Understanding the Decision-Making process for Haemodialysis Refusal in Oman: A grounded Theory Approach

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Dedication

I dedicate this thesis to the memory of my late father, may he rest in peace for instilling in me a profound fondness for acquiring knowledge and a resilient mindset.

This study project is dedicated to individuals living with end-stage kidney disease (ESKD) in Oman, the Gulf area, and Arab countries. The objective is to foster assistance for these individuals in managing their condition and improving their quality of life.

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Above all, I express my gratitude to Allah, the Almighty, for granting me the opportunity, supporting me in finishing this task, and providing me with the resilience, will, and forbearance required to do it.

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Publications and Conferences

Presentations

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June 6th, 2014: High Institute of Health Science, Nephrology Nursing program: Decision-Making Process to Refuse Haemodialysis Among Individuals with kidney Failure in Oman: A Grounded Theory Study. Oral presentation.

September 2023: RCN International Nursing Research Conference: A grounded theory of Haemodialysis refusal in people living with end-stage kidney disease in Oman. Oral presentation.

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Abstract

Background: Haemodialysis (HD) is an invasive routine life-sustaining therapy for End-Stage Kidney Disease (ESKD) individuals, and it remains the common modality of Kidney Replacement Therapy (KRT). ESKD is a permanent kidney failure due to complete or nearly complete loss of kidney function and the ability to eliminate waste and excess water from the body (Griva et al., 2013). Worldwide, ESKD results in a great burden on the healthcare system and has become a major public health problem (Li et al., 2021). The decision to initiate haemodialysis is generally made by the treating nephrologist alone; however, this decision cannot be acted upon without the individual's explicit permission, as their consent is crucial to proceeding with dialysis. Professional experience and published evidence have demonstrated that a proportion of individuals living with ESKD refuse HD as a treatment option, though quantitative data on prevalence are not available.

However, the decision to refuse HD is multifaceted and poorly understood, especially in Arab regions, including Oman.

Aim: To explore and understand the reasons underpinning the decision to refuse haemodialysis from the individuals affected by ESKD perspective in Oman.

Methodology: A qualitative study design, utilising a constructivist grounded theory approach (Charmaz, 2006), was employed to explore the research questions. The eligible participants were adults aged eighteen and above with stage five ESKD and no history of mental illness. Data collection took place in nephrology outpatient clinics and kidney dialysis units across eleven governmental hospitals under the Ministry of Health in Oman. Childress's (2019) ethical framework was applied to safeguard participant rights and uphold ethical standards throughout the study. Data were collected between October 2021 and April 2022 through in-depth, semi-structured interviews using an interview guide, with each interview lasting 30 to 60 minutes. The interviews were transcribed verbatim and translated into English. Analysis used constant comparative method, including line-by-line and axial coding, as outlined by Charmaz (2006), to enhance understanding of the social processes related to the decision to refuse haemodialysis and to facilitate categorisation.

Results: Research data indicate that twenty-seven participants' decision-making was a continuous and revisited process influenced by various factors that led to the refusal of haemodialysis. A significant knowledge gap was evident among those who declined haemodialysis, attributed to communication barriers with physicians, insufficient information about ESKD at stage five and haemodialysis, challenges in verifying information, and a tendency to selectively interpret information. Participants were also affected by the experiences of haemodialysis users, as well as input from family and peers.

Fear played a critical role in the decision-making process, driven by concerns over the potential negative consequences of haemodialysis and the associated stigma. A desire for self-control was another influential factor, leading some to seek alternatives and adopt a fatalistic perspective. From the data analysis, a grounded theory of haemodialysis refusal decision-making process was developed to outline the decision-making process for individuals with ESKD who choose to refuse haemodialysis. This grounded theory consisted of five categories: self-conceptualisation, information access, influencers, fear, and self-control.

The theoretical framework demonstrated how individuals balanced perceived benefits and risks, engaging in self-management, seeking second opinions, or relying on the advice of others while attempting to delay dialysis. Many participants were in a state of 'denial,' viewing themselves as healthy due to the absence of noticeable ESKD symptoms and opting to continue with oral medications. A few, however, considered kidney transplantation as an alternative option.

Conclusion: Omani individuals with ESKD in this study faced various factors and behaviours that influenced their decision-making, leading them to reassess and reinforce their choice to refuse haemodialysis. Denial and fatalism were the most prominent behaviours observed. Participants exhibited a limited understanding of their condition and its complications, highlighting the need to assess the quality and method of information provided, taking into account their values, beliefs, and preferences. A personalised, patient-centred approach may be more effective than a conventional disease-oriented strategy for this population. Multidisciplinary teamwork is crucial to developing effective and ongoing education and interventions, fostering a

comprehensive approach to treatment acceptance and improved health outcomes. Early pre-dialysis education and shared decision-making are vital for enabling timely interventions.

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List of Abbreviations

AFMS	Armed Forces Medical Services
ART	Antiretroviral Therapy
BIPQ	Brief Illness Perception Questionnaire
BMC	BioMed Central
BMQ	Beliefs about Medication Questionnaire
CKD	Chronic Kidney Disease
CVD	Cardiovascular Disease
DCE	Discrete Choice Experiment
DOTS	Observed Treatment, Short- Course
eGFR	estimated Glomerular Filtration Rate
ESKD	End-Stage Kidney Disease
HBM	Health Beliefs Model
HD	Haemodialysis
KRT	Kidney Replacement Therapy
MARS	Medication Adherence Report Scale
MMAS	Morisky Medication Adherence Scale
MOH	Ministry of Health
NCDs	Non-Communicable Diseases
PD	Peritoneal Dialysis
PDOMS	Petroleum Development Oman Medical Services
PrEP	Pre-Exposure Prophylaxis
RCN	Royal Collage of Nursing
RCRS	Renal Care Readiness Scale
ROPMS	Royal Oman Police Medical Services
SQUH	Sultan Qaboos University Hospital
TPB	Theory of Planned Behaviour
UK	United Kingdom
US	United State

Chapter 1 Introduction

1.1 Chronic kidney disease and haemodialysis.

A chronic kidney condition is a rapidly progressing disease determined by alterations in the structure and function of the kidney, resulting from various reasons. Chronic kidney disease (CKD) is generally characterised by a decrease in kidney function, specifically an estimated glomerular filtration rate (eGFR) below 15 mL/min per 1·73 m^2, or the presence of kidney damage indicators such as albuminuria, haematuria, or abnormalities detected through laboratory testing or imaging, which persist for a minimum of three months (Kalantar-Zadeh et al., 2021). Numerous factors contribute to CKD, encompassing both widely recognised and extensively studied causes like diabetes, glomerulonephritis, and cystic kidney diseases (Hill et al., 2016).

According to Levey et al. (2007), research conducted across Europe, Australia, and Asia validates the substantial prevalence of CKD. The consequences of CKD encompass not only the progression to kidney failure but also complications arising from decreased kidney function and an elevated susceptibility to cardiovascular disease (CVD).

Impaired kidney function is an indicator of the likelihood of being admitted to the hospital, experiencing cognitive impairment, and having a low quality of life. The healthcare burden is greatest in the initial phases due to a higher occurrence, impacting around 35% of individuals aged 70 and above (Hill et al., 2016).

The global impact of chronic kidney disease is significant and on the rise. Approximately 10% of adults worldwide grapple with some form of end-stage kidney disease (ESKD), leading to 1·2 million deaths and a loss of 28·0 million years of life annually. By 2040, CKD is projected to rank as the fifth leading cause of death worldwide, marking one of the most substantial increases among major causes of death (Kalantar-Zadeh et al., 2021).

According to the 2018 WHO report on NCD Country Profiles, it is evident that globally, low- and lower-middle-income countries experience the highest percentage of premature deaths under the age of 70 due to non-communicable diseases (NCDs). In

2016, the proportion of these early NCD-related deaths was 85%-in lower-middle-income countries, respectively, which is doubled compared to the proportion in high-income countries (12%) (Organization, 2018). However, NCD burdens worldwide lead to economic costs, with the US and UK estimating annual costs of $750 billion and $33 billion, respectively, in the next decade (Perico & Remuzzi, 2012).

ESKD is now acknowledged as a significant global public health issue. There is compelling evidence indicating that timely treatment can avoid or delay complications arising from reduced kidney function, decelerate the advancement of kidney disease, and mitigate the risk of CVD (Levey et al., 2007).

Presently, there are limited strategies that are accessible to impede the progression of ESKD. While kidney Replacement Therapy (KRT) has been accessible for decades in high-income nations, only half of those requiring KRT can be treated globally (Levin et al., 2017). The lives of kidney individuals have been enhanced and extended since the introduction of treatment methods like dialysis and kidney transplants. Haemodialysis, a viable option for individuals with kidney insufficiency, utilises a machine to mimic kidney functions, such as blood filtration and the removal of waste products (Theofilou et al., 2013).

Some individuals with ESKD may not exhibit clinical indications for KRT despite having a low eGFR. Additionally, some individuals may opt not to commence haemodialysis even when it is medically recommended (Faruque et al., 2013). Faruque et al. (2013) suggested that individuals with ESKD may choose not to start haemodialysis for several reasons, such as sudden death, a personal decision to decline treatment, a lack of recommendation from healthcare practitioners, or the absence of a clinical justification for haemodialysis despite having a low eGFR.

In Oman, there has been a notable shift from communicable diseases to non-communicable diseases, particularly chronic conditions such as chronic kidney disease (Al Alawi et al., 2017a). In 2014, there were 4,430 cases of kidney disease per 100,000 people (Al Alawi et al., 2017b). In 2017, a total of 2,386 individuals with ESKD underwent kidney replacement therapy. By the end of 2022, the number of ESKD patients receiving haemodialysis had reached 2,436 across 27 kidney dialysis units (MOH, 2022b).

1.2 The significance of studying refusal of haemodialysis

Research into individual refusal to undergo haemodialysis is crucial for several reasons. Firstly, individuals often decide about dialysis without fully exploring treatment options, highlighting the need for a proactive approach to encourage informed decision-making (Winterbottom et al., 2014). Secondly, choosing not to undergoing haemodialysis is a leading cause of death among individuals affected by ESKD, emphasising the importance of understanding the factors influencing such decisions. In Oman, numerous persons diagnosed with ESKD deny the seriousness of their condition and refuse haemodialysis, with justifications frequently unrecorded in medical documentation. As their health declines, individuals often necessitate hospitalisation for issues such as heart failure and pulmonary oedema, resulting in urgent dialysis. The lack of a database to track haemodialysis refusals contributes to resource constraints in dialysis facilities, including shortages of personnel, equipment, and available sessions. These challenges impact both individuals with ESKD and healthcare professionals.

Despite this, there is limited knowledge about why some individuals with ESKD choose to not undergo haemodialysis (Faruque et al., 2013). Furthermore, empirical research on individual decision-making in dialysis is sparse, with few studies addressing the underlying processes and how ESKD contexts impact dialysis treatment choices. Therefore, conducting comprehensive research in this area is essential to improve individuals’ outcomes and provide better support for individuals facing these difficult decisions.

1.2.1 The study contribution.

Although there has been a recent increase in scholarly and popular attention to haemodialysis refusal, there are still numerous unsolved questions regarding this topic. The purpose of this study is to address a lack of information in existing research regarding treatment refusal, specifically focusing on the experiences and viewpoints of Omani individuals who have choose not to undergo haemodialysis. Specifically, it will analyse the process of haemodialysis refusal and provide a method for comprehending the experience of haemodialysis refusal. Furthermore, its objective is to obtain a great understanding of the social factors that influence the decision-making process of Omani ESKD persons who refuse haemodialysis.

1.3 Researcher interest in the topic

The phenomenon of kidney replacement therapy choice stimulated my interest in exploring the decision-making process concerning the refusal of haemodialysis among individuals with ESKD. I was curious to understand why individuals with ESKD decide to refuse medically advised haemodialysis despite their kidney failure and late-stage condition. I also wanted to comprehend the factors influencing these individuals' decisions to not undergo haemodialysis. The aim of this study is to explore the factors that impact the decision-making process of individuals affected by ESKD regarding the refusal of haemodialysis. The study was conducted in nephrology clinics and kidney dialysis units in Oman, covering nine governorates.

I am a registered nurse who worked as a bedside nurse for four years, followed by four years as a ward nurse in charge, both in the male medical ward at a governorate hospital. Afterwards, I served as a hospital nurse supervisor for an additional three years and then as the head of nursing at the same governorate hospital for eight years before assuming the Director of Nursing Professional Practice role at the Ministry of Health in Oman. Throughout my career, I have been working with individuals suffering from CKD and ESKD.

The selection of this topic stems from a professional interest in the subject matter. Despite significant challenges, most kidney dialysis units in Oman continue to accommodate the increasing number of individuals affected by ESKD requiring unplanned haemodialysis. These individuals are typically diagnosed with ESKD but deny reaching ESKD and refuse to undergo haemodialysis. From my observation, the reasons for refusal were not identified or recorded in the individual's medical records.

Additionally, the medical team verbally designated this particular group of people as a waiting list group for dialysis, despite the fact that there was no list or concrete database to track these individuals.

Moreover, in Oman, when these individuals affected by ESKD condition deteriorates, they usually end up in the hospital with complications, such as heart failure and pulmonary oedema, which would require intensive care admission. Therefore, the incidence of individuals affected by ESKD presenting for dialysis without adequate preparation remains high, leading to shortages of human resources, materials, equipment, and available sessions in some dialysis units in Oman. Consequently, this situation poses risks to both individuals affected by ESKD and healthcare providers. However, at the Ministry of Health (MOH) level, numerous meetings and task forces have been convened to assess the status of kidney dialysis units across various governorates in Oman to accommodate this unplanned number of individuals affected by ESKD.

As a member involved in analysing these cases at the governorate and national levels, my participation would add value to the study in many ways without making assumptions. I have a good relationship with all directors and heads of nursing in the country. I am familiar with the kidney dialysis medical units in Oman, which has led to better access to information. However, I was not known to individuals affected by ESKD, nephrology nurses and nephrologists. This helps minimise question bias and participants' perceptions concerning researcher power and status.

Investigating the perspectives of individuals affected by ESKD regarding the refusal of haemodialysis despite medical advice is a crucial concept to explore.

1.4 Thesis outline

The structure of this thesis follows the conventional scientific approach in its aim to understand the phenomenon of the decision-making process around ESKD haemodialysis refusal. It begins by stating the research problem, setting the study in context and reviewing relevant literature. This informs the formulation of the research question, design, and methods used in the study. The findings are then presented and discussed within the context of the wider body of literature, and the thesis concludes with recommendations. The thesis is organised into eight chapters, each of which is outlined below:

Chapter one presents the problem of the study, addresses the primary area of interest, and explains my motivation for wanting to carry it out. It explains how the study originates from experiences in the field and from the problems I have identified regarding haemodialysis refusal among individuals affected by ESKD. Finally, the chapter details the thesis structure.

Chapter two provides the background information to set the study in context. It provides a summary of the history of chronic kidney disease, particularly end-stage kidney disease, and an overview of worldwide KRT, including haemodialysis. The chapter then provides an overview of Oman and Oman's healthcare system, including kidney replacement.

Chapter three is a literature review of global literature aimed at identifying why individuals make decisions to refuse treatment. The chapter outlines the methodology of the review and presents the findings from the fifty-four included studies. It highlights gaps in the knowledge base regarding individuals affected by ESKD haemodialysis refusal decision-making. Furthermore, the findings from the review informed the research question and the aim of the study.

Chapter four describes the research methodology of the study, arguing for a qualitative approach to fulfil the study's aim. It outlines the philosophical assumptions and theoretical perspective of the study. The chapter then justifies and explains the selection of grounded theory as the approach used in this research study.

Chapter five explains the research methods employed to perform the study; it provides comprehensive information about the setting, practical ethical considerations, sampling strategy, participant selection and recruitment, transcription quality, and the grounded theory data collection and analysis process.

Chapter six presents the study’s findings. The chapter begins with a presentation of the demographic characteristics of the participants, and it then presents each of the five categories that contributed to the development of the final grounded theory. The chapter ends with the presentation of the final grounded theory model and how the categories interlink.

Chapter seven addresses the research results within the framework of the empirical literature described in Chapter three. It examines and evaluates the contribution of this work to the existing body of knowledge. This chapter further analyses the theoretical framework of the Grounded Theory of ESKD haemodialysis refusal decision-making and establishes the connections between this study and models of grief such as the and dual process model of coping with bereavement (Stroebe & Schut, 2010) and the Kubler-Ross theory (Kübler-Ross, 2015).

Chapter eight serves as the concluding chapter of the thesis, encapsulating the study's findings, highlighting its primary contributions to the understanding of haemodialysis refusal among individuals affected by ESKD, evaluating both its strengths and limitations, and offering suggestions for future policy, practice, and research endeavours.

Chapter 2 Background

This chapter provides a general introduction to Oman, its healthcare system, and background information related to chronic kidney failure in Oman. Throughout the study, this chapter underwent continuous updates, taking into account relevant theories as they emerged from the findings' categories.

2.1 Chronic Kidney Disease (CKD).

Chronic kidney failure is becoming an increasingly significant public health concern, affecting 10% of the global population. Currently, rapid changes in disease patterns are being encountered worldwide, including in Oman. There has been a notable shift from communicable diseases to non-communicable diseases, particularly chronic conditions such as cardiac issues, obesity, diabetes, hypertension, and chronic kidney diseases. (Al Alawi et al., 2017b; Al Ismaili et al., 2017). In 2014, a total of 4,430 cases per 100,000 people were reported to have kidney or urinary diseases in Oman (Al Alawi et al., 2017a).

2.1.1 Meaning of chronic kidney disease.

Generally, CKD is understood to mean that the individual's kidneys function less well than normal and are not able to remove waste substances from the blood. Individuals with CKD are assessed by different methods: imaging studies, blood tests including serum creatinine levels to eGFR, spot urine examinations to detect proteinuria/albuminuria, and kidney biopsy (Couser et al., 2011; Gaitonde et al., 2017). Consequently, disease progression leads individuals to develop the condition of ESKD, requiring dialysis (blood filtration) or kidney transplantation to maintain their long-term survival (Zhang & Rothenbacher, 2008).

According to Griva et al. (2013), ESKD is characterised by a significant decline in kidney function, resulting in the inability to effectively remove waste products and excess water from the body. Haemodialysis is the prevailing method of kidney replacement therapy (KRT) in which blood is filtered through an external dialyser that mimics the activities of the kidney. Individuals with haemodialysis must adapt to a comprehensive and intricate treatment plan (Griva et al., 2013). Typically, people with ESKD need to visit the hospital three times a week for four-hour treatment sessions. They also need to manage their nutrition by carefully monitoring their diet and hydration consumption, taking various medications, and following exercise guidelines.

Alrajhi (2018) cross-sectional, correlational study stated that the estimation of ESKD prevalence ranges from 100 to more than 2,000 individuals per million population, with an annual increase of about 6 to 7%, exceeding the world population growth rate. In Oman, there is no evidence of the prevalence of individuals affected by ESKD (Alrajhi, 2018). However, a study conducted by Al Ismaili et al. (2017) revealed a total of 2386 individuals undergoing kidney replacement therapy, including 1,206 individuals on haemodialysis (HD), 1080 ESKD individuals who had kidney transplantation, and 100 individuals affected by ESKD on peritoneal dialysis (PD). According to the Ministry of Health Annual report (2022), at the end of 2021, the total number of individuals affected by ESKD on HD stood at 2,436 in 27 kidney dialysis units. In comparison to 2013, there were approximately 120 individuals affected by ESKD per million population. Moreover, by December 2022, a total of 252 individuals were receiving peritoneal dialysis (MOH, 2022a).

2.1.2 Causes of chronic kidney disease.

Worldwide, non-communicable diseases have replaced communicable diseases and are considered to be the most common causes of morbidity and mortality (Couser et al., 2011). In particular, diabetes mellitus (DM) and hypertension (HTN) are identified as the two primary risk factors universally associated with kidney failure. Additionally, cardiovascular diseases and hereditary kidney diseases are considered associated risk factors leading to kidney failure (Johnston & Noble, 2012b; Gaitonde et al., 2017). Therefore, poor health outcomes resulting from diabetes and hypertension contribute to kidney failure disease (Couser et al., 2011). For instance, diabetic individuals are prone to develop diabetic nephropathy by 40%, and the progression time from the first sign of kidney impairment to the time individuals with ESKD require dialysis may take about 15 to 20 years (Alrajhi, 2018).

In Oman, diseases such as hypertension, diabetes mellitus, glomerular disease, and inherited congenital kidney diseases are commonly associated with kidney disease problems. Al Ismaili et al. (2017) stated that changes in lifestyle and socioeconomic status have led to a shift in the main risk factor causing ESKD from chronic glomerulonephritis in 1983 to diabetic nephropathy in recent years. Hence, it is estimated that the number of diabetic individuals will substantially increase from 15 million in the year 2000 to approximately 42 million by 2030 in the Eastern Mediterranean Region, including Oman (Rate & Rate, 2008; Al Ismaili et al., 2017).

2.1.3 Chronic kidney disease staging.

Equations are often used in clinical practice to estimate the eGFR by considering both endogenous filtration markers (serum creatinine) and individual characteristics (age and sex). These factors are closely linked to the risks of ESKD and mortality caused by reduced kidney function. The diagnosis of CKD often relies on evaluating the GFR, conducting normal laboratory testing, and considering symptoms. However, given that the primary objective of GFR is to determine the illness's stages, GFR is typically not employed primarily for diagnosing the disease in its early stages (Akben, 2016; Bundy et al., 2022).

Estimating equations now used for GFR, which rely on serum creatinine levels (estimated GFR), are more dependable than using serum creatinine alone. These equations can identify a decline in GFR, which is a sign of advancing kidney disease. As kidney disease advances, the levels of GFR, which is commonly recognised as the primary indication of kidney function, decrease. Kidney failure, a crucial phase, is characterised by a glomerular filtration rate of less than 15 mL/min per 1.73 m^2 or requiring dialysis treatment.

The primary goal of CKD staging is to provide guidance for the management of CKD, which includes assessing the risk level for disease progression and consequences. Risk stratification is employed as a tool to determine suitable treatment options and the level of monitoring and individual education required (Levey & Inker, 2014).

According to Levey and Inker (2014), the CKD staging and classification scheme is as follows:

- Stage 1 (GFR >90 mL/min per 1.73 m2).
- Stage 2 (GFR 60 to 89 mL/min per 1.73 m2).
- Stage 3 GFR 45 to 59 mL/min per 1.73 m2 and stage 3b (GFR 30 to 44 mL/min per 1.73 m2).
- Stage 4 (GFR 15 to 29 mL/min per 1.73 m2).
- Stage 5 (GFR <15 mL/min per 1.73 m) or treatment by dialysis.

2.1.4 ESKD signs & symptoms

Good symptom management is identified by individuals as a very high priority, with symptoms being a key contributor to the overall disease burden (Murtagh et al., 2007).

As chronic kidney disease progresses to ESKD, individuals often exhibit characteristic signs and symptoms due to worsening uraemia. These include nausea, vomiting, fatigue, neurological dysfunction, bleeding tendencies, pleuritis, pericarditis, sleep disturbances, and volume overload. However, these symptoms can be nonspecific and subjective, making interpretation challenging, especially in the early stages. Some individuals may be asymptomatic but still require chronic dialysis due to poorly controlled hypertension or unresponsive hyperkalaemia. There are no specific diagnostic criteria for symptomatic uraemia, but worsening symptoms alongside kidney function decline are often used. Experienced physicians play a crucial role in diagnosing the uremic syndrome, providing invaluable support in clinical decision-making, particularly in multicentre trials where establishing symptomatic uraemia can be challenging (Agarwal, 2016).

According to Agarwal (2016), some individuals may remain asymptomatic and free from hyperkalaemia or poorly controlled hypertension despite having a very low eGFR). However, many of these individuals may still require the initiation of dialysis. A threshold of less than eight mL/min/1.73 m^2 may be permissible for initiating dialysis, where an experienced clinician may weigh the benefits against the risks. Therefore, when the physician deems that the benefit of KRT outweighs the risks of waiting for symptoms to develop, when eGFR has dropped to less than eight mL/min/1.73 m², and the individual undergoes chronic dialysis, such cases can be adjudicated as ESKD.

2.1.5 Kidney replacement therapy (KRT)

Kidney replacement therapy is required by individuals with CKD when conservative interventions fail to address fluid overload, hypernatremia, hyperkalaemia, and a decrease in urine output by 80%, as well as when pulmonary oedema is present and the eGFR is less than 15 ml/min. (Johnston & Noble, 2012b; Goumenos et al., 2016; Alrajhi, 2018; Han et al., 2019b).

KRT, comprising peritoneal dialysis, haemodialysis, and kidney transplantation, is the only treatment available for individuals with ESKD. Haemodialysis, recognised as a predominant and safe modality, is utilised as a life-saving intervention for individuals with ESKD and has been beneficial to approximately two million individuals worldwide. The blood of individuals with ESKD is effectively filtered from uremic toxins, and their body fluid status is corrected within a short period of time through haemodialysis (Kooman et al., 2018).

Studies conducted by Al-Marhuby (1998); Al-Za'abi (2018); Alrajhi (2018) highlighted the history of KRT treating the individuals affected by ESKD in Oman. Intermittent PD was initiated for individuals with ESKD in 1980, followed by the introduction of continuous ambulatory PD in 1992, which was further enhanced in 2007. Conversely, HD was initiated in 1983 and has persisted as it is regarded as the optimal option for treating individuals with ESKD. It remains the prevalent and preferred kidney replacement modality utilised worldwide (Alrajhi, 2018). Therefore, in Oman, the demand for KRT has shown a sharp progression due to the increase in ESKD prevalence (Al Alawi et al., 2017b). Currently, there are over 1,500 individuals undergoing haemodialysis and approximately 252 individuals receiving peritoneal dialysis, with the majority being young adults. Additionally, there are around 1,350 to 1,400 individuals who have undergone kidney transplantation (Health, 2018).

2.1.6 Cost of treating chronic kidney disease.

Chronic kidney disease has been regarded as a substantial cost burden on the global healthcare system. As a result, an estimated 2.5 million individuals with ESKD are receiving kidney replacement therapy worldwide (Hill et al., 2016; Al Ismaili et al., 2017; Alrajhi, 2018). Zhang and Rothenbacher (2008) stated that the average annual cost of RKT, excluding kidney transplantation, was between $70 and $75 billion globally in 2001. Additionally, these significant costs associated with treating individuals with chronic kidney failure impose a heavy burden on the healthcare system. For example, in the USA, approximately $30.4 billion (£23.4 billion) was spent on treating individuals with kidney failure in 2012 and $30.9 billion (£23.8 billion) in 2013. In Saudi Arabia, approximately 800 million Saudi Rials (£162 million) are spent annually to treat 14,562 individuals with kidney failure. In Oman, the total expenditure on kidney care is not known because neither publications nor MOH annual reports report it (Al-Za'abi, 2018). Al-Za'abi (2018) stated that in 1998, the total number of dialysis sessions was 191,638, which cost about 2,246,627 OMR (~ 4.5 million GBP). The dialysis sessions and treatment cost increased dramatically to 191,638 dialysis sessions for 9,543,572 OMR (~20 million GBP) in 2015.

2.1.7 Burden of chronic kidney failure

Non-communicable diseases have a major impact on the growth of the healthcare system, as well as productivity and costs (Couser et al., 2011). According to Couser et al. (2011), ESKD is considered to be a major driver for the healthcare system in developing countries. For example, the annual growth of dialysis programs in the past two decades ranged between 6% to 12%, and it continues to grow.

The increase in kidney failure incidence and the advancement in care management have led to an increased workload for professionals and care providers, such as nurses, nephrologists, and others. So, to provide the best care for kidney failure individuals, they are required to keep up to date with the latest epidemiological profiles of kidney failure, with the new technology interventions, with the best guidelines and intervention strategies and with the best evidence-based practice (Al-Za'abi, 2018).

On the other hand, in 2015, according to Luyckx et al. (2018), the reduction in glomerular filtration contributed directly to about 1.2 million deaths globally. Additionally, Luyckx et al. (2018) reported that in 2010, between 2.3 – 7.1 individuals died due to ESKD and without access to regular dialysis. Probably due to the underestimation of the kidney disease burden, the number of deaths increases every year. Oman has been ranked by the World Health Organisation (WHO) on the 51 positions where CKD is the most leading cause of death (Al Alawi et al., 2017b).

2.1.8 Information given to individual affected by ESKD in Oman

Individuals with Stage 5 CKD are informed of their treatment options, including transplantation, PD, and HD, before treatment is initiated. The importance of informed decision-making is emphasised to ensure that the best treatment option is selected by CKD individuals. Information is typically provided during nephrology consultations and is often supplemented with printed materials. Providing needed education empowers individuals with ESKD to make informed treatment decisions that align with their unique circumstances and preferences (St. Clair Russell & Boulware, 2018). Therefore, Treatment modality education take various forms—ranging from informal to formal, one-to-one session, and utilising printed materials. For example, brochures, pamphlets, and handouts are given to ESKD individuals and families.

For those considering KRTs, information is usually shared in the presence of family member or caregivers, and discussions frequently include details about dialysis permanent or temporary access, catheter insertion and care, and identifying doner for kidney transplant.

Moreover, the discussion about peritoneal dialysis involves identifying two caregiver who would be involved in two weeks PD training at the hospital and the continuation of PD at home. Whereas the discussion about undergoing haemodialysis includes practical steps before haemodialysis is started.

For example, once the nephrologist has performed a comprehensive medical assessment and decision made as haemodialysis found to be an appropriate kidney replacement therapy, a discussion about suitable vascular access will take place, including temporary access or permanent arteriovenous (AV) fistulas and grafts, as it takes a few weeks or months before dialysis starts to allow the access to mature.

Haemodialysis individual’s education includes the dialysis process, how dialysis works, and potential side effects during the dialysis session. Additionally, education includes dietary and fluid restrictions to manage waste buildup between dialysis sessions, therefore, the individual will be referred to dietician's department. Haemodialysis timing is also discussed with the individuals to adjust their lifestyle, work, and home situation.

The practical implications of having haemodialysis include frequency and duration. The individual attends a dialysis unit three times per week, and the dialysis sessions last about two to four hours. Therefore, it is a significant time commitment, and the individual may require work and personal schedule adjustments. Lifestyle adjustments require ongoing adherence to a restricted diet and fluid intake to prevent potential complications. An individual's ongoing care includes managing dialysis side effects, which might consist of experiencing fatigue, cramps, or other side effects that would impact their daily activities. Therefore, regular follow-up appointments with nephrologists are essential for monitoring health status, adjusting treatment, and managing complications.

2.1.9 Chronic kidney disease management in Oman

The healthcare system offers comprehensive universal medical coverage at no cost to citizens, hence reducing the likelihood of individuals refraining from seeking medical care. However, almost 50% of the population residing in Oman consists of noncitizens from Asia, namely the Indian subcontinent, who do not have access to free comprehensive healthcare. As a result, these individuals typically go back to their homes for permanent KRTs once they have developed ESKD, and information regarding these instances is not included in the register (Al Ismaili et al., 2017). The private health institutions in the country do not provide kidney replacement therapies. Primary care plays a crucial role in the early detection and management of CKD, which is essential for reducing the risk of progression to ESKD. Early intervention can help decrease the need for costly treatments such as dialysis or transplantation, thereby easing the burden on both healthcare systems and individuals (Fraser & Blakeman, 2016).

Primary care physicians are vital in understanding the nature and implications of early-stage CKD. They are responsible for identifying individuals with CKD, performing appropriate risk stratification, communicating diagnoses, and collaborating with individuals to ensure optimal management and risk reduction (Fraser & Blakeman, 2016).

Effective management in primary care is especially important in minimizing the risk of cardiovascular disease and other complications associated with CKD. However, for individuals with more severe kidney disease requiring KRT such as dialysis or transplantation, care is primarily managed in secondary care settings (Fraser & Blakeman, 2016).

According to MOH (2015) CKD is often caused by diabetes and hypertension, but it can also result from a range of other conditions. Referral to a nephrologist is advisable in situations such as unclear kidney disease aetiology, existing kidney disease, diabetes or hypertension, worsening proteinuria or albuminuria despite treatment, declining kidney function, persistent hyperkalaemia due to angiotensin-converting enzyme inhibitors or angiotensin II receptor blockers, and detection of small kidney size on a Kidney ultrasound.

Once individuals are referred to a nephrology clinic at the secondary hospital and evaluated by a nephrologist, laboratory investigations are repeated, disease staging is performed, and the treatment plan is developed. Individuals affected by ESKD at stages four or five are directed to a pre-dialysis clinic, where they are informed about KRT and guided in choosing the most suitable option. Additionally, as part of the consultation, individuals are referred to dietitians and health educators to support lifestyle modifications. For those who choose to not undergo KRT, regular appointments are scheduled for reassessment, and first-degree relatives are involved in the treatment plan. If choice to undergo KRT persists, documentation is made in the individual's medical record, and appointments at the nephrology clinic are continued until the condition deteriorates and haemodialysis is undergone in emergency status, following the individual's attendance at the hospital emergency department and subsequent admission to the intensive care unit.

2.2 Sultanate of Oman

The Sultanate of Oman is located in the Southeastern corner of the Arabian Peninsula. The sea of Oman in the northeast and the Indian Ocean in the southeast surround the sultanate of Oman. It has borders with United Arab Emirates to the north, the Republic of Yemen to the south, and Saudi Arabia to the west. Oman's land area covers about 309,500 Km2. The topographic features of the land area include valleys and deserts, which occupy almost 82%of the landmass; the coastal plains make up 3%, and the mountain ranges account for 15% (MOH, 2014; 2015; M.O.I, 2019; MOF, 2019; MOH, 2022b).

The challenging topography of Oman, coupled with its population distribution, presents difficulties for the healthcare system in providing accessible health services. The mountainous terrain forms a natural barrier between the coastal and desert regions, stretching from Musandam governorate in the north to Al Sharqia governorate in the south, thereby hindering access to healthcare for residents of the predominantly coastal areas. Moreover, the extensive desert landscape, particularly in Al Wusta Governorate, poses challenges for modern transportation, impeding the delivery of healthcare services to the dispersed population residing in these areas. Consequently, in terms of equity, Oman's healthcare system is dedicated to addressing the needs of the population, regardless of their geographical location, socioeconomic status, age, or gender, "*to live healthy and productive lives, through the establishment of a well-organised, equitable, efficient and responsive health system, grounded by societal values of equity and social justice*" (MOH, 2014).

Oman is geographically structured into eleven governorates, which are then further subdivided into 63 wilayats (districts or states or provinces). These eleven governorates are Muscat, Dhofar, Al Wusta, Al Buraymi, North Al Batinah, South Al Batinah, North Al Sharqiyah, South Al Sharqiyah, Al Dhahirah, Al Dakhliyah and Musandam. Each governorate is considered a healthcare region (MOH, 2022b). Oman, classified as a high-income country, has a population of approximately 4,711,149, with 38.9% being non-nationals, according to the National Centre of Statistics and

Information (NCSI). Population projections estimate that the total population will reach 4.7 million by 2050. Currently, children under the age of 5 years constitute 13.3%, and under the age of 15 years constitute about 38.4% of the population, while those aged 60 and above make up approximately 5.8%. Consequently, the productive age group, aged 15 to 64, comprises 75% of the total population. Furthermore, life expectancy has increased steadily since 1980, rising by 19.1 years to reach 77 years. Projections suggest that by 2050, individuals aged 60 years and above will represent around 13.1% of the total population(MOH, 2022b).

Figure 2.1 Sultanate of Oman in eleven governorates.

2.3 Healthcare System in Oman

The healthcare system in Oman has progressed through four distinct developmental stages. The first stage, from 1976 to 1990, focused on building the country's health infrastructure. The second stage, spanning from 1991 to 2005, concentrated on the development of various components within the healthcare system. The third stage, initiated in 2005 and ongoing, aims to achieve universal healthcare coverage by addressing specific demands through high-level strategic planning. The fourth phase of health planning commenced in 2011 with the initiation of the Health Vision 2050 development, which established the long-term trajectory of the health system for the subsequent four decades (MOH, 2022b).

The fourth phase of health planning, which began in 2011 with the initiation of Health Vision 2050 development, established the long-term trajectory of the health system for the subsequent four decades. This plan was introduced in 2014, aiming to invest in the healthcare sector to create a well-organised, equitable, efficient, and responsive healthcare system (MOH, 2022b).

Launched in 2016, Oman Vision 2040 is a comprehensive long-term development plan. It outlines various strategies and initiatives geared towards diversifying the Omani economy and fostering sustainable development (AL-ALAWI & JAWARNEH, 2023). As per the healthcare strategy outlined in Oman's Vision 2040, the Ministry of Health strives to provide comprehensive healthcare services across all levels, including preventive, curative, rehabilitative, and promotional aspects (MOH, 2022b).

The strategic health direction outlined in Oman Vision 2040 aims for a leading healthcare system with international standards. It describes a vision wherein Oman's healthcare system offers comprehensive coverage across all governorates through collaborative efforts between the government, private sector, and civil society. This involves expanding medical specialities and institutions, as well as enhancing medical staff training. Embracing international accreditation standards is deemed crucial across all healthcare facets. This transformation aims to foster a new societal outlook on health responsibility, bolstered by heightened community awareness and the pivotal role of technology in service delivery, disease prevention, communication, and education. Through technology, geographical barriers will be overcome, paving the way for universally accessible, top-tier healthcare services for Oman's citizens and residents (Unit, 2020).

According to the annual report published by the MOH in 2022, the expansion and enhancement of healthcare services in Oman are evident. The report indicates a total of 263 healthcare institutions, comprising 50 hospitals with a cumulative bed capacity of 4,954, 192 health centres, and 21 extended health centres primarily offering primary healthcare services. Additionally, 16 hospitals, spanning across 10 governorates, provide secondary healthcare services, with some functioning at a tertiary level. Notably, the Muscat governorate houses four referral hospitals specialising in tertiary healthcare (MOH, 2022b).

Furthermore, there are six additional governmental healthcare institutions catering to the needs of their employees and their families and managed by their respective authorities. These institutions consist of Sultan Qaboos University Hospital (SQUH), Armed Forces Medical Services (AFMS), Royal Oman Police Medical Services (ROPMS), Diwan Medical Services, Petroleum Development Oman Medical Services (PDOMS), and various private healthcare establishments.

Oman, under the rule of His Majesty Sultan Qaboos Bin Said, may his soul rest in eternal peace, the ruler of Oman from 1970 until January 2020, and under the rule of His Majesty Sultan Haitham Bin Tariq at present, has evolved into a modern country with state-of-the-art services and is described as a high-income country. Healthcare services are primarily for Omani nationals, with public financing mostly supported through government revenue, and approximately 81.1% is spent out of pocket for direct purchases (MOH, 2019). Conversely, non-nationals mainly receive their healthcare in private healthcare institutions.

The increase in Ministry of Health expenditure was observed from 1970 to 1990. Due to fluctuations in international oil prices, the Ministry of Health expenditure was influenced as the country's economy heavily depends on gas and oil. Therefore, economic issues impacted the country's healthcare status. The Ministry of Health expenditure decreased to 792.96 million (2016), 789.35 million (2017), and 699.53 million (2018), comprising (6.3%), (8.6%), and (5.1%) of government expenditure, respectively. Consequently, this may impact the ability to keep pace with healthcare service expansion, population demand and growth, disease patterns, and the increasing cost of healthcare services. Ministry of Health expenditures accounted for around 6.0% of total government expenditures in 2022 (MOH, 2022b).

In Oman, since 1970, the health coverage of the Omani population has improved. The Ministry of Health was able to reduce the rates of communicable diseases to 43% in 2012 (Al-Za'abi, 2018). The mortality rate for the below five years age group dropped to less than one in 100 children in 2014, and the country has been polio-free for 16 years with almost 100% polio vaccine coverage.

The healthcare system in Oman has subsequently shifted from addressing communicable diseases to non-communicable diseases due to their increased burden, necessitating ongoing management. Consequently, an individual-centred approach has been introduced to engage individuals in their treatment, promote a healthy lifestyle, and ultimately improve health outcomes and cost efficiency (MOH, 2019). In terms of transparency, the policy of the Oman healthcare system has enhanced individuals' choices in relation to their treatment.

2.4 Conclusion

This chapter presents the needed background knowledge for the present study and its specific context. It provides an overview of the key concepts of chronic kidney disease and explores its impact.

The subsequent chapter presents a literature review, emphasising the importance of this methodology within a grounded theory study. It also offers current insights into individuals' perspectives on treatment non-adherence, non-concordance with treatment, treatment refusal, and the various factors influencing this decision-making.

Chapter 3 Literature review

The aim of this chapter is to determine the primary themes in the study and emphasise the similarities and variations among studies in order to pinpoint areas where there are gaps in knowledge regarding the experiences of individuals who decline medically recommended therapy.

This literature review starts by providing a summary of the ongoing discussion on the role of literature reviews in grounded theory. This is followed by a justification for employing a literature review. Subsequently, it outlines the search methodology, provides a detailed account of the study's characteristics, synthesises the findings, and conducts a rigorous evaluation of the examined research. The chapter finishes by discussing the strengths and limitations of the studies conducted, as well as the gaps in the knowledge identified.

3.1 Literature review within the context of grounded theory research

The literature review conducted in this study preceded the selection of a method to identify gaps in the knowledge base for investigation. This study utilised the principles of grounded theory. Charmaz (2014) has argued that there has been ongoing disagreement regarding the appropriate period for consulting the literature in grounded theory. Glaser advised against examining the empirical literature at the start of a grounded theory study, as it could potentially bias the data by introducing biases to the researcher before data collection, so limiting the researcher's ability to approach the data with sensitivity (Glaser & Strauss, 1967; Glaser, 1978). Nevertheless, he suggested conducting a broader review of the theoretical literature at a later stage, specifically when common themes became apparent (Glaser, 1978). According to Corbin and Strauss (1990), it is recommended to engage with empirical literature early on in order to discover key ideas and utilise the researcher's expertise to expand data analysis. According to McGhee et al. (2007), it is not feasible to disregard previous knowledge in certain fields of interest. Dunne (2011) raised concerns about the feasibility of omitting a literature review in the initial phases of research. This component of a research proposal is crucial for researchers to obtain ethical approval and funding. Theoretical literature is highly regarded for its ability to provide justification and explanation for a certain study (McGhee et al., 2007). The background chapter in section 2.1 of this study includes a brief review of the literature that is relevant to the topic. As a doctoral student, it was necessary to review the existing body of research and present a concise overview of published studies in order to obtain ethical approval.

As I was doing the literature review ahead of a grounded theory study, I was committed to looking at the literature encompassing kidney disease. In order to gain a comprehensive understanding of my area of interest, I found it crucial to familiarise myself with a diverse array of publications and prior studies on various health problems. This allowed me to access different perspectives and ideas from other medical conditions, which might be applied to the management of my area of interest. The review was very beneficial to me as a novice researcher in determining and guiding the design of the current study. Due to my extensive personal and professional experience in the medical field, I found it difficult to approach the research subject without any preconceived ideas.

However, in this study, the review facilitated a thematic analysis of the existing knowledge concerning factors influencing treatment non-adherence, non-concordance, and refusal decision-making among adults with various diseases. Consequently, this review contributed to understanding relevant knowledge, aiding in the development of new knowledge and theory. It is argued that contemporary advocates of grounded theory, particularly Charmaz, endorse a prior literature review, contending that it informs both the formulation of questions and subsequent stages of theory development (Charmaz, 2006). Moreover, they advocate for researchers to ensure that early coding remains faithful to the data and is not excessively influenced by existing literature—a principle exemplified by how the coding is presented in the write-up, allowing readers to assess its fidelity to the data (Glaser & Strauss, 1967; Glaser, 1978).

