, and then changed to PD. This shows that some dialysis units actually provided dialysis information and treatment options to patients who had started with urgent HD, because of their deteriorated condition, or to those who were referred to a nephrologist at a late stage of their disease. This action opens up a new area of improving the practice of pre-dialysis education in the KSA, by providing dialysis information to patients even after they have started urgent dialysis. Similarly, in a previous UK audit examining pre-dialysis care of 750 patients, who started dialysis in a six month period in 13 renal units, it was recommended that patients who were referred late should be offered group education and review of treatment options within six months of starting dialysis (Lindley et al. 2006). In addition, recent recommendation also

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emphasised the provision of education after patients have started urgent dialysis (Covic et al. 2010; Isnard Bagnis et al. 2015; Goovaerts et al. 2015)

Late referral to a nephrologist has been discussed in the literature (Buck et al. 2007; Heatley 2009; Morton et al. 2010a; Liebman et al. 2012), which can explain the late presentation of treatment options, education and information received before starting dialysis. In the current study, 57.5% of the 92 patients saw a nephrologist in the 12 months preceding dialysis, which means that just over half of patients had a chance to be presented with treatment options before starting dialysis. This data is similar to data from the research by Mehrotra et al. (2005), where there were similar distributions of when patients got referral to a nephrologist before they started dialysis (Mehrotra et al. 2005). Other study findings suggested that even 12 months is inadequate to prepare patients for transition into renal RRT and that the definition of late referral should extend to at least 12 months (Buck et al. 2007). The clinical practice guidelines recommend beginning education once a patient reaches CKD stage 4, or he/she can receive education about dialysis options after his/her condition is has been stabilised (KDOQI 2006; Covic et al. 2010; Isnard Bagnis et al. 2015).

The finding of this present study does support these suggestions because, as stated above, 57.5% of patients have seen nephrologists 12 months before starting dialysis. This result is different from the research by (Hassanien et al. 2013), which showed that the majority of patients with CKD had not received pre-ESRD care, or that they had received less than six months of care, and also that most were referred from emergency for urgent HD. The findings of my study show that patients have access to the nephrology clinic but had to start urgent dialysis.

For example, a patient has 12 months' access to a nephrologist prior to starting dialysis and yet has to start urgent HD before receiving education and information about dialysis options. This indicates other reasons for the late presentation of dialysis options; for example, it could show either a fast deterioration of the patient's condition that led to urgent dialysis or lack of transparency between doctors and patients. Previous evidence indicates that specific medical conditions can lead to the unplanned commencement of dialysis. A retrospective study by Brown et al. (2015), to

identify the risk factors for unplanned dialysis in 649 advanced CKD patients, was conducted after the completion of my study. It showed a significant association in patients who initiated unplanned dialysis and had a higher rate of coronary disease (CAD),  $p=0.02$ ; diabetes,  $p=0.04$  and congestive heart failure (CHF),  $P=0.01$  (Brown et al. 2015). This research also presented findings that can explain that other factors might cause an unplanned dialysis start (Brown et al. (2015). In this regards, my study did not provide information about the patient's comorbidity, which might lead to an unplanned start for particular patients. As mentioned earlier, my study findings show that hospitals did provide patients with some information and treatment options. However, the lack of standardisation, or a clear structured pre-dialysis education programme, might lead to the delayed presentation of information about the treatment options and then a start to unplanned dialysis.

#### **6.5.1.2 Doctors' opinions**

Previous studies suggest that doctors' opinions do influence patients' choices (Wuerth et al. 2002; Mehrotra et al. 2005; Chanouzas et al. 2012). Similarly, in this present study, 69 (75%) participants indicated that a doctor's opinion was the most common factor that influenced their choices. However, it was found that in 11 (29.7%) of the cases, the doctor's advice was based on the patient's medical condition, meaning that the doctors advised or influenced the treatment choices of what was best for their patients. These results are similar to previous results by Mendelssohn et al. (2009), who prospectively evaluated patient eligibility for RRT. Age and anatomical concerns (adhesions, hernia) were the leading causes for non-eligibility for PD, while advanced age (mean=82, range 76-86 years), terminal illness, and cardio vascular instability (CHF) were the main causes for non-eligibility for HD. Other findings indicated that the ineligible patients had a significantly larger body mass than eligible patients ( $117 \pm 4.8$  versus  $83.6 \pm 0.7$  kg,  $p < 0.0001$ ). Similarly, Jassal et al. (2002) surveyed the attitude of British physicians towards dialysis modality selection. They reported that comorbid conditions were an important factor in the modality decision making, but only the presence of heart disease made more physicians choose PD over HD (Jassal et al. 2002). This topic has been debated in the literature; some researchers have argued that it is simply

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the doctors being biased (Wuerth et al. 2002; Mehrotra et al. 2005) or that some nephrologists were not familiar with the dialysis type, such as PD (Mehrotra et al. 2002). The doctor may not have received enough training during his/her medical education, which may make a certain procedure not a favourite for the doctor to recommend.

In the KSA in 2006, a survey of 145 physicians indicated that 44.6% of nephrologists admitted to having no expertise in managing patients with PD. There was also a significantly higher percentage of Ministry of Health (MOH) centres in comparison to non-MoH centres, where physicians in the centre did not have expertise in PD ( $P=0.001$ ) (Souqiyyeh & Shaheen 2006). These data may provide an explanation of the differences between this study's participants according to their affiliation; for instance, the high percentages of patients in Hospital 2 who opted for HD rather than PD because Hospital 2 is under the MoH sector, while Hospitals 1 and 3 were non-MoH. However, Hospital 4 was a MoH hospital but had higher percentages of PD patients compared to the others. There is a need for more studies to be conducted in order to focus on this particular area.

### **6.5.2 Cultural factors**

#### **6.5.2.1 Discussion of treatment options with patients**

The literature suggests that increasing the time known about the disease, or seeing a nephrologist, was associated with a greater chance of the patients receiving adequate information prior to commencing treatment, so enabling them to make an informed decision (Mehrotra et al. 2005; Finkelstein et al. 2008; Morton et al. 2010a; Hassanien et al. 2013). With regard to the current study, cultural differences may potentially play a role in the reasons for not discussing the patients' needs for dialysis and treatment options. This hesitancy may be because some nephrologists may not feel comfortable talking to patients about the later stages of the disease, until the patient actually reaches ESRD. They may not want to upset the patients by letting them know that they would eventually require dialysis for survival. Previous reports from the KSA indicate that many physicians find discussing some issues, such as death or dying, with patients to be stressful (Al-Jahdali et al. 2009). An earlier study conducted in the KSA by Mobeireek et al. (1996) assessed

physicians' attitudes towards sharing information and decision making with patients in the setting of a serious illness. This questionnaire-based survey, which involved a total of 249 physicians, showed that 75% preferred to talk to close family members rather than the patient, even when dealing with competent patients. However, from the analysis of the open-ended questions in this study, the results showed that most patients appreciated early information about their kidney disease and treatment options. These points will be included in the recommendations for improving practices in this regard.

#### **6.5.2.2 Patients' views and perceptions towards shared decision making**

The overall results illustrate that under half (46.1%) of all patients actually chose their treatment options; although, most of the PD patients (nearly two-thirds or 61.7 %) did chose their treatment options. These results are expected, given the results from the previous section regarding the unequal presentation of treatment options between HD and PD. Nearly three-quarters of the patients (73.2%) indicated that the medical team took the lead in making the decision about dialysis, and 25% said it was a joint decision between the patient, family, and medical team. These results are similar to previous studies conducted in other parts of the world (Wuerth et al. 2002; Chanouzas et al. 2012). It is worth noting that seven patients initially indicated that they chose their treatment type, then stated that it was a joint decision with the doctor, and one said that the doctor took the lead on the decision. It seems as if these patients felt that they chose their treatment, but when going to the next question, they realised that it was a joint decision with their doctors, rather than an individual decision. This 'real' outcome is because of the patients' natural inclination to follow doctors' recommendations, especially in Saudi culture where doctors are usually perceived as the ones who know best; a doctor's opinion would be highly considered. Previous reports in the UK show similar results, that 63% of patients felt that their chosen dialysis treatments were medically influenced (Chanouzas et al. 2012).

Patients in the KSA do not appear to have as much experience with shared decision-making, as occurs in most western countries. Most western countries have moved towards a "patient autonomy model," where full disclosure and respect for patients is vital (Farber et al. 2006). According to Mobeireek et al. (2008), the "physician-centred" model was replaced with "patient-centred

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relationship” in the western world. In Asia, “guided medical paternalism” is considered to be best (Lim 2002). In the current study, for instance, some patients described the reasons for specific choices as being better for them. Such reasoning can indicate that those patients might have been told that a specific type of dialysis (HD or PD) was better for them, based on advice or influence from their medical team. Patients’ views on the roles of doctor and patient in making decisions became apparent in the high treatment satisfaction among participants, showing cultural acceptance of the doctor’s role in the treatment decision.

However, the findings of Mobeireek et al. (2008) showed that 67% of physicians believed that patients should be told about the diagnosis of incurable illness, which suggests that physicians in the KSA are advocating a western model of disclosure and patient autonomy, while most patients still favour a family-centred model of care (Mobeireek et al. 2008). The difference between the two disclosure models, as described by Mobeireek et al. (2008), lies in the priority and weight given to patient rights, wishes of the family, and interest of the society as whole. Even within the same culture, one rigid model may not suit all patients and relatives.

As discussed in the background chapter, patients in the KSA value family opinion when making important decisions about a member of the family, especially for a female member, husband or father. It appears that family should be involved in all issues, including health education and the decision making process. In addition, other cultural factors can influence the choice; for example, in the current study two HD patients stated that the reasons for their decisions were simply that they heard that PD had too many problems and was not good. One participant said he chose HD because the majority of patients are on HD, which shows that how and what people talk about can affect patients’ choices. This finding is similar to the research by McCarthy et al. (2015) in explaining that unplanned vicarious factors affecting a patient’s choice, such as views of peers or their previous experiences of dialysis treatment, can have an influence on their behaviour. Patients’ perceptions that it was safer to have dialysis treatment at hospital were also noted within the responses to open-ended questions. Hence, care must be taken to provide planned educational programme to all patients in order to avoid



misunderstanding about the information or treatment options when provided by non-professional people, or from other family members with a history of the disease. Healthcare professionals need to consider the impact of unplanned or informal information that patients might acquire, experience at the clinic or receive from a family member. More discussion with the patients to identify those experiences is important when providing pre-dialysis education.

In addition, the results of the current study showed that nearly all participants (90%) considered it very important to be involved in the decision making of their treatment type. It would be helpful to include PDAs tool in the pre-dialysis education in the KSA, because such a resource can help patients identify their values and preferences and help them to be involved in the decision making process of treatment choice. The inclusion of PDAs tool was found to be effective in previous study by Prieto-Velasco et al. 2015) as discussed in chapter three (section 3.3.4). Through listening and active participation, the patients would be taught to improve their level of responsibility towards the illness and to help them perceive the concept of autonomy (Mobeireek et al. 2008). According to Politi et al (2013), some patients believe that there is one best treatment and the doctors know which it is, and that it is the responsibility of the doctors to inform the patients about the multiple options. The importance of a patient's own preferences in choosing treatment type is the first step in engaging patients in shared decision-making (Politi et al. 2013).

Indeed, according to Elwyn et al. (2012), patient's preference can be achieved in the deliberation phase of a shared decision-making process, where patients become aware of choice and understand their options. Patients can then have the 'decision talk' where they are supported by tools such as booklets, websites, video and DVDs for the patient and their family to use. This will help patients to consider their preference, based on what matters most to them after understanding the advantages and disadvantages of each option (Elwyn et al. 2012). This model were applied previously to patients with ESRD in Spain by Prieto-Velasco et al. (2015) as discussed in chapter three (section 3.3.4). A recent study (Robinski et al. 2016) identified that PD patients had better cognitive condition than HD patients did ( $P = 0.001$ ), and all patients were more satisfied when they were in a good psychological state. Therefore, the

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inclusion of psychological professionals, and screening patients' characteristics to inform their education, in order to identify the patient's preferred role in the decision making process, is important for patient satisfaction (Robinski et al. 2016).

According to the findings from my study, the shared decision-making model (Elwyn et al. 2012) can be applied as a framework to improve pre-dialysis education and patient involvement in the decision making about their medical treatment in the KSA. Two points need to be considered according to the needs of people in the KSA: first, the inclusion of PDAs, materials and booklets that match the people cultural and religious beliefs should be included in the 'option talk'. Secondly, the inclusion of a family member or members in the 'decision talk' would also need to be considered.