Furthermore, by doing a 'sharply focused' literature review, researchers can enhance the power of their argument and establish their credibility by acknowledging the significance of past research. Grounded theorists frequently engage in interdisciplinary exploration to accomplish this goal (Charmaz, 2006).

3.2 literature review using a systematic approach

The scientific literature has undergone significant expansion. Conducting systematic or other types of reviews enables researchers, practitioners, and policymakers to remain current with the latest findings. These reviews help users condense and integrate vast amounts of information available, serving different objectives.

A systematic approach is used to conduct the literature review in this study. This approach is also referred to as a research synthesis. It is a structured approach aimed at summarising pertinent studies into a single document. Unlike traditional literature reviews, which often lack a formal method for estimating treatment effects and primarily focus on concepts or theory, systematic review prioritises data analysis. The goal of systematic reviews is to provide reliable findings that can inform practice and policy and guide future research endeavours (Aromataris & Pearson, 2014; Munn et al., 2018).

A systematic review is best suited for studies with a clearly defined research question. It focuses on addressing specific inquiries rather than providing broad overviews of the literature on a subject. Its goal is to consolidate and condense existing knowledge rather than generate new insights. As such, it necessitates relevant research on the subject. The process of formulating the review protocol begins with careful consideration of the question (Aromataris & Pearson, 2014).

Various forms of evaluations offer a collection of instruments that the researcher must utilise correctly. When conducting a review, it is crucial to provide clear details on the search method and the corresponding decisions made (Collins & Fauser, 2005). The clarity of a review allows readers to assess it more effectively (Dijkers, 2009). As a beginner researcher, I utilised a methodical approach to searching for relevant literature in order to ensure the organisation and coherence of the review process and to present the findings of the review (Green & Glasgow, 2006).

Therefore, the review sought to critically examine and assess empirical research that has explored the experiences of adult individuals with chronic diseases experiencing treatment non-adherence, treatment non-concordance, or treatment non-compliance, as well as those who choose to refuse prescribed treatment. Furthermore, the purpose of the search was to analyse the research methodologies employed and identify any gaps in the existing literature. In general, the objective was to offer a comprehensive analysis of the experiences of adult individuals with chronic diseases experiencing treatment non-adherence, treatment non-concordance, or treatment non-compliance, as well as choice-based to refuse treatment.

3.3 Methods

3.3.1 Search strategy.

A comprehensive literature search of the existing primary literature review was carried out using the following electronic databases: Academic Search Premier, CINAHIL Complete, MEDLINE, APA PsycINFO, Business Source Premier and Education Research Complete. These electronic databases were relevant to the area of inquiry and accessed via the University of Hull Library website service.

The selection criteria for the review were based on PEO (Participants, Exposures, Outcomes), a regularly utilised framework in qualitative research, and the formulation of search questions (Aveyard et al., 2016; Bettany-Saltikov & McSherry, 2016). PEO is utilised to address the review question in this analysis: '*Why do Adult individuals with different diseases choose non-adherence to their prescribed treatment?'* as follows (see table 3.1).

Table 3.1 PEO review question

Participants	Adult individuals with different diseases.
Exposures	Chronic disease.
Outcomes	Delay or refuse prescribed treatment.

Then the following key search terms were formulated and used in combinations and together with the Boolean operators OR and AND to identify the most eligible literature: "decision making" Or "Medical advice" And "delay* treatment" Or "refuse* treatment" Or "Against medical advice" Or "therapeutic dissonance" Or "non-adherence" Or "non- concordance" Or "non- compliant" Not paediatric" And "mental health treatment". The search strategy was refined and verified in collaboration with a specialised librarian and two expert supervisors at the University of Hull. Along with that, the reference list of all identified studies was screened for additional publications.

The search strategy was not restricted exclusively to kidney disease. Instead, the scope was broadened to include a range of chronic diseases to capture insights and trends that may be transferable to kidney disease management. Chronic diseases, including but not limited to kidney disease, often present similar psychological and behavioural challenges, such as treatment refusal. By expanding the focus to encompass various chronic conditions, the review facilitates the exploration of a wider body of literature on individuals' responses to long-term treatments, enabling the identification of patterns that may also be relevant to kidney disease. Moreover, individuals with kidney disease frequently experience comorbidities such as diabetes or cardiovascular disease. Thus, insights derived from studies on chronic disease management could provide a more comprehensive understanding of the complexities involved in care and decision-making for individuals with kidney disease.

The literature search was limited to the last ten years from the initial review search (2010 – 2020) to extract the most recent publications on the reasons that influence individuals with different diseases to treatment refusal, delay, decline, or non-adherence behaviour. Manual article references were also searched for additional relevant publications. The final search was completed in July 2020. This search review considered the only publications in the English language and translated to English due to the inability to translate and interpret non-English publications. Furthermore, the search review inclusion criteria included only adult populations aged 18 years and above due to their decision-making capacity. Therefore, the search review excluded the below 18 years population publications on mental health and palliative care. Table 3.2 shows the criteria for selecting the eligible publication.

Table 3.2 Inclusion and Exclusion criteria.

Inclusion criteria	Exclusion criteria
• Articles written in English. • Publications included adult populations 18 years old and above. • Published data from 2010 to 2020.	• Articles without English translation. • Publications included paediatric populations (below 18 years old). • Individuals without mental capacity. • Individuals receiving end-of-life care.

3.3.2 Search outcome

The Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) principles statement 2009 were used to guide the overall search process, as shown in Figure 3.1.

A multi-database literature search yielded a total of 1,376, of which 526 duplicate studies were removed using the EndNoteX9 referencing software programme. An additional 68 articles were retrieved from the reference lists of relevant systematic review publications and ended up with 918 publications. These remaining (n= 918) studies were screened against the titles and abstracts in order to match the inclusion and exclusion criteria. As a result, n=725 were excluded, which reduced the number of included studies to n=190. Then, a further screening stage took place with the support of second and third reviewers, and the articles' full text was screened for eligibility. A further n=140 studies were excluded because they were irrelevant to the inclusion and exclusion criteria as described in the PRISMA flow diagram Figure 3.2. Consequently, the remaining n=54 was included in the review.

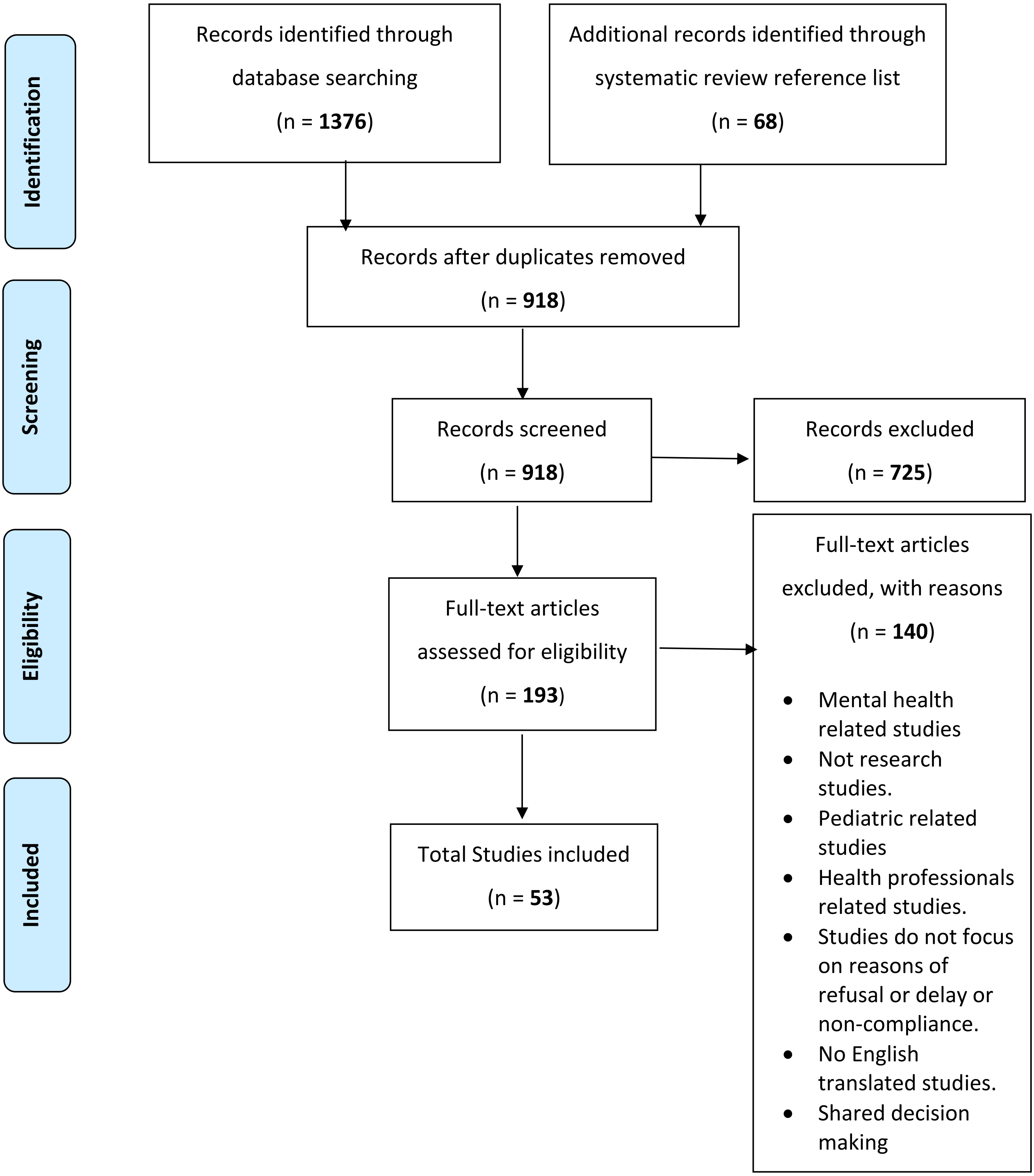


Figure 3.1 PRISMA flowchart of search strategy from reference (Moher et al., 2015).

3.3.3 Critical Appraisal and Matrix

The Clinical Appraisal Skills Programme instrument (CASP) is an educational instrument used widely to critique studies. It comprises different methodological checklists, each of which appraisal process was guided by a systematic number of questions (Purssell, 2020). Therefore, a relevant CASP checklist was adopted to critically appraise all the included studies in the review to address the research quality of reporting, conduct and risk of bias with the support of the second and third reviewers for validation. These were the CASP qualitative research checklist, the modified CASP cohort study checklist (Adams et al., 2019) and the Mixed Method Appraisal Tool (MMAT) version 2018 (Hong et al., 2018) see Appendix 2.

The scoring system was employed based on the number of affirmative "Yes" responses to the checklist questions. Extracted studies were categorised into three levels of quality: strong, moderate, and weak, using this scoring system. Each question on the CASP checklist was answered with "Yes," "No," or "Can’t tell." For the purposes of this literature review, only "Yes" responses were used to contribute to the overall score. After the CASP checklist was applied to the selected studies, they were categorised based on their quality scores. Studies with 8 or more "Yes" responses were classified as strong quality. Those with 4 to 7 "Yes" responses were deemed moderate quality. Lastly, studies scoring 3 or fewer "Yes" responses were categorised as weak quality.

In which (N=35) strong (one mixed method, eleven qualitative and twenty-three quantitative studies), (N=13) moderate (one mixed method, one qualitative and eleven quantitative studies) and (N=5) weak (two mixed methods, one qualitative and two quantitative studies). The results of appraisal checklist used are shown in Appendix 2.

3.4 Characteristics of included studies.

The matrix table in Appendix 1 lists all studies and includes details on methodology, participant sample, study locations, and tools applied within the research. This section offers an overview of the overall empirical evidence drawn from the systematic research strategy.

A total of 53 studies met the inclusion criteria for this literature review. Thirty-six of the publications reviewed were quantitative, thirteen were qualitative, and four used a mixed-methods design. There were nine studies from the USA and one from Canada. There were seventeen studies in Europe: six from the UK, two from the Netherlands and one from Germany, Spain, Portugal, Denmark, Sweden, Greece, Norway, France, and Turkey. Across Asia, there were sixteen studies: three from Iran, three from Pakistan, two from Korea, three from Singapore, and one each from Indonesia, Hong Kong, Lebanon, Nepal, and India. Six studies were carried out in Australia and two in New Zealand. While the African continent had five studies conducted from the total number in the review, there was a rate of study of one in each of Egypt, Ethiopia, Uganda, Malawi, and East Africa (Kenya and Uganda).

Across the body, evidence participants had a range of diseases. There was a range of papers focussing on individuals with Cardiovascular (N=8), HIV (N=5), Kidney (N=11), Diabetes Mellitus, and Osteoporosis (2). Other papers grouped into categories such as chronic diseases (N=5), rheumatology (N=5), and hypertension (N=5), as well as (1) study for each of the following diseases: Psoriasis, obstetric fistula, Cerebral Vascular Accident, Asthma, Cancer (general), Multiple Sclerosis and allergy. Additionally, there were four studies which did not specify disease profiles amongst populations.

The majority of the studies (N=37) discussed medication non-adherence. Other foci five studies were on the delay of treatment (N=4), declining treatment (N=6), and treatment refusal (N=7).

The sample size varied across studies, and this appeared dependent upon methodology/ study design. Across the four mixed-methods studies, a total of (N= 319) participants were recruited (with N=205 maximum and N=10 minimum). There were (N= 424) participants across the fifteen qualitative studies (N= 96 maximum and N= 9 minimum). As expected, quantitative studies had the most participants, offering responses from (N=177191) subjects with a maximum (N=19830) and a minimum of (N=34).

In terms of data collection, all four mixed-method studies used in-depth semi-structured interviews to collect qualitative data, except for one that used direct observation. One study developed a questionnaire to collect quantitative data, while the other three had no details. Furthermore, all the qualitative studies used one-to-one (face-to-face) in-depth semi-structured interviews using the topic guide, except one study used the telephonic interview. The majority of the quantitative studies (21) used a self-reported questionnaire through either face-to-face interviews or telephone interviews or internet-based, computerised, or mailed/ postal questionnaires.

Ten studies used self-reported questionnaires and linked data with individuals' medical records to extract information. One study used a self-reported questionnaire with laboratory data, one study used an interview with physical examination, and one study triangulated telephone interview data with individuals' medical records and data from their pharmacy. On the other hand, one study used individuals' medical records with forms requesting treatment. One audit project used a blood pressure check with biochemistry test data, urine test data, and imaging.

There was a total of eleven studies which did not report details on instruments used for data collection. Six used self-developed questionnaires individually pre-piloted and validated, and (14) adapted existing and validated tools very appropriate to the research focus. These tools included the following: response to systems questionnaire; A Discrete Choice Experiment (DCE); 8 items Morisky Medication Adherence Scale (MMAS); Brief Illness Perception Questionnaire (BIPQ); the Beliefs about Medication Questionnaire (BMQ); Medication Adherence Report Scale (MARS); National Health & Nutrition Examination Survey; Collaboration & Satisfaction about Care decision Scale; Health Beliefs Model (HBM) and the Theory of Planned Behaviour (TPB).

3.5 Review findings.

After thoroughly reviewing the literature and working with two additional expert reviewers, we identified 53 studies that were considered important to understanding how individuals perceive and experience delays or refusals of prescribed treatment. The researchers employed thematic synthesis, as described by Braun and Clarke

(2006), to combine the findings from the identified studies. Multiple themes surfaced in the analysed research that fit the issues posed in the review. The articles were analysed to identify key findings, and the review themes were used as subheadings in the synthesis to directly address the review questions. The allocation of papers based on the categorisation into four overarching themes and fifteen sub-themes can be found in Appendix 1. The examined papers explicitly examine the experiences of individuals who choose to avoid, or decline recommended medical treatments.

These main themes and sub-themes were developed by the findings' interpretation of each publication included in this review through abstraction, identification and coding. Therefore, discrepancies around the theme's categorisation were found until a consensus was reached. Table 3.3 displays the main themes and subthemes resulting from this literature review.

Table 3.3 Thematic table.

Main Theme	Sub-theme
Individuals' beliefs and knowledge of treatment and the potential outcome.	• Feeling well. • Faith. • Lack of knowledge. • Alternate sources of knowledge. • Fear of side effects.
Sociocultural context and influence.	• Culture. • Lack of support. • Lifestyle disruption due to undergoing treatment. • Physical environment and practicalities of access to treatment. • Financial.
Clinical treatment regimens.	• Treatment regimen complexities. • Drug availability.
Communication.	• Trust and empathy. • communication barriers. • Capacity to choose.

3.5.1 Theme 1 Individuals’ beliefs and knowledge of treatment and the potential outcome.

The first theme is about individuals’ beliefs and their knowledge of treatment and potential outcomes, and this varies between individuals with different diseases as well as recommended therapy.

Sub-theme1: Feeling well.

In this literature review, one finding was that some individuals tended to stop taking their treatment when they felt well (Wai et al., 2010) or felt satisfactory health status and not to start invasive interventions (Johnston & Noble, 2012a). Along with that, individuals repeatedly experienced misconceptions towards the discontinuation of treatment, so they would not refill their prescription nor attend follow-up clinics because they felt that they had recovered from their illness and do not require for medication anymore (Saqib et al., 2018).

Al-Hajje et al. (2015) mentioned that feeling better or worse led individuals to take a decision to cut back on their medication and believing that the drug therapy would not ameliorate their health condition and would cause them some side effects, which drove them to non-adherence to their treatment. Özdemir et al. (2017)and Kriegbaum and Lau (2018) stated that some treatment therapy normally advised to be taken as lifelong therapy. However, individuals often discontinue their recommended treatment regimen when they feel better after seeing such serum levels reduced in their blood or going back to the normal ranges. Perceived recovery also impacted the individuals’ refusal to treat. Some adjuvant therapies and concomitant prevention drug therapies were refused by individuals. As they were ‘feeling better’, they cited that ‘overuse of medicines had the potential to cause harm’ (Salter et al., 2014) or were ‘unnecessary’ (Lam et al., 2014; Aditama et al., 2020). For example, to prevent recurrent disease attacks, a secondary long-term drug therapy is recommended. Unfortunately, some individuals did not adhere to the advised medication because they often believe that they do not require further medication since they recovered (Sjölander et al., 2013). According to Johnston and Noble (2012a), some individuals reported that since they were feeling well with their prescribed medication, they were not required to undergo invasive treatment because they did not see any benefit from it. However, most of the participants were recruited from a single setting, therefore, the findings may not be generalised to overall population due to selection bias.

Sub-theme2: Faith

In addition to the above-mentioned concerns, Tumwine et al. (2012) sated that another possible explanation for these individuals discontinuing taking their medication was that they had strong, unwavering faith in God and miracles which would happen and heal them from their sickness without taking any medications. What is more, religious leaders play a significant role in advising individuals to stop their treatment and practice constant prayer to get a negative test. Witnessing healed individuals who rely on spiritual growth for their won healing motivated individuals to discontinue their advised treatment and cope with their diseases. Consequently, due to believing in God, these individuals did not feel worried about dying. Yet, in these findings, the sample size was relatively small, and participants were selected from a single setting, which ultimately caused difficulty in generalising the findings to the general population due to potential sample bias.

Sub-theme 3: Lack of knowledge

Individuals’ lack of knowledge about their therapy regimen contributed to major health outcomes and adverse reactions, which eventually put their health at risk of complications and death (Saqib et al., 2018). Hence, Farzandipour et al. (2015) and Shafi et al. (2018) stated that generally, the reason for individuals' refusal of the suggested treatment at different stages of their care would be a lack of knowledge about the nature of the treatment, negative consequences and alternative treatment choices.

For this reason, non-adherence to the treatment plan occurred due to individuals’ lack of understanding of their presentation and treatment and misunderstood the reasons for taking their treatment for a long period, feeling frustrated and not knowing the benefit from taking their treatment or not taking it (Salter et al., 2014; Shafi et al., 2018; Tan et al., 2019; Aditama et al., 2020). For example, some individuals with different diseases ignored the importance of health education in enhancing self-efficacy (Parrott et al., 2011; McKillop & Joy, 2013). In particular, individuals often believe that they would prefer to postpone seeking treatment and wait till disease signs are seen on their body or describe severe illness (Parrott et al., 2011; Lovell et al., 2017b; Han et al., 2019a). Or they tend to stop taking their treatment until they develop recurrent symptoms. This is because they do not understand the disease progression or the consequences of treatment non-adherence (Raghunath et al., 2019).

What is more, McHorney and Spain (2011) and Lovell et al. (2017b) found that many individuals were non-adherent to their recommended treatment due to their disease progression and treatment being misinterpreted, and they perceived that their health condition was under control.

Further, Lam et al. (2014) and Aditama et al. (2020) found that lack of knowledge caused some individuals with health diseases to perceive that strict adherence to treatment plans considered unnecessary due to no obvious changes made in their physiological responses or adverse consequences between non-adherence and adherence. Also, Stack et al. (2010), McHorney and Spain (2011), and Al-Hajje et al. (2015) reported in their studies’ findings that individuals with health conditions had concerns about their prescribed medications. So, due to individuals’ lack of knowledge and understanding, they perceived that these medications were ineffective in improving their health states because they did not see any evidence of medications' active action on their bodies. Therefore, they believe that they would stop taking their medically advised treatment because they were not in need of it and it may worsen their health status (Laba et al., 2012; Saqib et al., 2018; Bartolomé-García et al., 2019). They perceived these drugs as unimportant because it’s been prescribed as a supplement therapy for healthy people, where they can buy them without a prescription to maintain their health (Lam et al., 2014).

Again, individuals’ lack of knowledge, lack of motivation to take medication, and not noticing any improvement in their health conditions caused them to demonstrate non-adherence behaviour (Ghimire et al., 2017). For example, some individuals prioritise their medications as non-benefit because these drugs got washed out during some procedures; therefore, they believed that these medications remained ineffective for their bodies.

Yet another related reason was that, for instance, individuals’ lack of knowledge led some individuals to perceive that their taken drug did not make any difference in their bodies and had a doubt if that drug would prevent them from such risks as heart attack and lower their cholesterol (Fung et al., 2018).

Another example is the result of individuals' lack of understanding of diseases and treatments. Sofianou et al. (2013) found in their study that half of the individuals appeared to underuse their asthma controller therapy because they believed that their health condition was not a disease, they did not experience recurrent attacks, and their physician was able to cure their physical condition. Therefore, they decided that they did not require treatment anymore. Moreover, individuals' lack of information about the consequences of their decision to refuse treatment led them to leave the health institution against medical advice and perceive that their health status was manageable (Manouchehri et al., 2012; Noohi et al., 2013; Anees et al., 2014).

Kromer et al. (2015) stated that due to individuals’ lack of knowledge, some individuals experienced disagreement between individual preferences and required treatment, which commonly resulted in treatment non-adherence and satisfaction. For example, some individuals believed that aged individuals less valued treatment importance than younger individuals due to their worries about severe drug adverse reaction and their poor quality of life (Kromer et al., 2015). Too, Johnston and Noble (2012a); Seah et al. (2015) and Shafi et al. (2018) find that old-in-age individuals affected by ESKD preferred not to embark on any complex intervention due to their misconception of their quality of life. They did not see any major benefit from undergoing invasive intervention three times per week and following this path because they believed it was meaningless to prolong their life. As well as they believed it was time-consuming (Han et al., 2019a) because they were old enough (average age 75) and the approach of death inevitable. Also, the misconceptions about the past death of some relatives with the same disease caused them to refuse to start their treatment (Anees et al., 2014). However, the researchers in most of the studies involved were individuals who looked after the participants, which affected their perspectives and participants' responses, causing response bias. In particular, participants' responses were influenced by recall bias, overestimation and social desirability due to medication adherence self-reported assessment. In contrast, comorbidities and treatment experience played a significant role in influencing participants' treatment preferences. Additionally, sampling bias limited the generalisability of this finding because most of the participants were from one specific group who had a range of health conditions.

Sub-theme 4: Alternate sources of knowledge

Haberer et al. (2013); Anees et al. (2014), and Farzandipour et al. (2015) found that individuals were often influenced by family and friends’ opinions and engagement with treatment. For example, negative information generated through other individuals’ lived experiences or family members or friends influenced some individuals to give up and refuse to undergo some invasive innervations (Xi et al., 2011; Seah et al., 2015; Shafi et al., 2018).

Stavropoulou (2012) found that non-adherence to recommended treatment was due to seeking negative information about their treatment from media and internet platforms. For instance, sometimes individuals terminate their treatment by following negative information disseminated through social media and TV programmes about long-term drug utilisation and its’ serious consequences to their body organs like the liver (Özdemir et al., 2017; Kriegbaum & Lau, 2018). Yet, the limitation of the findings lies in the fact that these findings were based on participants’ perceptions and may not objectively reflect reality; therefore, information bias could possibly occur. Most of the participants were recruited from one setting, and the sample sizes were relatively small, so the generalisability of the findings was limited.

Sub-theme 5: Fear of side effects.

An important finding was that the lack of treatment adherence among adult individuals with health diseases mostly occurred due to generic anxieties about medication taken, experience and fear of medications' negative adverse reactions and perceived lack of necessity for medications.

Many study participants found it to be deliberately reduced treatment frequency or stopped because they experienced worries about the drug side effects on their body organs. For example, they preferred to replace their prescribed medications with herbal remedies because they believed that herbal treatments were safer on their body and would avoid such negative adverse reaction (Salter et al., 2014; Aditama et al., 2020) and others alternate their planned treatment with spiritual therapy or homoeopathic medication because they feared of undergoing procedure complications and believes that no treatment available in medicine to treat their diseases (Anees et al., 2014; Shafi et al., 2018). Another reported concern was that individuals had a negative sign about side effects due to long-term medication, and they perceived it as a toxic and harmful substance (Raghunath et al., 2019; Tan et al., 2019). As a result, they had no preference to continue with their prescribed medications (Laba et al., 2012) and tended to change their lifestyle (Raghunath et al., 2019). Yet, it appeared to be a major challenge due to low self-efficacy to adopt healthy lifestyle behaviour (Lam et al., 2014).

Salter et al. (2014); Laba et al. (2015), and Ghimire et al. (2017) highlighted that the medication non-adherence amongst some types of individuals was extremely common; some individuals experienced and perceived non-adherence and delays in starting their treatment were due to their scepticism on treatment efficacy and disbelieve on its necessity to prevent them from persistent diseases or death (Anees et al., 2014; Wouters et al., 2016). As an example, the aged individuals believed that falling and having fractures were a normal phenomenon for their age, and such medications would not prevent them from getting fractured (Salter et al., 2014; Laba et al., 2015). Because they perceived that there was a lack of agreement with medications that would keep them active and anticipated bone fracture would cause them disability (Solomon et al., 2011). Also, they believe that taking regular medications might cause current and future health problems (Laba et al., 2012). Therefore, they had a certainty that they could take care of themselves without any treatment (Solomon et al., 2011). Moreover, some individuals believed that starting on invasive treatment would lead them to death; therefore, they refused to start their treatment when it was offered to them (Anees et al., 2014; Shafi et al., 2018). However, these findings were subject to certain limitations. For example, potential sample bias and desirability bias are presented in most of the included publications. The participants were motivated to take care of their own health and reported positive experiences making decisions on their preferred treatment. They were studied in a single site with a limited number, which constrained the findings' generalisability.

Moreover, other individuals described some degree of feeling tired and unwell to continue taking their medications and felt that there was a need to alter their medication intake due to no immediate benefits and to fight their experience of medication side effects (McKillop & Joy, 2013; Laba et al., 2015; Han et al., 2019a). They also compared themselves with other individuals who were not compliant with their treatment regimen and stated that their treatments were not effective nor benefit their health (Laba et al., 2012; Aditama et al., 2020).

Also, a group of individuals referred for invasive procedures showed complete treatment non-adherence or not to undergo the procedure due to their experience of intervention negative adverse effects and potential complications due to comorbidities or witnessing peers with the same health conditions who experienced a negative impact on their life (Patel et al., 2016; Han et al., 2019a).

While Håkonsen and Toverud (2011) stated in their study findings that non-adherence to generic substitution medication is an issue among the immigrant population with health diseases and using lifelong drug therapy, where these individuals believed that it was difficult for them to shift to the non-branded drug, and some of them did not accept substitutions because they experienced poor drug effects and more side effects. These individuals believed that cheaper drugs were considered fake drugs because they labelled them as non-branded products with poor quality.

Whereas Malayala and Raza (2016) found that some individuals took the decision to discontinue their treatment and to be non-compliant with drug prescriptions because they reported serious drug side effects. Hence, they believe more in perceived self-efficacy to execute their decision and stop treatment because they want to compensate for the serious drug adverse effects impact (Malayala & Raza, 2016; Kriegbaum & Lau, 2018). Similarly, Dennis et al. (2011) identified that individuals believed that the recommended treatment did not show any benefits towards their health status, and they were more bothered by the treatment's negative side effects.

Likewise, Golub et al. (2013) stated that the clinical trials showed that adherence to oral antiviral pre-exposure prophylaxis (PrEP) was affected by concerns over the drug's side effects, the effect of the drug on their health due to prolonged use of it and their belief that PrEP would not provide them complete protection against HIV because it might affect the effectiveness of the antiviral therapy once individual became positive.

Zwikker et al. (2014), Gadallah et al. (2015), Betegnie et al. (2016) and Suh et al. (2018) found that recommended therapy would help reduce the disease progression and improve individuals’ functional outcome and quality of life for a long period. However, the majority of individuals in their studies were doubtful about their recommended medications. They believed that medications were not necessarily to be taken and those medications would not prevent them from future complications due to the negative drug adverse reaction that they experienced.

Likewise, Morris et al. (2016) noted that some type of individuals rationalised their decision for being non-adherent due to the intolerable treatment side effects and disease progression during the treatment regimen. Xi et al. (2011) reported that other individuals refuse to undergo the invasive procedure due to fear of the procedure and its potential complications and poor outcome (Anees et al., 2014). However, the main weakness of these findings is that the individuals’ medication beliefs and non-adherence-associated connections were difficult to measure due to the cross-sectional study design, which provides only correlation analysis. Moreover, due to the self-reporting technique, the response bias was expected, and studies small sample size limited the ability of generalise study's findings.

3.5.2 Theme 2 Sociocultural context and influence

The second theme is about the sociocultural context and its influence on an individual's treatment adherence, which would be associated with their overall good health outcome (McKillop and Joy (2013), enabling them to incorporate their diseases and its treatment therapy into their daily life (Lam et al., 2014).

There are many factors that challenge individuals in their everyday lives to be adherent and remain compliant with their recommended treatment therapy. Treatment regimens have a social, financial, physical and psychological impact on individuals and their families. So, adherence to regimes is often balanced with everyday lifestyle activities.

Sub-theme 1: Culture

As found in this literature review, some individuals often feared attending a specialised clinic to get their treatment. Because they believed that attending the clinic would indicate that they are positive openly in their community from a specific illness, which ultimately causes them to feel shamed and stigmatised (Parrott et al., 2011), some individuals were found to delay seeking treatment because they did not want to appear sick and weak in front of their family members, friends and the whole community; otherwise, that would lead them to feel shamed and accused of immoral behaviour (Parrott et al., 2011; Adefris et al., 2017). Moreover, they believed that once a disease was disclosed, it would lead them to lose their right to respect and feel stigmatised, as well as they would lose their marriage chance sometime or marriage dissolution (Parrott et al., 2011). Additionally, they had a sense of losing their autonomy in their daily life and normality once they were stuck in the treatment adherence path (Haberer et al., 2013; Lam et al., 2014; Ghimire et al., 2018; Han et al., 2019a). On the other hand, Johnston and Noble (2012a); Seah et al. (2015) stated that some individuals refused to start some invasive treatment because they believed in their right to make their autonomous decisions.

Another example, Adefris et al. (2017) reported that obstetric-related problems considered to be serious morbidities lead to maternal death (Adefris et al., 2017). Under these circumstances, Adefris et al. (2017) found that the contented reasons that some women present late to seek treatment were when they felt embarrassed and isolated themselves because they were afraid of disease disclosure and social stigmatisation. Limitations of this finding were information bias, as participants were interviewed at a single point in time, and no follow-up was performed on individuals who refused interventions. Researcher bias was a potential problem reported due to the principal researcher's dual roles as the researcher and individual looked after the participants. The sample size was relatively small, which limited a rigorous and detailed analysis of additional factors.

Sub-theme 2: Lack of support

A lack of support from family and friends was cited as a rationale for individuals' non-adherence to treatment. One finding in this literature review was that, in human immunodeficiency virus disease contexts, individuals' position of responsibilities within their family plays a significant role and is considered to be a barrier to seeking treatment (Parrott et al., 2011). Adherence to a specific treatment plan caused individuals to be disrupted in their daily routine activities (Betegnie et al., 2016).

For instance, individuals normally require some kind of confidential support to help them overcome their disease and its treatment challenges. As a result, many clinicians engage close relatives (spouse/ partners, friends and family members) as a source of individual support so that they remain compliant with their advised treatment plan (Parrott et al., 2011; Lovell et al., 2017b). For example, if individuals had a long-term illness or serious diseases, they would generally go back to their natal home to get support from their home members. However, the study by Parrott et al. (2011)

identified that some individuals required family member support to comply with their advised treatment, but they lacked such support, and they refused to seek it because they believed it might compromise their independence. This was emotionally hard on them when individuals themselves had been providers of support and advice to their relatives and family members. Therefore, lack of family support led these individuals to expose their health to the risk of disease complications and death (Parrott et al., 2011). On the other hand, lack of support led some individuals to feel undergoing regular invasive intervention would burden their family members and remain dependent on them and may undermine their quality of life and caregiving responsibilities, especially if they looked after someone. Therefore, they preferred not to start their invasive treatment and take care of themselves (Johnston & Noble, 2012a; Seah et al., 2015; Lovell et al., 2017b; Han et al., 2019a).

Furthermore, Tan et al. (2019) reported that a lack of family members' support and negligence were conducive to the individuals’ non-treatment concordance. For example, some elderly individuals experienced poor social support due to their children's negligence, which caused them to live independently and take care of themselves. They found it challenging to maintain their daily routine and treatment adherence.

This was especially relevant with regimes related to dietary restrictions. For example, Ghimire et al. (2018) stated that non-compliant individuals with dietary restrictions reported a lack of support from their significant family individuals in accepting and approving the diet restrictions plans for disease control. Those individuals were influenced by their family members who had demands that needed to be met.

Similarly, some individuals lack family support and have social responsibilities and family commitments, which influenced them to refuse the planned treatment and leave the health institutions against medical advice despite their sickness because they felt that their lives got disturbed by undergoing treatment.

Additionally, Patel et al. (2016) and Aditama et al. (2020) stated that individuals lack someone to help them read the instructions mentioned for the use of the medication prescribed and follow the daily drug's scheduling, leading them to often forget to take their medication and miss doses. These findings were limited in terms of self-reported data, and there was potential for misclassification of cases and control in some studies as adherence and non-adherence, which led to information bias. Besides, sampling bias constrained the study's analysis to the general population without including individuals who were most in need (Patel et al., 2016; Aditama et al., 2020).

Sub-theme 3: Lifestyle disruption due to undergoing treatment.

Lack of time, family and work commitments were cited across many studies, which caused most individuals to forget to take their due medications, miss doses, not attend their scheduled appointments and refill their prescriptions and finally to be non-adherent to their treatment plan (Wai et al., 2010; Håkonsen & Toverud, 2011; McKillop & Joy, 2013; Lam et al., 2014; Salter et al., 2014; Gadallah et al., 2015; Ghimire et al., 2017; Carneiro-Leão et al., 2018; Fung et al., 2018; Aditama et al., 2020). For example, individuals prioritise doing other activities overtaking their treatment, such as commitment to their work by working long hours, family commitment in looking after children, housework, church activities and other responsibilities, which ultimately contributed to poor medication adherence (Wai et al., 2010).

Al-Hajje et al. (2015) and Aditama et al. (2020) stated that individuals forgot to take their prescribed treatment on time due to busy daily schedules and lack of close relatives support in reminding them to take their advised medication. Some individuals relate their medication taken with their meals, so if they skip taking their meals, they end up not taking their due medications per day (Ghimire et al., 2017).

Similarly, social responsibilities and family commitments influenced some individuals to refuse treatment and leave the hospital against medical advice despite their acute sickness because they felt that their lives were disturbed by undergoing treatment (Manouchehri et al., 2012; Noohi et al., 2013).

In addition to this, some individuals tend to forget to take their medication while travelling because they often feel hassled to stick to their treatments (Gadallah et al., 2015). Similarly, they found it inconvenient to adhere to their treatment plan during the travelling period or performing outdoor activities, specifically if they would need to undergo specific intervention (Ghimire et al., 2017; Lovell et al., 2017b; Han et al., 2019a). Yet, these findings are limited to potential recall bias due to self-reported methods used for treatment adherence. Similarly, using the self-reported method led to information bias due to individuals' desirable answers provided. At the same time, the risk of response bias was reported because some individuals were interviewed during their intervention sessions, which caused them to be hesitant to respond freely while sharing their experiences.

Sub-theme 4: physical environment and Practicalities of access to treatment

One of the key reasons for individual non-adherence to treatment, as reported by Wai et al. (2010) and Johnston and Noble (2012a) in high-income countries, was concerns about transportation.

For example, some individuals reported a lack of transportation due to their home members' work engagement, which caused them not to adhere to their clinic appointments as planned and refill their prescriptions (Wai et al., 2010). Therefore, they ran out of medications for a long period because they were unable to collect their drug prescribed. Also, some individuals found it difficult to use such types of public transportation to commute to and from health facilities to collect their regular prescribed treatment due to their health problems, immobility and high transportation payments (Johnston & Noble, 2012a; Tan et al., 2019).

Nelson et al. (2013) and Ghimire et al. (2017) identified that, due to some individuals' remote locations, they experienced difficulty accessing some specialised medical services located mostly in towns or cities that are far away from their living places which may take them two days or more to reach the health facilities (Adefris et al., 2017). Therefore, these individuals also found it inconvenient to not refill their medication prescriptions for more than one month due to their health conditions, which resulted in their medication non-adherence (Ghimire et al., 2017) or even delay undergoing invasive procedures three times per week (Johnston & Noble, 2012a; Nelson et al., 2013). Likewise, Adefris et al. (2017) whose study found that some individuals living in suburban areas experienced non-adherence to their interventional procedures due to unavailability of roads and transportation issues. However, the limitations of these findings were in terms of potential of researcher influence on participants responses due to researcher's dual role which limited the findings validation. While most of the studies conducted in a single centre with a limited sample size which affected the study's findings generalisability.

Sub-theme 5: Financial

Healthcare is expensive and not always readily available to all individuals. Costs of treatment and access to healthcare, treatment and services vary across the globe. Thus, financial implications on adherence were raised in a number of studies.

Dennis et al. (2011) and Goldsmith et al. (2017) noted that worldwide, inflexible or decrease in out-of-pocket medication cost phenomenon was a key-driven factor that caused individuals not to refill their prescriptions, skip doses and stop taking their medications, which impacted negatively on their health outcomes and quality of life. Eventually, this is associated with an increase in individual emergency visit rates and hospitalisation.

Similarly, financial stress was found to be experienced by individuals with no regular income and in areas with limited resources. That is also considered a risk factor for increasing individuals' disease progression, complications and rate of death, which result from individuals' non-adherence to their planned treatments (McAllister et al., 2013; Betegnie et al., 2016).

Again, some individuals experienced financial constraints which hampered them to seeking for early treatment, to pay for medications prescription and refill prescriptions and start on regular invasive treatment (Parrott et al., 2011; Haberer et al., 2013;

McAllister et al., 2013; Nelson et al., 2013; Al-Hajje et al., 2015; Gadallah et al., 2015; Laba et al., 2015; Seah et al., 2015; Adefris et al., 2017; Ghimire et al., 2017; Goldsmith et al., 2017; Fung et al., 2018; Kriegbaum & Lau, 2018; Han et al., 2019a). For example, having multiple prescribed medications caused them to have cumulative costs, which by then caused individuals inability to afford them. Likewise, when some individuals' Medisave accounts got depleted, that caused them to delay obtaining treatment and the burden of paying for healthcare visits and expensive treatments (Nelson et al., 2013; Adefris et al., 2017; Tan et al., 2019).

Then, not having drug insurance and having a low-cost profile was considered to be another financial strain, which caused a burden on the individuals’ budget to buy the clinically preferred medications. Therefore, these issues led individuals to go for sub-optimal substitution drugs by buying the cheapest and non-branded medication to control their health condition (Håkonsen & Toverud, 2011; Goldsmith et al., 2017). Additionally, Goldsmith et al. (2017) and Tan et al. (2019) pointed out that most of the individuals with poor health and multiple health conditions could not balance between drug importance and drug cost burden due to other determines and necessary expenses, including household expenses, food and transportation.

Ghimire et al. (2017); Han et al. (2019a), and Tan et al. (2019) found that irregular financial support and lack of social support to be another challenge which left individuals in uncertain situations to balance between their daily life needs and their treatments needs. For instance, financial support runs for a short term, and most of the financially affected individuals do not know the application process for a social support system, or their application is often rejected. Another example is that due to disease complexities, some individuals require additional supplemented medications, which they cannot afford due to their financial constraints (Ghimire et al., 2017). Additionally, due to a lack of financial support sometimes, some individuals make decisions to discontinue their whole intervention plan and leave the health institutions against medical advice despite their illness severity (Manouchehri et al., 2012;

Gadallah et al., 2015) and feel that if the treatment was available for free of charge, they would adhere to the planned therapy (Golub et al., 2013).

The results of McHorney and Spain (2011); McAllister et al. (2013); Anees et al. (2014) Morris et al. (2016), and Carneiro-Leão et al. (2018) studies showed that poverty, financial hardship to pay prescribed medication or undergo invasive intervention and expensive hospital visit cost led individual with health disease appeared non-adherent to their treatment plan. Another example, some individuals with low-income experience discrimination because they cannot afford to buy the advised treatments. Moreover, the changes in individual's medication insurance and drug benefits also caused them financial hardship in maintaining their treatment adherence (McHorney & Spain, 2011).

Laba et al. (2012) reported that individuals private health insurance status influenced their decisions to stop or continue with their treatments. For instance, some individuals with some health illness had no private health insurance, which led to increasing their out-of-pocket cost of medications and caused them to decide not to continue with their medication due to financial burden. These findings encountered a number of limitations, such as limited sample size and limited statistical power, which led to the potential miss of additional factors associated with non-adherence. Also, the potential for information bias due to participants' self-reporting and self-beliefs; most of the participants' financial status was not assessed, and most of the interviews were conducted with participants who were healthy enough to participate in the interviews. In comparison, most of the involved studies were cross-sectional and could not be able to infer causality.

3.5.3 Theme 3 Clinical treatment regimens

The third theme explains that individuals' compliance with their treatment plan is influenced by healthcare providers, the healthcare system, and themselves (Aditama et al., 2020). Individuals with different health diseases usually receive a variety of prescribed treatments, and they often experience a number of drug therapy problems, which would lead them to treatment non-adherence behaviours.

Sub-theme 1: Treatment regimen complexities

Most of the time, complex prescriptions lead individuals to run out of their medication and delay refilling their prescriptions, which results in a negative effect on individuals' treatment adherence and managing their medications (McKillop & Joy, 2013). Along with that, Stack et al. (2010) stated that prescribing multiple medications and dosages (six or more drugs per day) caused some individuals with such health diseases to be non-adherent and non-persistent with their treatment plan. Therefore, to improve individual adherence and treatment outcomes, the prescribed treatment needs to be made very simple by fixing dosage and combining such medication if possible (McKillop and Joy (2013). Moreover, due to the drug prescriptions complexity, some individuals discontinued their treatment because they felt bored taking these medications for a long-term period (Laba et al., 2012; Aditama et al., 2020).

Laba et al. (2012), McKillop and Joy (2013); and Salter et al. (2014) reported that due to the complexity of medication prescriptions, some individuals found it difficult to cope with it. They often forget to take their medications due to multiple dosages per day and their interference with their daily routine work, specifically the one to be taken midday (Dennis et al., 2011; Ghimire et al., 2017). Further, some individuals made their decision not to take their prescribed medications because they felt tired and burdened taking medications throughout the day, which caused them to frequently forget to take their medications at bedtime (McKillop & Joy, 2013). However, some individuals with some health diseases refuse to undergo invasive treatment due to its nature and frequency; for example, they have to be on it permanently and twice or thrice per week (Shafi et al., 2018).

Acceptability of medication is an important factor in adherence. It includes palatability, swallowability, appearance, dosing regimens, perceived dose complexity and means of administration (Ghimire et al., 2017). Adherence is dependent on individual characteristics and the properties of the drug (McKillop & Joy, 2013). These factors were highlighted across a number of studies.

For example, Lam et al. (2014), Ghimire et al. (2017), and Aditama et al. (2020) found that some individuals reported that some kind of tablets were large, so they had difficulties swallowing them by then they decided to skip this type of drugs. Moreover, the unpalatable medication taste and medication package considered practical challenges led individuals to be non-adherent to their prescribed medications (Ghimire et al., 2017). Yet, these publications' findings' generalisability was limited due to sampling bias, and participants were recruited from a single health system level and did not include other health system levels and participants' experiences with multiple diseases and polypharmacy.

Sub-theme2: Drug availability

What is more, drug availability and dispensing less drug quantity than it should cause individuals to non-adherence to their treatment because they do not get back to the healthcare institutions to collect or refill their prescriptions (Aditama et al., 2020). Due to the inadequate quantity taken, individuals often believe that these prescribed medications do not produce the desired effect on their bodies. In terms of individuals undergoing invasive treatment, Anees et al. (2014) reported that some individuals refuse to start their treatment due to the non-availability of the needed services in nearby health institutions. However, the involved study’s findings were clinical observational mostly and no intervention measurement or individual follow-up took place, which ultimately led to information bias.

3.5.4 Theme 4 Communication

The fourth theme is about healthcare providers and individuals’ communication. Healthcare providers' effective communication and individual engagement play a significant role in individuals’ treatment adherence, disease management and control, and positive health outcomes (Ghimire et al., 2017; Tan et al., 2019).

Sub-theme 1: Communication barriers

communication barriers between individuals and healthcare providers were other findings found by Saqib et al. (2018) and Tan et al. (2019); some individuals had misconceptions about their diseases and treatment sustainability. So, these individuals believed that once they were not told to re-visit the health institutions, they would not go back for their follow-up visits or medication refills, assuming that either they become better due to the three days routinely dispensed medications, or the prescribed medications were ineffective. Additionally, these health professionals' lack of communication caused individuals to be unsatisfied with the advised health lifestyle modifications to improve their well-being (Tan et al., 2019).

Furthermore, Håkonsen and Toverud (2011) stated that immigrated individuals who were not fluent in the country's language often reported being poor adherent to their substitution medications because they would not attend and collect their treatment from the pharmacy by themselves and most of the time they found it difficult to communicate with the pharmacy personnel.

Saqib et al. (2018) reported that a lack of liaison mechanism and collaboration between the drug prescribers and dispensers in clarifying medication-related issues caused individuals to be confused about their dispensed drug dosage and frequency, which led individuals to be unsatisfied and to be not concordant with their prescribed drugs and adhere to them.

Another issue was that the use of health providers unclear and complex terminologies caused individuals confusion and misunderstood of the pharmacological terms and following their instructions, which led individuals to have concerns about the drugs prescribed in terms of how and when drugs should be taken, then they end up with impeded adherence behaviours and not comply with the provided instructions (Ghimire et al., 2017; Aditama et al., 2020). Yet, these findings reported the potential for sampling bias because participant recruitment focused on one specific group of population with one specific health condition, and the sample sizes were relatively small, which limited the findings' generalisability.

Sub-theme2: Trust and empathy

Individuals lack physicians' trust when they do not show empathy towards individual disease and treatment issues, which causes individuals to surpass their physicians' treatment recommendations (Ghimire et al., 2017).

For example, Salter et al. (2014) found that a number of individuals stopped taking their medications without notifying their physicians. This was because when they had queries about the effectiveness of their medications, they found that such interventions were not considered by their healthcare providers to monitor the effectiveness of their medications.

Noohi et al. (2013) and Laba et al. (2015) found that individuals sometimes fail to adhere to their planned treatment or even decide to leave health institutions against medical advice due to previous bad experiences and mistrust with their physicians and other healthcare providers. For example, health professionals' attitudes and behaviours, such as rudeness and anger, can cause individuals to hesitate in clarifying their doubts about their planned treatment, leading to non-compliance (Saqib et al., 2018). Moreover, Noohi et al. (2013) and Saqib et al. (2018) discovered that healthcare providers' lack of attention and carelessness toward individuals' concerns led to mistrust in health practices and non-adherence to prescribed treatments, resulting in individuals quitting healthcare services. However, these findings may be less generalisable to the overall population due to sampling bias. Additionally, these were single-point cross-sectional studies, making it difficult to assess causality and lacking follow-up to evaluate participants' decision-making outcomes.

Sub-theme 3: Capacity to choose.

Nelson et al. (2013), Farzandipour et al. (2015), and Laba et al. (2015) have highlighted that some individuals often refuse prescribed treatments and delay seeking immediate interventions or new medications due to a lack of information about their health conditions treatments and alternative therapies. Therefore, Salter et al. (2014), Farzandipour et al. (2015), and Laba et al. (2015) noted that healthcare providers' paternalistic communication style, along with a lack of regular interactions and follow-up with individuals, result in non-adherence to prescribed treatments. For example, in the studies by Nelson et al. (2013) and Farzandipour et al. (2015), several individuals reported that their healthcare providers never discussed different intervention options or the advantages and disadvantages of interventions, leading them to refuse their treatment plans. However, these findings were limited by information bias, as the data were based on participants' perceptions without measuring their decision-making capacity.

3.6 Literature review key findings summary.

This literature review examines the perceptions, experiences, and understanding of treatment non-adherence, refusal, delay, and declined treatment among adult individuals with various diseases. The review found that the majority of the literature focused on non-concordance with medication regimens, with a limited body of evidence regarding individuals' refusal or non-adherence to invasive interventions.

As detailed in the publications included in this review, four main themes and fifteen sub-themes emerged that influence individuals' adherence to their recommended treatment plans. Despite the significant issues associated with individuals' treatment adherence behaviours, studies have documented various factors linked to poor adherence to medications among individuals with different diseases.

According to the World Health Organisation's 2003 report on medication adherence, improving the effectiveness of adherence interventions could have a significant impact on population health, potentially exceeding the impact of specific medical treatment improvements (Lam & Fresco, 2015). Failure to comply results in approximately 125,000 deaths annually, with 33–69% of hospital admissions attributed to non-compliance (Lam & Fresco, 2015).

Arlinghaus and Johnston (2018) emphasised the importance of education in providing individuals with a deeper understanding of the personal significance of health information to enhance awareness. However, merely educating individuals about the general definition and consequences of diseases is unlikely to lead to behaviour change, treatment adherence, or concordance. Nevertheless, recognising the personal importance of adhering to a recommended treatment is crucial for individuals to maintain consistency in adherence. Therefore, personalised education is essential, integrating explanations of why information about the health condition and intervention is specifically relevant to each individual.

3.6.1 Misconception

The literature review highlighted that most individuals made decisions regarding treatment non-adherence, with some discontinuing their recommended treatment due to misconceptions such as feeling better and no longer deeming the advised treatment important to continue adhering to, as well as scepticism about medication efficacy.

These results reflect those of Marasine and Sankhi (2021), who also found that misconceptions about antidepressants are held by the majority of individuals. They believed that medication is unnecessary in the absence of signs or symptoms and that medication can be reduced or discontinued independently when feeling better. Moreover, adherence to antidepressants is predominantly influenced by the balance between perceived necessity and concerns regarding the safety and efficacy of the prescribed medication. Hence, there was a widespread belief among many individuals that long-term use of antidepressants may lead to kidney damage and is associated with toxicity. Additionally, concerns about addiction and psychological dependence on antidepressants were raised, all of which impacted adherence to treatment. These findings suggest that efforts should be made to increase individuals' adherence by strengthening physician-individual relationships. Physicians should emphasize individual education that includes an explanation of the drug, dosage, duration, and timing of administration, possible side effects, adverse effects, lag time before the onset of treatment and relief of symptoms, and consequences of non-adherence (Marasine & Sankhi, 2021).

Enhancing adherence and persistence to prescribed regimens is crucial for improving individuals' outcomes, as highlighted by (Ziller et al., 2013). Adherence, defined as the percentage of the prescribed dose taken within a specified time frame, was meticulously assessed through self-report using a standardised questionnaire. This evaluation, supplemented by interviews covering aspects such as side effects, attitudes towards breast cancer, treatment specifics, knowledge about breast cancer, and quality of life, offers a comprehensive understanding. Additionally, the review of hospital charts and prescription refill records from all participating physicians further contributes to a thorough evaluation of prescribed tablets. Implementing such a holistic approach is likely to contribute significantly to the overall well-being of individuals.

Furthermore, ageing and a diminished quality of life led some individuals to disagree with and prioritise their own preferences over treatment requirements. Collard et al. (2017) suggested that improving individual education among older subjects enhances their understanding of treatment, fosters adherence, and potentially enhances prescription safety while mitigating iatrogenic risks in geriatric care. Furthermore, enhancing individuals' adherence to their treatment regimen can be accomplished by utilising a combination of self-reported information and prescription refill counts. This approach is practical and provides a relatively objective means to assess adherence in real-life scenarios (Ziller et al., 2013).

3.6.2 knowledge

Additionally, individuals' lack of knowledge about their health condition, disease prognosis, and the benefits and risks of treatment regimens may ultimately lead to significant health complications and death. Conversely, media, the internet, and individuals' lived experiences have been identified as alternative sources of information that often convey negative perceptions about recommended treatments.

These literature review results echo Essack et al. (2023) findings on consumer beliefs and discussions surrounding sore throat, antibiotics, and antimicrobial resistance during the COVID-19 pandemic based on social media posts. Social media platforms are extensively used by stakeholders to share opinions and connect with peers, healthcare organisations, and professionals. When creating social media content, consider platform choice, adherence to guidelines, and content format, prioritising concise and visually engaging material. Use language that consumers understand and tailor messages to address specific misconceptions among different consumer profiles, considering the target audience's age group. Ensure accessibility to educational materials for all, especially those less familiar with social media, and provide appropriate training to future healthcare professionals on consumer profiles, antimicrobial resistance, and effective communication across digital platforms.

3.6.3 Sociocultural

Some studies in this current literature review have shown an association between individuals' sociocultural context and its influence on treatment non-adherence. Loss of normality and autonomy, feelings of shame, stigma, and accusation were issues rationalised by some individuals who attend health institutions regularly and engage with the treatment path. These results appear consistent with other research findings suggesting that lower medication adherence is contingent upon the individuals’ perceptions of their illness, which may vary based on their religious and cultural affiliations. Beliefs from various religions and cultures were documented in a study, revealing that in Malaysia, mental illness is perceived as a social punishment for certain individuals or as an affliction of the soul due to spiritual weakness. Similarly, Chinese culture views mental illness as indicative of a lack of self-worth, tied to achievements in education and financial success that bring honour to the family. Likewise, Indians attribute mental illness to malevolent forces. These beliefs collectively create obstacles to initiating and maintaining antidepressant regimens. Some individuals opt to experiment with prayer as a potential cure for their depression, leading them to discontinue medication (Marasine & Sankhi, 2021).

Additionally, Wong et al. (2020) found that Religious and cultural beliefs significantly influence the acceptance of Human papillomavirus (HPV) vaccination among parents and young adults in Asia. Concerns over the vaccine potentially promoting early sexual initiation are particularly prevalent among parents in affluent Asian regions like Hong Kong and South Korea, as well as in developing Muslim countries. Islamic values shape healthcare-seeking behaviours in Malaysia and other Muslim-majority nations, with some parents fearing that the vaccine may encourage risky sexual behaviours among teenagers. The social stigma associated with premarital sexual activity further complicates HPV vaccination decisions for young women in Asian societies, where norms emphasise sexual abstinence before marriage and value virginity. Consequently, many young women adopt a passive role in decision-making, seeking permission from elders despite being of legal age. Addressing these challenges requires culturally tailored education and community engagement efforts, involving religious leaders and delivering information within religious communities to improve vaccine acceptability.

3.6.4 Treatment complexity

Moreover, the findings from this literature review identified that most individuals' treatment adherence was influenced by the complexities of treatment regimens, including multiple medications and dosages, as well as factors such as medication palatability, swallowability, and appearance.

This outcome is contrary to that of Marahatta et al. (2020), who found that respondents exhibited a general awareness of the disease's name but lacked an understanding of key symptoms such as low-grade fever, cough, and blood-mixed sputum. Consequently, they turned to traditional healers like Dhami, Jhakri, and Lama, guided by entrenched beliefs attributing illnesses to past lives which resulted in significant repercussions, including incomplete adherence to medication due to the stigma attached to seeking daily treatment at health centres.

The complexity of the treatment regimen compounded the issue, as visiting health centres for daily doses was perceived as a major obstacle to adherence. Additionally, the stigma associated with being diagnosed with tuberculosis further deterred individuals from seeking treatment and complying with the lengthy and intricate regimen.

To address these challenges, a potential solution involves replacing the daily Directly Observed Treatment, Short-Course (DOTS) regimen with a monthly provision of medication monitored by a family or community member, accompanied by minimal counselling on proper administration. This approach leverages community engagement, empowering members to oversee medication intake effectively.

Furthermore, community engagement initiatives have the potential to mitigate the social stigma surrounding tuberculosis, foster social participation, and enhance the psychosocial well-being of individuals.

Some individuals may forget to take their prescribed medication regularly due to social responsibilities and work commitments. Therefore, it is encouraging to compare this result with the findings of Arlinghaus and Johnston (2018), who suggested that education is necessary to increase awareness about the importance of timely medication intake, along with training on effective methods to do so. Additionally, those who consistently forget to take their medication would benefit from training on developing a system to help them remember to take their medications on time. Hence, individuals need to comprehend both the reasons behind the need for change and the methods to implement it effectively.

Patzer et al. (2016) conducted in-person, structured interviews to assess how common it is for kidney transplant recipients to understand their medications and adhere to their entire drug regimens, as well as to explore how these factors relate to clinical outcomes. They suggested that strategies to help individuals who may have limited health literacy could include providing tools to decrease medication complexity, care coordination assistance via more simplified individual instructions or additional counselling, enhancement of medication labels using plain language, and providing at-risk individuals with periodic monitoring and feedback.

In summary, there is a crucial need for collaborative efforts to deeply understand individuals' needs and provide customised, person-centred care to both individuals and their families while considering their social and economic circumstances. This emphasises the significance of individual partnerships and the customisation of person-centred care to suit the unique needs of individuals and their families. This approach actively involves individuals in their care decisions, taking into account their preferences and requirements. Shifting from the traditional "care to individuals" model to a "care for individuals" model is essential, as prioritising individual engagement is essential for achieving better outcomes, improving the care experience, and ultimately reducing healthcare costs.(Clavel et al., 2021; Di Tosto et al., 2023; Vanstone et al., 2023).

3.7 Strengths and limitations

The strength of this literature review lies in its adherence to all EQUATOR guidance in reporting, ensuring transparency and consistency across the entire research strategy. A total of four researchers contributed to discussions and quality appraisal of the included articles, reaching a consensus opinion on the empirical evidence. The review utilised research with a variety of methodologies to address the original question, providing analysis from both qualitative and quantitative perspectives.

The search strategy was limited to the last ten years from the initial review search (2010 – 2020), and this may have reduced the number of eligible publications for review purposes (Meline, 2006). However, it is essential to maintain a clinically relevant context; therefore, studies over ten years old were considered outdated, and the search was completed in July 2020. Additionally, only empirical evidence published in English and with an English translation was included, which may introduce publication bias and limit the scope and validity of the study findings (Meline, 2006). Additionally, the search review inclusion criteria included only adult populations aged 18 years old and above, where it excluded publications on populations under 18 years, mental health. While this might shortlist the relevant studies that address the purpose of the review, it may bias the review findings, and ultimately, the literature review findings would not be generalisable to those excluded populations (Patino & Ferreira, 2018).

3.8 Conclusion

This literature review provided some useful insights into the individuals' perspectives related to treatment non-adherence decision-making and the interdependent themes and sub-themes that all act as key factors that led individuals with different diseases to make decisions and apply non-adherence behaviours towards their advised treatment. It identified a significant need to understand how and why individuals decide to digress from their physician's advice, and there is a significant lack of empirical evidence exploring how and why individuals make the decision to refuse advice or non-pharmacological treatment regimens.

The term 'refusal' was selected in the context of Oman, where individuals with ESKD stage five were provided with comprehensive information about the haemodialysis procedure, including its benefits, risks, alternatives, and potential outcomes, through nephrologist consultations and various printed materials such as brochures and booklets. Despite this thorough information, some individuals still chose to refuse medically recommended haemodialysis, reflecting their autonomy and right to informed consent. This decision acknowledges the importance of making healthcare choices based on personal values, beliefs, and preferences, even when those choices do not align with medical advice. Therefore, in this context, the term refusal' used descriptively to refer to an individual's decision to decline treatment without any judgment or implication of value. It is not intended to convey any moral or ethical evaluation of the individual's choice.

In this literature review, key terms such as treatment non-adherence, non-concordance, non-compliance, and refusal have often been used interchangeably, generally referring to the discontinuation of prescribed treatment or the refusal to refill treatment prescriptions. However, in this study, the term 'refusal' specifically implies a conscious and informed decision made by individuals with ESKD. This choice of terminology is intended to help interpret the participants' behaviours and actions within the specific context of this study.

This literature review revealed that most existing research focuses on medication non-adherence and refusal to fill prescriptions, with limited exploration of making decisions regarding invasive treatments, such as haemodialysis, among individuals with ESKD. Notably, the review identified a range of personal, social, and religious influences affecting individuals' treatment decisions. These findings highlighted critical gaps in understanding the nuanced reasons behind delayed or refused haemodialysis, such as misconceptions about the procedure, beliefs in divine intervention, and negative peer influences.

There was a significant lack of published evidence on individual’s refusal or delay in starting haemodialysis once they have been diagnosed with stage five ESKD.

Most of the available literature centred on Western populations and focused on the ageing population to the decision of undergoing dialysis or not since the introduction of the CKD conservative intervention (Helen et al., 2009; Johnston & Noble, 2012a; Han et al., 2019b). Despite highlighting the cultural elements of refusal, only three research projects were undertaken in Asia, and there have been no studies undertaken in Arab countries (including Oman).

Therefore, this literature review has highlighted a significant gap in research. To address these gaps, my primary data collection was designed to delve deeper into the personal and cultural factors that lead individuals with ESKD to make such decisions. The review informed the development of my research questions and guided the selection of participants, ensuring that my study would explore these under-researched areas and provide new insights into individuals’ decision-making behaviours.

3.8.1 Emerging research questions

The aim of this research is to understand the factors that influence individuals affected by ESKD decision-making about their haemodialysis treatment, so the research focus will be on this group of individuals. The objective of the study is to explore how and why they make decisions relating to their medical care.

The following research question is posed: Why do individuals with end-stage kidney disease decide not to comply with haemodialysis medical advice when recommended by their physician?

The next chapter will explain the research design approach and philosophy, sampling, and data collection techniques. The research instruments and instrument development, research setting, the data analysis approaches, rigour and the study's ethical considerations.

Chapter 4 Methodology

This chapter describes the philosophical underpinning of the study and the design and rationale of the research methodology. The chapter describes the use of constructivist grounded theory to explore the reasons behind Omani individuals affected by ESKD refusal of haemodialysis treatment.

A qualitative approach is essential to understand and explore why individuals with ESKD decide not to comply with medical advice on haemodialysis when medically advised. Having identified the gaps in the literature from the literature review, it is evident that no existing theories underpin the social and psychological process for these individuals. It is, therefore, appropriate to use a grounded theory approach for future construct information relating to the phenomenon. Constructive grounded theory will be used to understand the phenomenon of individuals affected by ESKD refusal of haemodialysis and explore the influential reasons that led the same individuals to make the decision. This thesis focuses on individuals diagnosed with ESKD and who have reached the fifth stage in Oman; therefore, throughout this thesis, the term ESKD will be used to reflect all individuals identified as ESKD in the study site.

4.1 Research aims and questions.

This study aims to explore the influencing factors contributing to end-stage kidney disease individuals' decisions to refuse to start haemodialysis in Oman, as perceived by those individuals themselves. Additionally, it seeks to understand the depth and possibly the hidden structures informing the decision-making process. Therefore, the research endeavours to answer the main question: why do individuals with end-stage kidney disease choose not to comply with medically advised haemodialysis?

4.2 Qualitative Research Design

The objective of this research is to understand the individuals affected by ESKD experiences and feelings about their treatment decision-making process. Therefore, the research design is qualitative in nature because it contributes to inquiry about the individuals affected by ESKD condition and explores the meaning of their experiences to create different options for the required changes (Taylor et al., 2013; Creswell & Creswell, 2017).

More importantly, the research strategy of qualitative research focuses on using the phenomenon descriptions, unlike quantitative research (Salvador, 2016). Hence, it aims to deeply understand individuals’ experiences and behaviours through constructed meaning and explanation and interpretation of that meaning (Castellan, 2010). Indeed, that always is followed by a natural interpretive approach depends on the conceptual study framework to develop understanding, generate insight and describe various realities (Castellan, 2010; Ritchie et al., 2013; Taylor et al., 2013). Qualitative research comes up with findings that are not reported by quantification sense or other statistical procedures (Ritchie et al., 2013). It produces a set of unique interpretive practices to visualise and transform the world into a series of representations, for instance, interviews, field notes, conversations, memos, or photographs (Castellan, 2010; Creswell & Poth, 2016). Since the qualitative research question or design is open and loose depending on the researcher's view, a literature review conducted before the research project takes place to smoothen the research field entry with an open mind rather than an empty head as a mark of respect to the research participants (Castellan, 2010). While grounded theory principles were used in this study, they are usually not recommended in early reviews of empirical literature to protect sensitive data and avoid data contamination. However, the literature review was done to find gaps in existing knowledge, provide a reason for the study, and help choose topics for data collection, which made it easier for the study to get ethical approval (Glaser & Strauss, 1967; Charmaz, 2006).

The review findings did not adequately explore perceptions of individuals affected by ESKD when deciding to refuse to undergo haemodialysis, specifically in Oman.

Qualitative research is an effective approach to exploring experiences and perceptions in order to obtain an accurate understanding of reality from an individual’s perspective. This allows an opportunity to develop further a theoretical explanation for a specific phenomenon, informed and underpinned by rich data (Arghode, 2012).

Qualitative researchers focus on how participants perceive the reality of the world from the ontological perspective of qualitative research, and it is continuously built in local situations (Castellan, 2010). Besides, in qualitative research, the breached objective separateness between the researcher and the participants is crucial to entering the participants’ subjective world and understanding the phenomenon from the participants' perspectives (Salvador, 2016).

According to Taylor et al. (2013), the qualitative research approach also endeavours to explore the subjective, unique, and context-dependent nature of knowledge using inductive thinking to form a statement of an investigated phenomenon. In qualitative research, participants are acknowledged as sources of information, and their shared personal expressions are valued as research outputs, meaning products. At the same time, words and language are essential to qualitative researchers because they are used as data that helps create meaning about human experiences. In addition, qualitative research findings are mostly appropriate for transferability rather than generalisability due to changes in people and phenomena circumstances (Taylor et al., 2013).

According to Gibson et al. (2004), one of the qualitative research characteristics is the participatory nature in the social world throughout construction and negotiation to understand specific experiences of people about a specific social phenomenon through a micro-scale analysis and a wider scale examination in the research participants' natural setting. It helps develop in-depth knowledge and detailed information about poorly understood or complex issues (Fossey et al., 2002; Moriarty, 2011).

Qualitative research is well-known and accepted in the social sciences field, but it only emerged as an acceptable approach in the health sciences field over the past couple of decades (Creswell & Creswell, 2017). Qualitative research is now considered a core part of health science research, exploring and understanding human beings' experiences regarding their health and illness. It helps to facilitate the changes required at different levels, such as personal and governmental, based on the best evidence and ultimately helps to advance medical and healthcare research (Taylor et al., 2013; Polgar & Thomas, 2020).

Therefore, qualitative research is the most appropriate methodology of the preferred approach to gain an understanding of the individuals affected by ESKD context in deciding to refuse medical advice embarking on haemodialysis, as well as to explore the contributing factors that led those individuals to make their decisions. More importantly, this phenomenon has not been studied earlier in the context of Oman.

Qualitative research originated from anthropology, sociology, humanities, and evaluation (Creswell & Creswell, 2017). René Descartes aimed to seek truth in 1637 by emphasising the importance of scholars preserving their analytical skills by distancing themselves from other influences. Individuals acquire information about the world through firsthand observation and sensory experiences. Wilhelm Dilthey emphasised the significance of comprehending individuals' life experiences for informed decision-making. Max Weber (1864-1920) introduced the concepts of direct observational understanding and explanatory understanding, asserting that while natural science focuses on producing propositions, social science seeks to understand individuals' meaningful experiences (Ritchie et al., 2013).

The following section will highlight the importance of understanding the philosophical underpinnings of social research development to grasp the various approaches to qualitative research (Ritchie et al., 2013).

4.3 Qualitative Research Approach and Philosophy

According to Creswell and Creswell (2017), research approaches highlight the research plans and procedures to identify the period for any research project, starting from broad assumptions to detailed steps of research data collection techniques, analysis, and interpretations. Choosing a concise qualitative research topic and setting well-planned data generation and data analysis procedures leads to successful qualitative research completion (Byrne, 2001).

The qualitative research approach occupies a crucial position within the research field due to its ontological, epistemological, and methodological paradigms (Arghode, 2012). Proponents such as Saunders et al. (2009), Becker (1996), and Guba and Lincoln (1994) have interpreted the meaning of these paradigms (Mkansi & Acheampong, 2012). Denzin and Lincoln (2000) defined a paradigm as a systematic set of beliefs, together with their accompanying methods, highlighting its role in understanding phenomena based on beliefs and assumptions to navigate real-world complexities (Patton, 2014). In this project, the paradigm refers to a collection of concepts and beliefs that influence what to research, how to conduct research, and how to interpret research findings (Creswell, 2007; Salvador, 2016). Therefore, researchers should consider their own assumptions and elements that make up the theoretical perspective. So, to understand the nature of reality and truth, paradigms will be explained to design the appropriate research methodology for this research project to understand the world's nature of reality and truth.

According to Salvador (2016), understanding research paradigms and their philosophical underpinnings is crucial for producing excellent research, as they are closely related to data collection and analysis methods. The key features of qualitative research involve addressing "what" and "how" questions (Ormston et al., 2014), which contribute to different qualitative research paradigms (Ritchie et al., 2013), including ontology, epistemology, methodology, and additional compatible assumptions that may be utilised to address the question "why" (Creswell, 2007; Salvador, 2016). Therefore, researchers should consider their own assumptions as elements that constitute their theoretical perspective. Thus, in order to understand the nature of reality and truth, paradigms will be elucidated to design the appropriate research methodology for this project and comprehend the nature of reality and truth in the world (Mkansi & Acheampong, 2012).

4.3.1 Qualitative ontology position.

The ontological assumption concerns understanding what constitutes the world and what there is to know about it (Arghode, 2012; Ormston et al., 2014; Salvador, 2016).

In other words, ontology refers to the meaning of "Being" and "reality" (Khan, 2014; Polgar & Thomas, 2020) by comprehending the social reality and the natural occurrences of the world through individuals' perceptions. Therefore, participants' lived experiences are considered an integral aspect of researchers' interests. Reality in qualitative research is often ambiguous because it is influenced by social interactions (Arghode, 2012). Consequently, researchers seek explanations from participants' beliefs, opinions, perceptions, and values. Thus, in qualitative research, data generation is based on participants' lived experiences to uncover existing realities (Arghode, 2012). Therefore, researchers report multiple realities by using multiple quotes to provide evidence of different individuals' actual words and present them from various perspectives(Creswell & Poth, 2016).

This study recognises that our understanding of the world is shaped by our social interactions and our perception of it. The premise proposes a concept of numerous realities instead of a single truth (Guba, 1990). It acknowledges that the perception of individuals forms the foundation for their actions in the real world. It recognises that reality is shaped by social construction through ongoing refinement and comparison between research participants and the researcher based on their collective experiences.

4.3.2 Qualitative epistemology position.

Epistemology is a theory of knowledge and the way knowledge is acquired ((Khan, 2014; Polgar & Thomas, 2020), and a study of the nature of knowledge and its justification (Arghode, 2012). Since it focuses on knowledge about the phenomena under consideration, researchers endeavour to find multiple explanations for that phenomenon instead of just one, as they believe in the existence of various truths through inductive reasoning (Arghode, 2012). In qualitative research, knowledge is generated from participants' beliefs and values; the researcher's main focus is on the knowledge construction process, not on whether knowledge is constructed or not. Therefore, the generated knowledge must be understood, interpreted, and unearthed to ascertain the validity of the findings (Arghode, 2012). Consequently, researchers in qualitative research immerse themselves in the field, living or working closely with participants to understand their perspectives and become insiders (Creswell, 2007; Creswell & Poth, 2016; Creswell & Creswell, 2017).

This study encompassed the understanding of individuals affected by ESKD refusal to undergo haemodialysis, their social and cultural backgrounds, and the expertise and experience of the researcher. Interpretivism posits that knowledge entails comprehending individuals' interpretations and the significance they assign to their experiences. The use of the interpretivism paradigm was deemed suitable for the research, as this paradigm recognises a relativistic ontological stance and values the concept that knowledge is socially constructed.

The ontological and epistemological standpoint of the study focuses on the world of significant meaning and the understanding of individuals. The selection of interpretivism and constructivism as the foundation for this study was informed by these ideas (Denzin & Lincoln, 1994).

The aim of this study is to obtain the viewpoints, beliefs, and experiences of individuals with ESKD and provide a detailed and analytical description and discussion of these perspectives (Lincoln & Guba, 1985; Charmaz, 2006). Hence, the study is firmly based on the interpretive tradition, with the objective of examining how individuals with ESKD interpret, understand, experience, construct, or establish their social world (Mason, 2002).

4.3.3 Paradigm interpretivism or constructivism.

According to Creswell and Creswell (2018), in social constructivism, people aim to understand their world and experiences, driven by specific objectives. In this paradigm, the nature of experiences is deemed subjective and diverse, thereby prompting researchers to pursue multifaceted perspectives rather than constricted ideas or categories. The research centres on participants' perspectives, shaped by interactions with others, history, and culture to gain shared understanding. This process generates theories or meaning patterns. Where researchers' own backgrounds influence their interpretations, therefore, it is essential to acknowledge their personal context. Thus, they interpret findings shaped by their own experiences to comprehend others' perspectives. The principles of constructivism are evident in the area of grounded theory, aligning with individuals' views.

Additionally, as highlighted by Ormston et al. (2014), delving into and comprehending the world reality and perceptions of research participants through their meanings and interpretations leads to the generation of knowledge. This understanding is shaped by the socially constructed meanings and interpretations derived from the viewpoints of participants in comprehending and interpreting their lived experiences. However, participants mould their understanding of the world through various factors, including psychological, cultural, historical, and social influences. Consequently, researchers endeavour to faithfully present the meanings of the social actions in which participants are embedded (Ormston et al., 2014).

The ontological position of constructivism emphasises social interaction by asking individuals' opinions about a phenomenon and building on individuals' lived experiences (Salvador, 2016). Hence, the act of building knowledge establishes a connection between the researcher and participants, achieved through the application of language and elements of the external world, thereby forming the foundation of social reality (Salvador, 2016).

In contrast, within the epistemological position, there is a deeper exploration of the impact and consequences of individuals' lived experiences (Salvador, 2016). Researchers engage with participants taking part in the investigation, resulting in the emergence of findings that evolve in complexity and depth as the study progresses (Salvador, 2016).

The constructivist methodological position constructs emergent themes that reflect the commonality of individuals' lived experiences, with trustworthiness and validation of findings determined by the participants themselves (Salvador, 2016). The decision-making process to refuse haemodialysis may exhibit commonalities among individuals affected by ESKD, but it is likely to vary based on individuals affected by ESKD unique experiences and backgrounds (Dyar, 2022).

So, semi-structured interviews using open-ended discussions, direct observation, and focus group discussions are methods researchers employ, using hermeneutic techniques to systematically explore the layers of meaning and interpretation within participants' constructions. Employing dialectical dialogues enables the exploration of various perspectives and viewpoints, fostering a dynamic interplay of thoughts and interpretations. Therefore, utilising both techniques would aid researchers in uncovering contrasting viewpoints and better comprehending the complex nature of participants' constructions (Salvador, 2016).

From an ontological standpoint, I hold the belief that reality is shaped, understood, and created through the interplay of many societal, political, cultural, economic, ethnic, and gender influences (Guba & Lincoln, 1994). The beliefs I have are a direct reflection of my experiences and background. Furthermore, my objective is to comprehend the behaviours and significance that are conveyed by every individual and to employ this comprehension to redefine and improve nephrology practice in regard to kidney replacement therapy (Mills et al., 2006). I adhere to the interpretivism paradigm, which recognises the significance of individual voices and the inclusion of various perspectives in research (Charmaz, 2014). Additionally, the interpretivism paradigm acknowledges that the researcher and participants collaborate to comprehend specific constructs (Guba & Lincoln, 1994).

4.3.4 Methodology

Methodology is defined as a theory of how research proceeds, encompassing the analysis of principles, procedures, and assumptions in a specific approach to inquiry (Arghode, 2012). It is considered the backbone of data collection and analysis techniques in research (Salvador, 2016). So it is regarded as a fixed process of research steps; Byrne (2001) aimed at gaining a comprehensive understanding of the viewpoints and actions of research participants regarding their life experiences (Ormston et al., 2014). Researchers may sometimes revise their research questions based on insights gained from the field, modifying or refining them to better understand the phenomenon under investigation (Creswell & Creswell, 2017).

4.4 Qualitative research approaches

The choice of methodology and methodological approaches should be guided by the research question. The selected methodology should enable the researcher to gain fresh insights while also illuminating the significance of the phenomenon (Dyar, 2022).

There are a number of types of inquiry procedures used by qualitative researchers to conduct their research and aid in determining the best approach for studying their research problem. For example, ethnography, phenomenology, case study, narrative research, and grounded theory will all be explained next (Creswell & Poth, 2016; Dyar, 2022).

4.4.1 Ethnography

Ethnographical procedures originated from anthropology and sociology, as summarised by Wolcott (2008) and Fetterman (2010), exploring individuals' cultural patterns, including behaviours, language, and actions over time (Creswell & Creswell, 2017). Ethnography is known as the "study of culture," with approaches categorised as classical, systematic, interpretative, and critical (Taylor et al., 2013), focusing on observing behaviours and exploring group culture's nature to uncover the meaning behind those behaviours and human actions (Taylor et al., 2013). Therefore, identifying an interesting culture or topic is crucial for researchers before undertaking any ethnographic research (Dyar, 2022). The theoretical assumption of ethnography focuses on investigating and describing people's ways of living, beliefs, and adaptation to changes in their daily lives (Dyar, 2022). Cultural immersion and living among the group are core characteristics of ethnographic research. Researchers are required to spend time in the cultural field, sitting, interviewing, listening, and observing a group of people to generate research data and capture social meanings (Castellan, 2010). Khan (2014) highlighted that data gathered in ethnography research describes and interprets shared patterns of a group's cultural behaviours, artefacts, or speech. Thus, the generated data is usually derived from interview transcriptions, field notes, and documentary analyses, relying on cultural immersion and researcher interpretations, which are considered the main research limitations (Dyar, 2022).

4.4.2 Phenomenology

The phenomenological method draws from philosophy, psychology, and education, as discussed by Moustakas (1994). Phenomenological research describes individuals' lived experiences of a phenomenon as articulated by the research participants involved (Creswell & Creswell, 2017). Therefore, it is defined as "studying the nature of phenomena and attempting to interpret being" (Taylor et al., 2013) to understand the essence of the phenomena (Castellan, 2010). Phenomenologists' intention is directed toward the phenomena themselves, exploring, discovering, and describing them. In phenomenology research, participants are considered research instruments because of the phenomena and contexts they elucidate (Dyar, 2022). Lived experience is a key aspect of phenomenological research, where individuals share their impressions of living in their world or express opinions about a phenomenon relevant to the research topic design (Creswell & Poth, 2016). Another assumption is that researchers access the nature of a phenomenon by exploring the being of human participants and narrating the phenomenon's essential structure, nature, reality, and the participant's relationship with the phenomenon (Dyar, 2022). Being in the world is a phenomenological concept that connects participants to their past, shapes their present decisions, and anticipates their future research phenomenon interests (Creswell & Poth, 2016). The fusion of horizons is an additional concept that allows the researcher to integrate the meaning of lived experiences into the phenomenon of research interest (Creswell & Poth, 2016), but it does not aim to form a theory (Dyar, 2022). In-depth interviews and multiple interviews are methods used to collect data from participants in a phenomenology study. The sample size in phenomenology research is typically small, ranging from five to twenty-five individuals (Creswell & Poth, 2016), especially when robust, rich data is collected, and data saturation is achieved (Dyar, 2022).

4.4.3 Narrative research

Narrative research originated in the humanities and was developed by Clandinin and Connelly (2000), who studied individuals' life stories (Creswell & Creswell, 2017). Narrative research is considered an appropriate qualitative approach for exploring human experiences and conditions because people tend to recount their stories in both factual and imaginative forms to depict their lived experiences. Researchers are typically interested in how participants narrate their series of stories to construct meaning for themselves and their audiences. They often immerse themselves in the participants' stories to gain deeper insights and explore their research interests (Taylor et al., 2013). The concepts of narrative research focus on people's life stories and the quality of their experiences, including content structure, sequence, and characters, to answer questions about the participants' stories. Storytelling concepts address how participants narrate their experiences by constructing meaning for themselves, their identities, and their realities. Therefore, the significance of the shared story, the storyteller, and the listener are the three main aspects considered in narrative research (Taylor et al., 2013). Researchers concentrate on collecting the stories of one or two individuals and presenting their experiences in chronological order. Thus, they invest a significant amount of time with the research participants, gathering their stories to understand their life context (Creswell & Poth, 2016).

4.4.4 Case study

Case study research is commonly found in the field of evaluation, where an in-depth exploration is applied to a specific phenomenon over a consistent period of time, as suggested by Stake (1995) and Yin (2009, 2012, 2014) (Creswell & Creswell, 2017). The case study design initially emerged in educational research and was utilised to evaluate the experiences of curriculum innovations. Subsequently, it became an intriguing approach in health science research, including workplace health research and public health issues (Castellan, 2010). It is a research design used to investigate a particular case of human interest and a set of issues within its real-life context, particularly when the boundaries between the phenomenon and context are not clear. Additionally, it is a preferred approach when attempting to answer the how and why questions (Dyar, 2022). Case study researchers depend on a variety of sources, such as documentation, interviews, observations, and artifacts, and may include quantitative data. Therefore, theoretical propositions guide the methods by which data collection and analysis occur to obtain rich, detailed information about the research interest (Taylor et al., 2013).

Furthermore, the case study approach gathers data to describe selected research interests to understand as much as possible about a specific research interest. It is usually designed according to the research context, aims, objectives, and questions. Case study research may sometimes appear simple or complex because it is considered a choice of an object rather than a methodology choice and suggests further investigation (Castellan, 2010). Data analysis in case study research is conducted in conjunction with data collection. Considering this, data analysis can be approached in different ways because there is no clear description of it in case study research; the researcher might use an inductive approach as in grounded theory or analyse the search data based on the theory's premises (Dyar, 2022). Similarly, the reporting of study findings relies on the dissemination method, such as storytelling, using chronological events, or comparing one case against another (Dyar, 2022).

4.4.5 Grounded theory

Grounded theory studies originated from sociology and were identified by Charmaz (2006), Corbin and Strauss (2007; 2015), and Strauss and Corbin (1990, 1998). A grounded theory study explores the social process of a specific action through participants' views and interactions to generate a direct abstract theory (Creswell & Creswell, 2017). Taylor et al. (2013) stated that grounded theory is defined as an objective process to discover and generate theories through theoretical sampling and persistent comparative analysis of data, continually collecting, analysing, and coding findings until a constant and essential area of inquiry emerges. This process aims to build comprehensive, formal, grounded theories that fit the intended research question (Taylor et al., 2013).

Furthermore, grounded theory is a research process systematically applied to gather and analyse data with a close relationship to generate a theory that addresses the research area of interest (Taylor et al., 2013). Grounded theory researchers usually do not have a preconceived theory in mind before data collection begins. Accordingly, the generated theory enhances researchers' understanding and provides insight into action because it derives from reality (Taylor et al., 2013). Grounded theory is seen as an inductive, comparative, emergent, and interactive methodology. Therefore, its theoretical assumptions vary from an objectivist point of view to a constructivist standpoint, and its process moves between them (Charmaz, 2006).

Typically, grounded theory focuses on building a theory, making it suitable when a specific phenomenon lacks a theoretical explanation or when data are incomplete. Instead, grounded theory facilitates the emergence of theory from the data, representing the real-world setting through the relationship between the researcher and the gathered data (Dyar, 2022).

Additionally, grounded theory is grounded in social science as it explores social processes. Individuals' reality and meaning are constructed through their own self-interactions or interactions with others within the social context to make decisions (Dyar, 2022). To allow theory to emerge from the data, researchers defer the literature review until research completion to discover any relationships and help explain the phenomenon through the developed theory (Dyar, 2022). According to Dyar (2022), data collection in grounded theory occurs through in-depth interviews, focus groups, observations, documentation, or a combination of these methods. The sample size is determined by the collected and analysed data to achieve data saturation, as data analysis takes place concurrently with data collection.

Indeed, exploring different qualitative research approaches, such as ethnography, phenomenology, case study, and narrative research, is not suitable for this research project. These approaches do not sufficiently align with the aim of this research question. In my opinion, adopting an ethnographic approach would not have been appropriate for investigating the experiences of Omani individuals with end-stage kidney disease who decline haemodialysis treatment. The purpose of this research is not to examine the cultural interpretation of haemodialysis or to comprehend the personal significance of individual experiences. Instead, it aims to elucidate the social dynamics of living with end-stage kidney disease and rejecting haemodialysis in Oman, as well as how individuals affected by ESKD adapt their decision-making refusal to their social context and perceive themselves from others' perspectives.

Therefore, grounded theory was found more suitable for understanding and exploring the influencing factors that lead individuals affected by ESKD in Oman to refuse haemodialysis once medically advised. It aims to generate data representing the finer details of the individuals affected by ESKD decision-making process phenomenon (Creswell & Creswell, 2017), as no research has been conducted on this phenomenon in the context of Oman or other Arab countries.

4.5 Grounded theory as a selected approach.

The journey of applying grounded theory began within sociology research, where researchers sought to provide a scientific explanation for quantitative research findings, thereby establishing legitimate grounded theories. The historical roots of grounded theory trace back to the 1960s, when sociologists Barney G. Glaser and Anselm L. Strauss collaborated on a study of 'dying in hospital' and developed systematic methodological strategies outlined in their book "The Discovery of Grounded Theory" (1967). Their work challenged the dominance of the quantitative research paradigm in social science, advocating for a systematic approach to qualitative inquiry. Subsequently, they validated qualitative research as a credible approach in its own right (Denzin & Lincoln, 2000; Charmaz, 2006; Taylor et al., 2013).