### 6.5.2.3 Family opinion

In this study, there is a significant association between treatment type and having a dependent at home ( $P=0.056$ ), or having someone at home to help manage dialysis ( $P=0.000$ ). For a patient to be able to administer PD at home, he/she needs to have someone at home to help, and they must be trained to do dialysis if the patient is not well. Transportation is also important for patients receiving HD and needs to be arranged in advance by the family member. In the KSA, most hospitals do not provide transportation facilities to patients requiring dialysis. Family and home environmental influences on the patients' choices of treatment in this study were expected, given the traditional mores of the population in the KSA; a population which is generally defined as having strong family ties. It is understood that the patients will take into account the opinions of their families and consider their home environments before making decisions about having treatment at home, as this process will affect their families. Previous studies, in other parts of the world, have reported similar results regarding the importance of family member involvement in decision making (Lee et al. 2008; Murray et al. 2009; Covic et al. 2010; Harwood & Clark 2013). This family involvement issue was considered in the recommendation for improving pre-dialysis education; for example, family members or the significant other can and should be included in discussions about treatment options.

#### 6.5.2.4 Satisfaction with treatment

Irrespective of all of the data identified regarding pre-dialysis education in the KSA, 58.6% of participants received information on treatment options that was too late after starting dialysis to make decision, and 51.0% considered it inadequate to make a decision about treatment type. However, most reported being either 'somewhat satisfied' (50%) or 'very satisfied' (35.9%) with the treatment they were receiving. This finding could be understood as a reflection of the cultural/religious nature of the people in the KSA. Patients are grateful for the healthcare services they are receiving and believe in sickness as God's will, and this belief helps give them comfort in accepting their sickness (Al-Jahdali et al. 2009). Another explanation for the ratings could be in the phrasing of the question itself (How satisfied are you with your current form of treatment?). If it was asking about patient's satisfaction with the pre-dialysis education, rather than the treatment itself, the results might have been different.

In contrast, previous studies exploring patients' experiences with dialysis, together with issues related to patients' choices, show that HD patients who did not receive formal pre-dialysis education and information were dissatisfied with the information they received (Lee et al. 2008). The main finding by Lee et al. (2008) is that none of the HD patients were given formal pre-dialysis education or a choice of dialysis treatment. Mehrotra et al. (2005) found a significant relationship between the timing of presentation of treatment options and the satisfaction with the information presented ( $p < 0.001$ ). In my study, a regression analysis was not able to identify any factors influencing the satisfaction rate with the treatment, because of the very low number of cases indicating dissatisfaction with their treatment. Future studies could be conducted specifically to explore patients' satisfaction in greater detail, in order to gain a better understanding of those patients. There were no significant differences between the patients' responses with regard to the different hospitals, and therefore the findings are not discussed here. Based on the findings from the questionnaire, and the statistically significant results regarding factors influencing the choices, it was clear that the factors which participants perceived as influential on treatment choices in the KSA, were a

mix of clinical cultural factors, together with the lack of pre dialysis education received by patients.

### **6.6 Patients' views and recommendations about improving pre-dialysis education**

#### **6.6.1 The need for more information**

Most of the patients considered it important to be involved in their treatment choice (90%), which is similar to a previous report noting that patients appreciate and need more information (Ormandy et al. 2007; Lee et al. 2008; Lewis et al. 2010). With regard to patient recommendations for improving pre-dialysis education, most of the comments were similar to the recommendations from previous study findings (Winterbottom et al. 2007; Lee et al. 2008; Ormandy 2008; Murray et al. 2009). For example, patients expressed the need for more information about the advantages and disadvantages of each treatment type to be given as early as possible, and for them to be presented with all options. One notable patient was disappointed because of a delayed discussion of his need for dialysis, since this patient had been seeing a nephrologist for seven years, but was never introduced to dialysis; nor had he received an explanation about his need for dialysis or the treatment options available when his kidney disease reached an advanced stage. This example shows that the practice of pre-dialysis education is still in need of improvement. Patients tend to appreciate early information to help them prepare for life on dialysis, rather than waiting until their need for dialysis is urgent.

In addition, it was evident from the study results that patients on HD were presented with less information about treatment options or had less time spent allocated to them for discussing treatment options. Hence, it was expected that patients on HD would comprise the majority of patients requesting more information. The significant associations identified between information about vascular access (fistula or catheter) and the treatment type HD ( $P=.000$ ,  $N=55$ ) and between information on PD catheter and the treatment type ( $P=0.000$ ,  $N=53$ ), provide evidence that those patients were in need of explanations about the vascular access in general, or the PD catheter in

particular. This is a vital element for dialysis treatment and patients should be able to provide care for this catheter or vascular access in their daily living.

### **6.6.2 The use of different educational materials**

Similar to the findings from Piccoli et al. (2000), the patients in this current study suggested the use of different materials (pictures, audio-visual, and demonstration) and need for explanations in laymen's terms, as well as providing more time and more explanation for non-educated patients. This issue is of particular importance, given the high rate of overall illiteracy in the KSA of 13.45% (Oxford 2013b). Data from this study indicated that of the population of 92 patients, 23.9% were illiterate. This means that some patients would not be able to read written information; therefore, other options should be employed, such as pictures, short video clips, a demonstration of treatment, meeting with patients receiving treatment, clinic visits. In addition, more reviews and discussions in this group of patients would be appreciated. The patients also requested the opportunity to visit the dialysis centre or have the chance to speak to patients already on dialysis. Previous literature also described patient testimonials helping other patients to understand the impact of different dialysis modalities on their everyday lives (Wuerth et al. 2002; Manns et al. 2005).

One experimental study, however, suggested using patients' testimonials with caution, as it can influence a new dialysis patient's choices (Winterbottom et al. 2012). In the UK, Winterbottom et al. (2012) conducted two studies comparing the impact of patients' and doctors' stories on hypothetical dialysis modality choices among an experimental population. An experimental study group (n=578) with nine conditions was arranged in a 2x2x2 mixed group design plus control: the independent between-group variables were format of information (written or video clips); source of information (patients or doctors); and order of presenting information (HD first or PD first). The control group (n=69) was provided with only basic information and no stories. In the experimental group, participants read two short paragraphs containing basic information about HD and PD and also viewed two stories. A significant main effect was confirmed regarding the impact of whether doctors or patients presented the information about HD or PD on treatment choices

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[ $F(1,1022)=4.63$ ,  $p<0.03$ ; partial  $\mu^2=0.01$ ]. With regard to the KSA, the involvement of patients actually in the education programme is not common. However, patients might be prepared to offer advice or feedback about their experiences with the treatment and how it fits with their lifestyle.

One important suggestion made by the patients was that educational materials and information should be reviewed by the patients and medical staff together. This would allow the patients a chance to discuss the information provided to them, and for any questions or worries that they might have to be answered. According to Isnard Bagnis et al. (2015), the latest guidelines for pre-dialysis education should be continued beyond the point where patients have made the treatment decision, by providing regular follow ups to check whether the patients remain satisfied or wish to transfer to another modality; or in case there are any early problems with the chosen modality.

### 6.6.3 The involvement of family in the education

The study findings show family (the spouse/significant other) also plays a major role in influencing the selection of treatment choices (32.6%). The patients, therefore, suggested that family members should be provided with dialysis education. The results are similar to previous systematic reviews of factors influencing the choices of dialysis (Harwood and Clark 2013; Murray et al. 2009). Family members help and support the patient's choice (Chanouzas et al. 2012). In the KSA, as discussed earlier, family members have strong relationships with one another. For instance, if an elderly member is in need of dialysis, a family member will accompany the patient during the dialysis session. Also, if the patient chooses peritoneal dialysis, one or two family members would be responsible for doing the dialysis at home for the patient. These cultural issues, relating to the involvement of family member in the decision-making of the treatment choice, should be taken into consideration when preparing pre-dialysis education programmes for patients with ESRD in the KSA.

## 6.7 Multidisciplinary team

Patients in this study requested information about the medication, diet, and the disease; a finding similar to previous reports (Ormandy et al. 2007;

Ormandy 2008; Lewis et al. 2010). As a chronic illness, ESRD involves a variety of treatments, and patients need to be educated about issues such as medication, diets, fluid intake, and vascular or catheter care. Therefore, it was suggested in the literature (Levin et al. 1997; Heatley 2009; Coovaerts et al. 2015; Chen et al. 2015) that pre-dialysis education should be provided by a multidisciplinary team to provide optimal care for the patient. The importance of considering the patients' cognitive and psychological status when providing education, suggests the need to include psychological professionals in the multidisciplinary team (Robinski et al. 2016). Because it is not possible, nor practical, for the nephrologist or nurse to cover and discuss all of these aspects of pre-dialysis education, a multidisciplinary team can provide the optimal educational solution.

## **6.8 The context of the national audit**

The results of the national audit show that structured pre-dialysis education programmes do not exist in the KSA. Some hospitals provided patients with information about treatment options at the nephrology clinics and this was mainly done by the nephrologist. This evidence shows that the findings of the four hospitals in the main study were in line with the general national audit. However, taking into account that the national audit was conducted in 2016, about three years after the main study was carried out, it is of interest that there is still only limited information about treatment options provided to patients with ESRD in the KSA. However, there are obviously some attempts by some units to focus on this issue. For instance, four dialysis units contain dedicated health educators, with nephrology backgrounds, who are responsible for providing information to patients about treatment options. However, it was acknowledged that this initiative was not provided as part of a structured pre-dialysis education programme. It is also worth considering that in 2014, one hospital started to offer home-HD as treatment options, although this was done in a private, non-MoH setting. The use of home HD will provide an extra option for patients; increases in the education offered about this option can improve its utilisation in governmental setting in future years. Furthermore, the audit shows that there are at least eight units providing information about pre-emptive transplantation, as an option for patients with ESRD.

## 6.9 Conclusions

To conclude, this chapter has discussed the main findings of the study in light of the previous literature. The findings were similar to previous studies in regard to the late provision of pre-dialysis education and information as a factor influencing dialysis treatment decisions. There were different presentations of treatment options between HD and PD patients. Similar to previous studies, HD patients rated pre-dialysis education poorly. The findings suggested relevance of the use of different materials for pre-dialysis education, such as audio-visual materials, visits to the dialysis unit and the use of group sessions with patients. These suggestions were important, given the fact that 23.9% of patients were illiterate; however, unlike previous studies, the findings show no association between patients' lack of knowledge and their level of education. Also, the time spent discussing treatment options with patients was similar to previous reports in this regard. This fact emphasised the need to increase the time spent discussing treatment options, without reliance on printed materials.

On the other hand, factors described by the patients as influential on treatment options were divided into two: first, clinical factors that were similar to other countries, where clinical issues were linked to late referral through nephrologists, patients' conditions, and the doctors' influences. However, the last point was linked to the patient's clinical history in some cases. Second, are cultural factors more related to the Saudi context, such as the culture of discussing the treatment and physicians' attitudes toward sharing information with patients. Other cultural factors, such as patients' views of shared decision-making, family involvement in the decisions, and the overall patient's satisfaction with the treatment, also need to be addressed. Patients, mainly on HD, requested more information about the disease, medication, vascular access and diet to be included in the pre-dialysis education. This highlights the need for the multidisciplinary team to provide the education; suggestions which were similar to ideas from a recent European conference (Goovaerts et al. 2015). Furthermore, the results of the national audit provide evidence that pre-dialysis education programmes are lacking at national level; patients being provided with little information during the nephrology clinic, and that information presented in an unstructured manner. The need to develop a



structured pre-dialysis education programme for patients with ESRD is the main outcome of this thesis. The final chapter will provide recommendations to improve the practice of pre-dialysis education in the KSA



## 7. Chapter 7. Conclusions and recommendations

### 7.1 Introduction

This study set out to examine what pre-dialysis education and information patients with ESRD were receiving about renal replacement therapy (RRT) in the kingdom of Saudi Arabia (KSA), as well as those factors patients perceived as influencing the type of dialysis treatment they received. The purpose of gaining this information was to develop recommendations to enhance pre-dialysis education programmes for ESRD patients in the KSA. This chapter will begin by identifying the main study results and how they answered the research questions. The chapter outlines recommendations for future research. Implications for practice and limitations of the study are also included.

### 7.2 Empirical results

The main empirical results of the study are listed in the results chapter (Chapter 5). This section will synthesise the results to answer the study's two research questions. It will also consider the findings regarding the patients' recommendations to improve the practice of pre-dialysis education while using the shared decision making model (Elwyn et al. 2012) and The Health Belief Model as guides in designing the pre-dialysis education programme.

#### *What pre-dialysis education or information was provided to ESRD patients in the KSA?*

- Most participants in the study knew very little or nothing about their kidney disease before they started their first dialysis treatment.
- Just over half of patients in the study (58.6%) received late information about treatment options.
- The findings suggest that there was a lack of consistency in dialysis education within, as well as between, the hospitals. This was further emphasised by the circumstance that two of the four hospitals in the study had provided information about treatment options but that the information did not have any formal structure.

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- The findings also suggest that patients were not provided with enough information about their treatment type (HD or PD).
- The findings indicate that patients on HD expressed their dissatisfaction with the pre-dialysis education and information they received.

### What factors do patients perceive as influential over their dialysis treatment-modality decisions?

- The vast majority of patients considered medical influence as the most important factor in making the decision.
- Family Influence such as having someone at home to help with the treatment or having a dependent at home was a predictor of modality selection in the study.
- Other influences such as late referral to the nephrologist, urgent commencement of dialysis and cultural factors were also considered influential in the decisions of treatment type.