The grounded theory offers a systematic and flexible approach to qualitative data collection and analysis, constructing a theoretical framework within collected data (Charmaz, 2006). Glaser initially defined grounded theory as a method of discovery, while Strauss and Corbin expanded it to force data and analysis into preconceived categories. By 1990, it had gained recognition for its positivistic assumptions, leading researchers to adapt it for mixed-method research projects (Charmaz, 2006). Despite initially aligning with positivism, grounded theory evolved due to scholarly critique, becoming a fundamental guideline adaptable to various studies (Charmaz, 2006).

Charmaz (2006) views grounded theory as a set of practical principles aiding researchers in understanding study topics and developing corresponding theories, emphasising that the research problem shapes the chosen method. The theoretical sampling process involves data collection, coding, constant comparative analysis, and determining additional data needed to foster theory development (Taylor et al., 2013).

The advancement of grounded theory in its second phase introduced an objective discovery process, utilising written memos, open and axial comparisons, and selective coding to form theories from microscopic data (Taylor et al., 2013). The last step forward is constructivist grounded theory, which sees human phenomena as socially constructed realities and stresses the importance of careful data analysis to make accurate theories (Taylor et al., 2013).

Grounded theory, proposed by Glaser and Strauss in 1967, aims to develop theories grounded in field data by employing constant comparative analysis and theoretical sampling, distinguishing it from other methodologies (Dunne, 2011). Widely used in healthcare research, particularly in nursing, grounded theory enables the conceptualisation of thinking and theory-building in social settings, emphasising an inductive and constructivist approach (Khan, 2014).

Based on people's real-life experiences, grounded theory uses in-depth interviews and observations to make sure that findings are true and closely linked to the data. This leads to new ideas and early analytical writing to make data collection easier (Charmaz, 2006:2).

4.6 Constructivist grounded theory.

Embracing constructivist grounded theory facilitates the development of a theory or fundamental concept regarding how individuals perceive their experience with ESKD and haemodialysis while recognising the social environment influencing that experience. This approach empowers researchers to interpret and construct the social landscape of Omani individuals facing ESKD and medically advised to undergo haemodialysis (Charmaz, 2014). Charmaz (2006) stated that a constructivist grounded theory makes a clear distinction between what is real and what is true (Khan, 2014). It operates under the assumption that both the researcher's and participant's perspectives contribute genuine knowledge and truth. In this framework, researchers construct a representation of reality rather than capturing reality itself. From a constructivist perspective, the researcher acknowledges the importance of interaction through shared language, wherein there is not a singular truth but rather a subjective truth shaped by the participant (Dyar, 2022).

Furthermore, utilising the constructivist research method can be valuable in comprehending the importance of personal experiences, which can subsequently be used to improve healthcare practices (Burns et al., 2022). The flexible structure of constructivist grounded theory permits the exploration of the experiences of individuals and their hidden perceptions, values, and beliefs (Creswell & Creswell, 2017). Hence, this methodology will enable the inductive construction of theories and concepts to explain the experiences of individuals (Charmaz, 2014).

Moreover, the constructivist grounded theory approach recognises the necessity for prior sensitivity and researcher awareness of the social process being investigated, treating the research process itself as a social construct (Charmaz, 2014).

The literature review conducted in this study preceded the selection of a method to identify gaps in the knowledge base for investigation. Following the classical approach would immediately preclude the use of a grounded theory approach. However, in this study, the review facilitated a systematic analysis of the existing knowledge concerning factors influencing treatment non-adherence, non-concordance, and refusal decision-making among adults with various diseases. Consequently, this review contributed to understanding relevant knowledge, aiding in the development of new knowledge and theory. It is argued that contemporary advocates of grounded theory, particularly Charmaz, endorse a prior literature review, contending that it informs both the formulation of questions and subsequent stages of theory development. Moreover, they advocate for researchers to ensure that early coding remains faithful to the data and is not excessively influenced by existing literature—a principle exemplified by how the coding is presented in the write-up, allowing readers to assess its fidelity to the data.

The constructivist grounded theory of Charmaz (2006) is chosen for this research project because this approach provides the opportunity to include the participant's voice in the study more prominently than the other grounded theory approaches. This approach is more flexible in that Charmaz's approach recognises that in practice, the logic of grounded theory is not often 'linear' and does not always engage with data collection and data analysis and ends with the writing of findings in that order but acknowledges that the researchers sometimes have to go back to the field for further and deeper data analysis. Coding and categorising, comparative data analysis, memo writing, theoretical sampling, and theoretical saturation are guiding tools used in grounded theory to construct an explanatory theory, in this case, used to explain decision-making that leads to the refusal of haemodialysis among individuals with an ESKD diagnosis, in an Omani context.

4.7 Rigour in qualitative research.

In qualitative research, rigour signifies a systematic and high-standard approach to the research process, ensuring integrity, competence, and, ultimately, trustworthiness in the findings. Upholding rigour enhances the likelihood of producing relevant results, thereby bolstering the credibility and reliability of the research outcomes. Lincoln and Guba (1985) offer alternative criteria for assessing trustworthiness in naturalistic (qualitative) research, emphasising the importance of rigour in maintaining the integrity and quality of the research endeavour, including credibility, dependability, transferability, and confirmability (Baillie, 2015).

4.7.1 Creditability and trustworthiness

Credibility in qualitative research is essential for authentic and naturalistic inquiry. Techniques to establish credibility include providing a comprehensive description of the study's design, member checking, triangulation, prolonged engagement, persistent observation, and peer debriefing. These strategies enable researchers to authentically present the experiences and meanings of the phenomenon, ensuring that the findings are credible to participants. Member checking entails providing feedback to participants, while triangulation involves collecting data through various methods and sources. Prolonged engagement necessitates investing time in interactions with participants, observations, data immersion, and analysis. Persistent observation offers depth and a multidimensional view of the phenomenon. Lastly, peer debriefing involves engaging an objective peer to review the study methods, methodology, and findings to identify implicit aspects (Guba & Lincoln, 1982; Shenton, 2004; Denzin & Lincoln, 2017; Dyar, 2022).

4.7.2 Transferability

Transferability is a crucial aspect of qualitative research, as it refers to the extent to which findings can be applied to another setting that has a comparable demographic. It is argued that generalisability is an illusion in qualitative research, as each situation is unique to the researcher and participants. To ensure transferability, researchers must provide descriptions and data that are sufficiently rich and thick, allowing readers to determine the appropriateness of transferring the findings to another situation. Strategies to enhance transferability include field notes, data saturation or redundancy, documenting methods to enhance study quality and rigour, and providing thick and rich descriptions (Guba & Lincoln, 1982; Shenton, 2004; Dyar, 2022).

Positivist research generally aims to establish the generalisability of its findings to a wider population (Shenton, 2004). However, naturalistic inquirers argue that even conventional generalisability is impossible, as observations are defined by the specific contexts in which they occur. Practitioners may relate the findings to their own positions. However, it is the duty of the investigator to present adequate contextual information regarding the fieldwork places, allowing the reader to make such a transfer (Shenton, 2004).

4.7.3 Dependability

Dyar (2022) and Shenton (2004) stated that dependability is a crucial aspect of ensuring the trustworthiness of qualitative inquiry. It entails assessing the stability of data over time and determining whether the findings would remain consistent if the study were replicated with similar participants. Researchers can enhance dependability by creating an audit trail, which involves systematically documenting the inquiry process, including a study timeline, memos, and data collection notes. This trail is made accessible to external reviewers, thereby enhancing confirmability and ensuring the reliability of the study.

4.7.4 Confirmability

Confirmability in qualitative research reflects the researcher's commitment to ensuring that the findings emerge from the participants' perspectives rather than the researcher's biases or motivations. This concept is similar to objectivity and is achieved when the findings authentically represent the voices of the participants. Researchers bolster confirmability through practices such as maintaining an audit trail, utilising raw data, employing triangulation, conducting member checks, and engaging in peer debriefing. Triangulation is particularly emphasised to mitigate investigator bias. Acknowledging and addressing one's own predispositions are critical aspects of achieving confirmability. When combined with credibility and dependability, confirmability enhances the transferability of research findings (Guba & Lincoln, 1982; Shenton, 2004; Dyar, 2022).

4.8 Conclusion

This chapter has outlined the concepts and methodology to be used for exploring the research topic in this study, which is focused on examining the decision-making of Omani individuals with ESKD who refuse haemodialysis. Charmaz's constructivist grounded theory was chosen as the most appropriate qualitative research method for developing a model or theory of haemodialysis refusal decision-making influenced by personal and social factors.

The following chapter explains the practical application of the methodological descriptions outlined in this chapter in the field. Specific elements of constructivist grounded theory are outlined, followed by a description of the process for ensuring the trustworthiness of the emerging theory.

Chapter 5 Method

When writing the qualitative method section for a particular study design, it is essential to include the protocol for data collection, recording technique, data analysis procedures, and methodology integrity approach (Creswell & Creswell, 2017). Chapter Five focuses on the approach used for this study.

The main research question in this thesis is ‘*Why do individuals affected by ESKD decide to refuse medically advised haemodialysis?’.* The study utilises a qualitative methodology and applies Charmaz's (2006) grounded theory method to develop an understanding of the decision-making process of Omani individuals with ESKD who refuse haemodialysis intervention.

This chapter addresses the application of the technique described in the previous chapter. It encompasses the study setting and the process of obtaining access, ethical considerations and approval, sampling strategy, and recruitment. Additionally, the chapter delves into grounded theory data collection and analysis, as well as the final phases of theory development.

5.1 Research setting

Qualitative research is a naturalistic research type typically conducted in participants’ natural settings, such as their homes or workplaces (Stewart et al., 2008). Researchers collect data in the participants’ natural environment, where they experience the problem or issue under investigation (Creswell, 2007; Creswell & Poth, 2016; Dyar, 2022). In qualitative studies, researchers serve as the research instruments, engaging in face-to-face dialogue with participants and observing their behaviours and actions within their context over a specific period (Creswell, 2007; Creswell & Creswell, 2017). Researchers delve deeper into the research phenomenon upon entering the field, which may lead to adjustments in various phases of the research process, including the research question, participants, data collection methods, and study sites (Creswell & Poth, 2016; Creswell & Creswell, 2017).

The data collection setting for the study was planned to be nephrology outpatient clinics at eleven governmental hospitals under the Ministry of Health in Oman (see appendix 14). Among these hospitals, ten provided secondary care levels, while one provided tertiary hospital care. These selected health institutions were chosen because they offered advanced healthcare services facilitated by the presence of nephrologists at the levels of consultant, specialist, and senior specialists, as well as nephrology nurses and counselling or pre-kidney transplantation clinics. Furthermore, primary healthcare institutions in Oman did not have nephrology clinics, resulting in nephrology individuals being referred to secondary-level care for proper diagnosis and continuous follow-up. All eleven hospitals were accessible to all individuals in the country, and nephrology treatment was provided free of charge to Omani individuals, as mentioned in Chapter 2 (Section 2.1.9). However, two hospitals among the eleven lacked nephrology clinics, and their nephrology individuals were referred to the nearest secondary hospital to their governorates. Consequently, no participants were recruited from these hospitals. The tertiary hospital provided care to all referred nephrology individuals from across the governorates in Oman, offering advanced consultations or diagnostic procedures. For a detailed breakdown of the names of the hospitals, their level of care status, and the number of recruited participants, refer to Table 5.1. To enrich the research data and thereby enhance the constructed theory, the recruitment of participants from ten health institutions facilitated the utilisation of purposive sampling concerning the socioeconomic backgrounds and ESKD conditions of the research participants.

Qualitative research is vital for gaining deep insights through the lived experiences of individuals in unique contexts. Typically, this requires close interaction between researchers and participants. However, the COVID-19 pandemic disrupted this process, particularly for individuals with ESKD. Physical distancing guidelines, which discouraged non-essential travel and group gatherings, limited participant engagement and researcher access, affecting the depth of interaction needed for the study (Tremblay et al., 2021).

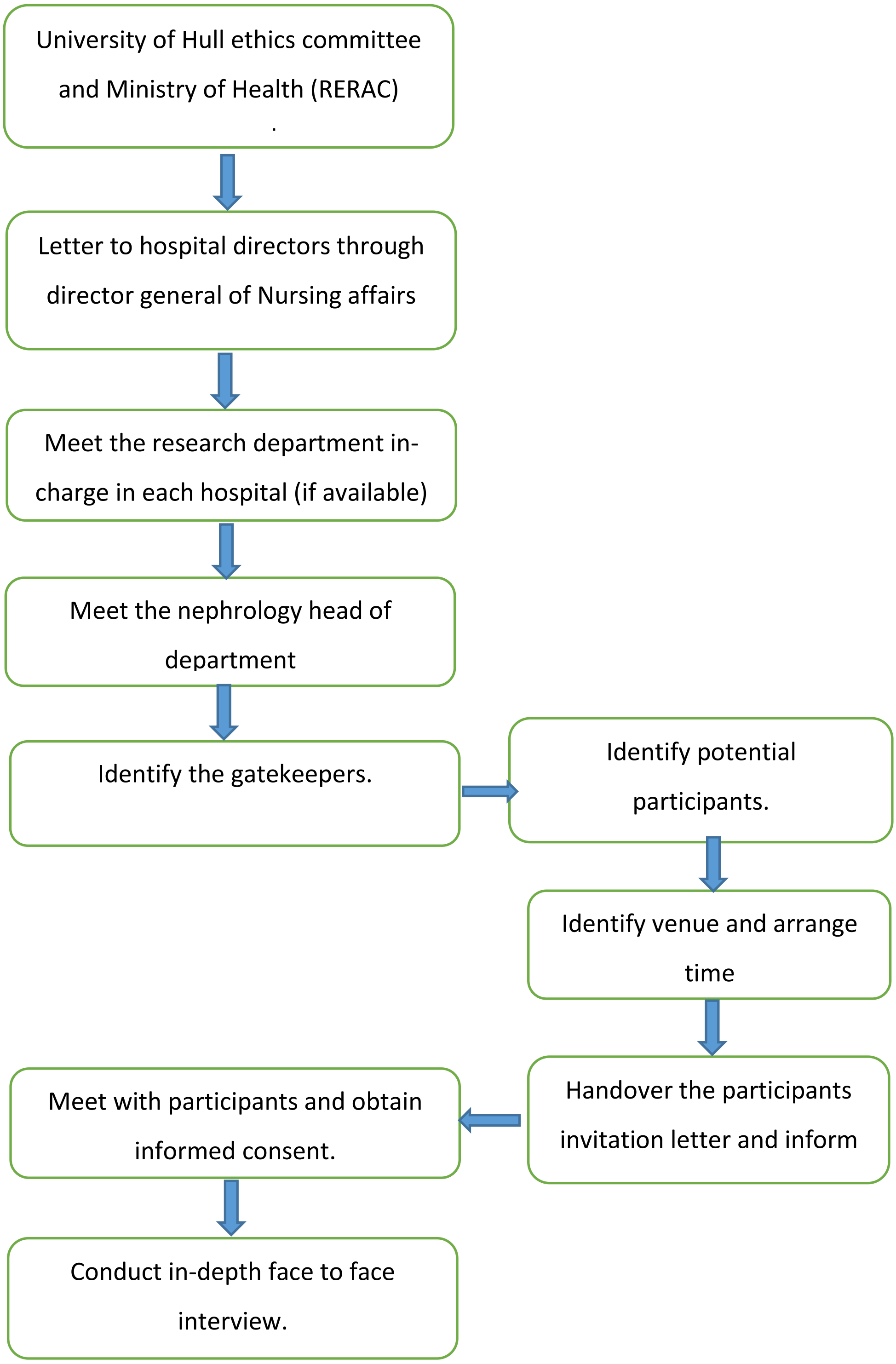
As a result of these disruptions, the pandemic posed significant challenges to participant recruitment for this research. Individuals with ESKD exhibited a reduced frequency of hospital attendance, primarily driven by concerns over potential infection. Among those who attended, many declined to participate in research interviews, opting instead to minimize their time in the hospital environment to reduce exposure risks. Moreover, the pandemic severely restricted opportunities for me to observe critical interactions between individuals affected by ESKD and their physicians, limiting my ability to witness key moments such as diagnosis disclosure and the initiation of haemodialysis. Despite these obstacles, I successfully recruited at least two to four participants from each governorate.

Table 5.1 Governorate hospitals in Oman.

Health institution	Nephrology Clinic /week	Number of participants	Healthcare level
Royal hospital	Every Tuesday	3 + 1	Tertiary care
Rustaq hospital	Sunday & Wednesday	5 + 3	Secondary care
Salalah hospital	Monday & Wednesday	2 + 1	Secondary care
Ibri Hospital	Every day	2	Secondary care
Suhar hospital	Every day	1	Secondary care
Al Burimi hospital	Every day	2	Secondary care
Nizwa hospital	Every Wednesday	2	Secondary care
Khasab hospital	No nephrology clinic	0	Nephrology individuals followed up at Suhar and Brimi hospital
Sur hospital	Tuesday and Sunday	2 + 1	Secondary care
Ibra hospital	Every day	1 + 1	Secondary care
Haima hospital	No nephrology clinic	0	Nephrology individuals followed up at Nizwa hospital

Figure 2 illustrates the recruitment plan. Following the acquisition of research study approval, a letter was sent through the Director-General of Nursing Affairs at the Ministry of Health headquarters to the hospital directors of the identified eleven hospitals in the country to streamline the recruitment process (see Appendix 4). At the Royal Hospital, only a research nurse was available to facilitate the recruitment and data collection processes. Conversely, in the remaining eight hospitals, the hospital heads of nursing identified a focal person, typically a nephrology nurse in charge or a nurse working in the nephrology outpatient clinic. Their role was to facilitate the identification of eligible participants and assist in the data collection process. Therefore, a thorough discussion about the research purpose and participants inclusion and exclusion criteria was conducted with the identified nurse and the nephrologist via phone before visiting any of the nine hospitals. This discussion was repeated in person for brevity, to identify the participants, and to arrange the venue.

Figure 5.1 Recruitment plan.



I provided the identified physicians and nurses with a copy of the approval letters. Upon my explanation of my research project's aim and objectives to them, they demonstrated enthusiasm and passion for assisting and recruiting eligible participants.

5.2 Ethical considerations

In qualitative research, researchers often encounter numerous ethical issues during field visits for data collection, analysis, and report dissemination. These may include concerns such as informed consent, confidentiality, non-maleficence, beneficence, and justice (Creswell & Poth, 2016).

In the constructivist paradigm, the autonomy and privacy of participants are often compromised during data collection using open-ended questions. This compromise might hinder participants from freely sharing their experiences, as researchers could inadvertently disclose sensitive data, inaccurate statements, or realities. Therefore, the ethical considerations surrounding this qualitative research approach are of paramount significance, emphasising the importance of safeguarding autonomy. It is crucial to note that participants retain the right to withdraw from the study at any point, especially if they feel uncomfortable or perceive the circumstances as precarious (Salvador, 2016).

Adhering to ethical standards promotes the research aim and values collaborative work with others, while also ensuring that researchers are held accountable towards participants. It also serves to emphasise the importance of human rights, social responsibility, and health and safety (Gajjar, 2013). Consequently, any violation of ethical principles would significantly harm research participants and evoke feelings of remorse (Gajjar, 2013; Beauchamp & Childress, 2019).

The predominant ethical framework used for evaluating ethical situations in the field of research is the one introduced by Beauchamp and Childress (2019). This framework encompasses four main principles: respect for autonomy, non-maleficence, beneficence, and justice.

In order to ensure strict compliance with the highest ethical principles in the design of the research project, it is crucial to include measures such as thorough planning and obtaining ethical review and approval from an institutional review board (Dyar, 2022). Approval for this research project was obtained from the University of Hull Research

Ethics Committee and the Research & Ethical Review & Approval Committee (RERAC) at the Centre of Studies & Research at the Ministry of Health Oman (see Appendix 3). Additionally, an amendment approval letter for additional recruitment due to theoretical sampling was obtained from the University of Hull Faculty of Health Science Ethics Committee (see Appendix 5).

Ethical concerns can surface at any stage of a research study, even when the project has been meticulously planned. Therefore, I reviewed all ethical considerations throughout the various phases of the study and addressed any issues that arose. The following ethical principles were considered while conducting the study process:

5.2.1 Respect for autonomy.

Nowadays, respect for individual autonomy is considered the primary ethical principle in any practice, including research (Beauchamp & Childress, 2019). According to Beauchamp and Childress (2019), respect for autonomy refers to the ethical principle that grants individuals the right to make decisions concerning their own lives and bodies. As self-determining agents with the capacity to make informed choices, they can act in harmony with their personal values, beliefs, and aspirations. This principle emphasises the significance of obtaining informed consent from individuals prior to conducting any procedure and participating in research, ensuring that they possess a clear comprehension of the associated risks, benefits, and alternatives as highlighted in the participants’ information sheet. Beauchamp and Childress also acknowledged that autonomy might be constrained in cases where an individual lacks decision-making capacity. Therefore, in this research project, individuals with cognitive impairment and mental illness were excluded.

To maintain participants' autonomy and ensure their agreement and understanding of the research study before commencing the interview. The participants in this study were provided with an invitation letter, including the information sheet highlighting the research title, aim and question and explaining the data collection process, including the research project period and place, the researcher's full name and contact number for any queries and contact details for any complaints. Therefore, I discuss the information sheet with the participants before obtaining their consent to make sure they understand the concept of their participation (see Appendix 6 & 9). They were given a period of time to read the information sheet and make their decision.

Before consenting to the participant, I explained to them that their participation was voluntary and that they had the right to refuse participation or withdraw from the study at any time. After that, Participants who agreed to participate in the study were given a consent form (appendix 10 & 11). For the participants who could not read and write, a right thumbprint was taken in the presence of their attendant and the nurse in the clinic or dialysis unit. After that, I signed the consent form with the participant's signature.

5.2.2 Beneficence (do good).

According to Beauchamp and Childress (2019), beneficence refers to the obligation to do what is beneficial and promote the well-being of individuals. It involves taking actions that benefit others and prevent harm. In the context of research, the principle of beneficence suggests that researchers have an obligation to act in the best interest of their participants by maximising benefits and minimising harm. While participating in this research project, participants were informed that the aim of the research is to provide evidence-based information for the benefit of the public. Therefore, the findings will not directly benefit them.

The interview was conducted in a private location away from the nephrology clinic and kidney dialysis unit. Participants were informed that although the study may not directly benefit them, it could aid other individuals with kidney failure in the future. Each participant was interviewed alone without any other individuals present, as most were accompanied by a family member.

The interview may evoke painful memories, potentially causing the participant distress (Orb et al., 2001). This was evident during interview number 17, in which an 84-year-old female participant requested to stop after 17 minutes due to feeling upset. In line with ethical responsibilities, the participant was not referred to a counsellor, as one was unavailable at the time. However, she was reassured that she could withdraw from the interview at any point without providing justification, that her name would not be recorded, and that her participation would remain confidential and voluntary. Additionally, it was emphasized that she could refuse to answer any further questions if she felt uncomfortable, and she was reassured that her decision would not impact her medical care in any way.

Respecting the principle of 'beneficence,' the participant’s choice to discontinue the interview was honoured. After her decision, her son was permitted to enter the room to provide support and comfort.

5.2.3 Non-maleficence (do no harm)

Non-maleficence is the principle of 'do no harm.' This means that researchers should avoid actions that could potentially harm participants or outweigh the potential benefits. Researchers must strike a balance that promotes individuals' well-being while respecting their autonomous decisions (Beauchamp & Childress, 2019). Therefore, participants received both verbal and written information (through the participant's information sheet) informing them that if discussing sensitive information places them at risk of harm, they retain the right to withdraw from participation at any time without needing to provide justification. Moreover, they were assured that their identities would remain undisclosed when the research findings were disseminated.

5.2.4 Justice

The concept of justice centres on ensuring an equitable allocation of benefits, risks, and resources. Consequently, individuals who choose not to participate in the research are informed that they will not experience any adverse effects on the care they receive or their well-being. Additionally, they were informed that participating in the research project would not give them any advantage.

I assured the participants that sharing any concerns they had about the care they received and its effect on their relationships with healthcare professionals would not impact the care they received. I also guaranteed that their confidentiality would be preserved during the research process. I informed the participants that agreeing to take part in the study would not result in preferential treatment at the clinic, such as being prioritised in the queue for clinic or dialysis appointments. Hence, there would be no benefits to their involvement.

As a nurse and professional, I had experience with end-stage kidney disease, but I transitioned to a role as a researcher. To reassure the participants, I stayed outside the nephrology care boundary. While collecting data, a young female participant with seven years of ESKD agreed to be interviewed under the impression that I could assist in speeding her kidney transplantation process at the ministry level, as she understood I was from the Ministry of Health. I informed her that I am a PhD student researching individuals with stage five kidney failure and clarified that I do not have the right to intervene in her treatment plan.

5.2.5 Confidentiality and data protection

In this study, participants were fully aware of their diagnosis stage and treatment situation, as well as their role during the interview. Confidentiality and anonymity were ensured by replacing participants' names and the institution's name with unique codes. I also informed them of the potential use of direct quotations in the thesis and related publications. These quotations were carefully selected to exclude any details that could reveal participants’ identities, and codes would be used in all scholarly outputs.

Participation was entirely voluntary, and participants were reminded of their right to withdraw from the study at any point during data collection without explanation. I clarified how the data would be used and who would have access, assuring participants that only the researcher would handle the data without involvement from their healthcare professionals or others.

To safeguard confidentiality, I used password-protected, encrypted storage devices. Each participant received a unique code, anonymizing all transcripts. The identifying code also indicated the recruitment setting (the hospital's governorate). Only I had access to the code key.

A soft copy of participants' documents—including consent and demographic forms—and audio recordings were stored securely on the university's digital repository, 'Box,' in compliance with the University of Hull's data storage guidelines. Following project completion, all stored data will be destroyed.

5.3 The technique used in CGT.

Grounded theory provides specific instruments that help researchers gather in-depth data and make sense of it through flexible guidelines(Charmaz, 2006). According to Denzin and Lincoln (2000), grounded theory techniques can be used in different forms of data collection to gather rich and extensive data with thick descriptions, which are analysed using coding, memos, and articles.

5.4 Research sampling population

A strategic sampling plan in qualitative research is typically established in advance, as sampling procedures may evolve during the study; consequently, researchers tend to exhibit greater flexibility (Castellan, 2010; Creswell & Poth, 2016). According to Fossey et al. (2002), the primary focus of qualitative research sampling is information richness. This is guided by the identification of individuals who can provide the most insightful perspectives for the study, thereby necessitating ample sources of information to comprehensively elucidate the phenomenon under investigation.

The objective of this study was to attain a comprehensive understanding of the experiences of individuals with ESKD refusing haemodialysis and the trajectory of such experiences. The inclusion of participants capable of offering in-depth explanations of the phenomenon under investigation is required by grounded theory (Glaser & Strauss, 1967). Therefore, the utilisation of an appropriate sampling method was deemed crucial (Bryant & Charmaz, 2007).

In grounded theory, sampling encompasses both purposive sampling, which selects individuals with diverse characteristics, and theoretical sampling, aimed at developing theories or key concepts to explain the studied phenomenon (Glaser & Strauss, 1967). The eligibility criteria ensure a high level of diversity in terms of age, health condition, and geographical area in this instance.

The nurses and nephrologists reviewed the clinic appointment list and identified eligible participants who met the recruitment's inclusion and exclusion criteria by accessing their medical records. From a sampling perspective, participants' medical records were utilised, not from an analytical standpoint, as the aim is to capture the individuals' voices. Table 5.2 presents the inclusion and exclusion criteria applied in the recruitment process for this study.

The clinically diagnosed ESKD stage 5 individuals at terminal or palliative stage were excluded as it is different issue to manage individuals effected by ESKD at end of their life and decided to withdrawal of haemodialysis, and individuals living with ESKD. For example, commencing haemodialysis typically occurs when an individual reaches ESKD, and their kidneys can no longer perform essential functions, forcing them to choose between starting a life-prolonging treatment or accepting the natural course of dying (Hussain et al., 2015). This decision is driven by the necessity due to declining kidney function rather than a true choice (Hussain et al., 2015). In contrast, the withdrawal from haemodialysis involves an active decision to permanently discontinue treatment, usually when it no longer improves the individual's quality of life or becomes burdensome due to complications, comorbidities, or personal preferences (Bhojaraja et al., 2021). This decision often arises later in the course of treatment, particularly in palliative care settings, where continuing dialysis may cause more harm than benefit, especially in frail or terminally ill individuals (Hussain et al., 2015). Reasons for withdrawal may include multiple access failures, severe complications, or overwhelming logistical and financial burdens (Bhojaraja et al., 2021).

Table 5.2 Participants' inclusion and exclusion criteria.

Inclusion criteria	Exclusion criteria
1. Adult ESKD stage 5 individuals aged 18 years and above. 2. Clinically diagnosed ESKD stage 5 individuals were advised dialysis but refused it. 3. Clinically diagnosed ESKD stage 5 individuals willing to be interviewed. 4. Adult ESKD stage 5 individuals aged 18 years and above started on dialysis from six months and below.	1. Clinically diagnosed ESKD stage 5 individuals below 18 years old. 2. Clinically diagnosed ESKD stage 5 individuals with serious mental illness. 3. Clinically diagnosed ESKD stage 5 individuals at terminal or palliative stage and withdrawal of haemodialysis according to their medical records.

5.4.1 Purposive sampling.

The ESKD participants were selected based on their experience with kidney failure refusal and the trajectory of this experience. Therefore, the initial sampling in the study followed purposive sampling to include participants with diverse characteristics, followed by theoretical sampling to aid in the development of key concepts. Table 5.3 outlines participant characteristics, including gender, age, educational level, date of ESKD diagnosis, and eGFR.

Table 5.3 Participant’s demographic data.

Participant’s code	Institution’s code	Age	Gender	Marital status	Occupational status	Educational status	Co-morbidities	Diagnosed with ESKD	eGFR
01F	01H	49	Female	Divorced	Part-time	Secondary school	HTN & SLE	21/04/2021	11%
02M	02H	37	Male	Married	Full time	Preparatory school	Diabetes and Hypertension	16/07/2021	13.9%
03F	02H	77	Female	Widow	Not working	Illiterate	Diabetic, Hypertension, Cardiac and Thyroid	16/05/2017	10.1%
04M	02H	82	Male	Married	Retired	Illiterate	Hypertension	15/06/2015	10.1%
05F	01H	74	Female	Married	Not working	Illiterate	Diabetic, Hypertension and Cardiac	20/10/2015	12%
06F	03H	32	Female	Married	Not working	Secondary school	Hypertension	16/03/2014	3.6%
07M	011H	46	Male	Married	Retired	Preparatory school	Diabetes and Hypertension	17/10/2018	11.4%
08F	011H	24	Female	Single	Not working	Secondary school	Hypertension	03/09/2019	8.7%
09M	07H	71	Male	Married	Retired	Illiterate	Diabetes and Hypertension	15/01/2017	13.4%
010M	07H	19	Male	Single	Student	Secondary school	Al Port's syndrome (Childhood)	14/09/2021	7.5%

011M	04H	40	Male	Married	Not working	Secondary school	Hypertension	24/08/2019	12%
012M	04H	54	Male	Married	Retired	Primary school	Diabetic, Hypertension, Cardiac, thyroid & Anaemia	01/04/2021	12.5%
013F	09H	47	Female	Divorced	Pension	Primary school	Diabetic, Hypertension and Cardiac	18/09/2021	10.1%
014F	09H	57	Female	Widow	Pension	Illiterate	Hypertension	11/05/2021	12.1%
015M	08H	32	Male	Married	Full time	Secondary school	Hypertension	15/03/2018	11%
016F	06H	63	Female	Married	Not working	Reading only	Diabetic, Hypertension and Cardiac	18/04/2021	11.5%
017F	06H	84	Female	Married	Not working	Illiterate	Diabetic, Hypertension, Cardiac & thyroid	22/11/2021	13%
018M	02H	68	Male	Married	Retired	Primary school	Hypertension	12/06/2021	11.7%
019F	01H	42	Female	Widow	Retired	Higher education	Diabetes and Hypertension	01/03/2021	7%
029M	02H	74	Male	Married	Retired	Illiterate	Diabetes and Hypertension	29/09/2020	5.7%

The first five participants were purposefully selected to provide rich data aligned with the research study's aim (Charmaz, 2006). Interviewing these initial participants allowed me to initiate the research project, refine the interview guide, and improve my interview skills and confidence.

Once the nephrologist found the eligible participant, he briefly explained the research goal to them in order to obtain their verbal consent. The nephrologist would refer the participant to me through the clinic nurse if they showed interest. I then requested permission from the ESKD individual to discuss my study while they awaited the results and before meeting with their physician. Subsequently, participants received an invitation letter and an information sheet (see Appendix 6 & 9). Once the participant showed acceptance and interest, I then asked the participant to sit with her/him after the blood collection and before seeing his physician to discuss my research project. Normally, the participant would experience a waiting period of one to two hours after the blood investigation takes place and before meeting with the nephrologist to discuss the results. I made it clear to the participants that they had the autonomy to choose whether or not to take part in my research project due to my fear that individuals affected by ESKD would be influenced by their doctors to join the study. I aimed to highlight the independence of individuals affected by ESKD in choosing whether to participate in the research.

5.4.2 Theoretical sampling

Simultaneous data gathering and analysis are involved in constructivist grounded theory to focus the researcher early and avoid mistakes in exploring leads. The relevance of emergent leads and the development of categories are facilitated by theoretical sampling, which can take various forms, such as collecting data from a new situation or group of participants, tightening up research questions, or collecting more data from the same or similar situation (Charmaz, 2006).

According to Charmaz (2006), theoretical sampling can be undertaken until the researcher is confident that no new properties are emerging or until theoretical saturation is reached. Starting theoretical sampling too early should be avoided by researchers, who should instead follow a process of open sampling for as long as possible. Charmaz (2006) warns against missing analytic possibilities and constructing superficial analyses, suggesting a solution of being open to the field, grappling with it, and returning and re-coding earlier data to see if new leads are defined.

The utilisation of theoretical sampling is deemed essential in grounded theory, driven by emerging themes from the data. As key concepts began to surface during the initial interviews, the application of theoretical sampling was initiated (Charmaz, 2006). Participants who could offer insight into specific concerns identified during the initial data collection and analysis were selected as the research advanced.

Once the key concepts emerged from the first five interviews, theoretical sampling began. For example, the significant impact of lack of knowledge on participants' decision-making emerged as a strong concept that required further exploration. Participants explained that their decisions regarding haemodialysis refusal were influenced by the knowledge they acquired from various sources, such as family members, friends, individuals with kidney failure, or contact with kidney failure experience. Additionally, they emphasised that their decision to refuse haemodialysis was also influenced by their treating physicians and the information they accessed through Google.

They reported feeling scared due to others' experiences and the knowledge they gained, which made them fear being unable to lead a normal life, fear death, and feel stigmatised. Despite this, they believed they were asymptomatic. These repeated statements prompted me to explore this issue further for a comprehensive understanding. Consequently, I considered the ask the participants about their understanding of ESKD and haemodialysis, if they comprehended their kidney failure status and the dialysis process, and whether they discussed their kidney failure and haemodialysis with their treating physician, family member or anyone else.

Subsequently, I modified the interview questions accordingly. I then theoretically selected participants who were young and educated; I asked them if they knew about their kidney problem and the dialysis intervention; I asked them about the type of resources available to learn about kidney failure and haemodialysis. Moreover, I asked them about the knowledge they gained and influenced their decision and asked them to justify it. These questions facilitated a deeper understanding of the concept and contributed to category development.

Most of the subsequent interviews were conducted to ensure the theoretical adequacy of the categories. This strategy was applied to all categories, aiding in synthesising the components of the experience and constructing theories about that experience (Charmaz, 2014). During this stage, questions were focused, aiming to check, refine, elaborate, and saturate, as well as to understand the relationship between the properties and dimensions of the theoretical categories developed. Another practical example is provided by one of the participants, who was elderly and indicated that her decision to refuse haemodialysis was influenced by her son's choice. This discovery prompted an exploration into a new area of inquiry: why participants believed that family members were responsible for making decisions regarding haemodialysis refusal and how this belief varied among younger participants. To explore this issue further, it was decided to recruit new young participants accompanied by their fathers or mothers.

Participants in this study encountered various circumstances that led them to decide to refuse to undergo haemodialysis. Initially, the study focused on understanding why individuals chose not to pursue dialysis treatment. Subsequently, the scope was slightly expanded to explore the reasons behind some participants changing their minds and opting for dialysis. Several factors were identified as reasons why participants refused haemodialysis treatment.

After conducting twelve interviews, an amendment was made to recruit participants who initially choose not to undergo dialysis but later changed their decision, aiming to capture their experiences and perspectives (see Appendix 5). This decision was reached after extensive discussions with my academic supervisors and refinement of ethical approval, as agreed by the Faculty of Health Ethics Committee. Consequently, the recruitment criteria were broadened to include adults with ESKD stage 5, aged 18 years and above, who had been on dialysis for six months or less.

Individuals under 18 years of age with ESKD were excluded from the study, as they are classified as children according to the Convention on the Rights of the Child, which defines a child as anyone under eighteen (Al-Saadoon et al., 2021). Minors are generally considered a vulnerable group in research, often requiring parental or guardian consent to participate. Additionally, they may not fully understand the potential risks, benefits, and complexities of participation, which are essential to ensuring informed and voluntary consent (Grootens-Wiegers et al., 2017).

The recruitment process remained unchanged, except for informing the nurse in charge of the kidney dialysis unit about the revised arrangement to identify eligible participants. Participants were met on their dialysis day before commencing their session in a designated room outside the kidney dialysis unit. Table 5.4 provides an overview of participants' demographic details, including gender, age, date of ESKD diagnosis, and commencement of dialysis.

Table 5.4 Extra participant's demographic data.

Participant's code	Institution's code	Age	Gender	Marital status	Occupational status	Educational status	Co-morbidities	Diagnosed with ESKD	Started on dialysis
001M	011H	40	Male	Married	Full time	Secondary	Diabetes and Hypertension	11/03/2019	29/10/2021
002M	09H	59	Male	Married	Retired	Higher education	Hypertension	02/01/2021	25/10/2021
003M	08H	51	Male	Married	Retired	Preparatory school	Hypertension	01/08/2021 but not compliant on dialysis	19/10/2021
004F	02H	62	Female	Married	Not working	Illiterate	Hypertension	18/03/2020	05/03/2022
005F	02H		Female	Widow	Not working	Read & write	Diabetes and Hypertension	26/01/2021	02/03/2022
006F	02H	25	Female	Married	Not working	Secondary school	Hypertension & SLE	09/01/2022 but not compliant on dialysis	06/02/2022
007M	01H	57	Male	Married	Retired	Primary school	Hypertension	June 2021 due to COVID & not compliant on dialysis	03/03/2022 as regular HD

5.5 Data collection process.

Researchers usually operate within the confines of theoretical frameworks because qualitative research aims to ensure that theory fits the data, enabling an understanding of people's personalities and experiences in a specific setting (Taylor et al., 2013). They focus on deriving meaning from collected data and employ observation and participant involvement in data collection (Arghode, 2012). Consequently, qualitative research researchers are viewed as key instruments in data collection and analysis. They gather data themselves using various methods, such as interviewing participants, observing behaviours, or examining documents. The choice of approach typically depends on the data to be collected in order to fulfil the study's objectives (Charmaz, 2006; Creswell & Poth, 2016; Creswell & Creswell, 2017).

They employ an open-ended data collection format to encourage participants to share their experiences, ideas, and beliefs freely, without being constrained by predetermined instruments or scales (Creswell, 2007; Creswell & Creswell, 2017). However, a specific protocol is employed as a guide to gather and record data, utilising unstructured or semi-structured interviews. These interviews take various forms, including individual or group face-to-face sessions, self-administered questionnaires, and surveys conducted through mail and telephone (Charmaz, 2006; Denzin & Lincoln, 2011; Creswell & Creswell, 2017).

The interview method stands out as the most common and powerful approach used to comprehend human perspectives in qualitative research due to its active interaction nature involving two or more individuals (Denzin & Lincoln, 2011). Despite interviews being an integral part of obtaining participant information, their response rate declined due to their reluctance to disclose their life experiences or to become selective about participating in interviews (Denzin & Lincoln, 2011). Hence, when modelling a phenomenon, researchers often consider participants' physical, emotional, social, and other pertinent factors (Dyar, 2022). Qualitative research does not necessitate a fixed sample size. Sampling can occasionally involve a small sample size; however, this is compensated by gathering a substantial volume of data through numerous interviews or diverse sources in a single session. This approach aims to achieve a comprehensive depth of information that effectively characterises the phenomenon under study (Fossey et al., 2002). Therefore, the qualitative sample size depends on the design used (Castellan, 2010).

5.5.1 Concurrent data collection.

In constructivist grounded theory, data collection is characterised by flexibility and a focus on meaning. Researchers refine and adjust their data collection methods throughout the process (Charmaz, 2006). This approach emphasises the co-construction of data between researchers and participants, leading to an interactive process where meaning is collaboratively derived (Charmaz, 2006; Khanal, 2018). The ongoing collection and analysis of data is a crucial aspect of grounded theory, with analysis beginning early and being integrated into all stages of data collection. Researchers continuously collect and analyse data iteratively, using methods such as interviews, observations, and document analysis (Creswell & Creswell, 2017). Open-ended questions are employed to elicit rich responses from participants, with data collection continuing until saturation is reached. The analysis involves open coding to create categories from which the grounded theory is constructed (Corbin & Strauss, 1990; Creswell, 2007).

5.5.2 Interview

The interview proved to be a valuable method for gathering data from participants, enabling an understanding of their social context and the factors influencing their decision to refuse haemodialysis initiation in Oman from their perspectives (Charmaz, 1990). This process allowed for immersion in their reported experiences through continuous interpretation.

Gathering primary data enables me to directly observe participants, including their facial expressions and body language, listen to their voices, witness interactions, and gain a sense of the setting. I maintained memos to record analytical insights that arose during the interviews (Charmaz, 2014). The data collection for this research commenced with semi-structured interviews and later transitioned to more structured and focused interviews.

5.5.3 Interview guide.

Based on Charmaz's suggestion to use an open-ended question, I prepared my interview guide (see Appendix 7), which was the initial version used before any modifications were made based on the discussion with supervisors, memo writing, and theoretical sampling. The interview guide was discussed with my academic supervisors, and then I translated it into the Arabic language version (see Appendix 8). As suggested by Charmaz (2014), the research questions shaped both the interview topics and the literature review. Through open-ended questions, I could delve into participants' thoughts and perceptions as they naturally surfaced during the interviews, allowing for an exploration of individuals affected by ESKD lived experiences given their 'voice' priority.

Each interview lasted approximately 30–60 minutes and adhered to a flexible interview schedule, especially during the initial interviews. However, adjustments were made as analysis and theoretical sampling directed the study's progression (Charmaz, 2001). The interview schedule utilised is outlined in Appendix 7 & 8. Additionally, field notes were documented after each interview to capture ideas, serve as memos, and document any non-verbal cues observed during the interview.

The questions and prompts outlined in the interview guide facilitated a deeper comprehension of the participants' experiences, behaviours, beliefs, and attitudes. They also provided assistance to participants who encountered difficulty articulating their experiences (Charmaz, 2014). Additionally, I sought the help of a bilingual translator to translate the study guide into Arabic.

5.5.4 Interview process.

After the participant read the information sheet and agreed to be interviewed, informed consent was obtained. The invitation letter, participant information sheet and informed consent were translated into Arabic because the participant speaks the

Arabic language (see Appendix 7 & 8). All interviews were audio-recorded using a Sony audio recorder, which was used solely for this research project data collection. Using the audio recorder helped me to focus my attention on the participants' talk and understand their responses, facial expressions and body language. On the other hand, the existence of a recorder in front of the participants restricted them from expressing their sensitive topics.

The timeframe of the 27 interviews was 30 to 60 minutes. Most of the interviews took place while the participants were waiting for their lab results in order to see their treating physician. Some of the interviews were conducted at a date and time convenient for the participants. All the interviews took place in the hospital at a quiet office away from the nephrology clinic and kidney dialysis unit.

Once the participants had read the information sheet and agreed to take part in my research project, I obtained their informed consent after I made sure that they understood the research project's purpose. Then, I asked their permission to audio record the interviews. I explained to them the purpose of audio recording the discussion and how that would help me conduct my research project and analyse the data. The participants were assured of maintaining their anonymity and confidentiality by using code numbers to replace their actual names and their health institutions. Therefore, I had no objection from all participants to recording the interviews except one who refused to be interviewed after the process of explanation.

Demographic data were collected prior to each interview to identify the participant’s characteristics (see Appendix 12). I asked the participants about the demographic data, which was translated into Arabic (see Appendix 13), which relieved their tension and helped me start the interview smoothly. Participants’ medical records were accessed before and after the interviews from the institution's health system to gather information about the participant’s date of diagnosis as ESKD and co-morbidities, eGFR history till reaching stage five and the date starting on dialysis.

After that, I started the interview with open-ended questions, which allowed the participant to share their experience by asking them to express and explain their health condition. Prompt questions were used to encourage participants to articulate their experiences, for example, tell me more about your dialysis refusal. As well as I also used the prompt questions to clarify issues stated by the participants and provide elaboration.

A total of 27 Omani individuals, including those who initially refused haemodialysis and then agreed to dialysis, participated in this research over a six-month period between October 2021 and April 2022. The interviews were all conducted in Arabic language, and I conducted the interviews myself, which helped me to ensure consistency and to improve my interviewing skills.

5.6 Transcription and translation

Data transcription in qualitative research is considered a critical and important stage, as it is one of the essential stages of data analysis (Point & Baruch, 2023). The data collected and analysed using qualitative research methods are often criticised for their subjective nature and the richness and extensiveness of the data (Easton et al., 2000). Transcribing collected data is highly desirable but also an extremely time-consuming process, as most qualitative researchers have commented because it demands a substantial commitment of both time and human resources (Matheson, 2015; Point & Baruch, 2023).

Researchers transcribing their own data allows them to immerse themselves in their data, become more familiar with the interview-collected data, and develop insights (Point & Baruch, 2023). According to Matheson (2015), going through the transcription process helps researchers build additional theoretical sensitivities because they listen to the recording carefully, pay attention to the voices and context of the interview, and use their memory and senses. Hence, researchers critique their own work, continuously learning and improving their interview techniques. Transcribing their own research data also smoothens the memo-writing process, providing researchers with the opportunity to see their data as pieces of a greater whole, reflecting their analytical assumptions, reactions, and feelings that took place during the actual data collection process (Matheson, 2015). Consequently, it leads the researcher to a better understanding and broader theoretical inquiries during the data analysis process. Listening to the interview recording repeatedly floods the researcher with thoughts and memories they may not have previously considered, which they can use as theoretical memos before they fade away, as they are important and can be used during the analysis and writing-up phases. Transcribing one's own data provides researchers with the opportunity to listen carefully to participants' words, non-verbal expressions (such as crying), silence, and pauses, helping them improve their data collection techniques and change or modify future data collection questions (Matheson, 2015).

All recorded interviews were coded and saved, and then I transcribed them verbatim into Arabic. Listening to the audio records helped me evaluate my interview skill and identify my weaknesses and where I used the leading questions and forced the data unintentionally. Each transcription process took about one day because I listened to the interview several times to ensure transcription accuracy and typed the words stated in Arabic. By listening to the recorded interview, I reflected on the conversation, and I took notes as a written memo, which helped me further understand the data and identify the gaps for further exploration.

5.7 Translation and back translation

Translating research data into another language is crucial to comprehending the research concepts or phenomena, and it is a fundamental cultural method required in conducting international research and scientific exchange (Abfalter et al., 2021).

Haldane et al. (2022) found that the translation process in qualitative research is a complex endeavour requiring meticulous attention to detail, cultural nuances, and linguistic intricacies. Researchers must allow ample time for translators to develop their voice and tone, ensuring the preservation of the original text's integrity and meaning. Addressing challenges such as untranslatable elements involve engaging in discussions and using notes to find appropriate equivalents. Maintaining clear communication with the implementation team and creating a word bank of translated terms promotes consistency and alignment with research objectives. Collaboration among translators for peer review and problem-solving enhances quality assurance. Recognising the importance of reflexivity and positionality allows for a more nuanced and reflective approach to translation, ultimately enhancing the authenticity of the translated materials.

I took the lead in translating the Arabic transcriptions since I speak the same language as the participants and share the same culture. During the interview, I used Arabic slang with the participants, which varied from one participant to another according to their residency area because I recruited my study participants from nine different governorates in Oman.

The constant positive feedback I received from my academic supervisors about the translated transcripts ensured their understanding of it. The initially translated interview transcripts were sent to a bilingual professional translator for a back translation to ensure the congruence between the translated transcripts in English and the original Arabic transcripts, as shown in Table 5.5.

Table 5.5 A sample of the back translation

ESKD Individual's verbatim	**Translated script**	**Back translation**
أجل ، لقد رفضوا غسيل الكلى. قالوا ، "لا نريد أن تخضع والدتنا لغسيل الكلى" ، كما تعلمين ، إذا قام شخص ما بغسيل الكلى مرة واحدة ، فسيستمر في غسيل الكلى. *(05F)*	*Yes, they rejected the haemodialysis: they stated that we don't want my mother to undergo haemodialysis, as you know, if a individual did once haemodialysis, then he would continue on haemodialysis. (05F)*	*أجل ، لقد رفضوا غسيل الكلى. قالوا ، لا نريد أن تخضع والدتنا لغسيل الكلى، كما تعلمين ، إذا قام شخص ما بغسيل الكلى مرة واحدة ، فسيستمر في غسيل الكلى.(05F)*

5.8 Research data analysis.

Data analysis may involve more than one analytic direction. In grounded theory, coding begins early in the analysis process. Researchers create codes from emerging data as they interact with it, posing questions to gain new perspectives and guide further data collection in unforeseen directions. This iterative process allows grounded theorists to stay attuned to their subjects' realities by sensitising concepts and constantly comparing data at every level of analysis. This comparative method involves comparing different individuals' views, situations, and experiences and comparing data from the same participants at different times, occurrences with occurrences, data with categories, and categories with each other. Researchers use selective or focused coding for initial codes that frequently reappear to manage large amounts of data and categorise them. Meanwhile, categories transform descriptions into a conceptual, analytical framework. (Denzin & Lincoln, 2000).

The qualitative analysis is used to gain insight into the individuals affected by ESKD decision to refuse dialysis. As mentioned in the methodology chapter, data collection and analysis in grounded theory occur simultaneously.

Utilising software could enhance the researcher's learning process, but simultaneously, it may diminish the intimate relationship between the researcher and the data (Bryant & Charmaz, 2007:24). Therefore, I opted to manually work on it to stay in touch with my data. Participant quotes are followed by a code number, which includes the institution number, gender, and sometimes age. Participants with the same institution number at the beginning of their code number were from the same health institution.

5.8.1 Coding

Coding serves as a critical intermediary step between data collection and theory development in grounded theory research (Charmaz, 2006). During the initial or open coding process, codes have emerged as the data is scrutinised and meanings are assigned by researchers. This process entails reading transcripts line by line and assigning codes to represent the content, whether at a descriptive or explanatory level. This meticulous approach aids in identifying important words or groups of words in the data, ensuring that no significant information is overlooked. Leads for further exploration are provided to researchers through line-by-line coding. If an important process is identified in a later interview, earlier interviews can be revisited by researchers to determine if that process explains events and experiences observed previously. Charmaz (2006) stated that seeking new respondents to shed light on the process.

Charmaz (2006) highlights that careful line-by-line coding brings researchers closer to fulfilling two criteria for completing a constructivist grounded theory analysis: fit and relevance. The progression of CGT analysis occurs when constructed codes, derived from the line-by-line and axial coding processes, are developed into categories (Charmaz, 2006). Axial coding is the process of connecting categories to subcategories, figuring out their properties and dimensions, and putting together pieces of data that were scattered during the initial coding phase (Charmaz, 2006).

These categories are aimed at clarifying the experiences of the interviewees and providing an analytical framework. This framework interprets ongoing processes, offering a lens through which the relationships between implicit processes and visible structures can be examined. Then, all these categories are gathered to define one more core category to form the basis of the final theory.

I maintained flexibility in the coding process, adapting to changing circumstances throughout the data gathering and analysis period, which enabled a theoretical sensitivity to emerge from the data. This approach facilitated the identification of significance within the data and the attribution of meaning (Corbin & Strauss, 1990:46). Engaged in an iterative cycle, and I transcribed interviews, scrutinised transcripts, and continuously reviewed recordings to identify codes and elevated them into higher-level categories. Employing a constant comparison approach across all materials concurrently, this integrative cyclical process heightened the analytical interpretation of the data, revealing gaps in both the data and sampling process. Moreover, it aided in clarifying the meaning, perspectives, thoughts, actions, events, and experiences captured within the data.

The initial phase of grounded theory analysis involves open coding, which begins after reviewing the complete transcription of the initial interview and extends nearly to the conclusion of data collection. During open coding, each significant line of data is labelled with a term that encapsulates its content. Concurrently, memos are documented to capture initial reflections on the data and to note topics for further exploration in subsequent interviews.

I analysed the data line by line to create the initial coding using the participant's own words, which helped me get engaged and immersed in the data and identify the gaps for further exploration at the early stage. See appendix 15 line-by-line coding.

After reviewing the initial coding of each interview, I revisit the initial coding of the previous interview before moving on to the next one. This method helps me stay closely connected to the data.

The second step involves applying axial coding. While Charmaz contends that this step is optional in theory construction, it proves beneficial when the data are robust and accessible, aiding in the development of a constructivist grounded theory by furnishing researchers with a framework to generate a conceptual model (Charmaz, 2006). Axial coding establishes connections between categories and subcategories, delineates the properties and dimensions of a category, and integrates fragmented data from axial coding to elucidate analytic concepts (Charmaz, 2006).

Here, the researcher begins by examining the open codes to identify patterns, similarities, and connections. This process entails several iterations of creating broader codes from the open codes, sometimes requiring the researcher to revise existing codes. Additionally, more data is collected and analysed during this stage, leading to the expansion or consolidation of axial codes (see Appendix 17).

During the theoretical coding phase, I applied advanced techniques akin to those utilised in the preceding stages. Here, the categories developed were derived from the axial codes. These axial codes, deemed to possess higher conceptual significance, were elevated to category status as they more accurately encapsulated the essence of the data (see Appendix 18). Additionally, they synthesised multifaceted layers of meaning and actions across participant groups. Subsequently, I created theoretical memos to provide detailed explanations of each category, describing its properties and interconnections with other categories in the data. This transition allowed me to move from representing diverse narratives to condensed yet profound and highly conceptual categories, explaining the study findings. Ultimately, five categories emerged from this phase, as will discussed in Chapter Six. To visualise and conceptualise the interrelationships between categories, I employed diagramming techniques, as suggested by Charmaz (2006; 2014). This facilitated the structuring of my analysis, paving the way for the formulation of my results.

Constant data comparison and memo writing aid in defining the most fitting ideas and interpreting the data as tentative analytical categories. When gaps arise within these categories, data are sought to address those gaps (Charmaz, 2006).

5.8.2 Constant comparative analysis.

The constant comparative analysis method, introduced by Glaser and Strauss (1967), is an essential element of grounded theory research and can be used with data sets of any magnitude. This iterative and inductive technique seeks to comprehend human phenomena by analysing their experiences and circumstances and comparing their similarities and differences. Constant comparative analysis is used throughout the data collection and analysis process. Researchers continuously compare and contrast new codes in an iterative manner, which eventually leads to the creation of categories and more complex structures (Glaser & Strauss, 1967). This method involves a continual comparison of incidents or data during coding. It begins with open coding to establish categories and progresses with further reductions and recordings to allow prospective core categories to emerge (Glaser, 1978; Charmaz & Mitchell, 2001). Glaser and Strauss (1967) introduced their coding work as a component of the constant comparative procedure in the grounded theory methodology. They identified three forms of constant comparison: comparing incidents to incidents, comparing emerging concepts to fresh incidents, and comparing conceptions to concepts (Glaser & Strauss, 1967).

Within the framework of constant comparative analysis, the practice of preparing memos is consistently observed, irrespective of the methodological perspective of grounded theory. As concepts emerge through continuous analysis and comparison, researchers reflect on the data (Santos et al., 2018).

Applying the principle of constant comparison to analyse the data in this study, I conducted code-to-code comparisons and compared the codes with emerging data. This process revealed overlaps among many codes, indicating similar underlying concepts, prompting me to initiate code categorisation. By scrutinising both shared and distinct properties of incidents across various interviews, I gained insights into individual participants' accounts and the overarching experience. Continuously evaluating the initial codes for focus and comprehensiveness, I conceptualised ongoing data trends and identified avenues for further exploration. This approach enabled me to adhere to the core principles of grounded theory analysis, ensuring alignment and significance (Charmaz, 2014). For example, to explore the initial reactions of individuals with ESKD upon learning their diagnosis, I compared their accounts and responses. Analysing these narratives unveiled profound insights into the shock and denial experienced at the diagnosis, shedding light on the factors influencing their decision to refuse haemodialysis. Through grouping similar incident properties and delineating differences, I formulated a core, overarching category elucidating the refusal experiences of individuals with ESKD.

5.8.3 Memo writing

Assumptions about reality are often made by researchers and participants to influence their perspectives and interactions. Therefore, researchers have an obligation to be reflexive about their biases and perspectives (Charmaz, 2006). Memo writing in grounded theory typically takes place between coding and the first analysis draft, encouraging researchers to explore their codes and data in new ways to justify coding expansion and theoretical sampling (Denzin & Lincoln, 2000). Researchers are kept engaged in their research and focused on data analysis by being informed about their analytic development stages, including the refining of categories and the defining of their relationships, to gain confidence and competence in data analysis (Denzin & Lincoln, 2000). The basis for structuring the research report is also provided by memos, offering preliminary analytic notes on merged codes, comparisons, and additional ideas about the data (Charmaz, 2006:3; Bryant & Charmaz, 2007). Additionally, categories are elaborated on, their properties are stated, the relationships between categories are defined, and gaps are identified in memos (Charmaz, 2006:6). When contradictory information arises in excerpts, it is crucial for them to be highlighted and coded, and memos about them to be written, as memos help reflect on contradictions and aid in formulating the analysis progress.

I wrote memos concurrently with my field notes, facilitating continuous engagement with the data. An electronic file was created for memos based on my reflections. When an idea emerged from one interview, it was noted in this memo file and further explored in subsequent interviews. Additionally, memo writing assisted in compiling questions for deeper exploration and guided the selection of the next sample. For instance, decisions on whether to interview a young or older man, a woman, someone well-educated, informed, accompanied by a father, mother, son, daughter, sister, brother, employed, or from another governmental health institution were informed by these memos (see appendix 16).

5.9 Theoretical saturation

Theoretical saturation is considered a critical concept based on subjective decisions. The point of theoretical saturation is reached when no new theoretical perspectives within the core category are uncovered by collecting additional data. Therefore, it is not a repetition of previously stated actions or statements but rather a situation where nothing new is occurring, and the additional data does not explain more about the core category (Charmaz, 2006). At its most fundamental level, the concept of saturation relates to the stage where no new ideas arise, and It provides guidance on determining the appropriate time to stop data collection (Charmaz, 2006). Bryant and

Charmaz (2007) suggest that researchers determine the point of saturation when they stop encountering new ideas during interviews and fail to uncover any new information during the analytic process.

In this study, the point at which no new ideas emerged was around interview 16, although additional interviews were conducted to ensure this was the case. According to Bryant and Charmaz (2007), theoretical saturation is attained by consistently comparing episodes in the data to elicit their characteristics and dimensions until no further properties and dimensions arise from constant comparison. After 23 - 25 interviews, no new codes were emerging. The analysis adequately accounted for and explained the variability between categories, and the researcher was satisfied that the categories developed at this stage had strength and supported an explanation of the process of decision to refuse haemodialysis. Appendix 18 identifies all categories and the related properties that form part of the grounded theory. By the time I reached the last two interviews (26 & 27), the grounded theory was nearly fully developed, and those last two interviews did not add anything. They simply fit within the grounded theory without taking it in any different direction. It was found that all participants were thinking the same thing. For example, they all talked about denial, alternative treatment, fear of haemodialysis, family influence, and fatalism.

However, for some categories that emerged in the middle of the interview series, saturation was not achieved; for example, refusing dialysis without a reason was mentioned by two male participants in different age groups (19 years and 40 years). This issue did not appear in the initial interviews nor in the later ones. Thus, I concluded that refusing dialysis without a reason was less common among individuals with ESKD. Regular discussions with academic supervisors and memo writing were instrumental in determining the level of data saturation.

5.10 Theoretical sensitivity

By pausing the study flow, reflecting, making comparisons, building on ideas, and reshaping the study direction to achieve 'thinking anew,' as outlined by Charmaz (2006:135), theoretical sensitivity was attained. I used my professional knowledge, along with the information from the initial literature review and the study's background, to shape my theoretical sensitivity. This was influenced by maintaining a reflective stance. I kept myself receptive and avoided pre-existing hypotheses and assumptions that could bias my perspective. My thorough literature review guided the refinement of the study's discussion. My review initially concentrated on specific aspects of the wider subject of treatment non-adherence and non-concordance, providing insights into the challenges experienced by individuals with different diseases. As the study advanced, my data revealed emergent patterns that went beyond the original findings from the literature review. The initial literature review improved my theoretical sensitivity by highlighting the need to recognise that each individual has their own unique culture and setting. This prompted me to approach data collection and analysis with an open mindset, acknowledging the possibility that the studied context and its conditions might differ from what I had encountered in my literature review. It also reinforced my perspective that the research context holds the most significance, constituting a distinct social reality worthy of exploration. Over the course of my four-year PhD program, I had the opportunity to dedicate more time to engaging with my data collection and analysis processes. This extended duration enabled me to deepen my theoretical sensitivity through extensive coding and recoding of the data (Charmaz, 2014; Charmaz & Thornberg, 2021). I had the opportunity to thoroughly review the transcripts multiple times and engage in discussions with my academic supervisors to validate them. This ensured that the codes I developed were rooted in the participants' experiences and narratives rather than my own personal or professional biases (Corbin & Strauss, 1990). This meticulous process was especially crucial for codes associated with social and cultural factors. As an illustration, the initial coding that emerged—'Denial', 'influence by other people's experience', 'accessing information', 'shopping', 'around', 'fear', and 'fatalism'—prompted me to revisit the recordings, carefully review the participants' transcripts, and share them along with the coding with my academic supervisors. This facilitated discussions during our monthly supervisory meetings, ensuring that the codes accurately reflected the experiences of individuals with ESKD and were not biased by my professional background.

5.11 Reflexivity

In constructivist grounded theory, reflexivity is fundamental to the researcher's role as the main instrument in data collection and analysis (Charmaz, 2014). This involves researchers consciously considering their influence on the research process and making it explicit, both to themselves and their audience (Gentles et al., 2014). Reflexivity ensures that researchers are aware of their biases and preconceptions, helping them to maintain rigour and accuracy in their interpretations of the data. McGhee et al. (2007) suggested that reflexivity involves consciously minimising researchers' influence on data by maintaining self-awareness, which is essential during both data collection and the constant comparison method integral to grounded theory. Additionally, it is necessary to prevent the researcher's existing knowledge from biasing their interpretation of the data.

In the previous chapters (1- 4) and including this chapter, I have outlined how my personal interests and background influenced the choice of research topic and primary research question. I have also provided justification for adopting the constructivist grounded theory approach and explained the rationale behind the decisions made regarding data collection and analysis methods. Furthermore, the concept of theoretical sensitivity, a form of reflexivity, was introduced in Section 5.8 and is consistently revisited throughout the thesis.

I maintained awareness of my role and impact within the research process (Finlay, 2002) and in shaping the picture of individuals affected by ESKD experiences (Gentles et al., 2014) (Gentles et al., 2014). Employing a reflexive approach throughout the entire research endeavour, I recognised that understanding people's experiences involves a social dimension with inherent social implications.

This reflexive stance, echoed by Cutcliffe (2000), emphasised that researchers should critically consider their influence on both data collection and interpretation. It prompts contemplation on how the study may impact the context and culture under investigation and how participants might perceive the researcher's presence (Brewer, 2000).

During the data generation phase, my original intention was to write memos throughout participant interviews. I attempted this approach during the first interview, but I quickly realised its challenges. I found myself overly preoccupied with writing, making it difficult to fully engage with the ESKD individual's expressions and storytelling details. Additionally, participants became curious upon noticing me taking notes in my diary, prompting inquiries about my actions despite my prior explanation of notetaking during interviews.

This discomfort expressed by the individuals affected by ESKD indicated that memo writing during interviews was impractical in my situation. It not only distracted participants but also diverted my attention away from their non-verbal clues. Consequently, I made the decision to stop writing memos during interviews unless a participant brought up a significant aspect of the studied phenomenon that required further exploration.

Qualitative researchers may analyse and respond to data through their subjective experience and personal bias. This may impact how information is prioritised, the emerging themes, and how narratives are presented (Ritchie et al., 2013). Reflexivity was consistently used in this research to ensure the credibility of the research results and to consider factors that could affect the research process and data interpretation (Finlay, 2002). I maintained a diary where I reflected on my own personal and professional experiences and preconceived beliefs, considering how they might have impacted my perception of the information provided by individuals affected by ESKD during the study process (Searcey, 2022). My reflective diary helped me become more aware of any potential bias I may have influenced as a researcher on the research results (Darawsheh, 2014). It was crucial for me to give detailed descriptions of my personal and professional background, together with my preconceived beliefs in the field of ESKD and recognise how they impacted the study process.

Reflecting on my experience as a nurse working with individuals affected by ESKD was crucial. I was worried that my previous thoughts about the ESKD journey could hinder an impartial investigation or comprehension of participants' viewpoints during data collection. To tackle this issue, I conducted self-reflection by documenting thoughts, ideas, and questions that emerged from my assumptions and professional ideals.

Engaging in reflexivity allowed me to acknowledge the different positions I played, such as bedside nurse, nurse supervisor, hospital head of nursing, director of nursing professional practice, national task force member and researcher, during the interviews. Recognising and accepting opposing perspectives helped reduce my own individual beliefs (Ben-Ari & Enosh, 2011).

In qualitative research, the researcher acts as the main tool for collecting and analysing data (Stewart et al., 2008). At the very start of this study, I presented a thorough description of my experience and knowledge regarding chronic kidney failure and how it is treated. I considered how my experience and the existing literature informed the development of the study question and theoretical framework. It was essential to familiarise participants with my professional background (Tinkler et al., 2018). The participant information sheets clearly indicated that this study was a component of my doctoral research. I made it clear to participants that, while being a nurse under the Ministry of Health, my expertise does not lie in nephrology. I clarified that my understanding of kidney disease was broad and that I did not have direct experience working with individuals affected by ESKD who refused haemodialysis during my time as a nurse. I did this to avoid letting my own biases impact the interviews and data analysis. I tried to prevent them from seeing me as a problem solver at the same time. I did not want to impress participants by offering solutions to their ESKD issues and refusal of haemodialysis. However, it was crucial for me to stay exact with myself during the interviews since I thought establishing a real rapport with participants was vital. This method was successful and enabled fruitful engagement with participants.

Researchers acknowledge that their personal backgrounds and social identities might impact how they analyse data and perceive the research context (Berger, 2015).

Professional experience and an insider or outsider position in the study setting are thought to influence the research's conduct. Out of the nine settings addressed in this study, I was familiar with only one (02H), where I had worked as a nurse until becoming head of nursing. My insider status facilitated the data-gathering procedure as I was familiar with the surroundings, and I had previously built rapport with the staff. Yet, I was concerned about losing sensitivity because of my experience with this study context.

In the remaining eight settings where I did not have a previous connection with nephrology personnel, I assumed a more proactive position as a researcher. However, I had reservations about the recruitment process and facilitating data collection. To address this issue, I arranged phone conversations with the nursing administration and hospital directors prior to data collection to understand the workflow and build rapport with gatekeepers. The discussions with administrative personnel, nephrology nurses, and responsible physicians were extremely helpful in recruiting participants and ensuring the smooth progress of the study.

Undertaking qualitative research, particularly a grounded theory study, marked my first independent research endeavour. To prepare for data collection, I studied a module on qualitative research data collection at the University of Hull. Throughout the process, I remained mindful of the importance of providing a detailed account of my decision-making process. I also adhered to the interpretive perspective, which underscores the recognition of subjective experiences and emphasises ongoing dialogue between the researcher, participants, and data. This approach aims to facilitate the reconstruction and understanding of the phenomenon under study (Charmaz, 2014).

5.12 Conclusion

In conclusion, this chapter describes the manner in which the methodology was put into practice in the field. It sets out the practical steps used to recruit participants in an ethical manner and describes how interviews were used to collect data. It then sets out with examples of the various stages of data analysis.

The next chapter will provide an overview of the sample demographic characteristics, the emergent categories, and the core category with an explanation of its development.

Chapter 6 Research findings

This chapter presents the research findings. First, it provides an overview of the research sample, and it describes the demographic characteristics of the participants, and then it examines the development of the core category, which is the overarching theme of ‘balancing’ as a key process by which end-stage kidney disease individuals choose to refuse haemodialysis. Subsequently, the five main categories that contributed to the development of the final grounded theory are discussed in detail, namely, self-conceptualisation, acquiring knowledge, influencers, fear, and self-control. Finally, the chapter elaborates on the interlinking and interconnectedness of these five categories, as well as their influence on individuals' decision-making processes.

6.1 Participants’ demographic data

A total of 27 Omani individuals, including participants who initially refused haemodialysis and then agreed to it, participated in this research project over six six-month period between October 2021 and April 2022. Details of the research setting and context of participants’ interviews are presented in the methods chapter (section 5.1). Participant demographic data characteristics are as follows:

6.1.1 Age

The participants' ages ranged from 18 to 80 at the time of the interview. Twenty-one participants were aged between 26 and 74, three were aged 25 and below, and three were above 75. This age range mirrors the Omani society profile, in which 52% of the population is between the ages of 15 and 74 (NCSI, 2023).

Table 6.1 Participants' age distribution.

Age in years	(18-25)	(26-35)	(36-45)	(46-55)	(56-65)	(66-75)	(76-85)
N=27	3	2	4	5	6	4	3

6.1.2 Participants marital status, occupational status, education level and comorbidities status

Table 6.2 shows that 52% (N=14) of the participant group were male and 48% (N=13) were female. The majority of the research participants were married (N=19). Of the nine single participants, two were unmarried (the youngest participants in the research project), two were divorced, and four were widowed. About 85% of the participants were not working (N=23), of which 10 were retired, and only one was a student at the time of the interview. More than 50% of the participants were educated, although to different levels (N=17); however, ten had not attended school, of which two were able to read and write, and eight were illiterate.

Table 6.2 Participants Demographic Data

Demographic data	**Total number of participants (N=27)**	
Sex	**Male**	**Female**
	14	**13**
Marital status		
Single	**1**	**1**
Married	**13**	**6**
Divorced	**0**	**2**
widowed	**0**	**4**
Occupational status		
Working	**3**	**1**
Not working	**1**	**11**
Retired	**9**	**1**
Student	**1**	**0**
Level of education		
Higher education	**1**	**1**
Secondary level	**4**	**4**
Preparatory level	**3**	**0**
Primary level	**3**	**1**
Read and write	**0**	**2**
Illiterate	**3**	**5**

All of those who participated in this research were diagnosed with ESKD with one or more comorbid diseases (Table 6.3).

Table 6.3 Participants' comorbidities status

Comorbidities	Hypertension	Hypertension & Diabetes	Hypertension, diabetes & Cardia	Hypertension & Systemic Lupus Erythematosus (SLE)	Al port syndrome
N=27	11	7	6	2	1

Almost 96% (N=26) of the participants had a diagnosis of hypertension associated with one or more comorbidities, including diabetes, hypertension, and Systemic Lupus Erythematosus (SLE). One male participant, the youngest individual in this study, was born with Al-port syndrome, a hereditary disorder characterised by hearing impairment, ocular changes and progressive glomerulonephritis leading to kidney failure (Kruegel et al., 2013).

6.2 Initial data analysis

As discussed in the method chapter (section 5.3.1), the initial sample of five participants was purposively sampled to align with the study aims, aiming to generate rich data and enhance the research interview guide. Notably, when the first five interviewed participants were diagnosed with ESKD and informed of the haemodialysis option by their treating physician, they experienced a state of denial and refused to undergo treatment as extreme as haemodialysis. This phenomenon was captured at a very early stage in the analysis by the code **'denial',** which was found to be a common theme among the initial sample of participants who had refused kidney dialysis.

> *"no, I did not have a kidney problem and nothing… no, not in failure, I do not have failure and nothing" (05F).*

> *"I myself, I do not imagine that one day I would reach the stage that I undergo dialysis" (02M).*

Those initial participants had asserted that they had not yet reached the failure stage of kidney disease. Therefore, they declined to undergo haemodialysis as they were not experiencing symptoms and were able to engage in their daily activities without difficulty.

> *"I saw myself, I do not have anything" (01F).*

> *"I do not want [HD], thank God, now I am not that weak, now I am able to carry myself, I am able to go and come, thank God I can eat, pray and stand" (03F).*

Consequently, they held the belief that haemodialysis was unnecessary as they felt able to manage their health condition through the use of prescribed oral medication.

> *"I do not want [HD] dialysis…., I did not do dialysis for how many years because I am using these tablets (oral medications)" (04M).*

Two participants, however, based their decision to refuse haemodialysis on biomedical markers such as eGFR, which they believed indicated that their kidneys were functioning well. They also mentioned that their treating physician reassured them not to worry because they would be re-evaluated at other stages and could maintain their current regimen of oral medication instead of opting for haemodialysis.

> *"Today I came to see the doctor, and he said I do not need dialysis because earlier my kidney was 7% and now11%..... and he said .. I continue with [oral] medication." (01F)*

> *"his [physician] plan, I take medication and weekly blood transfusion….for about three months" (02M).*

However, some of those initial participants negotiated their diagnosis and treatment plan with their next kin.

> *"yes, I did discuss it [HD] [with his wife]…. And she said, I [wife] do not advise you…. You need to find another way if you can" (02M).*

The analysis of initial interviews revealed that participants were influenced by the experiences of other haemodialysis users. The code of 'Influence' and the 'influence of others' experiences' played a significant role in the participants' decision to reject haemodialysis. For instance, family influence exerted a considerable impact on participants, leading them to believe that haemodialysis would result in the end of their lives.

> *“they [relatives] saw people….I mean each person [dialysed person] would end up dying” (02M).*

Family members and friends consulted by these initial participants assumed the role of health assessors, advising participants against undergoing haemodialysis. For example, a 37-year-old male participant with one year and three months of ESKD was influenced by a family member who held reservations about the concept of haemodialysis. Due to the participant's young age and the family member's perspective that it was early for him to undergo haemodialysis, the participant was swayed against the treatment.

> *“my family did not accept it [HD]; I mean it's difficult because [they said] you are a young boy with 37 years old and does kidney dialysis…. they [family] did not like the situation” (02M).*

Additionally, those five initial participants’ relatives held the belief that once an individual commenced haemodialysis treatment, it would be challenging to discontinue, and they would be required to continue with the treatment for the rest of their lives. Consequently, the sons of a participant, for example, assumed responsibility for refusing haemodialysis, fearing potential harm.

> *“They [sons] refused the dialysis; they said, we do not want our mother to undergo dialysis…. [because] they do not [want to have treatment that will] do me any harm” (05F).*

Accessing information was a code seen to influence the initial interviewed participants’ haemodialysis decision-making. For example, two of the initial group participants highlighted that the internet was a source used to access information about kidney failure signs and symptoms and compare it with the physicians’ findings.

> *“I saw on the internet…I enter google…. what I have seen in the net…. [was] different than the doctor” (01F).*

They also accessed information from wives, brothers, sisters, and other people to learn about kidney failure characteristics.

> *“I asked many people, they told me…. People with kidney failure got swelling in their hands, legs and face” (01F).*

The findings also revealed **'shopping around'** as another key issue highlighted by the first five interviewed participants. For instance, After the participants were informed about their kidney failure diagnosis and the treatment plan to undergo dialysis, they looked forward to furthering information gathering and information processing to find alternatives. Some of the participants recognised a lack of knowledge and thought of ‘shopping around’ and seeking second consultations either through another physician or another person and following their advice.

> *“I thought to go there [India] to make sure [about HD] …. they [physicians in India] told me, as long as you are alive, you do not need dialysis” (03F).*

It was clear that the initial participants engaged with the advice about their health they wanted to hear and did not acknowledge the advice that they did not want to hear, as shown in the (05F) quote, the 74-year-old female participant with six years of ESKD felt that the physician in India saved her kidney from haemodialysis because she did not require it.

> *“He [physician in India] said, I do not need dialysis….they gave me pills….my kidney got saved from the dialysis” (05F).*

Moreover, all of those five participants experienced a sense of 'fear'. This prompts them to persistently search for additional options while remaining firm in their refusal decision, which remains unchanged as they balance the benefits and risks of their decision all the time. A manifestation of this fear was evident in their requests to the physician for additional opportunities to pursue their prescribed oral medication to avoid haemodialysis.

“Please, doctor, you need to help me with medications, but I do not want dialysis” (01F).

In addition, the initial five participants' decision to refuse haemodialysis was influenced by the experiences of other individuals undergoing the same treatment, as they harboured concerns regarding the possibility of developing complications and experiencing mortality.

“I do not want to repeat their [niece and neighbour’s daughter] same experiences. As long as I am able to carry myself, I do not want to do like them” (03F).

“I am scared that one day I will [die] and leave them [children] due to this disease” (02M).

Finally, the findings from the initial interviews also identified 'fatalism' as a prominent code, where the participants in this research study attributed their fate and destiny to God (Ngueutsa et al., 2023). For example, the participants' responses indicated procrastinating in matters related to their health, with a preference to entrust their well-being to God. The participants further conveyed their readiness to undergo haemodialysis only if it was destined and permitted by God while remaining steadfast in their decision to refuse haemodialysis otherwise.

*“if something came from Allah (*God)*…. and I have fallen sick, there is no power except by Allah” (03F).*

“I left my matter to his mighty Allah…. If he wrote me to dialysis, [then] dialysis” (01F).

The initial findings from the first five interviews indicate that participants encountered various situations that led them to decide against haemodialysis. Their decisions were influenced by several unconnected factors (Figure 6.1), including denial, influence and influence of other people's experiences, access to information, shopping around, fear, and fatalism.

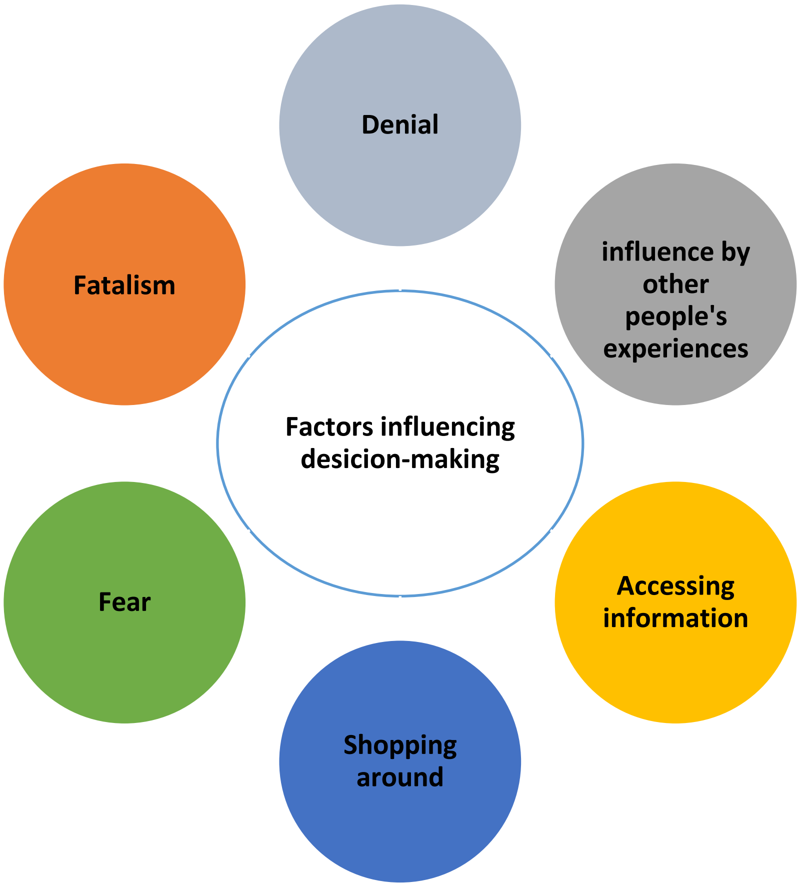


Figure 6.1 The initial unconnected influential factors of the haemodialysis refusal decision-making.

6.3 Complete data analysis

Then, to further understand the decision-making regarding haemodialysis refusal, I progressed through the interviews using theoretical sampling in order to add further depth and nuance to the codes and to consider how they were linked. This process further informed my understanding of the decision-making process that individuals went through in their refusal of haemodialysis. This ongoing analysis allowed a more focused identification of the core category and helped shape the direction of research-grounded theory (Charmaz, 2006).

The core category is the integration of all categories into a theoretical conceptual framework and represents the central aspect of the grounded theory based on the collected data (Harris, 2015). In the context of this study on haemodialysis refusal, it became evident from the participants' interviews that the main premise informing the decision-making process was the desire to avoid the dialysis sphere as much as possible. This avoidance was conceptualised as the core category of 'Balancing' the benefits and risks during decision-making that resulted in refusal to undergo haemodialysis.

Within this core category, I identified that participants' decision-making process involved a wide range of expectations regarding managing their health status without haemodialysis or delaying it as much as they could. Their responses to these expectations significantly influenced their level of uncertainty regarding haemodialysis and its potential positive impact on their health.

To ensure an in-depth analysis of the research participants' perspectives and experiences, I employed coding and the constant comparative technique. These methods ultimately contributed to the development of a theoretical framework that sheds light on the social experiences of individuals with ESKD who chose to refuse haemodialysis against medical advice. This framework helps us understand the decision-making process and its connection to their overall health status.

This theoretical framework consisted of five main overarching categories that underpinned the core category of 'Balancing' during the decision-making process: self-conceptualisation, acquiring knowledge, influencers, fear, and self- control. This process involved carefully considering the consequences of each decision related to the refusal of haemodialysis. The core category of balancing central role is evident in each category, as illustrated in Figure 6.2.

Figure 6.2 Factors influencing the decision-making process.

These five main categories provide an understanding of the experiences of individuals with ESKD in stage five who refused haemodialysis in Oman. They are explained in detail in sections 6.4 to 6.8.

6.4 Category one: Decision influenced by self-conceptualisation.

The first category identified from the data provided by those who refused haemodialysis in this study is Self-conceptualisation. This category is constituted by two sub-categories: 1) accepting ESKD diagnosis but not agreeing to haemodialysis, and 2) not accepting an ESKD diagnosis and haemodialysis.

Figure 6.3 represents how participants constructed their understanding of ESKD and medically advised haemodialysis. It also highlights how the previous and current experiences of individuals affected by ESKD shaped their understanding of kidney failure and haemodialysis. Thus, participants' self-conceptualisation reflected how they viewed themselves and made sense of their health condition.

Therefore, participants expressed binary concepts when asked about their kidney failure status and embarking on haemodialysis because they were not totally accepting the diagnosis of stage five kidney failure. However, in reality, their decision is not a binary one. Research data illustrate that participants' decision-making was an ongoing and re-visiting process, and within the self-conceptualisation category, the participants located between two sub-categories (Figure 6.3): 1) accepting and 2) not accepting end-stage kidney failure, and their decision-making process was influenced by a range of factors which led them to refuse haemodialysis.

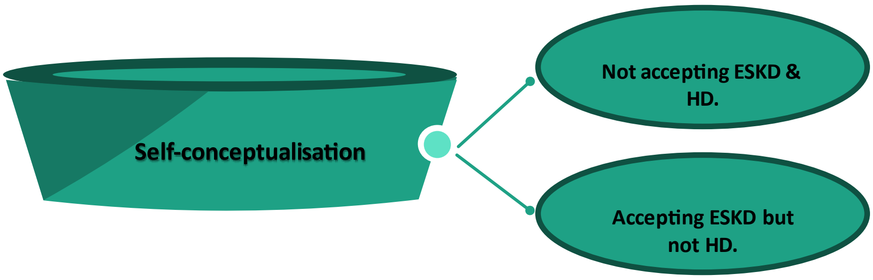


Figure 6.3 Category One: Self-conceptualisation.

6.4.1 Sub-category one: Not accepting end-stage kidney disease and rejecting haemodialysis.

All of the participants denied being at stage five of kidney failure and declined the medically recommended haemodialysis. Some participants exhibited an initial negative reaction and denied experiencing any kidney problems. This denial stemmed from the absence of disease symptoms indicating kidney failure, leading to their reluctance to undertake the dialysis procedure.

"I have no problem with my kidney" (010M)

Feeling asymptomatic is a dominant factor that caused most of the participants to reject the kidney failure concept and undergo haemodialysis. Feeling not having the right symptoms took different forms. For example, some participants experienced no obvious signs or symptoms of kidney failure, such as body oedema or vomiting. Therefore, they denied the kidney failure diagnosis.

> *"till now, I do not have these symptoms…. swelling, water in the kidney …. Vomiting…. I do not complain of anything…. I do not have kidney failure symptoms…. I do not accept, and I am not much convinced" (06F).*

Despite evidence from blood investigations supporting the kidney failure diagnosis, some participants denied reaching the stage five (kidney failure). Their denial stemmed from the absence of kidney pain and the lack of observable signs indicating kidney problems. Since they did not experience any apparent symptoms, they refused to accept their kidney failure diagnosis.

> *"Thank God, my kidney did not hurt me at all….. I do not have pain from it [kidney]…. I do not have it [kidney failure] even if it appeared by the investigations" (017F).*

As a result, they avoided thinking about kidney failure and haemodialysis.

> *"Myself I did not keep the kidney problem in my mind" (011M).*

A number of participants chose not to undergo a haemodialysis catheter insertion and questioned the reasons behind reaching kidney failure because they felt fine and observed a normal urine quantity and frequency.

> *"Thank God my kidney is fine because I go to the bathroom many times at night, for example, four times and five times….I swear, I feel normal" (014F).*

So, some of the participants denied the kidney failure diagnosis and remained unconvinced about the necessity of haemodialysis, citing stable health conditions, overall well-being, and a healthy appetite.