The results from the binary logistic regression contributed new knowledge into the field of study by providing empirical evidence that identifies the factors that patients perceive as influential over their dialysis treatment-modality decisions. The four hospitals that were part of this study provide snapshots into the patients' experiences of the pre-dialysis education situation in the KSA. This insight into patients' experiences highlights a need to improve on the current practice. One of the most noteworthy issues to consider based on the study's findings is that nearly all participants considered it very important to be involved in the decision-making of their treatment, regardless of their satisfaction level with the treatment, the influential factors, or their educational level.

## **7.3 Recommendations to improve pre-dialysis education practice in the KSA**

This study gives an overview of the practice of pre-dialysis education and the factors influencing treatment options in the western region of the KSA. One of the objectives of this study was to develop recommendations to improve the practice of pre-dialysis education in the KSA. The following recommendations were based on the main study and national audit findings, which indicate the

absent of structured pre-dialysis education program in the KSA. In chapter two (section.2.2) it was suggested that for effective programmed education, key principles of learning should be applied to the pre-dialysis education programme in KSA. These include presenting the information to patients in small steps, gaining rapid feedback on learning and providing patients with the space to learn by themselves. Also there is a need to have clear objectives for the education programme as the suggested by Thorndike's theory of learning (Hergenhahn & Olson 2005). After reviewing patients' comments, the most common recommendations were focused around three elements related to the timing of the education input, the principles of pre-dialysis education, and educational materials/resources used for pre-dialysis education.

### A) Timing of pre-dialysis education

Pre-dialysis education programmes should be incorporated into the work of the nephrology clinic and run by specific nursing staff with nephrology backgrounds. Pre-dialysis education should start as early as possible.

According to Goovaerts et al. (2015), patients should be enrolled in a Renal Replacement Therapy Options Education (RRTOE) programme at stage 4 CKD (15-29mls/min/1.73m<sup>2</sup>) or 12 months before the predicted start of dialysis. This idea is also consistent with the recommendation from a recent consensus conference in Europe where it was agreed that, as a minimum, the RRTOE team should consist of a nephrologist and a CKD nurse with practical experience of all treatment modalities (Isnard Bagnis et al. 2015). In cases where the patient has a late referral to a nephrologist, pre-dialysis education should begin as soon as the patient's condition is stabilised. Moreover, education should continue until after the decision to undergo treatment has been made. This outcome could be achieved by regular follow-ups to check whether the patient remains satisfied, elects to transfer to another modality and in case of early problems with the modality (Isnard Bagnis et al. 2015).

### B) Principles of pre-dialysis education

Patients have the right to be informed about all treatment options that are clinically relevant to them. Care must be taken to ensure that neither the healthcare provider/s nor the education biases the patient towards a specific type of treatment. Patients should be informed about the difference between haemodialysis (HD) and peritoneal dialysis (PD), as well as the advantages and

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disadvantages of each treatment. By employing this method, the healthcare provider's personal preference regarding a certain type of treatment can be minimised. A family member or significant other should be included in the process of pre-dialysis education, as such individuals have been shown to be helpful in the decision-making process. This was evident from the regression analysis, which showed that having someone to help with treatment as a predictor for dialysis options. It was also evident from the national audit that the unavailability of a family member to help with the treatment was one of the barriers to providing PD treatment options. Further, as discussed in the background, family involvement in the decision making process is expected, and therefore such an option is of cultural importance in the KSA. This point builds on recommendations reported by Isnard Bagnis et al. (2015), that pre-dialysis education should consider the religious and cultural background of both the patient and the healthcare provider. Pre-dialysis education can be performed in a hospital setting or private setting, through face-to-face discussion as well as group discussions of treatment options with patients and preferably with Arabic speaking staff. The time spent on discussion of treatment options should be sufficient to allow for unhurried decisions, and adjusted to patients' individual needs and levels of education.

### C) Educational materials and content of pre-dialysis education

Educational materials should include a variety of methods and not only printed information in order to ensure all ESRD patients can access relevant knowledge, including those unable to read. For instance, online websites; audio-visual material; videotapes and lectures can all be employed. Visits to dialysis centres to allow patients to talk to other patients who are already on dialysis were also highly rated as an informative initiative. The materials should be adjusted to fit with patients' educational levels. This outcome can be achieved by providing photos or illustrations as well as written explanations relayed in a language that can be easily understood by the patients regardless of their socio-economic background. According to Isnard Bagnis et al. (2015) the consensus conference recommends that materials used for RRTOE should be appropriate to the patients clients' level of education. Pre-dialysis education should include different information regarding ESRD, treatment options, kidney transplantation, medication, diet, vascular access and PD catheters.

The suggestions outlined in this section serve as elements of the definitive recommendations of this study, based on three sub-groups: the timing of education, the principles of pre-dialysis education, and the educational materials/resources used for pre-dialysis education. These findings may be used as evidence to address the current absence of a structured pre-dialysis education programme in the KSA. Moreover, the findings of this patient-focused-study can be used as the foundation to strengthen the need to provide pre-dialysis education and to define the guidelines to a structured pre-dialysis educational programme, on a national level.

The use of the model created by Elwyn et al. (2012) to inform decision-making can be incorporated into this recommendation, to include the three steps identified by Elwyn et al. (2012). This could be implemented as follows, step by step:

1) *Choice talk*: This would be undertaken to inform the patient about the disease and treatment management; it would also consider the patient's belief about the causes of the disease, because patients in the KSA have strong religious beliefs, as discussed in the background chapter. Therefore, accurate detailed information about the disease, and what causes it, provided by the healthcare provider, can help patients to understand that it was not a punishment from God, and to let them know that they do have a choice.

2) *Option talk*: This would offer the opportunity to explain the options available using decision-support materials/resources such as booklets, discussions and visits to dialysis units. This is also described as the 'deliberation phase' (Elwyn et al. 2012).

3) *Decision talk*: This is the determination phase where the decision is made, according to the findings of the study, when consideration of the cultural background of people in the KSA, the doctor, and the family need to be involved in the decision making. The influence of a doctor's opinions and family availability to help with the treatment were vital to treatment choice according to the results of the study. The application of the Elwyn model can be used in this way to improve clinical practice. In the context of the KSA, the use of the model will help to promote more structured pre-dialysis education

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programmes, and more patient involvement in the decisions about the type of dialysis treatment they finally receive.

### 7.4 Reflections

As a dialysis nurse and nurse educator by background, it was a challenge to conduct this study in the researcher role, especially when my study was concerned with patient education and the need for me to help patients complete the questionnaires. According to Colbourne and Sque (2004), it is difficult for the nurse (researcher) to find role identity when conducting research that involves direct patient contact. Conflicts arise from the fact that the nurse cannot ignore her/his professional background and role as a professional caregiver and advocate for the welfare of patients (Holloway & Wheeler 2002). Therefore, the need for self-disclosure and honesty is key. Colbourne and Sque (2004) suggested techniques to help patients understand the researcher role, such as including details in the patients' information sheet about the researcher's role as a nurse. Also, by not wearing the clinical uniform and at first meeting describing to the patient the researcher's nursing background, it can help to reinforce the researcher role.

These strategies were used when conducting my research. I also explained that any questions not related to the research or the questionnaire would be answered after the completion of the questionnaires. Therefore, at the end, some patients asked me for information about dialysis and treatment choices, so I explained these accordingly. This was considered important, given the fact that a high percentage of patients did not know about their disease. In those specific cases, it was an ethical obligation for me to disclose more information and, in addition, the patients were referred to their treating doctors for further information.

### 7.5 Recommendations for future research

Much can be done to improve the practice of pre-dialysis education in the KSA. The results provide a base for this improvement, informed by the patients' views and recommendations. The findings also highlight the need for more studies focused on shared-decision making, evaluation of the recommended structured pre-dialysis education programmes within the KSA, Future research



strategies can facilitate the goal of improving pre-dialysis education practices in the KSA. For instance, future researchers can replicate the study in different hospitals and regions to allow for generalisation to the nation's population. This study identified associations between the study variables, and these findings can be used as the basis for future studies to evaluate if these associated variables have a causative relationship. Future studies are also needed to explore or understand the nature of consultation, the types of decision making approaches used in the KSA, and patients' understanding of shared decision making. The questionnaire instrument, which was developed and adapted to suit ESRD patients in the KSA, could be used by other hospitals, on a national scale, to identify patients' experiences of pre-dialysis education and best practices.

Issues relating to data collection, such as the need for the researcher to read the questionnaires to patients who were unable to read, or who were not able to complete the questionnaire themselves as they were undergoing dialysis, should be considered. The approaches used to manage patients who are unable to read can inform future studies involving such patients. Furthermore, as this study focused on the patients' points of view regarding pre-dialysis education, it is worthwhile in future to investigate nephrologists' and nurses' views. In particular, what are their opinions regarding the current pre-dialysis education practices and the patients' involvement in the decisions about their treatment. Future researchers may also replicate this study to test if the results are similar or to identify further improvements in pre-dialysis education.

## 7.6 Implications

Evidence from several studies (Mehrotra et al. 2005; Morton et al. 2010a; Manns et al. 2005; Goovaerts et al. 2005; Goovaerts et al. 2015; Van Den Bosch et al. 2015) as well as from this thesis, point to the fact that pre-dialysis education should be planned, structured, and provide adequate information of treatment options to help patients make informed decisions about their treatment. The study has used empirical findings to show that the current practice of pre-dialysis education, and information provision offered to new ESRD patients in the KSA, is still inadequate and needs significant development. In this regard, the study results will influence practice in the KSA. For example, there is a need to a) design pre-dialysis education guidelines

## Conclusions

and standards of practice. This can be achieved by establishing a group of clinical experts (doctors and nurses), together with patients, to work together to start identifying how this can be done and bring this attention to the national field, and b) to promote shared decision making regarding treatment options to keep patients well informed.

With regards to the participating hospitals, every hospital will receive a report on the findings gathered from its dialysis centre results, with separate suggestions for improvement. These suggestions were based on patients' views and recommendations, such as the need for some hospitals to establish or improve their pre-dialysis education, and to introduce the provision of group sessions of dialysis education, where one-to-one communication is not possible because of limited hospital resources.

## 7.7 Strengths and limitations

The study has certain strengths: for instance, it was the first study conducted in the KSA employing a previously used questionnaire from a different context (USA). The study has offered novel evidence regarding the practice of pre-dialysis education and information provision in the western region of the KSA. It provides evidence that could help to inform future studies in this field. The study results help in the development of recommendations to improve and standardise the practice of pre-dialysis education in the KSA.

Nevertheless, as mentioned above, the study was conducted in only one region, that is the western region of the KSA and, as direct consequence of this approach, a number of limitations need to be considered. First, there is the difficulty of generalising the findings, as the study was conducted in SA's western region hospitals only. However, this limitation was countered by conducting a national audit of renal centres in the KSA. It could be argued that the addition of sections to the questionnaire from Mehrotra et al. (2005) might affect the validity of the tool. For example, Juniper (2009) suggested that questions should not be added as it may affect the responses to the questionnaire. Nevertheless, Juniper was referring to the use of a measurement tool whereas in this study, the questionnaire was used differently in that its purpose was to elicit information about patients' education and treatment options. Data collection was conducted in three ways to reach more

participants in a relatively short time: firstly, a face-to-face completion of the questionnaire, where the questionnaire was read to participants by myself; I then completed it according to their answers.

A second method was self-completion by the patients who I was not able to meet because of their dialysis schedules (late dialysis sessions, i.e. after midnight). Third, some patients completed the questionnaires over the phone. Therefore, there was a possibility of bias toward completing the questionnaire when completed with the principal investigator (face-to-face or over the phone). However, bias was minimised by following a structure: read the question, then read the options, and ask the patients which he/she chose to answer, and then complete the question. Another limitation was related to analysis: regression statistical analysis was not possible because there were an insufficient number of dissatisfied patients to identify predictions or relationship for treatment with satisfaction rates.

A further limitation was related to the questionnaire, as it did not include information about comorbid diseases that would influence the type of dialysis choice or viable option. For instance, some patients provided a rationale for the specific treatment type they receive, based on their medical conditions. However, it would have been better if this information was obtained for all patients, from their medical records, so that it could be included in the statistical tests. It was established and confirmed in the literature that justified clinical conditions can alter the type of dialysis treatment.

## 7.8 Conclusions

This study was aimed at investigating the education and information provided to patients with ESRD, and the factors considered influential in the treatment options, in order to develop recommendations to improve the practice of pre-dialysis education in the KSA. These aims were achieved, and the results provide significant new knowledge about the practice of pre-dialysis education and factors associated with treatment options available in four hospitals in the western region of the KSA. A set of recommendations to improve pre-dialysis education were also developed to be applied in the Saudi context. The study questionnaire can now be used in different regions in KSA to reveal the national practice. The study results considered the primary data collected from

## Conclusions

the KSA regarding pre-dialysis education. Hence, the results will inform future research in the field of pre-dialysis education for patients with ESRD in the KSA.

## Appendices



## Appendix 1 Permission to use questionnaire

**alhameedi r.s. (rsa1g10)**

---

**From:** Mehrotra, Rajnish <rmehrotra@labiomed.org>  
**Sent:** 08 September 2011 14:40  
**To:** Alhameedi R.S.  
**Subject:** Re: Permission to use Questionnaires

Sure.

Rajnish Mehrotra

On Sep 8, 2011, at 6:25 AM, "Alhameedi R.S." <rsa1g10@soton.ac.uk> wrote:

>  
 >  
 > Dear Dr. Rajnish Mehrotra,  
 >  
 >  
 > My name is Reem Alhameedi, I am dialysis nurse educator by background, now i am a Postgraduate Doctorate in Clinical Practice student at the University of Southampton,UK, I am intersetting to do study about predialysis education and patients involments in modality selections,  
 >  
 > during my literature searching I looked at your study " Patient education and access of ESRD patients to renal replacement therapies beyond in - centre hemodialysis"  
 >  
 > I wounder if I can have a permission to use the questionnaires (figure 1. modality selection project patient survey) used for your study and to adapt it for my study, I will survey patietns only.  
 >  
 > Your permission for me to use the questionnaires is highly appreciated  
 >  
 >  
 > Best Regards  
 > Reem





## Appendix 2: Pilot study questionnaire

### Questionnaire for patients on dialysis treatment

#### Introduction

Thank you for taking the time to participate in this study. The study is part of doctoral degree at the University of Southampton, UK. The aim of the study is to identify what information new dialysis patients in Saudi Arabia receive before initiation of dialysis (whether is it haemodialysis or peritoneal dialysis) through asking patients, renal nurses and consultant nephrologists about this by questionnaire. This questionnaire relates to your experience as a patient who is currently having dialysis treatment.

This questionnaire is divided into 5 sections. Section one ask about general information about you. Section two asks what information your received before starting dialysis treatment and where you got this information Section three asks about how a decision about your dialysis treatment was made. Section four asks about the things that may affect your choice of dialysis treatment and finally section five asks about your current dialysis treatment (Haemodialysis or peritoneal dialysis)

#### Instruction

While you answering the questionnaires please mark the questions which you feel are unclear or you have any comment or suggestion about it,, so we know how to improve it.

Most questions have tick box to indicate answers, others has a numbers to indicate your answers, and few questions have a line for you to tell us how much you agree or disagree with the sentences. Please place a mark where you feel is the best spot reflect your answers

#### For Example:

##### How much do you like to listen to the radio?

If I like to listen to the radio I will put my tick to the right side as below

Not at all \_\_\_\_\_ \ \_\_\_\_\_ Very much

## Appendices

But if I don't like to listen to the radio I will put my tick close to the left side as below

Not at all \_\_\_\_\_ Very much  
                    \  
                    /

### **Confidentiality of Information**

I would like to reassure you that the information you provide in this questionnaire will be strictly confidential and will be used only for purpose of the study.

**Thank you very much for completing the questionnaire**

## Section one: Questions about you and your Perception of disease/ dialysis options

### 1. Gender

Male ☐

Female ☐

### 2. Age

Under 20 ☐ 20-29 ☐

30-39 ☐ 40-49 ☐

50 or more ☐

### 3. Marital status?

Single ☐ Divorced ☐

Married ☐ Widow ☐

### 4. What is your education level?

High school ☐ Baccalaureate ☐

Diploma ☐ Masters ☐

Other ☐

Please specify.....

### 5. What is your employment?

Employed full time ☐ Unemployed ☐

Employed part time ☐ Retired ☐

Self employed ☐ Full time student ☐

Other please specify ☐

### 6. What dialysis treatment are you currently receiving?

Haemodialysis ☐

Continuous ambulatory peritoneal dialysis ☐

Continuous cycling peritoneal dialysis ☐

### 7. How long have you been diagnosed with kidney problems that required renal replacement therapy?

> than 6 months ☐

6-12months ☐

< 12 months ☐

## Appendices

### 8. How long have you been receiving dialysis?

> than 6 months ☐

6-12months ☐

< 12 months ☐

### 9. Do you know what caused your kidney problems? Please explain.

.....  
.....

### 10. How much do you feel you know about kidney failure?

Everything there is to know \_\_\_\_\_ nothing at all

### 11. Which of the following people live in the same household with you? Please tick one box only

I live alone ☐

I live with my husband/ wife ☐

I live with other relatives ☐

I live with other non-relatives ☐

### 12. Is there any family member willing to help you with treatment at home ?

Yes ☐

No ☐

Not sure ☐

## Section 2: Questions about any information you received before starting dialysis treatment

### 11. Did someone talk to you about your condition/ treatment options?

Yes ☐

No ☐

Don't know ☐

If No, why do you feel this was?

.....  
.....

If Yes, who did?

Doctor ☐

Nurse ☐

Other ☐

Describe who.....

**12. Did someone talk to you about your diet?**

Dietician ☐ Nurse ☐

Doctor ☐ Other ☐

Please specify.....

**13. Did anyone talk to you about your home conditions for home dialysis?**

Yes ☐

No ☐

Don't Know ☐

If yes, who? Social worker ☐ Nurse ☐ Other ☐

please specify.....

If you talked or discussed what treatment options you had, please answer the following:

**14. How many occasions sessions did you have in total?**

Once ☐ twice ☐ three times ☐ four times ☐ more than four ☐

**15. What was the length of time for the information sessions?**

<15 minutes ☐

15minutes - 30minutes ☐

30minutes - 45minutes ☐

>45minutes ☐

**16. How was the session conducted?**

One to one ☐

in Group ☐

other ☐

please specify.....

**17. Where did the session take place?**

Nephrology clinic ☐

Dialysis unit ☐

## Appendices

Home ☐

Other ☐

Please specify.....

**18. Were any of your family/ carer present during the information session about the type of dialysis?**

Yes ☐

No ☐

can't remember ☐

**19. Were you given any materials to information about dialysis?**

Yes ☐

No ☐

Don't know ☐

If No or don't know please go to questions 20

If Yes, please answer the following:

**A. What information did you receive? Please tick which are relevant, you can tick more than one.**

Lectures/talks ☐

Brochures/ Booklet ☐

Video tapes ☐

Hands on demonstration (simulation) ☐

Posters ☐

Meeting with other patients on peritoneal dialysis ☐

Discussion ☐

Others ☐

Describe 'Others' .....

**B. Please rate your view of the pre-dialysis education you have received as one of the following:**

Excellent ☐

Very Good ☐

Good ☐

Poor ☐

Totally inadequate ☐

**C. Why have you rated the pre-dialysis education as you have?**

.....

.....

**D. Please indicate how confident you are that you understand the information provided from the session**

Very confident \_\_\_\_\_ Not at all

**E. Please describe if and how the pre-dialysis education you received influence your decision about the type of dialysis you have:**

.....

.....

**F. How useful was the information in helping you make your decision?**

Very  
useful \_\_\_\_\_ Not at all

**20. Would you have liked any additional information to help you make your decision?**

Yes ☐

No ☐

**If yes, Please indicate what sort of information you would have liked to receive:**

.....

.....

.....

**21. Did you have to find information elsewhere?**

Yes ☐

No ☐

**If No please go to section 3**

If Yes please answer the following

**22. Are there any other sources of information that influence your choice?**

Spouse/ significant others ☐

Other family members ☐

Written information ☐

Other professionals (nurse) ☐

Friends ☐

## Appendices

Someone already on dialysis ☐

### 23. Where did you find your information about dialysis?

Internet ☐

Listened to other people ☐

Other ☐

Please specify.....

## Section 3: Questions about decisions on your dialysis treatment

In this section please put line to answer the statement

### 24. This decision on what type of dialysis to have was hard for me to make

Strongly \_\_\_\_\_ Strongly  
agree disagree

### 25. It was clear what choice was best for me

Strongly \_\_\_\_\_ Strongly  
agree disagree

### 26. I am aware of the choices I have to make a decision about dialysis

Strongly \_\_\_\_\_ Strongly  
agree disagree

### 27. I feel I know the risks and side effects of dialysis treatment

Strongly \_\_\_\_\_ Strongly  
agree disagree

### 28. I need more advice and information about the choices

Strongly \_\_\_\_\_ Strongly  
agree disagree

### 29. I know how important the benefits of dialysis treatment are to me in this decision

Strongly \_\_\_\_\_ Strongly  
agree disagree

### 30. I know how important the risks and side effects of dialysis treatment are to me in this decision

Strongly \_\_\_\_\_ Strongly  
agree disagree



**31. It's hard to decide if the benefits are more important to me than the risks or if the risks are more important than the benefits**

Strongly \_\_\_\_\_ Strongly  
agree disagree

**32. I feel pressure from others in making this decision**

Strongly \_\_\_\_\_ Strongly  
agree disagree

**If so who?**

Nurse ☐ Doctor ☐ Family member ☐ other ☐ Please specify.....

**33. I have the right amount of support from others in making this choice**

Strongly \_\_\_\_\_ Strongly  
agree disagree

**34. I feel I have made an informed choice**

Strongly \_\_\_\_\_ Strongly  
agree disagree

**35. I am satisfied with the decision about which treatment I receive**

Strongly \_\_\_\_\_ Strongly  
agree disagree

**36. Who made the decision about the type of dialysis you are receiving?**

**Please tick as many as apply.**

You ☐ Nurse ☐ Doctor ☐ Family member ☐ other ☐ Please Specify.....

#### **Section 4: Questions about things that can affect or influence what type of dialysis treatment you receive**

**37. Are you are aware of any other illnesses you have which affect the type of dialysis therapy you receive?**

.....  
.....

**38. Is the supply of electricity a problem at your house?**

Often ☐  
Regularly ☐  
Sometimes ☐  
Rarely ☐

## Appendices

Never ☐

### **39. Is a water supply always available at your house?**

Often ☐

Regularly ☐

Sometimes ☐

Rarely ☐

Never ☐

### **40. Have family support, electricity and water supply affected the choice of your dialysis treatment?**

Yes ☐

No ☐

Not sure ☐

### **41. How do you usually get to the dialysis unit?**

Drive yourself ☐

Driven by friend or relative ☐

Hospital car, alone ☐

Hospital car, with other dialysis patients ☐

Other.....

### **42. How long does your journey to dialysis usually take?**

> 15 minutes ☐

15minutes- 30minutes ☐

31minutes- 45minutes ☐

< 45minutes ☐

## **Section 5: Questions about your current dialysis treatment:**

We ask questions about both type of dialysis, please answers the questions related to the type you receiving

### **43. What is the advantage of the type of dialysis you are receiving?**

**For Patients on Haemodialysis** “you can choose more than one”

Let nurses / others take care of me ☐

Prefer treatment in dialysis centre ☐

Prefer planned schedule ☐

Prefer regular contact with others ☐

Other ☐

Please specify.....

**For Patients: on peritoneal dialysis “you can choose more than one”**

Rather do it myself ☐

Prefer privacy at home ☐

Flexibility of schedules ☐

Travelling is easier ☐

Easier to work ☐

Could be done at home while sleeping ☐

Other ☐

Please specify .....

**44. What is the disadvantage of the type of dialysis you are receiving?**

**For Patients on Haemodialysis “you can choose more than one”**

Do not like blood ☐

Do not want to be pricked with a needle ☐

Transportation to dialysis centre ☐

Fluid restriction ☐

Dietary restriction ☐

Duration of treatment (3x per week) ☐

Other ☐

Please specify.....

**For Patients on Peritoneal Dialysis “you can choose more than one”**

Do not like the tube in my abdominal area ☐

Do not want fluid in my abdomen ☐

Concerned about infection ☐

Body Image (Personal Appearance) ☐

Ordering, delivery and storage of supplies ☐

Duration of the treatment (7 x per week) ☐

Other ☐

Please specify .....

**45. How would you describe your level of satisfaction with the treatment you receiving? Please tick one box only**

- Very dissatisfied ☐
- Dissatisfied ☐
- Neither satisfied nor dissatisfied ☐
- satisfied ☐
- Very satisfied ☐

**46. What are the three most important things that influenced your dialysis treatment choice?**

1. ....
2. ....
3. ....

**47. The following statement ask you about the impact of dialysis on your daily living please complete by putting a tick on the line where best describe your answers**

**Dialysis limits my social life outside the dialysis unit**

Strongly \_\_\_\_\_ Strongly  
agree disagree

**Dialysis limits my partners/ carer social life**

Strongly \_\_\_\_\_ Strongly  
agree disagree

**48. Finally: Would you like to tell us anything more that was significant but was not mentions above regarding your pre-dialysis education or your treatment decision?**

.....  
.....

**49. How easy was it to complete this questionnaire? Any suggestions for improvement?**

.....  
.....