> *"I was surprised when they [physicians] told me I had a kidney problem; why is that and how it happened, because I see my health issues are fine and good, I pass urine…., I am not convinced to get dialysed because….. my body is normal, and good, I mean, not weak and not even …… my food, unlike, I cannot eat, no! or I feel tired" (013F).*

Some participants rationalised their negative reaction and refusal to accept the diagnosis of kidney failure and, therefore, the need for haemodialysis by emphasising their normal eating, drinking, and walking abilities. They believed that their treating physicians' statements seemed nonsensical and irrelevant, leading them to dismiss the importance of the diagnosis and treatment recommendations.

> *"These physicians did not know what to say, I do not have anything because I am able to eat, drink and walk; these physicians are senile" (004F).*

Performing normal daily activities and normal life were additional factors that led participants to refuse the kidney failure diagnosis and haemodialysis. For example, participants considered themselves as 'normal' because they were able to roam around walking and performing sports without any health issues that hindered them from doing so.

> *"Alhamdullah [Thanking Allah], I walk and go around, and I do not feel anything, and I do sport" (014F).*

Self-awareness and self-trust played significant roles in the decision-making process of participants who refused to accept the kidney failure stage and undergoing haemodialysis. They felt that they knew themselves better than anyone else, they trusted their own judgment and felt that they were in the best position to determine what was right for their health. This stance influenced their decision to refuse haemodialysis.

> *"I do not have [kidney problem] …….I feel of myself…. is there anyone who does not know himself ……. I know myself that I do not have a kidney problem" (017F).*

Another factor influencing participants' refusal to accept the kidney failure stage is their perception of feeling fine while engaging in social interactions. Participants mentioned that they were able to talk, laugh, and interact with their family members and colleagues without experiencing any significant discomfort or limitations. This sense of normalcy in their social interactions further reinforced their belief that they were not in a state of kidney failure, leading them to refuse to undergo haemodialysis.

> *"I do not agree….I do not have any problem, I go, talk and laugh with my colleagues and family…. I have nothing and no issues" (018M).*

A 61-year-old female participant with one year of ESKD expressed her refusal to accept that she had reached the kidney failure stage based on her perception of being asymptomatic. Despite feeling tired, she believed that she did not exhibit any noticeable symptoms of kidney failure. She emphasised that her urine flow was normal, and she was able to move around without feeling unwell. As a result, she saw no reason to acknowledge or accept her kidney failure status.

> *"I did not feel sick, and my urine was flowing well, though I felt tired, I was able to roam here and there" (005F).*

6.4.2 Sub-category two: Accepting end-stage kidney disease but not haemodialysis.

On the other hand, some participants showed acceptance when informed about their kidney failure status. They expressed that sharing this information with others would provide them with emotional support, help them stay strong, and contribute to their overall well-being and resilience.

> *"no, I do not feel it is embarrassing…..the opposite, I received support when I informed my colleagues at work, my family and my siblings…. everyone would pray for me" (015M).*

Other participants, for example, regularly followed their health condition with the treating physicians and felt that they accepted the disease diagnosis against their will because the blood investigations and the oedema signs proved the kidney failure status. Despite that, they declined to undergo haemodialysis.

> *"Against my will…. yeah, the results of my investigations say that [kidney failure], and at present, oedema in my legs is the main proof ….regarding the dialysis…. I [am] not convinced…. I refused it" (019F).*

When some participants were asked about experiencing any kidney disease complications, they expressed feeling fine and that their health was within normal ranges. Consequently, they did not see the need to undergo haemodialysis.

> *"Till now I do not feel that [complications], …. I do not feel anything" (03F).*

Despite not experiencing any pain, some participants understood that their kidney condition could worsen if they did not adhere to the prescribed medication.

> *"it's not because I have pain, I have no pain, but sometimes the kidney gets weaker when I do not use the medications" (04M).*

A 51-year-old male participant with an intermediate level of education expressed a sense of surprise and shock upon being informed by his physician that he had ESKD. The participant believed that he was in good health and was caught off guard by the sudden realisation that his kidney disease had progressed rapidly.

> *"the news surprised me……. I got shocked because I was fine and doing well roaming here and there, and…. in one moment informed to have [ESKD]" (003M).*

Some participants accepted their kidney failure diagnosis but refused to undergo haemodialysis due to various factors. For instance, 03F felt that she had not experienced any serious symptoms of kidney failure that hindered her from carrying out her normal daily activities, and she believed that the disease would persist as long as she lived.

> *"yes, I am convinced….. I have the disease, and it will go along with me, thank God I don't feel anything, I am not very sick like weak lying on the bed, I can carry myself" (03F).*

Yet, one male participant (018M) with a primary level of education and one and a half years of ESKD refused to undergo haemodialysis because he was not experiencing kidney pain.

> *“as a health problem, I have weakness in my kidney…. They [physicians] were about to do me dialysis, but I refused….[because] I do not have pain” (018M).*

Some participants who accepted the diagnosis of kidney disease progression pointed out that if there was something wrong with their bodies due to their kidneys, they would expect to feel signs such as oedema. However, because they did not experience obvious complications of kidney failure, they refused to undergo haemodialysis.

> *“if my body is fine, then it is fine. If my body is not fine, then it is not fine…. if I have pain, I would feel it..... I did not have oedema or anything else; even today, the physician asked to see my legs” (017F).*

There were a few of the participants who acknowledged their kidney failure status but expressed their preference for kidney transplantation. Consequently, they chose to adhere to their prescribed oral medications while awaiting a suitable kidney donor for the transplantation procedure, opting not to undergo haemodialysis.

> *“… I will not accept it [HD], I will continue on the medication until I get a donor…… basically… I refuse the dialysis….. let us be on the medications” (07M).*

While a few participants acknowledged that they might undergo haemodialysis one day but were not convinced to undergo it, they preferred to postpone it because they were in an asymptomatic status.

> *“I am persuaded that I will undergo dialysis…. [but] I will delay it [HD]……. now I saw myself…. I am fine” (015M).*

> *“I am not convinced to get dialysed….I see myself fine; [asking physician] you just give me some time” (013F).*

Some participants expressed satisfaction and a sense of accomplishment because they had not undergone haemodialysis since they were first informed about it, and they suggested that their kidneys had been functioning well without the need for haemodialysis.

> *"I resisted from 2018 up to date, and I did not undergo dialysis. That means it [my kidney] was [doing] good" (015M).*

To some extent, in a similar manner, some participants agreed to undergo haemodialysis if their health condition deteriorated. However, they preferred to continue taking their prescribed medications as they met their health needs.

> *"If it got worse maybe …. I would undergo dialysis, but thank God; the disease has not worsened or increased, I use the tablets, and life is going on" (04M).*

In addition to the reasons for refusal mentioned above, the eGFR emerged as a significant factor associated with some participants' refusal to undergo haemodialysis, particularly in the context of end-stage kidney disease. This finding underscores the critical role of eGFR in shaping individual's decision-making.

Upon being informed of an eGFR of 15%, some participants understood that their kidney function was severely compromised, indicating end-stage kidney failure and necessitating the need for haemodialysis. Despite this understanding, they decided not to consider undergoing haemodialysis.

> *"I mean [reached] the end condition ….. it is over, the kidney is weak …….. it is over, [kidney function] reached 15%, it reached approximately 15%.... it means over, I reached the dialysis level…. almost dialysis…. [but] I am not going to think much about it" (02M).*

Whereas one 74 years old participant, uneducated knew that his eGFR had dropped from ten to seven percent as informed by his treating physician, but he declined to undergo haemodialysis because he found no serious symptoms such as dizziness or vomiting. Instead, he had good urine output and the ability to maintain a normal lifestyle.

> *"he told me it was ten….[and] become seven percent…. But it did not cause me any issue….I find myself having nothing serious…. for example, [not] complaining of dizziness or vomiting; the urine flows well, and I walk… currently, I bring the house stuff" (020M).*

A number of participants were informed by their physicians of a slight improvement in their eGFR and advised observation, citing an increase from 7% to 11% as an example. That elicited a positive response and fostered hope among participants that haemodialysis could be avoided.

> *“He [physician] told me that your kidney [function] was 7% and now is 11%.… honestly, today I am very happy…. [It]made my day” (01F).*

Furthermore, a few participants refused haemodialysis from the beginning without providing a specific reason, stating that they were not obligated to embark on haemodialysis, as they felt fine and were able to lead a normal life, engaging in various activities, for example, roaming around.

> *“No, I will not agree [to undergo HD] …. for no reason….. and it is not a must to undergo dialysis because I am fine….I am able to go and come normally” (010M).*

They believed that refusing to undergo haemodialysis was within their rights as they perceived themselves to be healthy and saw no need to discuss haemodialysis with anyone.

> *“The decision is my decision…. I am refusing [HD] because…. I feel better and….I am well and in good health” (016F).*

Whereas some participants displayed a lack of mental readiness to undergo dialysis due to their dissatisfaction with the decision made by their physicians.

> *“right now, no, I do not want…. I am not in a hurry of it [HD]…. psychologically I am not ready because I do not accept their [physicians] decision…. I do not want” (02M).*

In conclusion, the research findings indicate that participants' decisions regarding haemodialysis refusal were influenced by whether or not participants accepted the diagnosis of their kidney failure condition in combination with associated factors such as feeling asymptomatic and their levels of eGFR. The next section will present the findings from the second category explored in this research, which focuses on how individuals with ESKD acquire knowledge to inform their decision-making. This section addresses issues related to individuals' understanding of kidney failure symptoms, their current stage of the disease, knowledge about eGFR, and when these factors suggest the need for haemodialysis or kidney transplantation and their implications.

6.5 Category two: Acquiring knowledge.

With regards to acquiring knowledge about their disease condition and recommended interventions, the research participants had a diverse range of understanding constructed based on the information gained through various medical and non-medical consultations, which often superseded the information they had acquired from some healthcare professionals and helped them in their decision-making process. They relied on multiple sources to gain knowledge regarding their kidney failure signs and symptoms and haemodialysis as a recommended intervention.

Participants who denied haemodialysis demonstrated a significant knowledge gap. This was a result of barriers to communication with their physicians, lack of comprehensive information received about haemodialysis and potentially the complexities of a kidney transplant, difficulties in confirming information, and their tendency to selectively process information. These factors contributed to their denial of reaching kidney failure stage five and their refusal of haemodialysis. As a result, this second category of acquiring knowledge encompasses three interconnected subcategories displayed in Figure 6.4: 1) information provided by the physician, 2) information gathering, and 3) knowledge gaps.

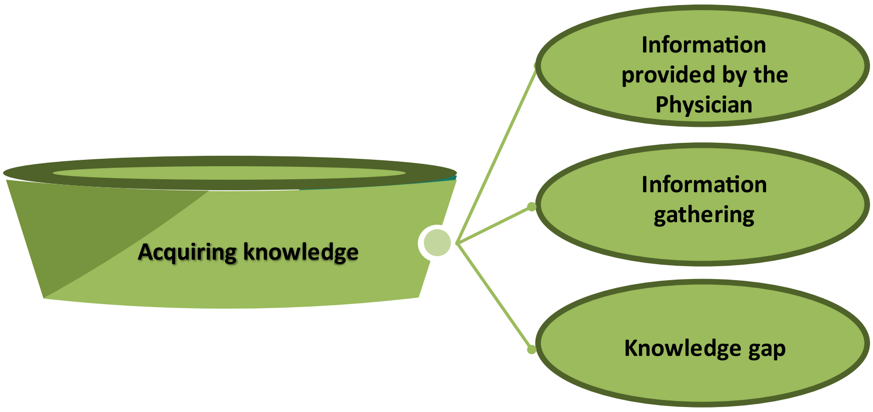


Figure 6.4 Category Two: Acquiring knowledge.

6.5.1 Sub-category one: Information provided by the physician.

As mentioned in the introduction to this section, when participants were asked about the source of the information that helped them understand kidney failure and the haemodialysis process, some of their responses indicated a preference for receiving information from their treating physicians. Despite the information provided by their treating physicians, they chose not to undergo haemodialysis for various reasons based on their perceptions. This decision was influenced by their ability to absorb a specific type and quantity of information at a time.

For example, a young male participant (02M) with one year of ESKD expressed a preference for receiving information about his health condition and the initiation of haemodialysis exclusively from his treating physicians as he believed that physicians possessed superior knowledge compared to others. Consequently, if his physicians did not explicitly recommend starting haemodialysis, he would postpone the decision until he received advice and information from his physician, despite his medical record indicating that he had declined his physician’s orders to undergo haemodialysis.

> *"I do not like anyone to talk with me except the physician because he knows and understands my health condition, so it's between me and the physician … The physician did not tell me yet [to start HD]….I am waiting for the physician's words" (02M).*

However, the same participant (02M) exhibited contradictory behaviour by initially showing a positive response to accepting information from his treating physician but later refusing haemodialysis when informed. For instance, his treating physician indicated an eGFR of 15%. Despite this medical advice, he remained unconvinced that he had reached the end stage of kidney failure**.**

> *"They [physicians] told me your kidney approximately reached the end level, 15% or 16% like that….I am not really convinced" (02M).*

However, a 74-year-old male participant (020M), despite the information provided by his treating physician, preferred to wait for the progression of his health condition, and the complications became evident, and his eGFR dropped as low as 5%.

> *"They [physicians] said, we will create the device [fistula] for you, and at any time you develop complications …. and your kidney reached five, you must come to….[the] hospital…. but I postponed it….I find myself having nothing serious" (020M).*

In contrast, a young male participant with a secondary level of education and three years of ESKD expressed anger towards information received from his treating physician. Participant (001M) was instructed by his physician to undergo haemodialysis during hospital follow-ups, and he claimed that he did not receive a clear justification for initiating the procedure as he lacked knowledge about haemodialysis. Instead, he acquired information from non-medical individuals, which led to his frustration and subsequent refusal of haemodialysis.

> *"I was following up with them [physicians]…..they informed me that I have to start on dialysis…… Ok, what were the reasons? …. Not just to start me on dialysis…. I got nervous….. I do not have any background…..what the dialysis process is, I just hear about it from here and there [others]" (001M).*

Some participants expressed a lack of comprehension regarding their treating physician's decision not to update them about the progression of their kidney disease and to instruct them to undergo haemodialysis. For example, participant 018M, who has a low level of education and is retired, stated that he did not understand why his physicians withheld information from him about the deterioration of his kidney status and advised him to undergo haemodialysis when he lacked knowledge about the procedure.

> *"They did not tell me that I have weakness in my kidney, I really, myself, do not understand anything about dialysis…. and I do not understand these physicians" (018M).*

Instead, some participants learned about the need for haemodialysis and their kidney status through sources other than their treating physicians. For example, 47-year-old female participant 013F, who has a primary school education and is divorced, stated that she received information about her kidney filtration rate from her brother, who had been informed by her treating physicians that her eGFR had dropped to 10% and that she would need to undergo haemodialysis. However, she declined to undergo haemodialysis because she did not hear this information directly from her treating physician.

> *"He [Physician] spoke to my brothers…. my brothers told me your kidney reached ten, and…. [I] must undergo dialysis…. [and] they were…. panic, but the physician himself did not tell me by his tongue" (013F).*

Some participants claimed to have no knowledge or understanding of their treatment plan, as they were not involved in any discussions with their treating physicians. For instance, 57-year-old participant (014F), who was illiterate and widowed, expressed that her treating physician preferred to discuss and deliver the information about her kidney condition primarily with her daughter, as the daughter was more educated and capable of comprehending the physicians' discussions effectively.

> *"I have no idea about my treatment plan" (010M).*

> *“He [physician] told me I got a [kidney] weakness….my daughter….always…. comes with me [to the hospital] because she is educated, and she understands him…. She will explain it to you…….. [but] he did not tell me about the dialysis [plan]….” (014F).*

In addition to the above-mentioned, some participants did not seek clarification regarding their eGFR readings from their treating physicians. Instead, they relied on individuals with medical backgrounds, assuming that these individuals had a comprehensive understanding of the medical terminology used by the physicians. For instance, one participant's daughter worked as a dietician in the hospital, leading the 54- years-old male participant to believe that she was familiar with all medical terms and could interpret them accurately.

> *“I, myself, did not ask the physician what the 12% meant…. Because my daughter was with me…. attends the follow-up…. and she studied in the university, and she knew about all of those medical terms and their meaning…. she has more medical information” (012M).*

Despite some participants being informed by their treating physicians that dialysis should be initiated when the eGFR drops to 15% or below, they chose alternative paths and held to the hope that their kidney condition would improve. For instance, participant 005F who had only basic reading and writing skills, did not fully understand haemodialysis when the need for this was indicated by her treating physician, which made her fearful. Consequently, she decided to explore alternative treatment options.

> *“the kidney enzymes started to drop down sharply…….. they [physicians] informed me that from 15[%] and below, I must undergo dialysis…….I refused….I got scared because I did not know what dialysis meant, I decided to go [and search] for [another] treatment to avoid this one[HD], and maybe….my kidney[would] improve a little bit” (005F).*

As discussed above, the statements provided by treating physicians had a significant impact on the participants' decision-making process regarding the acceptance or rejection of their kidney failure status and haemodialysis treatment.

In this study, some participants emphasised that during the initial stages, when they were informed about their health conditions and the potential need for haemodialysis, they were satisfied with the physician's advice to continue with their prescribed medications and schedule a follow-up appointment for re-evaluation. Participants interpreted this guidance as an indication that their health is stable, and that haemodialysis is not immediately necessary. Consequently, they developed the perception that they were fine and did not require immediate initiation of haemodialysis.

> *"he [physician] told me …. I should continue on [my] medication and I will come next month to see the doctor …. but I do not need dialysis" (01F).*

Other participants exhibited positive reactions as they received clear explanations regarding their updated health condition and the recommended treatment from their treating physicians in a timely manner. These participants appreciated the fact that they would be periodically re-evaluated and informed about the precise timing for initiating haemodialysis. Hence, they indicated a sense of reassurance and understanding to delay the start of haemodialysis.

> *"he [physician] told me,…. they will give me [blood transfusion] and then they will see me every week,….they will inform me if I would need dialysis or not, and they will give me blood every week for about three months" (02M).*

Indeed, the word "fine" used by treating physicians when describing the participants' investigation results played a significant role in their decision to decline to undergo haemodialysis. For example, when the physician reassured elderly female participant (05F), who was diagnosed with ESKD seven years ago, that her investigations were fine, it alleviated her stress and concerns about the immediate necessity of dialysis. The term "fine" conveyed a sense of stability and normalcy, leading her to believe that her health condition was not critical and did not require the intervention of haemodialysis.

> *"at the beginning, they scared me, they informed me that I must undergo dialysis….[but] physician (F)told me everything is fine….that my investigations are fine, I was really scared, but now I am not scared, thank God" (05F).*

On the contrary, some participants experienced feelings of stress and fear when physicians informed them about haemodialysis as the only treatment option. These statements from physicians created anxiety and apprehension among the participants, ultimately leading some of them to leave the hospital and avoid further engagement with the healthcare professionals.

> *"so when they [physicians] told me that there is no hope except I undergo dialysis …. I told them no….[and] I went out of the hospital" (011M).*

Finally, some participants reported feeling frightened by physicians' explanations regarding haemodialysis, particularly the prospect that they might not tolerate the treatment after a few months and could potentially face mortality or remain on dialysis forever. As a result, participants became hesitant and reluctant to undergo the treatment.

> *"the physician says…… it's possible that in four or five months the person might get fine with the dialysis…… [but] other body might not tolerate the dialysis…… that's it yatkharaj [die]…… [or] remain whole of his life on dialysis" (07M).*

6.5.2 Sub-category two: Information gathering.

In the case of participants' information gathering, most of the participants in this research study browsed the internet to search for information that could potentially help them avoid undergoing haemodialysis.

> *"Frankly, I searched on the internet….the point I was trying to avoid…. how I would live with dialysis forever" (002M).*

Therefore, nearly all the participants utilised internet browsing as a means to access information regarding the signs and symptoms of kidney failure, as well as to gather knowledge about haemodialysis. Google emerged as the primary search engine employed by the participants for this purpose.

> *"I have the internet, I accessed it and read….in Google" (015M).*

> *"I checked…. On the internet…. what does dialysis mean and how [it performed]" (06F).*

However, some participants remained unconvinced by the information they found on Google because they felt that it did not directly apply to their specific health status, even though there were some similarities to their apparent signs and symptoms.

> *"I search in Google about…. the symptoms ….[I found] something close to what I have…. but I mean not exactly" (011M).*

Another point of difference was that many participants took advantage of the internet to verify and cross-check information with what their doctors had told them. For instance, they discovered that the information they came across did not align with their own situation, as they did not exhibit the signs and symptoms mentioned, and they were able to carry out their daily activities as usual.

> *"I found many things….I saw symptoms [like]….swelling, fluid….slow movement, nausea….[but] till now, I do not have these symptoms…. I am normal, I do not complain of anything…. I go to the toilet normally….. I mean, my urine is normal" (06F).*

The participants reported that the information found on Google could be incomplete or overwhelming and possibly influenced by the writer's knowledge and biases. As a result, they preferred to seek insights and advice directly from individuals who had undergone dialysis, valuing their real-life experiences as more reliable than relying solely on information obtained from internet sources. They believed that other people's personal accounts and first-hand knowledge provided a more accurate and trustworthy understanding.

> *"the information [in Google] could be uncompleted or overloaded….by the writer…who might miss a piece of information.... Frankly, …. I always contact people…. because they would tell you about their experiences…. [as] they underwent dialysis for at least twelve or fifteen years" (003M).*

In this study, many participants experienced a sense of shock upon receiving the information about their kidney failure diagnosis and the recommendation for haemodialysis. However, despite this, some participants reported that they did not actively search and explore information about their kidney failure status and the recommended intervention. They disregarded the advice provided by their physicians and instead delegated the task of gathering information to others. For instance, a wife took charge of searching for information and browsing the internet on her mobile device. She also reached out to friends and neighbours, seeking to learn from their experiences and stories related to kidney failure and undergoing dialysis.

> *“I did not search…., I did not keep it in my mind….[yes] I had a shock, but I ignored it at that time…. She [wife] searches in the net, and she hears from this person and another person that this happened to them” (011M).*

Moreover, when the physicians informed the participants about their kidney failure status and the necessity of undergoing haemodialysis, some participants chose to refuse the dialysis because they expressed the need to consult other family members who worked as health professionals to understand the advantages and disadvantages of haemodialysis. If these family members confirmed that dialysis was an acceptable option, the participants would proceed with the haemodialysis.

> “*yeah, he [physician] told me that I need dialysis…. till now, I am not agreeing ….I told him that I would discuss it [HD] with my daughter because she works here [in the hospital]…. she knows about it [HD]…. if she said*

Furthermore, there were participants who declined to undergo haemodialysis after learning about the pain experienced by individuals who had undergone the procedure. They obtained this information through WhatsApp messages shared by individuals who had undergone dialysis themselves. The accounts of pain and discomfort shared in these messages influenced their decision to refuse haemodialysis, as they were apprehensive about experiencing similar negative effects.

> *“Frankly, I read in the WhatsApp messages…. because those who underwent dialysis three times a week have pain” (015M).*

Among the participants, there was only one individual who demonstrated an understanding of the haemodialysis procedure. This highly educated female participant (019F) expressed gaining knowledge about the process by watching videos that detailed the various steps, beginning with catheter creation and concluding with the actual dialysis procedure. Despite gaining this understanding, the participant made a personal decision not to undergo haemodialysis.

> *"I saw it [HD] in the video…. they stated that they tie an artery with a vein together and left it for a specific period till it gets healed, then use it for dialysis…….. but I do not want dialysis" (019F).*

Despite having knowledge about the frequency and duration of dialysis sessions per week, participants made a conscious choice not to seek further information. Their decision was driven by a desire to avoid falling into a state of depression or anxiety by constantly thinking about dialysis. They firmly believed that when the appropriate time for dialysis arrived, they would accept it and deal with it accordingly.

> *"What I know is, it [HD] is performed for three hours …. but I do not want to know additional information ..... I want to go there [for HD]….to be in reality" (06F).*

When participants were asked if they inquired about their kidney failure status with their treating physicians, most of them expressed a lack of interest in seeking clarification. They felt content with their current food and fluid intake and ability to carry out their daily activities, including walking. As a result, they wondered about the possible reasons behind kidney failure development without actively seeking explanations or further information from their physicians.

> *"I did not ask the physician…. I drink water, I walk, and I eat natural food….now I am surprised how I developed a kidney problem?" (013F).*

Only one 32-years-old male participant with a secondary level of education and four years of illness relied solely on hospital materials as a source of information to help him preserve and manage his remaining kidney function. He aimed to take measures to prevent their kidney function from worsening because he was told 25% of kidney function is better than 5%. Therefore, this participant placed their trust in the hospital booklets, considering them to be reliable sources of information as they were Ministry of Health publications.

> *“ I read what they gave me here in the clinic…. they gave me booklets [to read]…. And I depend on the booklets most of the time…. to protect what remained from my kidney…. [because] they told me….25% is better than 5%, so try to keep it safe….because they are more reliable resources ….because they are from ministry of health” (015M).*

The same participant (015F) faced challenges in accessing and reading English scientific publications from the internet as English was not his first language. He explained that if he were a nurse, understanding scientific publications, including those in Arabic, would be easier for him.

> *“First, the problem of the research is in English, and the second thing is the translation would be difficult for me, I need to understand a lot of things, if I were a staff nurse, I would understand [it] even if [written] in Arabic” (015M).*

Finally, as discussed previously, participants sought alternative ways to gather information about kidney-related signs and symptoms and intervention in the hope of avoiding a diagnosis of kidney failure and the necessity for haemodialysis.

6.5.3 Sub-category three: Knowledge gaps

There appears to be a significant gap among the research participants regarding not just the gathering of information and comprehension but also the interpretation and acceptance of that information within the context of their own health conditions. Despite being aware of experiencing symptoms related to other comorbidities, some participants did not fully accept or understand that they were actually ill and in need of haemodialysis.

Several participants expressed that they actively desired to suppress any awareness or memory of the term 'kidney failure' altogether. This significantly impacted their acceptance of the kidney failure condition and their decision-making about whether to undergo haemodialysis.

> *“I do not want to know; I even want to forget its name” (016F).*

Some participants conveyed a sense of indifference towards knowing their eGFR results. They claimed that because they were not educated, they could not understand the physicians' explanations about the eGFR readings, such as 17% or 18%. They did not perceive it as significant or meaningful information in relation to their health condition.

> *"not important [to know] …. I am not educated; I do not know…. but this was his [the physician] talk …. it was 18, and now it is 17, do I know what does 17 and 18 mean?" (03F).*

> *"How I would know. I am not educated" (014F).*

Due to a lack of knowledge, some participants highlighted that they did not know whether their kidneys were functioning normally or they were weak because they were in denial status regarding their progression towards kidney failure.

> *"Really, I don't know. I don't know if [my kidney] is normal or weak" (04M).*

Consequently, they were unaware of the physicians' justification for initiating haemodialysis for them.

> *"I do not know why he [physician] wanted that [HD]" (017F).*

Moreover, some other participants expressed denial about reaching the stage of kidney failure because their treating physicians had referred to their condition as "kidney weakness" instead. However, when questioned about the meaning of "kidney weakness," these participants were unable to provide a clear definition and expressed frustration, stating that they were not physicians and, therefore, they did not have the knowledge to understand the precise definition of the term. Interestingly, despite their lack of understanding, these participants did not proactively seek clarification from their physicians regarding the exact meaning of "kidney weakness.

> *"He told me, you got a weakness, and I do not know, I am not a physician; frankly, I do not know…. I did not ask him [physician]" (014F).*

Some participants shared their lack of understanding regarding the meaning and purpose of haemodialysis. Which ultimately led them to refuse haemodialysis medical advice**.**

> *"I know nothing" (020M).*

> *"I do not understand it [HD], I do not understand anything about dialysis, and I do not know anything about it" (018M).*

Some of the participants did not feel like asking and clarifying about the dialysis procedure from their treating physicians. Instead, they preferred to hear from other haemodialysis individuals who informed them that dialysis was performed with chemical substances. Therefore, due to their lack of knowledge, they decided not to think about their sickness.

> *"to tell you the truth, I do not much understand it [HD]…. I did not ask…. I am trying my best to forget my sickness in any means,…. but I heard…. those who undergo dialysis got dialysed with chemical substances". (02M).*

Lack of knowledge about the haemodialysis process and the machine led to misconceptions among some participants, ultimately influencing their decision to refuse to undergo haemodialysis.

When inquiring about the participants' perceptions of the dialysis process, it was revealed that certain individuals held misconceptions regarding the function of the haemodialysis machine, which was primarily derived from information provided by others. These participants had the impression that the haemodialysis machine mixes the blood within the kidney using a tube, leaving them uncertain whether the machine mixes blood or water.

> *"I do not know what it mixes the blood or the water…. [but] They [other people] told me it is a machine…. mixes the blood with each other…. inside the kidney….[and] the tube will be inside [the kidney]" (013F).*

Several participants held misconceptions about the haemodialysis procedure, which contributed to their refusal to undergo haemodialysis or accept the diagnosis of end-stage kidney failure. For example, an uneducated 57-years-old female participant had the opportunity to witness the haemodialysis procedure while accompanying her mother. Based on her observations, she formed a misconception that haemodialysis involved the filtration of "bad" blood to extract toxins and then return it back to a clean state.

> *"I did see it [HD]. They take out the blood and return it back to them; they pull out the bad blood, or what is called poisoning, and after that, they return it back again" (014F).*

Another uneducated 74-years-old male participant held a misconception about the haemodialysis process, believing that during the procedure, the blood would be extracted from the body and filtered to remove dirt, poisons, and oil before being returned to the body.

> *"During the dialysis, they would take out the blood to clear it from the dirt, toxins, and oils that a human has, and God knows" (020M).*

Furthermore, participant 09M, who was a 71-year-old uneducated male with five years of ESKD, feared the dialysis procedure, as he heard that the dialysis machine flips the individual up and down. Where in fact, this male participant had never personally witnessed a dialysis machine or visited a dialysis unit himself. Instead, he was influenced by second-hand information and anecdotal accounts from others, such as stories heard from his brother.

> *"my brother told me…. it is a machine kept on the bed, then it flips…. [and] shakes you up and down…. : I am scared of it…. and I did not enter the dialysis place" (09M).*

A few of the participants saw the dialysis machine and described that they saw two wires connected to the dialysis machine; one wire takes the blood from the individual to the machine, and the other wire carries the filtered blood from the machine to the individual's body.

> *"I saw the machine; I saw there was a wire that takes out the blood, and another wire returns the blood" (020M).*

Some other participants held misconceptions about the haemodialysis preparation procedure, particularly regarding catheter creation. They expressed reluctance towards the idea of having a catheter inserted, as they perceived it as a metal object being inserted into their skin. This misunderstanding has contributed to their refusal to undergo haemodialysis.

> *"I did not get convinced, yeah, because it is a metal placed in the flesh" (017F).*

Others refused to undergo haemodialysis because they described the haemodialysis catheter as a device, nail or hose implanted in their forearm. They also believed that if they did not adhere to the required follow-up visits, they would ultimately face death.

> *"A device will be placed there[forearm]…. [or]something like a nail placed here[forearm]…. and they would use …. that hose…. and if they[individuals] did not follow up…. the device, bye [would die]. (007M).*

In contrast to the participants who held misconceptions and fears about haemodialysis, there were a few participants who demonstrated a good understanding of the haemodialysis procedure.

Some were aware of the mechanism of dialysis and understood the purpose of the dialysis machine.

> *"they filter the blood through the machine, then return it [blood] clean and free of toxins" (019F).*

Some showed a good understanding of the dialysis process, and their knowledge was derived from reliable sources. For instance, a 61-year-old female participant mentioned that she had heard about the dialysis procedure from her late husband, who worked at a renal dialysis unit. But despite that, she refused to undergo haemodialysis.

> *"I knew it [HD] from my late husband because he was working here [dialysis unit]…. I know this machine has two bloodlines; one takes blood from one side, and the other one filters the contaminated blood …. and the machine separates it" (005F).*

In summary of this section, the research findings indicate that participants' decision to refuse to undergo haemodialysis was influenced by information or lack of information provided by their treating physicians, information gathered from various sources, as well as knowledge gaps that resulted in misconceptions, despite some participants having a good understanding.

6.6 Category three: The influencers.

In addition, and in connection with the two previous categories, the decision-making process of most research participants to decline haemodialysis was influenced by several sub-categories falling under the main category in this section, as illustrated in Figure 6.5. These sub-categories include 1) being influenced by the experiences of HD users and 2) being influenced by family members and others.

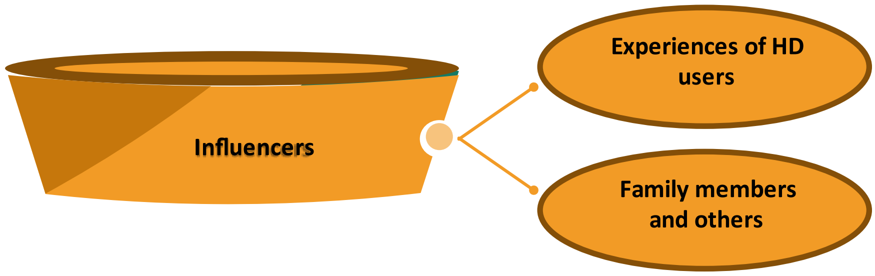


Figure 6.5 Category Three: Influencers.

6.6.1 Sub-category one: Influenced by the experiences of HD users.

Some participants expressed satisfaction in not undergoing haemodialysis, as they observed that dialysed individuals exhibited signs of post-dialysis fatigue and a lack of vitality. Therefore, they rejected undergoing haemodialysis. In contrast, the participants reported feeling well and capable of carrying out their daily activities without hindrance.

> *"I have seen those who came out from their dialysis session….. on a pulled wheelchair or ….walking with a stick…. looked dead…. tired…. and did not have life…. ? If I underwent dialysis, I would definitely become like them….[but] now, I am fine and doing well (018M).*

The friends of several other participants undergoing haemodialysis described the procedure as challenging, causing tiredness and dizziness. Therefore, the participants believed that this condition would be physically exhausting and draining, impacting their overall well-being based on the experiences shared by other dialysis individuals.

> *"I am refusing the dialysis….[because] my friends are those…. who have undergone dialysis already ….. all of them complained and stated…… dialysis is not something easy ….. you [would] come out from the hospital tired and dizzy….[so] if they told you to undergo dialysis, do not undergo dialysis. (07M).*

Likewise, some participants opted against haemodialysis, and this decision was influenced by personal experiences, such as the death of close family members whom they believed passed away as a result of haemodialysis.

> *"my uncle did dialysis ….. and he did not continue….I mean, may God have mercy on him [died], I refused because of that" (07M).*

One participant's decision to decline haemodialysis was influenced by a friend's experience. This 57-year-old male participant (007M) who was newly diagnose with ESKD, believed that the absence of proper follow-up after the creation of a haemodialysis fistula could have fatal consequences. He cited the case of a friend who passed away because he did not attend regular follow-up appointments in regard to the fistula and its utilisation.

> *"One of my friends who had the permanent catheter; he died because he did not come for his dialysis [catheter follow up]" (007M).*

On the other hand, some other participants' decision-making to undergo haemodialysis was influenced by other kidney disease individuals experience who reached the dialysis stage and waited for some time and did not embark on haemodialysis, and then their kidney failure stage improved and did not require haemodialysis. Therefore, the participants followed the same experience and decided to wait, hoping their kidney failure might improve.

> *"Maybe my matters would get improved because I have heard from some people that "someone's kidney reached the dialysis stage and after some time it became better", then I decided to wait for some time and see" (005F).*

6.6.2 Sub-category two: Influenced by family members and others.

Nearly all participants in this study discussed their health condition and potential interventions with others, such as family members or friends, who held reservations about accepting the reality of kidney failure and the necessity of haemodialysis. Consequently, the opinions expressed by these individuals significantly influenced the participants' decision-making process, leading them to reject the notion of being in the kidney failure stage and the need to embark on haemodialysis. These participants believed and relied on the views of family members (such as sisters, brothers, wives, and father) and friends, as they saw these members as having extensive experience gained by witnessing different dialysed individuals' situations. Therefore, some of those family members were given the full power to decide on behalf of the participants.

For example, certain family members believed that their ESKD individual was too young to undergo haemodialysis and instead encouraged them to explore alternative treatments such as kidney transplantation.

> *"In the beginning, my family said it's impossible you undergo dialysis and try to find other solution…. it's difficult that you undergo dialysis and your age[is] 37 [years]…. you try to travel abroad [and] do [kidney] implantation" (02M).*

Several participants provided justifications for their reluctance to undergo haemodialysis by citing accounts they heard from others about HD users who had experienced negative outcomes as a result of undergoing haemodialysis. For instance, a brother and sister mentioned hearing about the unfortunate deaths of individuals who had undergone haemodialysis. These stories contributed to their apprehension and reinforced their decision to avoid undergoing kidney haemodialysis.

> *"my brothers and sisters told me that we had heard much from people who said…. many people….from…. relatives had dialysis and died" (01F).*

Simultaneously, some participants depend on their wives when reaching a decision and perceive a sense of accomplishment due to the support they receive from them.

> *"If I decided to make a decision, her [wife[decision would be the decision…. She does whatever she wants to do ……. She orders, and I implement" (007M).*

Some participants encountered various perspectives during the discussions about their health condition with close family members. For instance, one participant's wife discouraged her husband from undergoing haemodialysis, urging him to seek alternative treatments instead. Her own personal experience influenced her advice, as her father had undergone haemodialysis and died.

> *"My wife's father was doing dialysis …. she said,….my father stayed for a period of time,…. I do not advise you [undergo HD] …. you need to find another way if you can" (02M).*

A 40-year-old male participant, unemployed with a secondary level of education, chose not to undergo haemodialysis based on the instruction of his wife, who firmly prohibited the haemodialysis option for him. In addition to the participant's friends, she advocated for the use of medicinal herbs as an alternative approach to treatment.

> *"my wife….told me that dialysis is prohibited…. and they [friends] told me not to undergo dialysis…. they advised me and told me ……… there is a place…. for medicinal herbs" (011M).*

Besides, some participants were significantly influenced by their parents' strong opposition to haemodialysis as a treatment option and rejected undergoing haemodialysis. Instead, their parents advised them to wait for a suitable kidney donor for a kidney transplantation, disregarding the deteriorating state of the participant's health condition.

> *"My mother knew about my condition…. it means my condition is deteriorating…. she told me, you just wait, and if God willing, we will get a donor for you." (07M).*

Furthermore, certain participants had family members who worked either as healthcare professionals with expertise or healthcare professionals and were without formal expertise in a healthcare institution. Consequently, these participants' decision-making processes regarding haemodialysis were negatively influenced as they placed significant trust in their family members' expertise and relied on their advice. For instance, one participant, upon being informed by a treating physician about the need for haemodialysis, became anxious about the potential impact on her ability to conceive. This anxiety was boosted by information shared by her sister, who worked in the hospital's food catering department and relayed a story suggesting that undergoing dialysis could potentially interfere with completing a pregnancy.

> *"They [physicians] said it is very rare that who does dialysis gets pregnant…. I asked my sister, who works here in the hospital…. and she said there was a woman who was pregnant and aborted…. it could be that the dialysis….substance that the baby could not tolerate" (06F).*

Most of the participants in this research were advised clearly by their friends not to undergo haemodialysis when consulted about the participants' kidney failure condition, and these friends had heard that haemodialysis caused tiredness and exhaustion. Therefore, they directed the participants to undergo kidney transplantation or search for other alternative treatment, otherwise to undergo kidney haemodialysis if no other treatment option.

> *"I got…. Football friends…. Who heard that dialysis causes tiredness and exhaustion" (001M).*

> *"some people contacted me because they heard about my issue, and they told me not to undergo dialysis…. if you are not sick and weak, I advise you to remain as you are normal….but if you are sick and tired, that would be something else" (011M).*

This section aimed to briefly explain the influence of external factors on the decision-making process of the research participants regarding whether to accept or reject kidney disease progression and the initiation of haemodialysis. The subsequent section will explore the participants' reasons for refusing haemodialysis, driven by feelings of fear.

6.7 Category four: Fear

Fear of undergoing haemodialysis was identified as a significant driver for refusing haemodialysis in this research study and played a crucial role in the decision-making process. Fear manifested in two sub-categories: 1) fear of haemodialysis's negative consequences and 2) fear of feeling stigmatised. These factors (see Figure 6.6) strongly influenced nearly all the main categories that impacted the participants' decision-making.

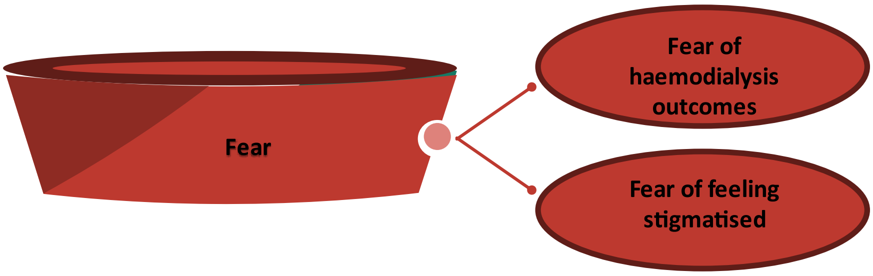


Figure 6.6 Category Four: Fear

Most of the participants were hesitant to experience the same situations as other individuals who were undergoing dialysis, as they felt asymptomatic and expressed a lack of desire to learn about dialysis due to fear.

> *"I do not want [to know about HD], I am afraid" (05F).*

6.7.1 Sub-category one: Fear of haemodialysis negative consequences.

When participants were asked about their feelings towards haemodialysis, the common response was that they were scared because the idea of dialysis and the term haemodialysis was frightening.

> *"of course, I got scared" (07M).*

> *"the word is scary" (011M).*

A number of participants in the study reported that they declined to undergo haemodialysis due to the negative consequences they learned about haemodialysis from other dialysed individuals or from their own observations.

For instance, some participants feared experiencing the same symptoms and complications as others who had undergone haemodialysis. Therefore, participants wanted to avoid the potential suffering and discomfort that they had heard or witnessed from others and declined to undergo haemodialysis.

> *"dialysis is too scary…. when you see it [HD]on others, you would say, I might [go through same path]…. I am scared of this [HD], it would be too difficult…. and painful…. [because] when you go home, you would be tired and cannot carry yourself" (016F).*

However, some other participants believed that undergoing haemodialysis would result in a restricted life, as it would require them to attend dialysis sessions regularly and limit their freedom to go wherever they wanted. Therefore, they believe that their quality of life would be compromised by undergoing haemodialysis.

> *"I am afraid…. I am not encouraged …. If I underwent dialysis…. I feel the life would stop…. my movement will be restricted…. I won't be able to go*

> *out…. I cannot go to any place…. my life would depend on the dialysis" (06F).*

A highly educated female participant (019F), diagnosed with ESKD for less than one year, explained that she refused the idea of haemodialysis specifically due to the requirement of undergoing a haemodialysis fistula creation procedure, which scared her when she saw it on the dialysed individual's hand. The participant expressed fear and discomfort when she saw the fistula on the hand of a dialysed individual. She found the idea of having a foreign body in her body and being injected with a large needle during the needling process overwhelming. She featured the needle to a sheep injection, which further added to her concerns and reservation to undergo haemodialysis.

> *"I told them [physicians] I do not want [HD]…. I saw her [dialyses individual] hand and that thing [AVF] created in her hand…. I cannot tolerate that you look at something in your body…. It is an injection, and I imagined it as a sheep's injection, not a human's" (019F).*

In addition to the negative haemodialysis consequences, some other participants felt that undergoing haemodialysis would be a lifetime commitment. They believed that for those who would start on haemodialysis, there would be no way to come out of it, and it would become a permanent part of their routine life, which might negatively impact their life. For example, attending the hospital every three or four days would impact their ability to fulfil personal and professional responsibilities.