**Thank you very much for taking the time to complete this questionnaire. Please return it to the unit secretary**

### Appendix 3: Participants' Information Sheet (Pilot study)

**بيان المعلومات**

عنوان الدراسة

اختيارات المرضى لطريقة إجراء الغسيل الكلوي في المملكة العربية السعودية

المرضى الأعزاء

تهدف هذه الدراسة إلى تحديد المعلومات التي يحصل عليها مرضى الغسيل الكلوي المستجدون في المملكة العربية السعودية قبل بدء الغسيل الكلوي سواء كان غسيلاً كلوياً أو غسيلاً للغشاء البروتوني

وستطرح عليكم أسئلة حول العوامل التي تؤثر على اختياركم فيما يتعلق بكيفية إجراء الغسيل الكلوي كما سيتم الاستفسار عن معرفتكم بغسيل الغشاء البروتوني ونوع المعلومات الخاصة بالمرحلة التي تسبق الغسيل الكلوي التي حصلتم عليها قبل بدء الغسيل الكلوي

سأطلع أنا والمشفرون على الدراسة فقط على البيانات الأصلية. وسيتم التخلص من تلك البيانات في نهاية المشروع باستخدام خدمات التخلص من البيانات السرية الخاصة بالجامعة. قد يتم نشر نتائج الدراسة أو تقديمها في المؤتمرات المهنية، دون الكشف عن هويات الأفراد أو المؤسسات

وتعد مشاركتك في الدراسة أمراً تطوعياً بالكامل. وذلك حيث إنك غير مضطر للمشاركة إذا لم تكن ترغب ولن يؤثر ذلك على العلاج الخاص بك في المستقبل. وعلى الرغم من أنك ربما قد لا تستفيد بشكل مباشر من اشتراكك في هذه الدراسة، فإتني أتمنى أن يستفيد مرضى الغسيل الكلوي المستقبليون من نتائج تلك الدراسة.

يسعدني الإجابة عن أية أسئلة حول الدراسة، ويمكنك الاتصال بي على العنوان [reem\\_alhameedi@yahoo.com](mailto:reem_alhameedi@yahoo.com) أو الاتصال بالمشراف على الدراسة د. سارة برين على العنوان [c.f.smith@southampton.ac.uk](mailto:c.f.smith@southampton.ac.uk) ود. S.Brien@soton.ac.uk. كلير سميث على العنوان

أو سكرتيرة القسم صالحة على 6401000 تحويلة 17237

إذا قررت المشاركة في الدراسة، فيستعين عليكم استكمال الاستبيان المرفق ثم إعادته في الظرف المرفق إلى وحدة السكرتارية. برجاء الاحتفاظ ببيان المعلومات هذا للرجوع إليها في أي وقت لاحق.

نشكركم على وقتكم

ريم الحميدي



## Appendix 4: Ethical Approval (Pilot study)

KINGDOM OF SAUDI ARABIA

Ministry of Higher Education

KING ABDULAZIZ UNIVERSITY

Faculty of Medicine

Ref FM: .....

Date :     /     /

Encl : .....



المملكة العربية السعودية  
 وزارة التعليم العالي  
 جامعة الملك عبد العزيز  
 كلية الطب  
 الرقم ٢٨٤٨/٢٠١٤  
 التاريخ: ٢٠/١٤٢٩  
 المرفقات:

**UNIT OF  
 BIOMEDICAL ETHICS**  
 Research Committee

TO : Ms. Reem Alhameedi

From : Professor H Nasrat

Date : TUESDAY, JANUARY 04, 2011

CC : Vice-Dean, University /Hospital Director &amp; File &amp; Expedite approval File

RE " Proposed pilot study Haemodialysis or Peritoneal dialysis -Patients' choices in Saudi Arabia "

(Reference No 456-11)

The above titled research/study proposal has been examined with the following enclosures:

- The study protocol
- Consent form
- Information sheet

The REC recommended granting permission of approval to conduct the project along the following terms:

1. Annual report
2. Any amendments to the approved protocol or any element of the submitted documents should NOT be undertaken without prior re-submission to, and approval of the REC for prior approval.
3. Monitoring: the project may be subject to an audit or any other form of monitoring by the REC.
4. The PI is responsible for the storage and retention of original data of the study for a minimum period of five years.
5. The PI must inform / report REC & Sponsor by any SAE "Serious Adverse Event" within one working day

The Organization & operating procedure of the KAU, Faculty of Medicine - Research Ethics Committee(REC) are based on the Good Clinical Practice (GCP) Guidelines.

PLEASE NOTE THAT THIS APPROVAL IS VALID FOR ONE YEAR COMMENCING FROM THE DATE OF THIS LETTER.

  
 Professor Hassan A Nasrat

Chairman of the Research Ethics Committee

Mohammed al searee (Reference No 456-11 )





## **Appendix 5.A Main study questionnaires (English)**

UNIVERSITY OF SOUTHAMPTON



## Appendices

### **Introduction**

Thank you for taking the time to participate in this study. The study is part of my Doctoral degree at the University of Southampton, UK. The aim of the study is to identify what information new dialysis patients in Saudi Arabia receive before starting dialysis treatment. You have been asked to take part in this study as you are currently having dialysis treatment and your experience would be very valuable to us

This questionnaire is divided into 4 sections. Section 1 asks about general information about you. Section 2 asks what information you have received before starting dialysis treatment and where you got this information, how a decision about your dialysis treatment was made. Section 3 asks about the things that may affect your choice of dialysis treatment and Section 4 asks about your current dialysis treatment (haemodialysis or peritoneal dialysis).

### **Instructions on completing this questionnaire**

Most questions have tick boxes for you to provide your answers. Generally you are required to complete only one tick box, however in some questions you can tick more than one box; where this is the case it is stated after the question. In addition, some questions ask you to explain your answers. Please write your answers in the space provided. If you need more space, please complete your answer on back of the page. Please ask the researcher if you are unsure how to answer.

### **Confidentiality of information**

You are not asked to provide your name or address when completing this questionnaire.

I would like to reassure you that the information you provide in this questionnaire will be strictly confidential and anonymous. Only the researcher and her supervisors will have access to the data you provide; your care team will not have access to this. Finally, I would like to reassure you that the data from this questionnaire will be used only for the purpose of this study.

**Thank you very much for completing the questionnaire.**

**SECTION ONE: Some general information about you**  
*(In this section please only tick ONE box)*

**1. Are You?**

- ☐ Male  
☐ Female

**2. How old are you?**

- ☐ Under 20                      ☐ 50-59  
☐ 20-29                      ☐ 60-69  
☐ 30-39                      ☐ Over 70  
☐ 40-49

**3. What is the highest level of education you have achieved?**

- ☐ Some grade school                      ☐ Grade school graduate  
☐ Some high school                      ☐ High school graduate  
☐ Some college / technical training                      ☐ Technical school graduate  
☐ College graduate or above                      ☐ Illiterate  
☐ Other Please specify.....

**4. What is your employment?**

- ☐ Employed full time  
☐ Employed part time  
☐ In education  
☐ Retired  
☐ Unemployed  
☐ Other Please specify.....

**5. How much do you feel you know about kidney failure?**

- ☐ I feel I know everything there is to know about kidney failure  
☐ I feel I know enough about kidney failure  
☐ I feel I know very little about kidney failure  
☐ I don't know anything about kidney failure

**SECTION TWO: About the education you received before you started dialysis**

*(In this section please only tick ONE box unless indicated otherwise)*

**6. How long have you known that you have kidney failure?**

- ☐ Less than 1 month                      ☐ 1 to 3 years  
☐ 1 to 3 months                      ☐ 3 to 5 years  
☐ 4 to 6 months                      ☐ More than 5 years

## Appendices

- ☐ 7 to 12 months ☐ Don't know / Don't remember

**7. How long were you seeing a Nephrologist (kidney specialist) before you started dialysis?**

- ☐ Less than 1 month ☐ 1 to 3 years  
☐ 1 to 3 months ☐ More than 3 years  
☐ 4 to 6 months ☐ Don't know / Don't remember  
☐ 7 to 12 months ☐ Not applicable here

**8. To the best of your recollection, WHEN were the different types of treatment options-such as haemodialysis, peritoneal dialysis and transplant first presented and explained to you?**

- ☐ Not until dialysis was started  
☐ Less than 1 month before beginning dialysis  
☐ 1 to 3 months before beginning dialysis  
☐ 4 to 6 months before beginning dialysis  
☐ 7 to 12 months before beginning dialysis  
☐ Don't know / Don't remember  
☐ Treatment options were not presented to me

**9. Which of the following options were initially offered to you as possible methods of treatment?**

*(Please tick which are relevant, you can tick more than one).*

- ☐ Haemodialysis (blood) at a dialysis centre  
☐ Haemodialysis (blood) treatment at home  
☐ Peritoneal dialysis (PD) through abdomen / belly at home at night using a machine  
☐ Continuous Ambulatory Peritoneal Dialysis (CAPD) through abdomen / belly; no machine involved  
☐ Some form of Peritoneal Dialysis (PD) through abdomen / belly - not sure of type  
☐ Kidney transplant

- ☐ The choice to refuse treatment
- ☐ Don't know / Don't remember
- ☐ Treatment options were NOT given to me; or I didn't know I had a choice

**10. Who discussed your treatment options with you?**

- ☐ My family doctor
- ☐ My Nephrologist (kidney doctor)
- ☐ My nurse from the dialysis centre
- ☐ A nurse from the Nephrologist's office
- ☐ A social worker
- ☐ Other .....
- ☐ Don't know / Don't remember
- ☐ Options never given to me

**11. Please indicate the types of materials used to explain your treatment options?**

*(Please tick which are relevant, you can tick more than one).*

- ☐ Face to face discussion(s) with doctors and / or nurse
- ☐ Classes and / or seminars
- ☐ Discussions with others patients already on haemodialysis (blood)
- ☐ Discussions with others patients already on peritoneal dialysis (through abdomen)
- ☐ Visit(s) to dialysis centre(s)
- ☐ Printed materials such as pamphlets, brochures, books etc.
- ☐ Cassette audio tapes
- ☐ CD ROM educational disks
- ☐ Video
- ☐ Kidney websites on the Internet
- ☐ Don't know / Don't remember
- ☐ Treatment options were NOT given to me

**12. Do you feel that you were provided with enough information to make an informed decision on the type of treatment that would be best for you?**

- ☐ I received more than enough information to select a treatment
- ☐ I received enough information to select a treatment

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- ☐ I received some information but not enough to make an informed decision
- ☐ I received very little information and it did not help me make a decision
- ☐ I received no information on the various treatment options
- ☐ Don't know / Don't remember

### **13. How much time would you say you spent, in total, discussing your treatment options with a healthcare professional?**

- ☐ No time
- ☐ 5 to 30 minutes
- ☐ 31 minutes to 1 hour
- ☐ 1 to 2 hours
- ☐ More than 2 hours
- ☐ Don't know / Don't remember

### **14. What form of treatment for your kidney failure are you currently receiving?**

- ☐ Haemodialysis at a dialysis centre
- ☐ Haemodialysis treatment at home
- ☐ Peritoneal dialysis at home at night using a machine (CCPD/Cycler)
- ☐ Continuous Ambulatory Peritoneal Dialysis (CAPD)
- ☐ Not receiving any treatment at this time

### **15. Did you choose this type of therapy?**

- ☐ Yes
- ☐ No

**15a. If yes, why?** .....

### **15b. If no, who chose / arranged this treatment for you?**

- ☐ My medical team (doctors, nurses, social workers) took the lead in deciding my dialysis therapy
- ☐ It was a joint decision made by me, my family, and the members of my medical team
- ☐ Don't know / Don't remember

### **16. Is your current treatment the same one you started on?**

- ☐ Yes

☐ No

**16a. If no, the type of treatment modality was changed because:**

.....

**17. Did you change your mind about the type of dialysis you wanted before starting?**

☐ Yes

☐ No

☐ Options were never presented to me

☐ Don't know / Don't remember

I was not placed on my first treatment choice

because.....