> *"frightened me because it would be a commitment process….I will live the whole my life on dialysis and for forever" (002M).*

As a result, many participants refused haemodialysis due to their reluctance to attend the hospital frequently and to be in-patient.

> *"I did not want to be in the hospital every day, and I did not want to be a patient" (006F).*

In addition to the life commitment, participants felt that undergoing haemodialysis would limit their mobility and upset them as it would disrupt their lives and it would significantly impede their ability to travel, both within their country and abroad, due to the challenges associated with arranging haemodialysis sessions at different locations.

> *"Yes….[it is] commitment…. [and] it would disturb…. [the] life…. if you are having dialysis on alternate days, you…. do not have freedom…. to go anywhere….[and] how would you arrange the dialysis …. if you want to travel out of Oman… a person [would] feel upset because….this disturbs your life too much" (012M).*

Some other participants felt scared they would become bed-bound due to haemodialysis; they had heard that people undergoing haemodialysis faced difficult experiences when they were in the hospital and developed tiredness post-dialysis.

> *"I have heard….who underwent dialysis got tired and remain screaming….in the hospital" (002M).*

> *"I will be bedridden" (001M).*

One of the other reasons that made some of the participants refuse and fear undergoing haemodialysis was experiencing pain.

> *As an idea, I always think about the pain" (015M).*

However, some other participants refused haemodialysis due to their fear of the dialysis machine and their inability to tolerate the sight of blood.

> *"I am scared of the machine and scared of seeing blood" (005F).*

Therefore, death emerged as a significant negative experience factor, leading many participants to decline haemodialysis intervention. Some participants deemed it unnecessary to follow the same path that others went through and expose themselves to the risk of death as they felt asymptomatic and capable of performing their routine daily activities.

> *"I do not want to repeat their [HD individuals] same experiences. As long as I am able to carry myself, I do not want to do like them" (03F).*

Many participants reported that they had heard about the death of dialysed individuals within three or four sessions of haemodialysis. For example, a 46-year-old male participant with an intermediate level of education and four years of ESKD, felt that he had had enough and was fed up (Mataqed) with hearing frequently about the death of his friends or people he knew. As a result, he felt there were no positive outcomes associated with undergoing haemodialysis.

> *"there were people who died, I asked about them….some of them got three sessions, and others got four sessions…. But I do not know …. The reasons that led them to die fast" (02M).*

> *" Taqadet [I get fed up]…. frankly, I see... the negative thing [from]... dialysis... [because] half or ten of my friends [who] underwent dialysis, tkharajo, which means they died" (07M).*

A 57-year-old female participant with less than one year of ESKD and limited education had a distressing experience witnessing the death of other individuals with ESKD during haemodialysis while accompanying her mother. Consequently, she became frightened when informed of her own need to undergo haemodialysis and subsequently refused the treatment.

> *"I do not want to undergo dialysis…. telling you the truth, I am scared…. there are people who died when on dialysis; we have seen them many times…. when we followed up…. with our mother" (014F).*

Other participants held the view that undergoing haemodialysis would end their lives, and they had some concerns about some of their family members. For example, they would leave behind their young children who cannot manage their lives alone and would have no one to look after them. Additionally, another significant concern was the thought of not being able to see their family again.

> *"dialysis scares me…. if I underwent dialysis …. I am scared that I may not see my family again" (08F).*

> *"it [death] made me scared because I am thinking about my children all the time…. my children are small, I am scared that one day I will leave them due to this disease" (02M).*

> *"I got scared, and I remained thinking….I will die and leave my daughter…. how would my daughter manage her life?" (013F).*

Most of the participants in this research study constructed their fear of undergoing dialysis based on their perception of death as a potential consequence. They perceived that they must think about death because they were worried that their vein might be cut off and they would die during the process of filtration of blood. Furthermore, they emphasised worries about their bodies being unable to tolerate dialysis and potentially resisting the treatment, and they were unsure if they would remain alive.

> *"I am thinking, God knows what would happen to me after the dialysis….will I remain alive? Will I resist or tolerate it [HD]?.... people must think about it[death]…. could be while taking out my blood, I die, or while processing the operation, they might cut off my vein, and I die" (020M).*

6.7.2 Sub-category two: Fear of feeling stigmatised.

Feeling stigmatised is another potentially negative consequence of haemodialysis and the second sub-category within the fear category. A set of the participants in this research experienced feelings of stigmatisation, leading them to avoid community social gatherings due to the pity and sympathetic perceptions associated with their health condition. This stigmatisation deeply frustrated them, as it further exacerbated their existing vulnerability.

> *"yes, I feel shame……… I mean, you would feel like you are thrown in a deep hole, and everyone looks at you from different angles, so you imagine yourself small …… everyone talks about you, for example…… you find everyone throws talks on you" (02M. 37 yrs old).*

A few participants in the study expressed that individuals within their community labelled those with ESKD who required haemodialysis as individuals who were nearing death. This labelling contributed to the stigmatisation and negative perceptions associated with ESKD and haemodialysis.

> *"people would perceive that ….who continue on dialysis means ….that this person reached the end [die] ….. everyone would say reached the end and reached the end" (07M. 46yrs old).*

So, those participants expressed a reluctance to discuss their illness and their potential need for haemodialysis with others in the community because people in the community often enquired about the reasons behind their disease occurrence and questioned why they had developed kidney disease at a young age, for example, at 23 years age (see Table 4.3). Therefore, they wanted to avoid being perceived as weak or labelled based on their kidney failure condition.

> *"[due to] society's perception... I avoid talking about my health condition...[as] they [community people] keep telling me that I am still young ….. and how this [kidney failure] happened" (06F. 23yrs old).*

Another 42-year-old female participant expressed that she could not bear the thought of others seeing the haemodialysis catheter on her forearm.

> *"I cannot tolerate that…. [someone] looks at something in your body [forearm]…. [such as] device appearance" (019F. 42yrs old).*

In summary, the findings from this section revealed that participants' fear was influenced by haemodialysis's negative consequences and feeling stigmatised, leading them to reject medically advised haemodialysis. The subsequent section will also explore several factors contributing to participants' refusal of haemodialysis and taking control of their health condition.

6.8 Category five: Self-Control

Almost all the participants in this research study rejected undergoing haemodialysis when treating physicians discussed the treatment plan with them once they reached the fifth stage condition. When discussions focused on future plans and the potential for their condition to deteriorate, they reconsidered their initial decisions and contemplated alternative approaches to self-manage their health condition, seeking to avoid undergoing haemodialysis. The desire to have self-control is one of the influencing factors that caused participants to refuse to undergo haemodialysis. It consists of two sub-categories, as displayed in Figure 6.7: 1) Looking for alternatives and 2) Fatalism.

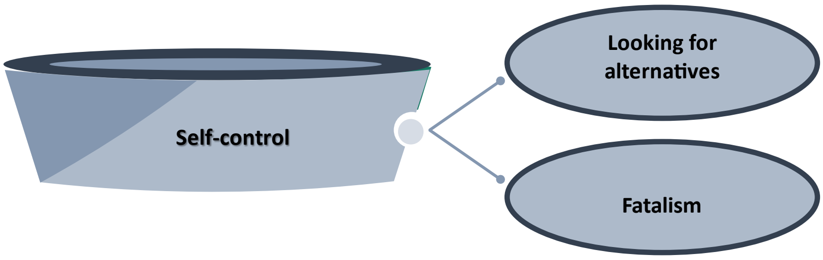


Figure 6.7 Category Five: Self-control

6.8.1 Sub-category one: Looking for alternatives.

Some participants expressed a desire to delay the initiation of haemodialysis as they preferred to continue on their oral medication, seek second consultations, both locally and internationally, and explore alternative treatments rather than undergoing haemodialysis.

> *"I have no intention of undergoing dialysis….I will try to postpone it a little bit" (02M).*

In regard to seeking a second consultation, some participants chose to decline haemodialysis after travelling abroad for a second consultation, as they were content with the opinions and recommendations provided by the physicians they consulted. These participants were able to avoid undergoing haemodialysis by following the prescribed course of oral medications and regular follow-up appointments.

> *"my kidneys got saved from the dialysis…. [because]he [physician abroad] said, she [participant] does not need dialysis…. and they gave me medications…. and said, come again for follow-up" (05F).*

In the case of some participants, physicians abroad informed them that they had not yet reached the stage of kidney failure that necessitated haemodialysis. Consequently, these participants were advised to continue with their prescribed oral medications, as they were deemed sufficient for their condition.

> *"he [physician abroad] told me, do not undergo dialysis…. because your current stage did not require you to undergo dialysis…. you just need medications only…. [you] continue on your medications" (011M).*

As a result, some of these participants believed that physicians in other countries possessed superior knowledge and expertise compared to physicians in Oman because they were able to save them from undergoing haemodialysis.

> *"You see, they [physicians in Oman] would trouble me with their decision and dialysed my kidneys" (05F).*

Some participants strive to maintain their health through a balanced diet and prescribed medication, with their primary focus being to undergo a kidney transplant

> *"I will maintain it [kidney] through the diet and taking medications…. my vision is going for implantation if Allah permits" (019F).*

On the other hand, a male participant with an eGFR of 11% reported that their treating physicians recommended travelling to Thailand for a second consultation and better treatment. After the experience in Thailand, the participant thought of travelling to India. This would offer the participant the potential for treatment via intravenous infusions, avoiding the need to undergo haemodialysis.

> *"he [treating physician] said the treatment would be better in Thailand….after that, I had an idea to go next to India…. because I believe people in India wanted money…… and they would not tell you this [HD]…. he [physician in India] told me, if you did not undergo dialysis, I would treat you…. [with] infusion" (018M).*

In addition to the aforementioned factors, a number of participants opted for non-medical therapies as an alternative approach to avoid undergoing haemodialysis as they believed that these non-medical therapies are safe and free from harmful side effects.

> *"I use the folk medicine therapy; it is not like what you would say harmful to the body. No" (012M).*

As an example, one such folk remedy involved the use of frankincense and pumpkin. They believed that soaked frankincense acted as a diuretic, causing them to pass urine frequently throughout the day. They viewed this practice as a natural way to promote kidney function and potentially alleviate the need for haemodialysis.

> *"I use frankincense…. I soak it in a Still water bottle…. I take one glass…. before breakfast…. so this works as a diuretic and makes me urinate" (012M).*

Furthermore, some participants held the belief that pumpkin was 100% effective in treating kidney disease, which they had learned from others who were on the edge of undergoing dialysis. They also considered pumpkin to be a safe remedy and even regarded it as a palatable addition to their diet.

> *"The second thing I use pumpkin…. this pumpkin is number one and good for kidney treatment 100%.... people who tried this pumpkin…. were close to undergoing dialysis…. So, the pumpkin is too beneficial….it does not harm…. it is a taste that is added to the food" (012M).*

6.8.2 Sub-category Two: Fatalism.

In terms of self-control, in this study, participants engaged in fatalistic behaviour to indicate that they have no power to change their health condition and procrastinate undergoing haemodialysis, where everything is in God's hands.

> *"Lives are in Allah's hands" (001M).*

Most of the participants at the time of the interview expressed that they were feeling fine and rejected the idea of undergoing haemodialysis. However, they emphasised that if the actual day of haemodialysis were to arrive, they would agree to and begin haemodialysis. They believed that their deteriorating health condition at that point would be the compelling factor and acknowledged that they would not have the power to avoid undergoing haemodialysis. Therefore, they will wait till that day reach.

> *"I will not undergo dialysis since I am [able to] carry myself…. [but] when that day comes, and I become sicker after that there is no might nor power except in Allah, I cannot do anything, but now…. I do not want [HD]" (03F).*

They regarded the need for haemodialysis as the outcome predetermined by God's judgment, accepting it as their destined path.

> *"so if it happened, it happened" (07M).*

> *"I wish if Allah is willing not to undergo dialysis…. [but it's] Allah's judgment" (08F).*

Moreover, the participants perceived that if God granted them the ability to live without the need for haemodialysis, they would carry on their lives accordingly. However, if God determined that haemodialysis was necessary for them, they believed they had no power to reject it. They considered themselves equal to those who had already undergone haemodialysis, including women, youth, and children whom they had witnessed. Nonetheless, they prefer not to undergo haemodialysis as they fear death and their desire for a longer life.

> *"When we attend the follow-up clinic…. we see them ourselves…. most of them are youth, women, and …. children on dialysis…. so, I am not better than those people…. but Allah chose them to be on dialysis, so, if I would have live without dialysis, I will live, and if Allah chose me to be on dialysis, I would handover…. that to his mighty Allah …. [but] anyone does not prefer to undergo dialysis…. [as]everyone feared death and…. would like to have prolonged life" (012M).*

Some other participants refused to undergo haemodialysis because they felt fine; they explained that they were not scared of undergoing haemodialysis and they would accept whatever God planned for them, as he is the ultimate healer of their disease. In addition, when the time comes and complications develop, physicians are free to do whatever they want, as the matter is in God's hands.

> *"Really, I am not scared, I swear, I am not scared…. I accept whatever comes from Allah…. I have nothing, and Allah is the healer…. [but] I told him [physician] once I become tired you do whatever you want that time ….but now I feel myself is fine and have no problem" (017F).*

Consequently, the findings revealed that the participants preferred to pray to God, believing their health condition would be healed, and consequently, they procrastinated undergoing haemodialysis.

“I would pray to God, and maybe something might happen.” (006F).

In contrast to the experiences of other participants, one individual felt no shame or hesitation in discussing his kidney failure condition and the recommended intervention of haemodialysis with others. This participant held the belief that his disease was given by God and trusted in God‘s ability to heal his disease.

“I am not ashamed; this is a sickness given by Allah, and Allah will heal me”
(09M. 71 years old).

At the conclusion of this section, the individuals in this study relied on the reasons that led them to refuse haemodialysis and relied on God in making their decision. They believed that they could manage their condition without dialysis by exploring alternative options, such as seeking a second consultation and following recommendations, especially when dialysis is not the choice. Otherwise, they preferred to explore traditional treatments based on the experiences and guidance of others.

6.9 Participants who underwent haemodialysis.

In addition, it is important to highlight the findings that focused on the participants who initially refused haemodialysis and then accepted to undergo haemodialysis. Section 5.1.3 explained the theoretical sampling and the recruitment amendment that was made to include the ESKD who were at stage five and started on haemodialysis after their initial refusal. Those participants' decision-making was found not to be a definite process when they initially refused haemodialysis, and their decisions were always influenced by different factors, whereby their decision changes were similar to those of the refusal ESKD group. For example, if they felt extremely symptomatic or the treating physicians informed them that their eGFR became worse, that then triggered them to re-visit their initial decision and make a new decision based on their current health status. So, this implies an ongoing decision-making process. When their ESKD condition deteriorated and undergoing haemodialysis was unavoidable, they accepted and surrendered to undergo haemodialysis because it became real.

> *"yeah, I was not agreeing, but when he [physician] informed me that my condition was deteriorating and I must undergo dialysis now and immediately ….. I said, what to do…. I must agree, and I have no other choice" (001M).*

> *"I got convinced when ….. the axe fell into the head" (007M)*

Of those seven participants who started on dialysis, five of them felt regret that they did not start dialysis on time, and they felt that they would advise others to undergo haemodialysis when medically advised.

> *"I regret that I did not undergo catheter creation….I did not know what I was thinking, I was trying to procrastinate and avoid it [HD]…. I would tell him [ESKD individual], the good thing, you go for it [HD], and do not wait" (005F).*

Despite undergoing haemodialysis and feeling better, two participants were not convinced to continue on haemodialysis, and their medical records showed inconsistency in attending dialysis sessions. These participants had faith in God that their kidneys would recover, and they would lead a normal life without haemodialysis.

> *"till now, I am not convinced…. I hope Allah heals me…. that my kidney would function again" (006F. 25yrs old).*

> *"I did not come; it was on Wednesday. They told me to attend the dialysis on Wednesday, but I told them I am not coming" (007M. 57yrs old).*

In summary, the decision-making process for the haemodialysis refusal group and the group that opted for haemodialysis almost followed the same pattern of influences. In addition, the main trigger for undergoing haemodialysis is the deterioration of their health condition with obvious complications and symptoms.

6.10 Grounded theory and interrelation of categories

As indicated previously, the five identified categories were more than just an overlapping set of factors that influenced the individuals affected by ESKD in this research study to refuse haemodialysis; they are part of a continuous process where those categories were being completed, continuously revisited in different ways by different people as a part of the decision making.

The fundamental social process of these five categories demonstrates an ongoing development that is not entirely sequential for most of the participants, where most of the categories took the form of revisiting or re-evaluating processes. Each category has its own characteristics, and sub-categories were found to repeatedly influence each other and affect the refusal decision-making process of an individual.

In this study, the social process of ‘balancing’ while making a decision to refuse haemodialysis is an ongoing, revisiting choice process over time and an endless cycle as a ‘spiral movement,’ establishing its connection with the five key factors that influence individuals affected by ESKD decision-making and considering the balance benefit-risk decision (Figure 6.8). Notably, progressing forward does not hinge on completing the previous decision-making process. The primary process of ‘balancing’ was at the core of the grounded theory on haemodialysis refusal decision-making among individuals with ESKD in this study.

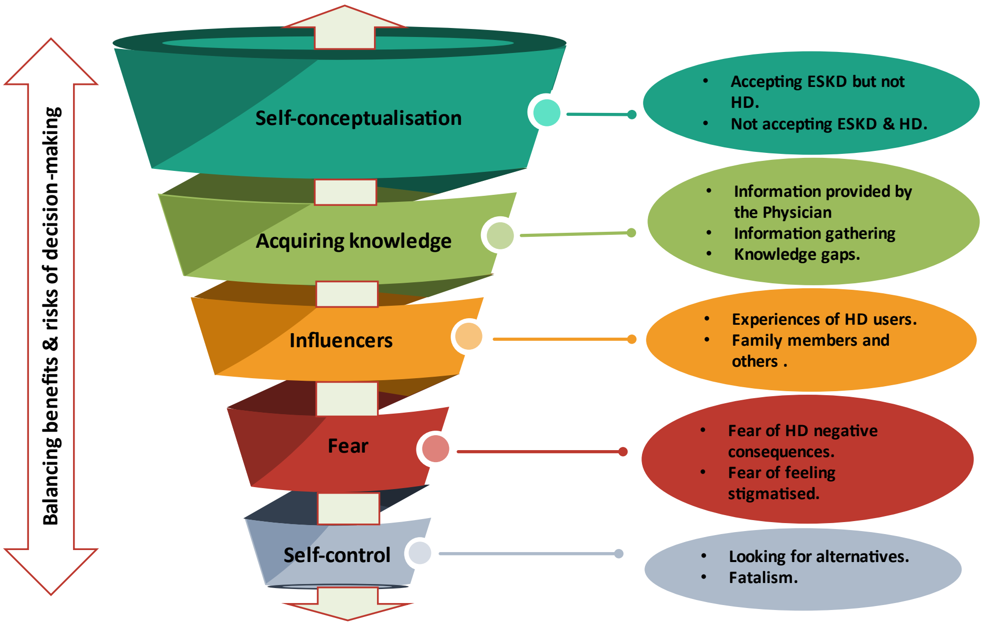


Figure 6.8 The Haemodialysis refusal decision-making process theoretical Framework.

This section explains the grounded theory's connection to the balance of the factors that help the participants make decisions. Figure 6.8 displays the relationship between the decision-making process within the five categories and the categories' interconnections. The participants' decisions were influenced by several factors, ultimately leading them away from undergoing haemodialysis. The highlighted factors stand as standalone categories; the interconnecting factors are described as follows.

Each participant in this study went through different stages, with various factors influencing their decisions to refuse haemodialysis at different points. Each participant had a personal journey encompassing all of these factors.

For example, in the case of participant 018M, an interconnection appeared between the information given by the treating physician advising him to undergo haemodialysis due to his weakening kidney condition and the participant's understanding of his illness *"I have weakness in my kidney….and the weakness doubled*". At that stage, he refused to undergo haemodialysis because he conceptualised that he did not complain of kidney pain, *"I do not have pain in my kidney or complications",* and he did not reach the dialysis status as he did not develop any complications. Then demonstrating a knowledge gap was another linked factor as he was convinced that the prescribed medications would prevent him from developing kidney complications and maintain his kidney function: *“It [medication] prevents this from enlarged [the complications] … and increase the flow of this [urine]”*. Consequently, he balanced these factors and decided to refuse dialysis regardless of his kidney’s current level. Another knowledge gap is highlighted, as he believed his kidney condition is hereditary and would not lead to complications “*It is hereditary….I do not think there would be complications”*. This belief is interlinked with fatalism feeling since he believes that if he developed kidney complications at any time, he would undergo dialysis to relieve his pain: “*If I was sick…. I would agree to it….because dialysis would relieve my pain*". Therefore, a clear interconnection emerged between the participant's decision to refuse haemodialysis, the information provided by the physician, the participant's self-conceptualisation, knowledge gaps, and feelings of fatalism.

Another example demonstrates the interconnection between participant 005F, her realisation of biomedical markers, specifically a significant reduction in eGFR over five months, and the physician's recommendation for her to undergo haemodialysis due to the substantial drop in kidney enzymes haemodialysis. However, she did not feel that she had reached the stage of kidney failure yet, stating, "*I was not convinced….I do not feel sick*." Consequently, she did not fully consider the treating physician's information and advice because her main concern was that she felt asymptomatic, had good urine flow, and was able to move around despite feeling tired at times, *"my urine was flowing well …. although I felt tired, I was able to roam here and there."* The interconnection in this element seems to be related to her perception of herself as fine and asymptomatic despite the evidence from biomedical markers and the physician's information and advice. She had to weigh the benefits and risks of accepting the diagnosis of kidney failure and opting for haemodialysis against her current state of feeling fine, but she preferred to refuse haemodialysis.

Almost all the participants experienced fear of undergoing haemodialysis, and it had different impacts on their experiences of weighing up the direction to avoid haemodialysis. Therefore, fear presented a strong relationship with almost all of the factors in this study. For instance, one of the interconnections is the negative experiences of haemodialysis users such as sisters, nieces, mother-in-law, uncle, brothers, and others, which influenced most of the participants to fear undergoing haemodialysis and decided to refuse it because they did not want to undergo the same negative experiences (fear of HD negative consequences). Therefore, they bargain with their treating physicians to delay the haemodialysis and provide them with a chance to continue with their prescribed oral medications, as they feel asymptomatic and performing normal life (Self-conceptualisation). Another link is due to fear of dialysis; the participant decided to seek a second consultation either within the country or abroad to find alternative treatment replacing the haemodialysis because they believed that starting on dialysis would not end. Therefore, on some occasions, the participants relied on the second consultation advice to continue the orally prescribed medication and omit the dialysis as much as they could (information provided by the physician).

Moreover, fear due to some misconceptions, for example, that the haemodialysis machine shakes the individual up and down, influenced the participants’ decision to refuse to undergo haemodialysis and prefer to travel abroad to search for alternative treatment.

They also demonstrated fear of being committed to attending dialysis sessions because it would limit their movement and restrict their diet and fluid intake, as they heard and witnessed other haemodialysis users' experiences (influencers). Therefore, they decided to consult their family member and pray to God.

Fear of pain and becoming bed-bound had a relation to refusing the haemodialysis and delaying the maximum time to go for kidney implantation (looking for alternatives).

Additionally, Lack of knowledge about kidney failure disease was a factor that influenced some participants to refuse dialysis, as they held a concept that if they started on dialysis, their kidney condition would turn into a chronic condition.

Moreover, fear of death is linked with participants' decision to refuse haemodialysis and start on folk remedies, for example, frankincense and pumpkin, as they are safe to use and have no side effects (looking for alternatives). Finally, because they wish to live long periods of life, they believe that God would take over their health matter and decided to ignore the fact and wait till the defiant day of dialysis arrived, and at that time, they would have nothing to do except accepting the fact of undergo haemodialysis (fatalism).

6.11 Conclusion

This chapter describes the study data analysis and the emergence of grounded theory. Through data analysis, a grounded theory was developed, and the decision-making process related to refusing haemodialysis was outlined. This theoretical framework consisted of five distinct categories, which aimed to explain the factors influencing the decision-making journey of individuals with end-stage kidney disease who choose to refuse haemodialysis.

The theoretical framework illustrated how individuals' decisions to refuse haemodialysis are influenced by various factors and how they 'balanced' the benefits and risks involved. This process involved self-management, seeking second opinions, or relying on the advice of others while trying to delay dialysis as much as possible.

Most of the participants in the study engaged in a state of 'denial,' to refusing haemodialysis. They perceived themselves as healthy due to the absence of noticeable ESKD symptoms, and many preferred to continue with orally prescribed medication. However, a few participants considered kidney transplantation as an alternative option.

The role of spirituality and religion played a fundamental part in the decision-making process for some participants. They believed that they had no power to change their health conditions, as everything was in God's hands. Their faith led them to try and delay undergoing haemodialysis for as long as possible, but they would ultimately surrender to God's will if the need arose. They recognised their limited power and believed that they had no authority to reject haemodialysis if God determined that haemodialysis was necessary for them. In the end, they would continue to pray for healing.

The next chapter will discuss the research outcomes by situating them within the framework of both practical observations and theoretical literature.

Chapter 7 Discussion

This chapter provides a comprehensive overview of the principal findings emerging from the current research study, offering valuable insights into the decision-making processes under investigation. It systematically examines the implications of the study's results, drawing comparisons with other pertinent empirical research within the field.

The experiences of Omani individuals affected by end stage kidney disease in this study contributed both novel and confirmatory findings related to their refusal of haemodialysis. The analysis of research data revealed that the central social process of 'balancing' is an integral part of the decision-making process, which is underpinned by various interconnected factors that influence individuals affected by end stage kidney disease refusal of haemodialysis. This refusal is part of the decision-making process, which is connected with the core category of balancing benefits and risks. The main overarching categories identified in this study demonstrated individuals' decision-making process and its impact on their overall health status. Although each individual experienced the decision-making process related to haemodialysis refusal differently and at different stages in their journey, they exhibited almost the same influencing factors.

The concept of refusal in this study is based on the Omani context. The refusal to undergo haemodialysis among individuals with ESKD emerges as a significant concern. The term ‘refusal’ in this context, refers to the decision by Omani individuals choose to decline to undergo haemodialysis treatment despite medical advice indicating its necessity for sustaining life and managing their condition. This decision, though rooted in the principle of individuals' autonomy, often reveals underlying factors that complicate the notion of making a decision. Through my PhD research project, it became evident that many individuals who refused haemodialysis in Oman were not fully informed about the implications of their decision.

Therefore, several key factors have contributed to the phenomenon of uninformed refusal to undergo haemodialysis among the individuals affected by ESKD stage five in Oman.

Decision-making is an essential task that guides individuals facing illness in treatment preference situations, where they must choose one treatment option from among several alternatives (Chandaran et al., 2021; Kim & Son, 2022). In this study, the main factors that influenced the individuals affected by ESKD decision-making included self-conceptualisation, acquiring knowledge, influencers, fear, and self-control, as shown in Figure 6.8. A literature review conducted by Chandaran et al. (2021) identified a number of main factors influencing the decision-making of individuals with chronic diseases. For example, personality and experiences, as found by Chandaran et al. (2021), align to some extent with this study's findings about self-conceptualisation and influencers. Where Chandaran et al. (2021), discuss awareness and knowledge, this study found the process of acquiring knowledge to be an important factor influencing individuals with ESKD to refuse haemodialysis. Chandaran et al. (2021) reported that values and internal beliefs influenced the decision-making of individuals with chronic diseases, which is consistent to some extent with this study's results about feeling fear and fatalism. However, the communication, socio-demographic, and psychological factors found by Chandaran et al. (2021) did not manifest in the current study population.

In general, decision-making entails individuals evaluating the risks and benefits linked to different options, requiring an understanding of the risks and the capacity to compare them with alternative treatment options (Chandaran et al., 2021). The decision-making process of initiating or forgoing kidney interventions in ESKD is complex and dynamic, developing over time. People with Chronic Kidney Disease (CKD) conveyed feelings of denial about prognosis, subjective perception of deteriorating health, and ultimately refusing dialysis (Ashby et al., 2005; Chan et al., 2020). In this chapter, the most prominent finding identified is that the decision-making process is associated with feelings of denial and fatalism. These two significant key factors are interlinked and shape the individuals' lived experience of haemodialysis refusal.

Four key concepts are discussed in this chapter:

1. Haemodialysis refusal decision-making process.
2. Denial.
3. Fatalism.
4. Models of grief.

7.1 Haemodialysis refusal decision-making process.

The grounded theory in this study is constructed around the haemodialysis refusal decision-making process, indicating that the decision-making process for Omani individuals with end-stage kidney disease (ESKD) is a continuous and revisited process. Almost all individuals affected by ESKD in this study who refused to undergo haemodialysis consistently engaged in contemplating and balancing the benefits and risks of their haemodialysis refusal decision. They revisited triggering factors and constantly reflected on the decision, demonstrating that the haemodialysis refusal decision is not a fixed decision but an ongoing process as most individuals affected by ESKD consider their feelings and how they feel about different influencing factors, for example, denial of reaching the end-stage kidney failure condition, fear of haemodialysis, the experiences of other haemodialysis users, misconceptions about haemodialysis, and applying fatalistic behaviour.

The decision-making process among individuals with Chronic Kidney Disease (CKD) mandates continual adaptation to align with dynamic circumstances, evolving as individuals' health conditions progress along their disease trajectory (Hussain et al., 2015; Chan et al., 2020). In this study, the results were clear and prominent, and the core category of the decision-making process, supported by five main categories, effectively balances the benefits and risks. Participants in this study highlighted the challenges that they faced in their journey towards decision-making regarding haemodialysis refusal. Within those five main categories, factors that link them were identified, displaying interactions shaped like a spiral. This structure involves a progressive circular movement, each step building on the previous decisions made in relation to these factors, as shown above in Figure 6.8.

In this study, individuals affected by ESKD perceived that commencing haemodialysis would actually shorten their lives. A considerable number demonstrated a lack of comprehension regarding the progressive nature of their disease, influenced by factors such as denial, feeling asymptomatic, the level of GFR, and fatalism. However, some haemodialysis users shared negative experiences with the aim of dissuading individuals affected by ESKD from opting for haemodialysis. Additionally, the family members and friends of individuals affected by ESKD also played a significant role in influencing their decision to refuse to undergo haemodialysis.

In contrast, another interconnected factor, as described by participants in this study, pertained to the fear of negative consequences associated with haemodialysis, including complications and mortality. Where some participants expressed concerns about potential stigmatisation associated with being identified as individuals with ESKD and undergoing dialysis, the possible explanation for these differences might be that individuals with ESKD discussed their health condition with family members, such as spouses, children, and friends, seeking advice regarding the diagnosis of end-stage kidney failure and the medically advised option of haemodialysis. Some individuals affected by ESKD described their family members or friends encouraged them to avoid undergoing haemodialysis. This is primarily attributed to their family and friends' beliefs and lack of understanding of kidney failure conditions and dialysis. Moreover, the individuals affected by ESKD lack of symptoms and concerns about haemodialysis complications may have persuaded their family members and others that undergoing haemodialysis was unnecessary. Instead, they preferred to continue with their orally prescribed medication, considering it sufficient, or explore alternative treatments such as kidney transplantation.

However, these findings contrast with those of Hussain et al. (2015), whose systematic review of qualitative research on individuals affected by ESKD and healthcare professionals decision-making regarding initiating and stopping kidney dialysis revealed that families encountered substantial challenges in decisions to withdraw treatment. Families often found it difficult to distinguish between 'allowing death' and 'actively choosing it,' leading to a deep sense of guilt associated with these choices.

Individuals with ESKD in this study used Google as their primary search engine to seek information about signs and symptoms of kidney failure, as well as information that could potentially help them avoid undergoing haemodialysis. Furthermore, they highly valued the real-life experiences of other haemodialysis users and sought direct advice and insights from them because they believed that the personal accounts of haemodialysis users provided a trustworthy understanding. WhatsApp messages from fellow haemodialysis users influenced participants with ESKD in this study to reject the treatment due to fears of negative effects. This resistance may stem from their satisfaction with daily activities and a reluctance to seek clarification from healthcare providers regarding their condition.

Engels et al. (2022) demonstrated that a kidney failure decision aid could support individuals with ESKD in selecting treatment options. The aid included a paper handout, an interactive website, and a personalized summary sheet. The interactive website offered comprehensive information, featuring customisable elements such as questions, exercises, infographics, and videos. This tool was regarded as essential for informed decision-making, with enhanced navigational buttons and an option for individuals with ESKD to share their summary sheets directly with clinicians. However, such support may not always be effective in practice.

Chan et al. (2020) randomised control trial study showed that Individuals in the advanced stage of chronic kidney disease often experience regret when faced with decisions about whether to undergo dialysis or choose palliative care. The individuals often find the decision-making process emotionally challenging in such situations. Therefore, a brief hope intervention is employed to assess the hope level, decisional conflict, and quality of life in individuals with ESKD. A higher level of hope in individuals was associated with a decrease in both physical and psychological symptoms (Chan et al., 2020). These did not appear to be the case in this research study.

The finding of this current study is consistent with that of Boateng et al. (2018) framework, as they reported that decision-making among individuals with ESKD who undergo kidney replacement therapy and decide to withdraw or discontinue dialysis is a continuous and recurrent process. As they were faced with the challenges of coping with and managing ESKD and actively adapting to the treatment's new reality, the individuals with ESKD must reassess their decisions each time they approach a scheduled treatment. There are similarities between the interlinked factors expressed in this study and those described by (Boateng et al., 2018). For instance, personal factors play a significant role, as individuals with ESKD perceive that initiating treatment will save their lives, viewing it as a curative intervention. Additionally, most of them lack an understanding of the chronic nature of their disease, with their perceptions influenced by a lack of knowledge and shaped by religious and spiritual beliefs.

This study also confirmed that searching for alternatives and using traditional treatment is consistent with that of Boateng et al. (2018), who reported that individuals with ESKD preferred seeking kidney transplantation overseas and occasionally used traditional medicine and faith healing alongside biomedical approaches. Furthermore, a support network, as described by participants in Boateng et al.'s (2018) study, was observed among individuals with ESKD within the dialysis unit. In this network, they shared information and ideas with other individuals affected by ESKD to strengthen the decision to continue treatment. Contrary to this, the narratives of individuals with ESKD revealed that their association with haemodialysis users within their network had a detrimental impact, leading them to distance themselves from haemodialysis. This influence was attributed to the dissemination of negative consequences associated with haemodialysis, including fatigue, lifestyle restrictions and death.

Boateng et al. (2018) demonstrated that financial considerations and the availability of dialysis centres were influential factors in treatment sustainability and broad consistency with Mohamed Hussin and Syed Jamaludin (2023) findings. However, no evidence of health service availability and costs was detected in this study, as health services are available for each 10,000 population, and all health services, including haemodialysis, are free for Omani citizens in Oman, as described in section 2.2.

In contrast, a literature review (Duma et al. (2020); Kaltenmeier et al. (2020); Dias et al. (2021); Birkenbeuel et al. (2022); Hu et al. (2022)) focusing on individuals with various types of cancer revealed that the influence of social networks, family and friends, and treatment negative consequences were not evident among those with cancer conditions. However, socio-demographic factors such as advanced age, marital status, race, ethnicity, gender, earlier cancer stage, and lower income, particularly being uninsured or reliant on Medicaid, were found to be associated with the refusal of medically recommended chemotherapy or cancer surgery and were further linked to a poor prognosis (Duma et al., 2020; Kaltenmeier et al., 2020; Dias et al., 2021; Birkenbeuel et al., 2022; Hu et al., 2022; Jabbal et al., 2023). Furthermore, in the context of COVID-19 vaccine status, some individuals decline to receive the COVID-19 vaccine due to negative information about its safety and efficacy that they have encountered through social media and friends (Soares et al., 2021). This aligns with the earlier findings of this study.

In accordance with the results of the present study, the decision-making process is continuous and revisited by individuals affected by ESKD when it comes to refusing the initiation of haemodialysis medical advice due to different interlinked factors indicated in this study. Strohschein et al. (2011) took a pragmatic utility approach to examine the concept of decision-making among older individuals with cancer. They have demonstrated that some qualitative studies, particularly focusing on older individuals with cancer, indicate a prevailing perception that decision-making is not a one-time event but an ongoing process involving various steps and revisitation over time. It is initiated at diagnosis and persists throughout the disease trajectory, extending into end-of-life care. This process is individual, highlighting interactions among ill individuals, family, and healthcare providers.

Some individuals in those studies acknowledged the significance of family involvement, considering factors like not burdening family members or family roles in decision-making. Despite valuing family input, individuals also stress the importance of personal ownership and autonomy in decision-making. The balance between individual and communal decision-making is influenced by cultural contexts. Moreover, Strohschein et al. (2011) reported that the individuals highlighted the role of interactions with healthcare professionals as integral to their decision-making. Some viewed treatment as their physician's choice and willingly followed prescribed plans, while others faced challenges in deciding against recommended treatments. Whereas in tourism literature, Decrop and Snelders (2005) found, in their qualitative study using grounded theory, that vacation decision-making is a complex and ongoing process influenced by various factors, including environmental, personal, interpersonal, and situational elements. For example, emotional factors play a significant role, sometimes leading individuals to make spontaneous decisions based on momentary moods. The decision-making process extends beyond the initial choice, with late decisions often influenced by risk reduction and situational variables.

Additionally, Griva et al. (2013) emphasised that the decision-making process for individuals undergoing haemodialysis is influenced by various internal and external factors, which can either support or challenge adherence to treatment. Internal factors encompass elements such as knowledge, beliefs about medication, personal control, risk perceptions, and lifestyle preferences. External factors include the impact of family, peers, and societal influence. In the present study, the experiences of individuals with ESKD in refusing haemodialysis were shaped by the influence of family, peers, and friends.

Culturally, Omani families typically take the form of extended families, with the father serving as the authoritative figure and the mother playing a pivotal role as the primary agent in socialisation (AL-Sawafi et al., 2021). Parents in Oman frequently take on the responsibility of making significant decisions for family members, including those related to education, marriage, and treatment (Al-Barwani & Albeely, 2007). Omani families are characterised by robust interpersonal relationships and interactions, and they typically handle family matters internally.

In the Omani cultural context, families frequently participate in decision-making when it comes to illness and wield a significant impact on treatment choices (Arabiat et al., 2021). Individuals are often accompanied by family members during their medical consultations, in this study, individuals with ESKD placed their trust in their families regarding treatment options, considering the past experiences and knowledge of family members related to the illness or its treatment. They believed that ESKD and haemodialysis are life-threatening and might lead to complications and early death. Therefore, they advised individuals with ESKD to refuse haemodialysis and rely on prescribed oral medication or explore alternatives, including seeking a second medical consultation, or undergoing kidney implantation abroad, or considering folk remedies.

These findings align with the data reported in the systematic review by Lamore et al. (2017), which identified family members as significant contributors to treatment decision-making in fifteen studies. Family members were found to offer various forms of support, including emotional, informational, and esteem support, with informational support being the most frequently provided. Specifically, family members often summarised and reiterated the information presented by physicians to individuals with chronic diseases. Additionally, they filtered out treatment options that conflicted with either the individuals' or the families' preferences, aiming to prevent overwhelming those effected by chronic diseases.

Consistent with Lamore et al. (2017), this research found that family members often serve as intermediaries between individuals affected by ESKD and their treating physicians. Family members can act as active advocates for individuals with ESKD, defending their interests, providing important information such as medical histories, and asking questions to better understand treatments, including alternatives and potential outcomes. This role highlights the strong alliance between those affected by

ESKD and their families. However, this study was unable to demonstrate that family members attending medical consultations often act as messengers to the extended family, sharing information from the consultation and supporting the haemodialysis refusal decisions of individuals with ESKD. This role can be stressful and may lead to family conflict.

Furthermore, in the context of haemodialysis refusal decision-making in individuals with ESKD, the findings of this study are consistent with those of Lamore et al. (2017). Family members frequently exert direct influence on treatment decisions by offering not only emotional and informational support but also through specific actions, such as expressing opinions on treatment options, encouraging individuals to consider the family's perspective, or persuading them toward particular choices. This direct influence can significantly shape critical decisions, including treatment refusal, and may ease the burden of decision-making on the individuals.

In this study, some elements within that decision-making process mirror some of the elements of the grieving process highlighted in the …… Kübler-Ross, such as denial and bargaining.

Peer influence plays a critical role in shaping individuals' treatment decisions. Positive experiences in others may motivate individuals to pursue similar treatments, whereas witnessing complications can lead them to reject certain options. Additionally, when considering treatment choices, individuals are often guided by a desire to maintain their current lifestyle and the opinions of family and friends. (Morton et al., 2010).

This study corroborates the findings of the systematic review by Lamore et al. (2017), indicating that family influence can be perceived negatively when family members interfere in the decision-making process by pressuring individuals with chronic diseases, exhibiting a dominant attitude, or overwhelming them with information. Furthermore, the presence of family members during consultations can create tension and inhibit individuals from discussing certain topics. In some cases, when family members act as the primary communicators with the medical team, individuals with chronic diseases may struggle to fully comprehend the decision-making process.

It is encouraging to compare the findings of this study with those of Lamore et al. (2017), which reported that twelve studies indicated family members were more involved in the decision-making process when individuals did not speak the same language as the physician. In these cases, family members often acted as translators, which could lead to difficulties in accurately conveying medical terminology.

The individuals diagnosed with ESKD at stage five, upon being informed of the need to undergo haemodialysis, reacted with shock and denial regarding their ESKD status. They preferred to discuss and consult with family members and friends, seeking their advice. Family members, especially spouses, sons, fathers, and mothers, were the main influencers on the trajectory of kidney failure disease.

This finding is consistent with Murray et al. (2009) systematic review study, who identified family influence as a crucial factor in the decision-making process for individuals with CKD. The opinions of family members, interpersonal dynamics, and the self-perceived burden placed on loved ones frequently shape CKD individuals' treatment decisions. This influence is particularly pronounced among older individuals, who are more likely to rely on both their family and healthcare providers when making decisions regarding their care.

A comparison with the findings of Morton et al. (2010) systematic review reveals that fourteen studies identified the significant influence of family and caregivers on individuals' treatment decisions. This influence varied from providing practical support, such as transportation for dialysis, to offering kidney donations, and even withholding information about treatment options that conflicted with the family's preferences.

The expectation of unfavourable information and the subsequent encounters with it proved to be consistently devastating for numerous ill individuals. In certain cases, the impact was as shocking as the initial revelation of the diagnosis (Thorne et al., 2014). Almost all of the individuals affected by ESKD in this study denied that they had not yet reached the end-stage kidney disease status despite the substantial drop in eGFR and the information provided by physicians regarding the individuals affected by ESKD kidney condition. They believed their kidneys were in a stable condition because they had not developed obvious complications that hindered their ability to perform their normal daily activities.

This finding is consistent with that of Ashby et al. (2005), where, in their study, four participants with ESKD exhibited a reluctance to acknowledge their kidney issues. This reluctance resulted in familial discord and fostered ambivalence concerning their choice to avoid initiating dialysis. Furthermore, the findings of this study mirror those of a qualitative study that explored perceived factors leading to Lower Extremity Amputations (LEA) in individuals with type two diabetes (Ben chmo et al., 2023). The study reported that denial was identified as one of the intrinsic personal attributes, where some participants believed that the consequences of Lower Extremity Amputations would not apply to them. Therefore, in terms of denial in this invisible illness Ben chmo et al. (2023) stated that individuals' responses to their health status varied from rationalisation to outright denial. Some experienced great health outcomes despite undergoing amputation and completely disassociated themselves from any responsibility for the outcome. Others acknowledged being in a state of denial regarding diabetes management, despite possessing adequate knowledge and education about the condition. For individuals living with diabetes for more than two decades, denial regarding the risk of LEA often involved rationalisation. Some participants believed they were immune to such consequences, dismissing the likelihood of experiencing LEA.