**18. Generally speaking, how satisfied are you with your current form of treatment?**

☐ Very satisfied

☐ Somewhat satisfied

☐ Neither satisfied nor dissatisfied

☐ Somewhat dissatisfied

☐ Very dissatisfied

**SECTION THREE: How would you like education about dialysis treatment to be given to you? (*In this section please tick only ONE box unless indicated otherwise*)**

**19. Please rate your view of the pre-dialysis education you have received as one of the following:**

☐ Excellent

☐ Good

☐ Neither good nor bad

☐ Poor

☐ Totally inadequate

**20. Would you like any of your family / carers to be present during the information session about the type of dialysis?**

☐ Yes

☐ No

**21. How would you like your information session to be conducted?(*can tick more than one*)**

☐ Privately at home

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- ☐ Privately at hospital
- ☐ In a group at hospital
- ☐ Companied ( in group/privately)
- ☐ Internet / web based

### **22. Would you have liked any additional information to help you make your decision?**

- ☐ Yes
- ☐ No

#### **22.a. If yes, please indicate what sort of information you would have liked to receive:**

*(Please tick which are relevant, you can tick more than one).*

##### **1. Theoretical knowledge**

- |  |  |
|--|--|
| Kidney function                                      | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| Basic introduction of End Stage Renal Disease        | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| Principle of dialysis therapy                        | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| Differences and similarities between both treatments | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| Complications of both treatments                     | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| Managing dialysis with everyday life                 | <input type="checkbox"/> Yes <input type="checkbox"/> No |

##### **2. Technical aspects**

- |                                     |  |
|-------------------------------------|--|
| Managing diet                       | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| Managing my medication              | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| Vascular access (fistula, catheter) | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| Peritoneal dialysis catheter        | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| Fluid restriction                   | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| Other Please specify.....           | <input type="checkbox"/>                                 |

### **23. What factors would influence your choice of dialysis treatment ? Please tick which are relevant, you can tick more than one.**

- ☐ Opinion of my spouse / significant others
- ☐ Having a dependent at home
- ☐ Having more written information



- ☐ The opinion of my doctors
- ☐ The opinion of my nurses
- ☐ The opinion of my friends
- ☐ Talking to someone already on dialysis
- ☐ I have someone at home to help me manage my treatment
- ☐ I don't have someone at home to help me manage my treatment
- ☐ Other Please specify.....

**24. How important do you feel it is that the patient should be involved in choosing their dialysis treatment?**

- ☐ Very important
- ☐ Somewhat important
- ☐ Neither important or non-important
- ☐ Somewhat non-important
- ☐ Not Important
- ☐ Don't know / Not sure

**25. What are the three most important things that influenced your dialysis treatment option and WHY?**

- .....
- .....
- .....

**26. How do you consider pre-dialysis education could be improved?**

.....

**SECTION Four: What do you feel about your current treatment?**

If you are on haemodialysis please go to Question 27

If you are on PD please go to Question 28

**27.a. What is the advantage of the type of dialysis you are receiving?**

*Please tick which are relevant, you can tick more than one.*

- ☐ Let nurses / others take care of me

## Appendices

- ☐ Prefer treatment in dialysis centre
- ☐ Prefer planned schedule
- ☐ Prefer regular contact with others
- ☐ Other Please specify.....

### **27.b. What is the disadvantage of the type of dialysis you are receiving?**

*(Please tick which are relevant, you can tick more than one).*

- ☐ Do not like blood
- ☐ Do not want to be pricked with a needle
- ☐ Transportation to dialysis centre
- ☐ Fluid restriction
- ☐ Dietary restriction
- ☐ Duration of treatment (3x per week)
- ☐ Other Please specify.....

Please now go to Question 29

### **For patients on peritoneal dialysis ONLY**

### **28.a. What is the advantage of the type of dialysis you are receiving?**

*(Please tick which are relevant, you can tick more than one).*

- ☐ Rather do it myself
- ☐ Prefer privacy at home
- ☐ Flexibility of schedules
- ☐ Travelling is easier
- ☐ Easier to work
- ☐ Could be done at home while sleeping
- ☐ Other Please specify.....

### **28.b. What are the disadvantages of the type of dialysis you are receiving?**

*(Please tick which are relevant, you can tick more than one).*

- ☐ Do not like the tube in my abdominal area
- ☐ Concerned about infection
- ☐ Body image (personal appearance)

☐ Ordering, delivery and storage of supplies

☐ Duration of the treatment (7x per week)

☐ Other Please specify.....

**29. Finally, would you like to tell me anything you feel is important that you have not mentioned above, or would you like to discuss in more detail regarding your pre-dialysis education or your treatment decision?**

.....  
.....

**Thank you very much for taking the time to complete this questionnaire. Please return it to the unit secretary**



**Appendix 5.B: Main study questionnaire (Arabic)**

# استبيان خاص بمرضى الغسيل الكلوي

تأثير التعليم ما قبل غسيل الكلى  
على اختيار العلاج في المملكة العربية السعودية

### مقدمة :

أشكركم على توفير بعض من وقتكم للمشاركة في هذه الدراسة ، الدراسة هي جزء من شهادة الدكتوراه الخاصة بي للحصول عليها من جامعة ساوثامبتون في المملكة المتحدة ، والهدف من هذه الدراسة هو التعرف على ما هية المعلومات التي يتلقها مريض غسيل الكلى في السعودية قبل بدء علاج غسيل الكلى ، وقد طلب منك المشاركة في هذه الدراسة لأنك تحصل حالياً على علاج غسيل الكلى وتجربتك ستكون مفيدة لنا .

تم تقسيم الاستبيان إلى أربع أجزاء ، الجزء الأول يسأل عن معلومات عامة عنك والقسم الثاني يسأل عن ما هية المعلومات التي تلقيتها قبل بدء علاج غسيل الكلى ومن أين حصلت على هذه المعلومات وكيف يتم اتخاذ قرار عن علاج غسيل الكلى الخاص بك والجزء الثالث يسأل عن الأشياء التي قد تؤثر على اختيارك لعلاج غسيل الكلى والجزء الرابع يسأل عن علاج غسيل الكلى الحالي الخاص بك (تصفية الدم أو غسيل الكلى البريتوني) .

### إرشادات حول ملء هذا الاستبيان :

معظم الاسئلة بها مربع علامات لتوفير الإجابات ومطلوب منك بصفة عامة أن تكمل مربع العلامات واحد فقط ومع ذلك معظم الاسئلة يمكنك أن تؤثر على أكثر من مربع واحد بالإضافة إلى أن بعض الاسئلة تحتاج منك أن تفسر وتشرح إجاباتها ،الرجاء أن تسأل الباحث إذا لم تكن متأكد عن كيفية الإجابة .

سرية المعلومات :

لن يطلب منك أن تعطي إسمك أو عنوانك عند إكمال هذا الاستبيان وأحب أن أطمئنك أن المعلومات التي تقدمها في هذا الاستبيان ستكون سرية ومجهولة ، وإن الباحثة ومشرفيها فقط هم الذين يعرفون البيانات التي تقدمها ولن يحوز أي فريق على هذه المعلومات ، وفي النهاية أود أن أطمئنك أن البيانات في هذه الاستبيان سيتم استخدامها فقط من أجل غرض هذه الدراسة.

شكراً جزيلاً على إكمال الاستبيان .

**الجزء الأول : بعض المعلومات العامة عنك :**  
(في هذا الجزء برجاء أن تؤشر على مربع واحد فقط)

**1- هل أنت ؟**

☐ ذكر

☐ أنثى

**2- كم عمرك ؟**

☐ أقل من عشرون

☐ 20-29

☐ 30\_39

☐ 40-49

☐ 50-59

☐ 60-69

☐ فوق السبعين

**3-ما هو أعلى مستوى تعليمي وصلت إليه ؟**

☐ بعض من التعليم الابتدائي

☐ خريج المدرسة الابتدائية

☐ بعض من التعليم الثانوي

☐ خريج المدرسة الثانوية

☐ بعض من التعليم الفني / الكلية

☐ خريج كلية أو ما فوق

☐ أمي

☐ أخرى من فضلك حدد .....

**4- ما هو عملك ؟**

☐ وظيفة بدوام كامل

☐ وظيفة بنصف دوام

☐ في التعليم

☐ متقاعد

☐ لا يعمل

☐ أخرى من فضلك حدد .....

**5- ما قدر المعرفة الذي تشعر به عن متاعب الكلية ؟**

☐ أشعر أنني أعرف كل شيء موجود عن متاعب الكلية .

☐ أشعر أنني أعرف قدر كافي عن متاعب الكلية .

☐ أشعر أنني أعرف القليل عن متاعب الكلية .

☐ لا أعرف أي شيء عن متاعب الكلية .

**الجزء الثاني : عن التعليم الذي تلقينته قبل ان تبدأ غسيل الكلى**

(في هذا الجزء يرجى أن تؤشر على صندوق واحد فقط ما لم يحدد شيء آخر)

**6- منذ متى عرفت أنك تعاني من متاعب الكلية ؟**

☐ أقل من شهر واحد

☐ 1 إلى 3 سنوات

☐ 1 إلى 3 شهور

☐ 3 إلى 5 سنوات

☐ 4 إلى 6 شهور

☐ 7 إلى 12 شهر

☐ لا أعرف / لا أتذكر

**7- منذ متى كنت تذهب إلى أخصائي أمراض الكلى قبل ان تبدأ غسيل الكلى :**

☐ أقل من شهر واحد

☐ 1 إلى 3 سنوات

☐ 1 إلى 3 شهور

☐ 3 إلى 5 سنوات

☐ 4 إلى 6 شهور

☐ 7 إلى 12 شهر

☐ لا أعرف / لا أتذكر

☐ غير قابل للاستخدام هنا

**8- متى تم عرض وتفسير الأنواع المختلفة للخيارات العلاجية مثل غسيل الكلى الدموية وزرع الأعضاء أول مرة إليك ؟**

- ☐ لم يكن تم البدء بغسيل الكلى
- ☐ أقل من شهر واحد قبل بدء غسيل الكلى
- ☐ 1 إلى 3 شهور قبل بدء غسيل الكلى
- ☐ 4 إلى 6 شهور قبل بدء غسيل الكلى
- ☐ 7 إلى 12 شهر قبل بدء غسيل الكلى
- ☐ لا أعرف / لا أتذكر
- ☐ لم تقدم خيارات علاجية إليّ

**9- أي من الخيارات التالية تم تقديمها من البداية لك كوسائل علاجية محتملة ؟**

- ☐ (الرجاء أن تؤثر على ما هو ملائم يمكنك أن تؤثر على أكثر من واحد)
- ☐ الغسيل الدموي في مركز غسيل الكلى
- ☐ الغسيل الدموي في المنزل .
- ☐ الغسيل البروتيني من خلال البطن في المنزل ليلاً باستخدام آلة .
- ☐ الغسيل البروتيني المتنقلة والمستمرة (CAPD) من خلال البطن : لم يتم استخدام آلة .
- ☐ نوع معين من غسيل الكلى (PD) من خلال البطن ليس متأكد من النوع
- ☐ زرع كلية
- ☐ اختيار عدم الغسيل الكلوي
- ☐ لا أعرف / لا أتذكر
- ☐ لم تقدم خيارات علاجية إليّ

**10- من ناقش الخيارات العلاجية معك ؟**

- ☐ طبيب العائلة
- ☐ أخصائي أمراض الكلى
- ☐ ممرضة من مركز غسيل الكلى
- ☐ ممرضة من مكتب أخصائي أمراض الكلى
- ☐ العامل الاجتماعي
- ☐ آخرون .....
- ☐ لا أعرف / لا أتذكر
- ☐ لم تقدم خيارات إليّ

**11- وضح أنواع المواد المستخدمة في تفسير خيارات العلاجية ؟**

- ☐ (الرجاء ان تؤثر على ما هو ملائم يمكن أن تؤثر أكثر من واحد)
- ☐ مناقشات مباشرة مع الأطباء والممرضين :
- ☐ الحلقات والندوات
- ☐ مناقشات مع مرضى آخرين على الغسيل الدموي
- ☐ مناقشة مع مرضى آخرين مصابين على الغسيل البروتيني ( من خلال البطن ) .
- ☐ زيارات إلى مركز غسيل الكلى
- ☐ مواد مطبوعة مثل الكتيبات والنشرات والكتب
- ☐ شرائح الكاسيت
- ☐ أقراص واسطوانات تعليمية
- ☐ الفيديو
- ☐ مواقع امراض الكلى على الانترنت
- ☐ لا أعرف / لا أتذكر
- ☐ لم تقدم خيارات علاجية إليّ



- 12- هل تشعر أنه تم تقديم معلومات كافية لك لاتخاذ قرار ملائم عن نوعية العلاج التي تناسبك جيداً؟**
- ☐ تلقيت معلومات أكثر من كافية لاختيار العلاج .
- ☐ تلقيت معلومات كافية لاختيار العلاج .
- ☐ تلقيت بعض المعلومات ولكنها ليست كافية لاتخاذ قرار ملائم .
- ☐ تلقيت القليل من المعلومات ولم تساعدني على إتخاذ قرار ملائم
- ☐ لم أتلقي معلومات عن الخيارات العلاجية المتنوعة .
- ☐ لا أعرف / لا أتذكر
- 13- ما مقدار الوقت الذي قضيته بوجه عام في مناقشة خياراتك العلاجية مع أخصائي الرعاية الصحية؟**
- ☐ ليس هناك وقت
- ☐ 1 إلى 2 ساعة
- ☐ 5 إلى 30 دقيقة
- ☐ أكثر من ساعتين
- ☐ 31 دقيقة إلى 1 ساعة
- ☐ لا أعرف / لا أتذكر
- 14- ما شكل العلاج الذي تتلقاه حالياً لعلاج متاعب الكلية ؟**
- ☐ الغسيل الدموي في مركز غسيل الكلى
- ☐ الغسيل الدموي في المنزل .
- ☐ الغسيل البروتيني في المنزل ليلاً باستخدام آلة (CCPD)
- ☐ الغسيل البروتيني المتنقل والمستمر (CAPD)
- ☐ لم أتلقي أي علاج في هذا الوقت
- 15- هل قمت باختيار هذا النوع من العلاج ؟**
- ☐ نعم
- ☐ لا
- 15 أ) لو نعم فلماذا ؟** .....
- 15 ب) لو لا فمن الذي اختار هذا العلاج لك ؟**
- ☐ الفريق الطبي الخاص بك (الاطباء / الممرضين ، الموظفين الاجتماعيين) هم الذي حددوا علاج غسيل الكلى
- ☐ كان قرار مشترك اتخذته أنا والعائلة وأفراد فريقي الطبي
- ☐ لا أعرف / لا أتذكر
- 16- هل العلاج الحالي هو نفس العلاج الذي بدأت به ؟**
- ☐ نعم
- ☐ لا
- 16 أ) لو لا لم يتم تغيير الوسيلة العلاجية بسبب : .....**
- 17- هل غيرت رأيك بشأن نوع غسيل الكلى الذي كنت تريده قبل البدء ؟**
- ☐ نعم
- ☐ لا
- ☐ لم تقدم خيارات إليّ
- ☐ لا أعرف / لا أتذكر
- 18- بصفة عامة ما مدى رضائك عن نوعية علاجك الحالي ؟**
- ☐ لم أحدد أول خياراتي العلاجية بسبب .....
- ☐ راضي جداً
- ☐ راضي إلى حد ما
- ☐ لست راضياً أو العكس
- ☐ غير راضي إلى حد ما
- ☐ غير راضي جداً

الجزء الثالث : كيف تحب أن يقدم إليك التعليم عن علاج غسيل الكلى ؟  
(وهذا الجزء برجاه أن تؤثر على صندوق واحد فقط ما لم يوضح شيء آخر)

19- صنف رؤيتك لتعليم ما قبل غسيل الكلى الذي تلقينته كواحدة من الآتي :

- ☐ ممتاز  
☐ جيد  
☐ ليس جيد أو العكس  
☐ ضعيف  
☐ غير ملائم تماماً

20- هل تود أن يتواجد أي من أفراد عائلتك أثناء جلسة المعلومات عن نوع غسيل الكلى ؟

- ☐ نعم  
☐ لا

21- لا كيف تحب ان يتم إجراء جلسة المعلومات ؟ (الرجاء أن تؤثر على ما هو ملائم ويمكنك أن تؤثر على أكثر من واحدة)

- ☐ بصورة خصوصية في المنزل  
☐ بصورة خصوصية في المستشفى  
☐ في مجموعة .  
☐ في مجموعة / بصورة خصوصية .  
☐ على الانترنت

22- هل كنت تود الحصول على أي معلومات إضافية تساعدك في اتخاذ القرار ؟

- ☐ نعم  
☐ لا

22 – لو نعم الرجاء توضيح ما نوع المعلومات التي كنت تود الحصول عليها :

(الرجاء أن تؤثر على ما هو ملائم يمكنك أن تؤثر على أكثر من واحدة )  
1- المعرفة النظرية .

- |                             |                              |   |
|-----------------------------|------------------------------|---|
| <input type="checkbox"/> لا | <input type="checkbox"/> نعم | وظائف الكلى                             |
| <input type="checkbox"/> لا | <input type="checkbox"/> نعم | مقدمة أساسية عن نهاية مرحلة أمراض الكلى |
| <input type="checkbox"/> لا | <input type="checkbox"/> نعم | مبادئ علاج غسيل الكلى                   |
| <input type="checkbox"/> لا | <input type="checkbox"/> نعم | الاختلاف والتشابهات بين كلا العلاجين    |
| <input type="checkbox"/> لا | <input type="checkbox"/> نعم | مضاعفات كلا النوعين من العلاج           |
| <input type="checkbox"/> لا | <input type="checkbox"/> نعم | إدارة غسيل الكلى في الحياة اليومية      |

2- المجالات الفنية :

- |                             |                              |   |
|-----------------------------|------------------------------|---|
| <input type="checkbox"/> لا | <input type="checkbox"/> نعم | إدارة التغذية                             |
| <input type="checkbox"/> لا | <input type="checkbox"/> نعم | إدارة الأدوية                             |
| <input type="checkbox"/> لا | <input type="checkbox"/> نعم | منفذ الأوعية الدموية(الفستوله أو القسطره) |
| <input type="checkbox"/> لا | <input type="checkbox"/> نعم | قسطرة غسيل الكلى البريتوني                |
| <input type="checkbox"/> لا | <input type="checkbox"/> نعم | تقييد شرب السوائل                         |

آخرون الرجاء حدد .....

23- ما العوامل التي تؤثر على اختيارك لعلاج غسيل الكلى (الرجاء أشر على ما هو ملائم يمكنك أن تؤثر على أكثر من واحدة)

- ☐ رأي زوجتي / الأفراد الآخرين المهمين .  
☐ وجود أفراد أعولهم في المنزل .  
☐ المزيد من المعلومات المكتوبة  
☐ رأي الأطباء  
☐ رأي الممرضين

- ☐ رأي أصدقائي  
☐ التحدث مع شخص مصاب بغسيل الكلى بالفعل .  
☐ لدي شخص في المنزل لمساعدتي في إدارة علاجي .  
☐ ليس لدي شخص في المنزل لمساعدتي في إدارة علاجي .  
☐ أخرى الرجاء حدد .....

24- ما مدى أهمية ان يشترك المريض في اختيار علاج غسيل الكلى الخاص بهم ؟

- ☐ هام جداً  
☐ هام إلى حد ما  
☐ ليس مهم او غير مهم  
☐ غير مهم إلى حد ما  
☐ غير هام  
☐ لا أعرف / لست متأكد

25- ما هي الثلاث أشياء الأكثر أهمية التي تؤثر على خيار علاج غسيل الكلى الخاص بك ؟ ولماذا

- .....  
 • .....  
 • .....

26- كيف ترى وسائل تحسين تعليم ما قبل غسيل الكلى ؟

.....

الجزء الرابع: رأيك حول نوع الغسيل الكلوي الذي تتلقاه الآن  
 إذا كنت تتلقى الغسيل الكلوي الدموي, الرجاء الذهاب إلى سؤال رقم 27  
 وإذا كنت تتلقى الغسيل البروتيني, الرجاء الذهاب إلى سؤال رقم 28

27- أ) ما مميزات نوع غسيل الكلى الذي تتلقاه ؟

- (الرجاء ان تؤثر على ما هو ملائم ويمكنك أن تؤثر على أكثر من واحدة)  
☐ أسمح للمرضين / الآخرين بالاعتناء بي  
☐ أفضل العلاج في مركز غسيل الكلى  
☐ أفضل جدول محدد ومخطط  
☐ أفضل الإتصال المنتظم بالمرضى الآخرين  
☐ آخرون الرجاء حدد .....

27- ب) ما عيوب نوع غسيل الكلى الذي تتلقاه ؟

- (الرجاء أن تؤثر على ما هو ملائم ويمكنك أن تؤثر على أكثر من واحدة)  
☐ لا أحب الدم .  
☐ لا أحب الوخز بالإبر .  
☐ النقل إلى مركز غسيل الكلى .  
☐ تقييد شرب السوائل.  
☐ الحميه الغذائية  
☐ مدة العلاج (3 x كل أسبوع )  
☐ آخرون الرجاء حدد.....  
 الرجاء الذهاب الآن إلى السؤال الـ 29

خاص بمرضى غسيل البروتيني فقط.

28- أ) ما هي مميزات نوع غسيل الكلى الذي تتلقاه ؟

(الرجاء أن تؤثر على ما هو ملائم ويمكنك أن تؤثر على أكثر من واحدة)

☐ أفضل أداءها بنفسه

☐ يفضل السرية في المنزل

☐ مرونة الجداول

☐ سهولة الانتقال

☐ سهولة العمل

☐ يمكن أدائه في المنزل أثناء النوم

☐ أخرى الرجاء حدد .....

28- ب) ما هي عيوب نوع غسيل الكلى الذي تتلقاه ؟

(الرجاء أن تؤثر على ما هو ملائم ويمكنك أن تؤثر على أكثر من واحدة)

☐ لا أحب الأنبوب في منطقة البطن .

☐ قلق بشأن العدوى

☐ صورة الجسم (مظهر شخصي)

☐ ترتيب ، تسليم وتخزين المؤن

☐ مدة العلاج (7 x كل أسبوع)

☐ أخرى الرجاء حدد .....

29- في النهاية هل تود أن تخبرني أي شيء تشعر أنه هام ولم تذكر فيما سبق أم هل تود أن تناقش

بتفاصيل أكثر فيما يتعلق بتعليم ما قبل غسيل الكلى أو قرار علاجك ؟

.....

.....

شكراً جزيلاً على الوقت الذي قضيته في إكمال هذا الاستبيان برجاء اعادته إلى سكرتير الوحدة .

## **Appendix 6.A : Introductory letter to the participants (English)**

### **Introductory Letter**

I am a student at the University of Southampton undertaking a Doctoral Degree exploring Saudi Arabian pre-dialysis education and the selection of renal replacement therapy, which is a new area of research. My PhD is being funded by the Ministry of Higher Education. I previously worked as a specialist renal nurse in Saudi Arabia for four years and as renal educator for three years based at King Abdulaziz University Hospital.

The purpose of the study is to examine the effect of pre-dialysis education on dialysis modality selection among ESRD patients beyond in-centre haemodialysis. Patients will need to complete Questionnaires about their pre-dialysis education and dialysis modality selection, the investigator will be available for help in the dialysis unit.

If you decide to participate in the study, Please contact the researcher on 00966504687592 or e-mail: [reem\\_alhameedi@yahoo.com](mailto:reem_alhameedi@yahoo.com).

Reem Alhameedi  
 DClinP student  
 Building 45  
 Faculty of health Science  
 University of Southampton  
 Highfield  
 Southampton SO17 1BJ, UK  
 E-Mail: [rsa1g10@soton.ac.uk](mailto:rsa1g10@soton.ac.uk)  
 Tel: +966(0)504 687592

## Appendix 6.B. Introductory letter (Arabic)

### خطاب تمهيدي

أنا طالبه في جامعة ساوثمبتون أقوم بإجراء بحث للحصول على درجة الدكتوراه عن قبل غسيل الكلى التعليم واختيار العلاج ببدائل الكلوي، والذي هو من جديد مجال البحوث. ويجري تمويل البحث من قبل وزارة التعليم العالي. عملت سابقا ممرضة متخصصة في غسيل الكلى لمدة أربع سنوات ، ومن ثم مسؤوله عن تنقيف التمريض بقسم غسيل الكلى لمدة ثلاث سنوات في مستشفى جامعة الملك عبد العزيز بجده في المملكة العربية السعودية.

الغرض من هذه الدراسة هو دراسة تأثير التعليم ما قبل غسيل الكلى على اختيار طريقة الغسيل الكلوي بين مرضى الداء الكلوي بمراحله الأخيرة بعده في قسم غسيل الكلى. المريض سوف يحتاج إلى استكمال استبيانات حول التعليم ما قبل غسيل الكلى وتأثيره على اختيار طريقة غسيل الكلى ، سوف تكون الباحثة متاحة في قسم غسيل الكلى للمساعدة.

إذا قررت المشاركة في هذه الدراسة ، يرجى الاتصال على الباحثة 00966504687592  
أو البريد الإلكتروني : reem\_alhameedi@yahoo.com.

ريم سعيد الحميدي

بناء 45

كلية العلوم الصحية

جامعة ساوثهامبتون

هايفيلد

ساوثمبتون SO17 1BJ، المملكة المتحدة

البريد الإلكتروني : rsa1g10@soton.ac.uk

الهاتف : 00447891938244

## **Appendix 7.A: Participants Information Sheet(Main study) English**

Study title

The effect of pre-dialysis education on the selection of renal replacement therapy beyond in-centre haemodialysis in Saudi Arabia

Dear Patients

The aim of study is to examine the effect of pre-dialysis education on dialysis modality selection among ESRD patients beyond in-centre haemodialysis.

You will be asked questions about what kind of pre-dialysis education you received before you started dialysis, your understanding of dialysis treatment options and your satisfaction with treatment.

Original data will only be read by me and the study supervisors. Destruction of the data will be at the end of the project using the university confidential waste services. The results of the study, may be published or presented at professional conferences, without exposure of any identity of individual or organisations

Your participation in the study is totally voluntary. You do not have to participate if you do not want to and that will not affect your future treatment. The clinical staff will not know if you agree or not to participate and the information you provide will not be put in your notes or files. Although you probably will not benefit directly from participating in this study, I hope that future dialysis patients will benefit from study findings.

I will be happy to answer any questions you may have about the study, you may contact me at [rsa1g10@soton.ac.uk](mailto:rsa1g10@soton.ac.uk) or / [reem\\_alhameedi@yahoo.com](mailto:reem_alhameedi@yahoo.com) or my supervisor Dr.

Sarah Brien at [S.Brien@soton.ac.uk](mailto:S.Brien@soton.ac.uk) and Dr. Claire Smith at [c.f.smith@southampton.ac.uk](mailto:c.f.smith@southampton.ac.uk)

If you decide to participate in the study, Please contact the researcher on 00966504687592 or e-mail: [reem\\_alhameedi@yahoo.com](mailto:reem_alhameedi@yahoo.com) . Please keep this information sheet in case you want to refer to it later.

Thank you for your time

Reem Alhameedi

## Appendix 7.B. Participants' Information Sheet (Main study) Arabic

### ورقة المعلومات

### عنوان الدراسة

تأثير التعليم ما قبل غسيل الكلى على اختيار العلاج الكلوي بين مرضى غسيل الكلى في المملكة العربية السعودية  
أعزائي المرضى

الهدف من الدراسة دراسة تأثير التعليم ما قبل غسيل الكلى على اختيار طريقة الغسيل الكلوي بين مرضى الداء  
الكلوي بمراحله الأخيرة في قسم غسيل الكلى.

سوف يطلب منك إجابة الأسئلة حول التعليم الذي تلقينه قبل بدء الغسيل الكلوي، وفهمك الخاص بخيارات  
علاج غسيل الكلى وارتياحك مع العلاج الخاص بك.

سوف يتم قرأه البيانات الأصلية للباحث الأساسي والمشرفين على الدراسة فقط. سوف يتم تدمير البيانات في نهاية  
المشروع في النفايات السرية بالجامعة. ، قد يتم نشر أو تقديم نتائج هذه الدراسة في المؤتمرات المهنية، ولكن دون  
التعرض لأي هوية من الافراد أو المنظمات .

مشاركتم في هذه الدراسة هو طوعيه تماما. ليس عليك الاشتراك ، إذا كنت لا تريد، وأنه لن يؤثر على العلاج  
الخاص في المستقبل. لن يعرف الكادر الطبي ما إذا كنت موافق على المشاركة أو قررت عدم المشاركة في  
الدراسة، ولن يتم وضع المعلومات التي تقدمها في ملفك الطبي. على الرغم من أنك ربما لن تستفيد مباشرة من  
المشاركة في هذه الدراسة ، أمل أن مرضى غسيل الكلى في المستقبل سوف يستفيدو من نتائج الدراسة.

سأكون سعيدا للإجابة على أية أسئلة قد تكون لديكم حول هذه الدراسة ، يمكنك الاتصال بي  
reem\_alhameedi@yahoo.com أو المشرف الدكتور سارة برين في s.brien@soton.ac.uk أو  
دكتور كلير سميث في c.f.smith.southampton.ac.uk.

إذا قررت المشاركة في هذه الدراسة ، يرجى الاتصال على الباحث 00966504687592 أو البريد الإلكتروني :  
reem\_alhameedi@yahoo.com. الرجاء الاحتفاظ بهذه المعلومات في ورقة حال كنت تريد الرجوع إليه  
لاحقا.

شكرا لك على وقتك



## Appendix 8: Adult Consent Form (Arabic)



وزارة الصحة  
Ministry of Health  
مديرية الشؤون الصحية بمحافظة جدة  
التخطيط والتطوير  
الموافقة المستنيرة

موافقة اشتراك مشاركين في بحث للبالغين	Adult inform consent
اسم الباحث:	ريم سعيد الحميدي
اسم البحث:	تثقيف وإختيارات مرضى غسيل الكلى
العنوان:	
تليفون:	0504687592
المكان الذي سوف تتم فيه الدراسة:	مركز الكلى
مدة البحث:	6 أشهر
الجهة المسنولة عن البحث:	جامعه ساوث هامبتون بالمملكة المتحدة
العدد المتوقع للبحث:	100

أنت مدعوة للمشاركة ببحث علمي سريري سيجري في... قسم غسيل الكلى.....

الرجاء أخذ الوقت الكافي لقراءة المعلومات التالية بشأن قبل أن تقرر (ي) إذا كنت تريد (ين) المشاركة أم لا، بإمكانك طلب إيضاحات أو معلومات إضافية عن أي شيء مذكور في هذه الاستمارة أو عن هذه الدراسة ككل من طبيبك.

(1) وصف البحث العلمي وهدفه وتفسير مجرياته:

.....إستبيان لمرضى الغسيل الكلوي  
الهدف من البحث معرفة تأثير تثقيف المرضى بأنواع الغسيل الكلوي على إختياراتهم للعلاج

(2) سوف تتم أخذ عينة من:



مديرية الشؤون الصحية بمحافظة جدة  
التخطيط والتطوير

□ أخرى

□ البراز

□ الدم

(3) أذكر التأثيرات السلبية أو ردات الفعل التي يمكن أن يسببها الاشتراك في هذا البحث (جسدية، نفسية، اجتماعية، اقتصادية)

..... لا يوجد.....

.....

(4) أذكر الفوائد التي قد تنتج عن هذا البحث:

معرفته.....  
تأثير تنقيف المرضى بأنواع الغسيل الكلوي على إختياراتهم للعلاج.....

.....

الأشخاص المضمونين في البحث:

(5) إذا كان هناك أخذ عينات دم:  
أذكر كمية الدم المسحوبة وعدد مرات سحب الدم وطريقة حفظ العينات وتشفير لعينات، وأن الدم سوف يستعمل فقط في هذه الدراسة ويتخلص منه بعد هذه الدراسة:

..... لا يوجد.....

.....

.....

(6) إذا وافقت على الاشتراك بهذا البحث سوف تبقى المعلومات سرية، وحدهم الأطباء والجمعيات الأخلاقية والمحققين في المؤسسات العامة يمكنهم الإطلاع على النتائج بناء لأمر قانوني:

إقرار الباحث باستلام التعهد بالاشتراك:



وزارة الصحة  
Ministry of Health

لقد اطلعت بالتفصيل مديرية الشؤون الصحية بمحافظة جدة بالاشتراك في البحث مع.....

(اسم المريض ، ممثلة القانوني ، قريبه ، وصيه) وأفهمت المريض الغاية من هذه الدراسة ومن أخطارها وفوائدها وقد أجبت المشترك على جميع الأسئلة التي تقدم بها بوضوح تام وتعدت له بإعلامه عن أي تغيير يطرأ في موضوع هذا البحث.  
اسم الباحث أو المشترك بالبحث: \_\_\_\_\_  
التوقيع \_\_\_\_\_

التاريخ:

إقرار المريض بالمشاركة في البحث:

أنا الموقع أدناه وبعد أن اطلعت واستوعبت كل جوانب هذا البحث وأجبت عن كل أسئلتي أوافق بملء إرادتي على المشاركة في هذه الدراسة وأنا على علم تام بأنني أستطيع الاتصال بالدكتور.....

الرقم.....

أو بأي من ممثليه الضالعين بهذه الدراسة وذلك إن أردت توجيه أي سؤال، كما إنني أعلم أنه فيما لو أن أسئلتي لم يتم الإجابة عليها بطريقة مقنعة يمكنني الاتصال بأحد أعضاء لجنة الأخلاقيات على الرقم..... كما أنني أعلم أنه يمكنني الانسحاب من المشاركة في أي وقت شئت حتى بعد التوقيع على هذه الوثيقة وأن العناية التي ألقاها لم تتأثر بهذا الانسحاب وإنني سوف أزود بنسخة عن هذه الوثيقة.

اسم المريض أو ممثلة القانوني/ قريبة أو وصية \_\_\_\_\_  
التوقيع \_\_\_\_\_


التاريخ:

اسم الشاهد \_\_\_\_\_

التوقيع \_\_\_\_\_

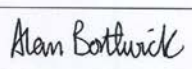


## Appendix 9: Advanced peer review approval (University of Southampton)




Peer Review: Overall Assessment	
	<b>Accept</b> (will be returned <b>electronically</b> to the student/researcher)
	<b>Minor revisions</b> – will be returned <b>electronically</b> to the applicant: ✓ IF a student: revisions to be checked by main supervisor <b>OR</b> if a researcher: revisions to be checked by PI <b>OR</b> if a PI: revisions to be checked by Head of Research Group <b>OR</b> if a Head of Research Group: revisions to be checked by Director of Research. The 'authorised person' (Supervisor/PI/Head of Research Group/Director of Research) completes the final sign-off* below to notify RESO that revisions are satisfactory.
	<b>Revisions required</b> (will be returned <b>electronically</b> to the supervisor for discussion / researcher and PI for discussion with revisions to go back to peer reviewer via the RESO). When the Peer Reviewer can confirm the revisions are satisfactory the Peer Reviewer completes the final sign-off* below to notify RESO.
	<b>Reject</b> (will be returned <b>electronically</b> to the supervisor/PI/Head of the Research Group/Director of Research for discussion)

Name of Applicant	Reem Alhameedi
Title of Proposal	The effect of pre-dialysis education on the selection of renal replacement therapy beyond in-centre haemodialysis in Saudi Arabia
Name of Reviewer	Dr Alan M Borthwick
Reviewer's Signature	
Date review completed	28 <sup>th</sup> June 2012

* Final sign off when no amendments necessary	
Name of authorised person	DR SARAH BAILEY
Signature of authorised person	
Date of final sign off	16/7/2012

**Thank you for taking the time to complete this project review.**  
**Please return the completed form via email to [sohsreso@soton.ac.uk](mailto:sohsreso@soton.ac.uk)**


**Please also post the signed last sheet to Research & Enterprise Services Office,  
 Faculty of Health Sciences, Building 67, University of Southampton, Highfield,  
 Southampton, SO17 1BJ**

Building 67, Faculty of Health Sciences, University of Southampton, Highfield Campus, Southampton SO17 1BJ United Kingdom.  
 Tel: +44 (0)23 8059 7979 Fax: +44 (0)23 8059 7900 [www.southampton.ac.uk](http://www.southampton.ac.uk)



## Appendix 10 Ethical Approval for Hospital 2 and Hospital 4



Ministry of Health  
Kingdom of Saudi Arabia  
Directorate of Health Affairs - Jeddah  
Research Center

**Date:** 11. Apr. 2012

**To:** University of southampton, Southampton,UK

**Subject:** Ethical Approval of Research Proposal.

---

This is to certify that research proposal titled:

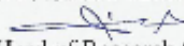
**"The effect of pre-dialysis education on the selection of renal replacement therapy beyond in-centre haemodialysis in Saudi Arabia"**


Submitted by: " Miss Reem Alhameedi " was reviewed by the research and ethics committee (H-02-J-002) with respect to protecting of the rights of human subject involved in the research project.

I am pleased to inform you that the committee approved the above mentioned Proposal as fulfilling the ethical requirement.

**Please submit to the research center your progress report.**

**Best Regard.**

**Dr / Hanan Alattas (M.D)**  
  
 Head of Research Center - Jeddah

**Dr / Osama Obaid Dhafar (M.D)**  
  
 Asst. Director of Directorate  
 Of Health Affairs, Jeddah  
 Head of Research Committee - Jeddah





## Appendix 11 National Audit questionnaire for Dialysis units in KSA

### A. Unit characteristic

#### 1. Unit affiliation

- ☐ Government Hospital (Ministry of Health)
- ☐ Government/Non-MoH

#### 2. How patients with ESRD are referred to Nephrology Care

- ☐ Emergency Room
- ☐ Primary healthcare Centre
- ☐ Nephrology clinic
- ☐ Other departmental referral

### B. Information about treatment options

#### 1. What type of RRT does your unit provide to Patients with ESRD? (can tick more than one)

- ☐ Haemodialysis (blood) at a dialysis centre
- ☐ Haemodialysis (blood) at home
- ☐ Automated Peritoneal dialysis (APD) through abdomen/stomach at home at night using a machine
- ☐ Continuous Ambulatory Peritoneal Dialysis (CAPD) through abdomen/stomach; no machine involved
- ☐ Kidney transplant
- ☐ Pre-emptive transplant

#### 2. Do you provide structured pre-dialysis education and information about treatment options?

- ☐ Yes
- ☐ No

**Explain:**.....

#### 3. When is the pre-dialysis education and information provided to patients with ESRD

- ☐ Not until dialysis is started
- ☐ Less than 1 month before beginning dialysis
- ☐ 4 to 6 months before beginning dialysis
- ☐ More than 4 months
- ☐ Other

## Appendices

**4. Who provides the information about treatment options or the pre-dialysis education?**

- ☐ Nephrologist
- ☐ Dialysis nurse
- ☐ Health Educator/Patient educator
- ☐ Other

Please specify.....

**5. What are the educational materials used for information provision?**

.....  
.....

**6. What type of information is provided?**

.....  
.....

**7. How many sessions in total do the patients receive?**

- ☐ No sessions
- ☐ 1 to 2 sessions
- ☐ 3 to 4 sessions
- ☐ 5 or more sessions

**8. Which of the following factors do you consider are possible barriers or obstacles to the provision of information or pre-dialysis education?**

- ☐ Late referral to nephrologists
- ☐ Communication (Language barrier)
- ☐ Non-compliance
- ☐ Patient's education level
- ☐ Nurse shortages
- ☐ Other

Please specify.....

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