Furthermore, most of the individuals affected by ESKD in this study experienced fear when medically advised to undergo haemodialysis, and this fear significantly influenced their decision-making process to refuse haemodialysis. The primary concern that surfaced was the potential impact on their future life as they anticipated a restricted lifestyle because they would depend on attending haemodialysis sessions for three hours a day and two to three times a week, and that would limit their movement as they will not be able to visit different places within the country or outside the country.

Consequently, individuals with ESKD in this study engaged in continuous contemplation, weighing the benefits and risks of medically advised haemodialysis. They revisited triggering factors, drawing on the negative experiences of other haemodialysis users in the same community and reported post-dialysis health status changes, such as sickness, tiredness, and death. Therefore, they had no desire to undergo the same experiences. These negative perceptions extended to foster sceptical attitudes regarding the potential benefits of the haemodialysis intervention (Kustimah et al., 2019).

These results reflect those of Mohamed Hussin and Syed Jamaludin (2023), who also in their phenomenological study, discovered that certain individuals with chronic kidney disease in Malaysia, opting against haemodialysis, expressed apprehensions about dependency on the haemodialysis. They also harboured fears that undergoing haemodialysis would restrict their mobility and impede their ability to carry out daily activities. Although undergoing haemodialysis allowed longer survival of individuals with ESKD (Morsch et al., 2006), these findings broadly support the findings of other studies in this area, linking the fear of dialysis with negative consequences, the fear of becoming dependent on dialysis and concerns about mortality if haemodialysis is forgone (Anees et al., 2014; Kim & Son, 2022; Mohamed Hussin & Syed Jamaludin, 2023).

Whereas Ahmed et al. (2018) explained that individuals' decisions to refuse ART treatment were influenced by emotions such as fear and anxiety, particularly regarding clinically recommended changes affecting their current lifestyle. The perceived constraints included the overwhelming list of requirements, lifestyle modifications, and the need for a life-long commitment, leading to hesitancy in accepting the recommended treatment. Coping and resilience strategies and self-determination were effective factors that promoted and supported individuals in initiating medically recommended treatment and accepting their medical condition. It can thus be suggested that healthcare professionals recognise the fears of individuals with ESKD regarding both kidney failure and haemodialysis, and fostering open communication about these fears is essential (Thorne et al., 2014).

In this study, a rather surprising result emerged, as individuals with ESKD primarily focused on the negative consequences of initiating haemodialysis, neglecting considerations of the kidney disease prognosis and potential complications. Consequently, their intention was oriented towards seeking alternative treatments to haemodialysis or opting for kidney transplantation overseas.

The individuals affected by ESKD in this study constantly ruminated over the decision as they balanced the benefits and risks of their decision and perceived that the prescribed oral medication would prevent them from developing kidney complications, assuming their condition was merely a simple kidney weakness. This aligns with the findings of Shafi et al. (2018), who conducted a cross-sectional study using a non-probability consecutive sampling technique with a sample size of 100 individuals diagnosed with stage five CKD. In their study, 54.7% of those who refused haemodialysis indicated that they would continue with medical treatment when asked about their future plans.

At the same time, the participants in this study explored alternative treatment options by sending medical reports abroad for second consultations and to avoid undergoing haemodialysis to the greatest extent possible. Despite the availability of all kidney replacement therapies in the country, most individuals affected by ESKD have placed their faith in kidney implantation. Therefore, they worked on saving money and searching for countries where safe and legal kidney transplants could be performed. A potential explanation for this trend can be found in the research by Al Rahbi and Al Salmi (2017), who conducted in-depth questionnaire-based interviews with 106 individuals who had travelled abroad for commercial kidney transplantation. Of these participants, 44% had received commercial transplants. When asked about their reasons for choosing this option, the majority (71%) cited the unavailability of living-related donors. Additionally, 13% expressed objections to receiving a kidney from a family member, while 9% were concerned about the implications of taking a kidney from a relative. Furthermore, 60% of the participants reported that they lacked financial support for overseas transplantation, relying instead on their own savings to cover the costs.

Some other individuals with ESKD in this study utilised folk remedies such as frankincense, pumpkin, and parsley, perceiving that these substances promote kidney function and potentially alleviate the need for haemodialysis, given their natural composition of 100% and perceived lack of adverse effects.

Additionally, most individuals with ESKD in this study were reinforced the decision to use traditional treatments by their family members and friends, and by following some Omani celebrities on different social media platforms, who advertised centres treating chronic conditions such as diabetes, hypertension, and kidney diseases. These participants refrained from disclosing their use of folk treatments to their attending physicians, deeming it unnecessary, as they perceived it to be within their rights to explore alternative therapies as a means to avoid haemodialysis. Additionally, the belief that traditional medications could stimulate kidney function and potentially prevent the necessity for haemodialysis influenced their decision-making. As a result, the utilisation of traditional treatments remained undocumented in their medical records because these individuals felt more comfortable expressing their health problems to the traditional healers in their local dialects than to their treating physicians and medical professionals. Moreover, some individuals integrated folk medicine with modern medicine without keeping their physicians informed. They often believed folk remedies were safe because they were derived from naturally occurring plants, assuming that being natural implies safety without adverse effects, unlike modern medicines. However, they neglected the fact that traditional medicines contain bioactive compounds that have the potential to be toxic. These individuals neglected that compounds considered safe at low doses could become toxic at higher doses and vice versa. Concerns about the toxicity of folk medicines included issues such as their potential to cause cancer, liver damage, genetic mutations, and genetic damage, as shown in some literature (Okaiyeto & Oguntibeju, 2021).

Also, these present study results are in accord with a scoping review conducted by Lunt and Fung (2022), which showed that cancer Individuals travel abroad for diverse reasons, such as obtaining second opinions on diagnosis and treatment, accessing treatment unavailable in their home country, and undergoing standard treatments not accessible within the local health system, sometimes necessitating regionalised travel. Furthermore, some individuals travel internationally seeking genuinely specialised care that is exclusively available abroad. However, Thorne et al. (2014) reported that individuals who have received cancer diagnosis keenly recognised the significance of their decisions, understanding that an incorrect move at this crucial point could dictate the outcome of the treatment, either success or failure.

This study findings also accords with Okaiyeto and Oguntibeju (2021) and Kustimah et al. (2019), who stated in their studies that many users of a mixture of herbal medicines. Okaiyeto and Oguntibeju (2021) often recommend herbal preparations to individuals in their vicinity who share similar ailments. The underlying assumption is that if these remedies have proven effective for others, they would likewise serve the same purpose for any ill individual experiencing similar symptoms. In addition to microbial contamination, heavy metals have been identified as contributors to the toxicity of herbal products, resulting in life-threatening situations or fatalities. The results of this study align with those observed in an observational cross-sectional comparative study conducted by Jermini et al. (2019). In their research, they noted that individuals undergoing cancer treatment commonly utilised complementary medicines, such as green tea, herbal tea, homoeopathy, dietary supplements, and herbal medicines. The study highlighted potential risks associated with the use of herbal complementary medicine (CM), including interactions with anticancer agents. These interactions were primarily attributed to interference with liver enzymes or transporters and, at times, through unknown or non-pharmacokinetic mechanisms, posing a significant risk of clinical impact. Despite these identified risks, the majority of individuals who were diagnosed with cancer perceived CM as harmless and safe, holding the belief that these therapies could enhance the efficacy of anticancer agents and mitigate their adverse effects.

These study results also reflected those of Chiaranai et al. (2022), who also found that apart from adhering to contemporary medical treatment plans, ten breast cancer participants mentioned incorporating herbal regimens into their health practices. These herbal approaches were neither recommended nor prescribed by their treating physicians; however, the participants believed in their efficacy for curing breast cancer. The herbal regimens employed included lemongrass juice, lingzhimushroom extract, crocodile blood extract, and soursop leaf juice.

The findings of this study align with Ceylan and Yangöz (2024) descriptive qualitative research involving seventeen HD individuals, which explored their experiences with complementary and alternative medicine (CAM). The study revealed that many individuals turn to CAM to regain a sense of control over their health, motivated by a desire for autonomy. Some participants perceived these therapies as natural, non-pharmacological alternatives with fewer side effects, which contributed to their psychological resilience and hope for improved health, symptom relief, or even a cure. However, a significant number of participants were hesitant to discuss their use of CAM with healthcare providers due to concerns about judgment or lack of support.

Oman has a significant history of utilising traditional and herbal remedies, alongside a longstanding tradition of trade with countries in Africa, the Indian subcontinent, and more distant regions such as Europe and China (Al-Kindi et al., 2011; Al-Riyami et al., 2023). In Oman, prevalent traditional medicine practices encompass the use of herbal oils in traditional massages, a technique called branding (locally known as Wassam), cupping (locally known as Hijama), and the administration of herbal medications (Al-Riyami et al., 2023). Al-Kindi et al. (2011) highlighted that despite the substantial progress in the country's healthcare system, coupled with the availability of free health facilities and medications, traditional medicine continues to be prevalent. The inclination towards Complementary and Alternative Medicine (CAM) usage likely stems from the nation's cultural heritage. Traditional healers supply these remedies, or individuals acquire them independently, using them to address a broad spectrum of both acute and chronic conditions. Family, friends, and traditional healers serve as the primary sources of information on CAM for treating diabetes. These products have been utilised across generations without apparent harm. Notably, there is a lack of quality control for these products, which are readily accessible through specialised outlets in the market (souk). Herbal remedies are widely considered to be inexpensive (Al-Kindi et al., 2011).

The present study raises the possibility that some individuals with ESKD in Oman have limited health literacy, which leads them to not understand the nature of kidney disease and the need for intervention and traditional treatment.

The decision-making process for haemodialysis refusal among individuals with ESKD is intricately tied to their values, beliefs, and personal experiences, as noted by Harwood and Clark (2013). Interestingly, certain aspects of Kubler-Ross's insights resonate with the findings from Omani individuals affected by ESKD in this research project. This is highlighted in our study; participants with ESKD often denied reaching the kidney failure stage due to a lack of evident disease signs and symptoms, while others actively suppressed the term 'kidney failure' from their memory as they fear the kidney failure condition and undergoing haemodialysis.

Therefore, as individuals with ESKD progressed to another stage in the decision-making process, they weighed the risks and benefits of their decision. In this study, some individuals with ESKD based their choice to refuse haemodialysis on misconceptions about the procedure. They perceived it as a machine that shakes individuals up and down. Meanwhile, others feared potential harm, speculating that they might die if blood returned due to a possible cut in the dialysis lines. However, some individuals with ESKD believed that continuing dialysis sessions would result in severe restrictions on their lives and a transformation of their kidney condition into chronic kidney disease. As a consequence of adhering to their refusal decision, there was a belief that if the inevitable day of haemodialysis arrived and their condition worsened with noticeable signs and symptoms, they would have no choice but to rely on the power of God. In their view, their health condition is in God’s hands, and God would take control of their kidney issues.

These results reflected those of Alzahrani et al. (2023), who explored the lived experience of haemodialysis among middle-aged individuals in Saudi Arabia. Some of their research participants reported that due to haemodialysis, they felt isolated and restricted despite the family, healthcare professionals and the government's strong support. Moreover, findings from Mohamed Hussin and Syed Jamaludin (2023) phenomenological study about CKD individuals experience to refuse haemodialysis confirmed the misconception of individuals affected by ESKD that undergoing haemodialysis might limit their capacity in physically demanding tasks and might result in irregular attendance at work. While Ahmed et al. (2018) systematic review study about individuals living with HIV and refused to initiate ART, some individuals claimed awareness of the benefits of ART, and studies revealed misconceptions about its impact on mortality and morbidity, such as the belief that ART causes cancer, deterring them from accepting treatment.

These study results agreed with the findings of other studies, in which a qualitative study conducted by Ben chmo et al. (2023) to explore diabetic individuals-perceived factors that lead to their lower extremity amputations. They reported that participants exhibited various forms of denial regarding their health, rationalising positive outcomes despite amputations, ignoring their conditions, or feeling resigned to inevitable complications and poor health outcomes.

Within the Omani context, a recent study has highlighted an attitude of disease ignorance, particularly concerning cancer, though not for ESKD. A study by Al-Azri and Al-Awaisi (2022) delved into the perceptions of 17 Omani women with symptomatic breast cancer, investigating reasons for delaying medical help-seeking. The findings revealed various reasons aligned with this study's findings, such as denial of breast cancer symptoms due to fear of death, strong personal beliefs in the healing power of God, and anxiety associated with hospitals and medical procedures. The normalisation of breast cancer symptoms and the misinterpretation of these symptoms as being linked to other diseases or conditions were factors that led to delayed cancer treatment. Moreover, the pursuit of alternative medicine remedies, receiving false reassurance or incorrect advice from family members or friends, and practical barriers such as focusing on childcare responsibilities or lacking access to transportation caused these women with breast cancer to ignore their health condition and delay seeking treatment. It is suggested that understanding the signs and symptoms of kidney failure is essential for prompting the correct help-seeking response and mitigating individual-related refusal of haemodialysis.

According to Rezaeipandari et al. (2023) coping mechanisms play a crucial role in managing the stressors of daily life, particularly for individuals confronting chronic diseases, which can profoundly impact health and quality of life. For many, religiosity serves as a vital alternative coping strategy when dealing with negative life events. Religious coping refers to the process of trying to understand and manage life stressors through methods that are connected to the sacred. Common religious coping mechanisms include practices such as praying, meditating, attending religious services, and engaging with sacred texts, reflecting a personal understanding of one’s spirituality. Across various cultural contexts and religious backgrounds, such as Islam, turning to religion during times of crisis is a widely recognised method for alleviating physical, psychosocial, and spiritual distress, especially in the face of chronic illness (Rezaeipandari et al., 2023).

Yodchai et al. (2017) an exploratory qualitative study found that most Muslim participants perceived their CKD as a consequence of sinful behaviour or as a form of divine punishment for their transgressions, viewing CKD as a test from God, which they accepted with patience. Consequently, participants also faced the challenge of seeking ways to reduce or atone for their wrongdoings. Family members often prayed on behalf of participants who were unable to plead with Allah themselves. However, the findings of this study suggest a different perspective. While most participants acknowledged reaching CKD, there was notable resistance to accepting stage five CKD and the need for haemodialysis. Nonetheless, these findings are consistent with Yodchai et al.'s (2017) observation that ESKD participants viewed stage five ESKD and the need for haemodialysis as ultimately 'in the hands of God. As a result, some participants decided to refuse haemodialysis and instead pray to God, believing that one day they would be healed from ESKD. Notably, certain elements of the Stroebe and Schut model of grief align with the findings observed among Omani individuals affected by ESKD in this research project.

This study aligns with evidence from qualitative research exploring individuals' decision-making regarding ESKD treatment in Ghana (Boateng et al., 2018). While participants recognised the severe and life-threatening nature of ESKD after their diagnosis, their treatment decisions were strongly influenced by personal values and beliefs, particularly religious convictions, as well as their expectations about the disease's progression—they often held onto the hope of a future cure. Some participants expressed faith in the possibility of healing during the period when they were making choices about starting and continuing treatment. Consequently, they did not generally view ESKD as a terminal condition, nor did they report engaging in discussions with healthcare providers about conservative treatments or end-of-life care (Boateng et al., 2018).

Cassidy et al. (2018) narrative review highlighted that effective education and informed decision-making in the CKD population face multiple challenges, largely due to individuals with CKD unique values and beliefs and generally low health literacy. Addressing these barriers requires a patient-centred approach involving a multidisciplinary care team and clear, accessible educational materials. Strategies should prioritise understanding individuals’ needs, involve them in research, and improve communication skills among clinicians. Enhancing health literacy through simplified language, visual aids, family involvement, and techniques like "teach-back" can help individuals better manage their care and make informed treatment choices, respecting cultural differences in decision-making autonomy.

Moreover, Cassidy et al. (2018) conducted a narrative review that identified several challenges to effective education and informed decision-making within the CKD population. These challenges are primarily attributed to individuals' diverse values and beliefs, as well as generally low levels of health literacy. Overcoming these barriers requires a patient-centred approach, incorporating a multidisciplinary care team and clear, accessible needs, involving them in research processes, and enhancing clinicians' communication skills. Improving health literacy is crucial and can be achieved through the use of simplified language, visual aids, family engagement, and communication techniques such as the "teach-back" method. Additionally, it is essential to respect cultural differences regarding autonomy in decision-making, ensuring that care is both sensitive and individualised (Cassidy et al., 2018).

In conclusion, the Omani individuals with ESKD in this study underwent various factors and behaviours that influenced their decision-making process, leading them to re-evaluate and build upon their decision to refuse haemodialysis. The most prominent of these behaviours are denial and fatalism. Therefore, to comprehend the implications of the study findings, the next section discusses the gaps identified by individuals affected by ESKD in denying their stage five kidney failure and medical advice for haemodialysis.

7.2 Denial

As a defence mechanism, denial involves rejecting the acceptance of a certain reality or life fact. Depending on the duration, denial may become maladaptive at a specific point in time. (Gagani et al., 2016). It was observed that almost all the individuals with ESKD in this study were in a state of denial regarding various aspects of their kidney failure, manifesting in several ways.

Denial emerged as a frequently observed response in conversations among individuals with ESKD in this study, particularly when they mentioned that their kidney disease had not progressed to reach stage five of end-stage kidney failure. This occurred as they conceptualised themselves as active and normal because they did not experience any obvious kidney disease complications (Silva et al., 2018). Carrillo-Alarcón et al.

(2015) stated that denial is seen as a conscious or unconscious resistance to accepting facts, information, or the reality of a situation. Individuals may find themselves stuck in this stage when faced with a significant change that can be overlooked. It is observed when they do not follow their recommended treatment diet and continue with the same lifestyle (Carrillo-Alarcón et al., 2015).

However, in this study, faced with the diagnosis of kidney failure and the crucial decision of whether to undergo haemodialysis, individuals with ESKD experienced overwhelming fear and anxiety about their informed prognosis and the suggested intervention. Their refusal to undergo haemodialysis stemmed from a limited familiarity with the management of kidney failure. Rashidi et al. (2021) highlighted that the concept of self encompasses various dimensions, including the Diseased Self, Coping Self, and Transformed Self. The self-concept of individuals with ESKD in this study is primarily centred on the Diseased Self. Some individuals with ESKD, upon learning from their treating physicians about their diagnosis of kidney failure, expressed shock and a sense of surprise at the sudden realisation that their kidney disease had progressed rapidly. This emotional distress caused them to ignore the treating physicians' diagnosis and intervention and search for alternatives that would satisfy their desire, for example, seeking a second consultation or trying traditional treatment, as discussed earlier in this chapter. These findings support the work of Kübler-Ross (2015), who identified denial as an initial reaction to grief, serving as a defence mechanism against the painful acknowledgement. It is also consistent with that of Rashid Thorne et al. (2014), who reported that cancer individuals experienced feeling barraged by an inappropriate quantity and/or quality of information with respect to their diagnosis and potential outcomes. The individuals who diagnosed with cancer preferred to receive the information in stages rather than in bulk, considering the sensitivity of cancer terminology. As a result, they were able to process information before making a decision. Thorne et al. (2014) suggested that the decision-making process for disease diagnosis and intervention often occurred within a condensed timeframe, and this period persisted during discussions about the initial treatment. The current study findings are consistent with Kustimah et al. (2019) and

Gagani et al. (2016) and partially contrasted with the Yousaf et al. (2022) study, which suggested that the majority of Covid 19 individuals do not employ denial to such a great extent. They may discuss the reality of their situation and then express an abrupt inability to confront it realistically any longer.

However, the asymptomatic nature of the disease led affected individuals to reject the diagnosis and refuse the prescribed intervention (Shahin et al., 2019). This current study established that all chronic kidney disease (CKD) individuals denied reaching ESKD and chose not to undergo haemodialysis because they perceived themselves as 'fine' and 'healthy' as they do not experience noticeable symptoms of end-stage kidney disease, such as oedema, vomiting, kidney pain or oliguria. Moreover, individuals affected by ESKD perceived themselves as 'normal' because they did not encounter any apparent health issues that impeded their ability to carry out daily activities and engage in social interactions. This feeling of normalcy further strengthened their conviction that they were not in a state of kidney failure. At this stage, their decision to reject haemodialysis was not a binary one, as it was influenced by information gathered through different sources, for example, searching the internet regarding signs and symptoms of kidney failure or asking peers. They remained unconvinced to accept the fact of the kidney failure stage, as the information they gathered from their perspectives did not directly apply to their situation despite some partial similarities.

This also accords with Patierno et al. (2023), who conducted a systematic review and revealed that denial of illness emerged as a substantial predictor of diagnostic delays across various cancer conditions. The primary contributing factor was the denial of symptom severity. In the case of non-melanoma skin cancer, delayed diagnosis and treatment were attributed to cancer individuals postponing their physician visits due to illness denial. The most frequently cited reasons for individuals diagnosed with cancer delaying medical care were the belief that the condition would resolve on its own and the perception that it was not significant, but that was not the case with the individuals affected by ESKD in this study, as most of them feared undergoing haemodialysis due to perceived negative experiences and preferred to continue with their orally prescribed medication and search for alternative treatment and avoid haemodialysis as much as they can.

In this study, it was evident that individuals with ESKD also perceived that they continued to pass urine normally and maintained a stable health condition despite their eGFR indicating otherwise; they ignored and disbelieved it and chose to continue with their current prescribed treatment and not to undergo haemodialysis. Where some ESKD denied the disease progression and the requirement for dialysis as they remained for years without dialysis since they were initially diagnosed with ESKD. Additionally, it was found that a slight improvement in eGFR, when communicated by their treating physicians, elicited a positive response among the individuals affected by ESKD in this study and fostered hope that dialysis could be avoided. So, they avoided contemplating their kidney condition and the recommended haemodialysis. As a result, most of these individuals preferred to adhere to their prescribed oral medications, while some aimed to undergo kidney transplantation.

This finding aligns with that of the Horter et al. (2017) study. They reported that questioning and disbelieving a positive Human Immunodeficiency Virus (HIV) result are linked to the absence of HIV-related symptoms, undermining the acceptance of one's status and the initiation of Antiretroviral Therapy (ART). This is due to the HIV individuals' fear of negative judgement and perceived stigma.

This current study found that some participants experienced stigma related to their ESKD, leading them to withdraw from social gatherings to avoid pity and sympathetic perceptions. The community often viewed those requiring haemodialysis as being close to death, prompting participants to refrain from discussing their illness to avoid being seen as weak or questioned about the cause of their condition.

The findings of this study are consistent with those reported by Casey et al. (2014) in their systematic review and thematic synthesis of qualitative studies. Casey et al. (2014). found that, to avoid stigma, individuals affected by ESKD were particularly concerned about how others perceived them. Many felt that the visibility of their vascular access attracted unwanted attention, describing the experience as feeling 'like an animal in the zoo.' The presence of visible puncture marks led some individuals to worry that they might be misjudged by others, resulting in heightened self-consciousness in public spaces. This sense of visibility and scrutiny also affected individuals affected by ESKDs' feelings of social belonging, with some expressing that it made them feel like 'an outcast.’

It is encouraging to compare the findings of this study with those of Zhang et al. (2022), who found that stigma among haemodialysis individuals in China is influenced by physical changes due to treatment, social isolation, and economic challenges. Frequent hospital visits disrupt daily life, leading to concerns about employment, future prospects, and experiences of discrimination. Traditional Chinese values, which emphasize moral excellence, clash with the visible and demanding nature of haemodialysis, thereby intensifying stigma. Economic insecurity, social isolation, internalised shame, and social rejection are significant factors, with younger individuals particularly affected by financial pressures. Furthermore, body image issues, diminished sexual function, and limited social interactions contribute to feelings of loneliness and social exclusion.

Furthermore, according to Joseph-Williams et al. (2014), a systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision-making emphasized that, beyond knowledge, individuals need empowerment to actively participate in shared decision-making. Many barriers can be addressed through changes in attitudes among individuals, clinicians, and healthcare organisations.

This current study indicates that although the treating physician informed the ESKD individual of the updated disease prognosis, some ESKD expressed anger that their treating physician stated nonsensical and irrelevant talk about their diagnosis. Consequently, they overlooked their end-stage kidney failure status, placing reliance on their personal judgment. They felt a profound understanding of themselves, surpassing that of others, and firmly believed in their ability to discern any issues with their bodies, specifically related to their kidneys. This mindset played a pivotal role in their acceptance of the disease condition and the decision to refuse haemodialysis.

On the other hand, Gagani et al. (2016) highlighted that denial serves as a defensive mechanism wherein individuals reject acceptance of a certain reality or life circumstance. Those in denial frequently exhibit a form of resistance to treatment, manifested through various behaviours such as neglecting follow-up appointments, non-compliance with prescribed medications, and outright disbelief. Consequently, individuals in denial may struggle to recognise and appropriately address the expected emotional responses following a diagnosis, such as feelings of sadness, loneliness, depression, and apathy. Therefore, their qualitative study utilised the Renal Care Readiness Scale (RCRS) to evaluate the stages of acceptance and denial among individuals with chronic kidney disease before the administration of the CKD course modules. This scale is exclusively employed to construct a reliable and valid testing instrument for assessing the stages of acceptance and denial among CKD individuals. The RCRS scale encompassed six factors: appreciation, adherence, assumption, awareness, anticipation, and affective. Gagani et al. (2016) suggested that questions from the Renal Care Readiness Scale (RCRS) could be applied to other illnesses, facilitating comparisons across different groups.

When considering participants experiences reported in this study in relation to the RCRS scale, all individuals diagnosed with ESKD in this study demonstrated a resistance to accepting their condition as being in its terminal stage, which impeded their ability to adopt more efficient coping mechanisms to handle the difficulties associated with ESKD. As a result, they refused to undergo haemodialysis due to a condition of denial. They commonly believed that their disease was not severe and that they could prevent problems by faithfully following their prescribed medications. Furthermore, these individuals with end-stage kidney disease had a deficiency in their knowledge and understanding of their illness, failing to actively pursue or get further information about their condition and the suggested treatments. In addition, most of the ESKD in this study indicated a preference for seeking kidney transplantation overseas and purchasing kidneys rather than obtaining kidneys from their own family members.

In contrast, LeBlanc et al. (2017) reported that individuals diagnosed with cancer commonly characterise their diagnosis of acute myeloid leukaemia as 'overwhelming,' 'devastating,' and 'blindsiding,' leaving them unable to process information and make decisions about treatment. The majority had not anticipated this substantial change in health. The intensity of shock and suddenness prompted many individuals diagnosed with cancer to entrust their physicians with the decision-making regarding treatment. That was not the case in this study; most of the individuals affected by ESKD felt that they held the responsibility to decide on their treatment as their right to decide for themselves.

Hence, within the scope of this study, most individuals diagnosed with ESKD exhibited a similar preference for not asking or searching for detailed information about their kidney failure disease and the associated treatment. This tendency stemmed from their denial of having reached the ESKD level and undergoing haemodialysis. Some of them consciously repressed the term 'kidney failure' from their recollection, asserting their right to decline medically recommended haemodialysis, as they were not mentally prepared to accept reaching the kidney failure stage and did not wish to acknowledge the progression of their kidney failure. However, some other individuals affected by ESKD opted to consult a family member with a medical background or seek a second medical opinion. Despite this, they tended to favour information aligned with their preferences and ignore aspects they were unwilling to hear. The observed outcome could be clarified by noting that individuals diagnosed with ESKD might be in a state of denial concerning their illness. This denial could manifest as either a limited comprehension of the actual nature of their condition or an ongoing refusal to recognise their disease status and anticipate potential negative consequences, including the prospect of death (Gagani et al., 2016).

This result is in agreement with those obtained by Kustimah et al. (2019), they reported that a predominant theme in individuals affected by ESKD statements was characterised by apprehension towards the 'unknown' and the prospect of undergoing dialysis. Beresford and Sloper (2003) brought attention to the reluctance of adolescents with chronic conditions, including cystic fibrosis, diabetes, epilepsy, juvenile chronic arthritis, or Duchenne muscular dystrophy, to inquire with their treating physicians due to the anticipation of negative consequences. For example, they hesitated to ask questions that might reveal symptoms worse than initially reported, fearing the prospect of hospitalisation. Some participants also refrained from seeking information to avoid learning about potential lifestyle restrictions. Meanwhile, other individuals with ESKD assumed that their treating physician might have misdiagnosed their health condition, as they were aware that kidney failure is an incurable disease.

The findings indicate that achieving the desired outcome in this particular situation requires effective communication between individuals with ESKD and health professionals. A significant number of individuals with ESKD and their families often face challenges in navigating the initial phase of grappling with the illness. (Khankeh et al., 2023).

7.3 Fatalism

Fatalism plays a significant role in the Islamic faith, signifying that God possesses prior knowledge of the timing and location of all events and decrees them accordingly. Belief in fate is a fundamental aspect of the Islamic faith (Aydoğdu et al., 2017).

In the current study, the narratives provided by individuals with ESKD underscored the significance they attribute to their religious beliefs when recounting their experiences with illness. This suggests a perception that they consider their circumstances beyond their control. Each individual with ESKD portrayed fate as an external locus of control. Interestingly, while the term 'fate' was consistently employed to articulate the haemodialysis refusal decision-making, none of them gave it as a reason for why they reached ESKD. Instead, all participants believed that they held no influence over their illnesses, attributing control solely to God. In this study, individuals with ESKD tended to rationalise their responses to the health condition and their attitudes towards undergoing haemodialysis in fatalistic terms to some degree.

Individuals with ESKD conveyed the belief that their kidney ailment had been ordained by God, and they placed their faith in God’s ability to restore their well-being. They regarded the necessity for haemodialysis as an inevitable consequence dictated by God’s divine decree, and they embraced it as their preordained journey. However, they recognised that if God bestowed upon them the capability to live without relying on dialysis, they would continue their lives accordingly. This finding corroborates with some authors' statements; individuals who attribute their health to destiny perceive their well-being as beyond personal influence, relying instead on fate or God (Turan & Çiftçi, 2023). As Franklin et al. (2008) assert, the acceptance of fate, a fundamental aspect of Islam, is prevalent in Islamic societies and significantly shapes individuals' attitudes and behaviours. The belief in fatalism strongly influences people's approaches to various aspects of life. Due to the inherent notion of low change associated with fatalism, expectations related to self-care, self-efficacy, development, change, and achievement, including health management, are limited (Aydoğdu et al., 2017).

The individuals with ESKD in this study felt responsible for their health but did not always choose to exercise that responsibility by complying with medical treatment; instead, some opted for traditional treatments. According to Hamdy (2009), Islam’s fatalism does not suggest that individuals lose control or disregard their circumstances. Instead, it is regarded as divine instruction from God that moulds individuals' lives and holds them responsible for their actions, choices, and judgments.

Within the context of fatalism in this study, the connection between undergoing haemodialysis and adverse outcomes, such as death, is believed to be a contributing factor in the decision to refuse haemodialysis. Consequently, most individuals with ESKD expressed the belief that they lack the ability to alter their health status and, as a result, procrastinate undergoing haemodialysis, attributing everything to the will of God. Hamdy (2009) highlighted the significance of promoting an attitude of accepting

God's will. He suggests that it's essential not to overly constrain people's sense of control over their lives based on external factors like structural constraints and religious beliefs. He also advised against making assumptions that individuals reject all treatment choices solely because of a belief in fate. Similarly, he discouraged the presumption that individuals exclusively rely on divine intervention to find comfort, emphasising that these choices may also be influenced by factors like limited access to treatment.

All individuals affected by ESKD in this study recognised the existence of CKD but declined to characterise the illness as end-stage kidney disease because there were no signs or symptoms of disease consequences. Consequently, they persisted in the belief that when the unavoidable day arrived, and they exhibited evident signs and symptoms of their deteriorating health, they would be compelled to submit to divine intervention and undergo dialysis in order to alleviate their suffering. This outcome contradicts the findings of Al Sharji et al. (2022), who observed that individuals undergoing haemodialysis commonly employ optimistic, confronting, and supportive coping mechanisms. The optimistic approach is prevalent, often attributed to religious beliefs that promote optimism. This approach aids individuals in effectively managing their ESKD and haemodialysis treatment. They hold onto the promise of improvement and make an effort to identify positive aspects associated with having ESKD and undergoing haemodialysis treatment.

Some participants believed they could delay undergoing haemodialysis for as long as possible, but if the day came, they would surrender and accept it, recognising that their power was limited to God’s will. For others, if God determined that haemodialysis was necessary for them, they felt they had no power to reject it, as they believed they were no better than those who underwent haemodialysis, and they would continue praying to God till their health condition healed. Individuals exhibiting a pronounced degree of health fatalism tend to view their well-being as predetermined by fate or a higher power, such as God. Nonetheless, religious beliefs can serve as a beneficial asset for mental and physical health, offering potential integration. These beliefs have the capacity to contribute to emotional relaxation, support recovery, and provide assistance in coping with various challenges (Dayapoglu et al., 2021). Religious individuals who have received a cancer diagnosis, generally view their belief in a higher power as a primary source of inner resilience, aiding them in coping with cancer and combatting their natural worry and fear of mortality (Al-Azri & Al-Awaisi, 2022). According to Ellison (1991), spiritual well-being encompasses both religious and psychosocial dimensions. Conversely, there is a feeling of relief in establishing a connection with God, along with a practical comprehension of life's purpose and the standard of living.

The individuals affected by ESKD expressed a profound sense of faith and acceptance regarding the prospect of undergoing haemodialysis when the time arrives. Fear was notably absent at that stage, as they willingly embraced whatever God had planned for them, considering Him the ultimate healer of their health condition. Their preference was to turn to prayer in preparation for the challenges ahead.

Moreover, they clarified their stance on haemodialysis, stating that they would continue to refuse the procedure. However, in the event of developing kidney complications, they would entrust treating physicians with full authority to take the necessary actions. This decision was rooted in their unwavering faith, as they believed their health issue ultimately rested in God’s hands.

It has been suggested that individuals diagnosed with type 2 diabetes expressed that their religious beliefs helped counteract feelings of fatalism and inspired them to adopt healthier lifestyle choices in response to this 'test from God.' Individuals with type 2 diabetes also held the belief that God would offer them advice on managing their illness. They felt a divine expectation for them to prioritise self-care and make efforts to conquer their illness. The individuals' decision to alter their lifestyle was primarily driven by a strong sense of religious duty, but there was also a notable apprehension regarding the potential consequences of diabetes (Saidi et al., 2018). This does not appear to be the case.

In general, the participants with ESKD in the current study displayed a negative attitude toward their health condition, particularly regarding haemodialysis. They did not perceive fatalism as a notion suggesting a lack of control over their sickness; instead, they linked fatalism to increased accountability and autonomy in decision-making. Some individuals perceived that their decision-making process was influenced by family members and the experiences of other individuals undergoing haemodialysis. Hence, it is evident that the individuals' fatalistic behaviours did not fully account for their comprehension of their ESKD condition and their attitudes toward haemodialysis. Instead, their reactions to the prognosis of ESKD and the recommended haemodialysis, as described in this study, mirror some of the stages of grief outlined by Kübler-Ross for individuals diagnosed with a terminal illness. These stages include shock, denial, anger, bargaining, depression, and acceptance (Horter et al., 2017).

7.4 Models of grief

The study of grief has evolved from early foundational theories to more nuanced understandings. Researchers like Parkes, Kübler-Ross, Bowlby, and Worden initially laid the groundwork, examining the psychological consequences of loss. By the turn of the millennium, newer frameworks, such as the Continuing Bonds Theory and the Dual-Process Model, introduced a deeper, more complex view of bereavement (Guldin & Leget, 2024).

Grief is now seen as a dynamic, individualised process with multiple paths, rather than a linear journey. Theoretical models are shaped by cultural and research paradigms, influencing how grief is understood and how support is tailored across diverse cultural contexts, highlighting the need for a culturally sensitive approach (Guldin & Leget, 2024).

7.4.1 Dual process model of coping with Bereavement

Schut (1999) highlights the limitations of traditional bereavement theories, particularly the ‘grief work hypothesis,’ which may not fully capture the diverse ways individuals cope with grief. In contrast, the Dual Process Model identifies two main stressors—loss-oriented and restoration-oriented—and suggests that effective coping requires alternating between confronting and avoiding these stressors, allowing for a more flexible and personalised grieving process.

Bereavement can significantly impact physical and mental health, making effective coping strategies essential for minimizing health risks. The Dual Process Model provides a nuanced understanding by distinguishing between emotional responses to the loss (loss-oriented) and practical adjustments (restoration-oriented). It underscores the need for a balance between confrontation and avoidance, recognising both personal and social dimensions of coping.

The current study reveals that certain facets of the decision-making process experienced by individuals affected by ESKD partially align with the Dual Process Model of Coping with Bereavement (loss-oriented and restoration-oriented) as delineated by Stroebe and Schut. In this study, almost all participants continuously experienced the process of loss, less process of restoration and oscillation during their decision-making process to refuse to accept reaching ESKD stage five and undergoing HD.

In this study, individuals with ESKD reported feelings of being overwhelmed by their diagnosis and upcoming initiation of heamodialysis, alongside experiencing anticipatory grief regarding future losses and the implications of dialysis. It highlighted those individuals affected by ESKD experienced loss-oriented stressors, with grief characterised by feelings of anger and resentment towards their diagnosis and the prospect of undergoing haemodialysis, which ultimately led them to refuse treatment.

Some participants in this study showed surprise and wonder when being informed by their physician of their ESKD and the necessity for haemodialysis. The participants were under the impression of being in good health and were taken away by the sudden realisation of the quick progression of their kidney illness. They declined to undergo haemodialysis due to their ability to move freely. Consequently, they begged the attending physician for additional time to persist with their recommended oral prescription. They were apprehensive about potential losses associated with undergoing haemodialysis, expecting discomfort and exhaustion based on the experiences of other haemodialysis users.

This results are in agreement with those obtained by Marcussen et al. (2023) a phenomenological - hermeneutical approach. Nurses observed that individuals on haemodialysis expressed their grief through frustration, anger, passivity, and sadness. They noted several areas of these individuals' lives impacted by loss throughout the course of their illness. Many individuals experienced a decline in daily activities and a reduced sense of autonomy, largely due to the progression of health complications, worsening comorbidities, and the demanding nature of haemodialysis. Fatigue often left individuals unable to engage in activities they once enjoyed. This loss also extended to their sense of identity and interpersonal relationships. Furthermore, the progression of the disease and the treatment altered individuals' outlook on the future, leading to feelings of hopelessness (Marcussen et al., 2023).

Another grief reaction (loss-oriented stressor) identified in this study was the frustration some participants felt over not understanding their physician's decision to withhold updates on the progression of their kidney disease and to recommend haemodialysis.

This result is consistent with findings obtained in Marcussen et al. (2023) research. They found that nurses noted grief reaction that individuals receiving haemodialysis often appeared extremely passive, expressing a lack of knowledge about haemodialysis and deferring all decisions to the treating physician, as they preferred not to engage with details about their treatment. This aligns with the findings of Palm et al. (2023), who conducted an online survey of individuals who lost a significant other during the COVID-19 pandemic. The study revealed that medical staff did not provide sufficient information about the health conditions of their relatives.

Some individuals with ESKD in this study demonstrated a restoration process, partially accepting their diagnosis by continuing with oral medications while refusing haemodialysis and seeking alternative treatments. In contrast, those who eventually began haemodialysis did so only when their health had significantly deteriorated, making the procedure unavoidable due to serious complications and a tangible necessity.

Additionally, this finding is consistent with that of Marcussen et al. (2023), who observed that nurses reported grief as an ongoing process, with individuals affected by ESKD gradually adapting to their circumstances after starting haemodialysis and eventually accepting it as a necessary part of life. They also noted that grief remained a persistent and dominant experience for individuals with ESKD, present throughout the course of the illness and when confronting the prospect of death.

However, most of the participants in this study exhibited partial coping and adaptation to their health status related to ESKD. Many expressed fatalistic attitudes, perceiving their condition as beyond their control and attributing their acceptance of haemodialysis to divine will, believing that initiation of dialysis would occur at a predetermined time according to God's plan.

A potential weakness of the Dual Process Model of Coping with Bereavement, as highlighted by Fiore (2021) in her systematic review, is the limited application of the model in guiding psychotherapeutic interventions. While the model effectively captures the bereavement experience, the scarcity of empirical studies exploring its utility in clinical practice underscores the need for further research to establish its practical applicability.

In terms of the restoration process, most participants in this study expressed a desire to undergo kidney transplantation and were actively seeking living donors from abroad. Some had sent their medical reports overseas for consultation, while others were awaiting compatibility test results. Additionally, some were in the process of gathering sufficient funds to support the transplantation procedure, viewing it as a permanent solution to their kidney failure without fully considering the potential side effects.

This also accords with Moran (2022) qualitative study, which showed that most dialysis participants had high expectations of receiving a kidney transplant and returning to a normal life. They misunderstood the term ‘average’ wait time for a transplant, interpreting it as the ‘actual’ wait time. This misconception led them to believe the transplant would happen within a specific period, affecting how they coped with their circumstances.

The dual process model of coping with bereavement explains how individuals navigate loss and grief, and this framework can also be applied to the grief experienced during illness, highlighting the need for support from the kidney care medical team (Schut, 1999; Stroebe & Schut, 2021; Marcussen et al., 2023).

7.4.2 Kübler-Ross model of grief

Within the context of denial and fatalism, it is crucial to delineate the stages of grief elucidated by Elisabeth Kübler-Ross (1989) in her work 'On Death and Dying': denial, anger, bargaining, depression, and acceptance. The effect of receiving a diagnosis for a chronic illness mirrors the stages of grief, presenting a formidable challenge that significantly impacts self-image and self-esteem. Individuals facing such diagnoses, akin to those experiencing grief, traverse through several stages where their emotions can undergo diverse phases (Germain, 1980; Silva et al., 2018). Hence, within the current study, certain aspects of the decision-making process undergone by individuals with ESKD parallel some elements of the grieving process outlined by Kübler-Ross.

Kübler-Ross observed that not every individual facing a chronic illness attains a state of acceptance during the final stage of their life (Asghari & Arabi, 2019). This is consistent with the findings of this research, where individuals with ESKD did not accept the physicians' diagnosis upon reaching the kidney failure stage; consequently, they were not able to accept medical recommendations to undergo haemodialysis.

Individuals affected by ESKD in this study realised that kidney failure disease is incurable; therefore, they were induced to psychological suffering such as anxiety and fear due to their disease's complex nature as well as the individuals affected by ESKD and their families subjective meaning and understanding of the kidney end-stage kidney failure disease, that the kidney disease causes pain, tiredness, fatigue, oedema, oliguria, death and the real experiences of kidney failure in the lives of other individuals affected by ESKD who underwent haemodialysis. Therefore, individuals affected by ESKD in this study denied reaching ESKD and were afraid to undergo haemodialysis, as it might cause this death. Thus, they had a sense of insecurity, daily life disturbance, and psychological distress. The consequences led them to refuse medically advised haemodialysis.

The decision-making process to deny the end-stage kidney failure and refuse the recommended haemodialysis was seen to be stressful among the individuals affected by ESKD in this study and affected their hope to get cured of the kidney failure status.

According to Asghari and Arabi (2019), the initial phase encountered by individuals with incurable diseases is the stage of disease shock, during which the ill individuals remain in disbelief that a severe illness has impacted them.

In this study, the denial stage that individuals with ESKD experienced was upon being diagnosed with ESKD and advised to undergo haemodialysis. At this stage, the individuals affected by ESKD did not believe that their kidney disease progressed and reached end-stage kidney failure (stage five) and required to undergo haemodialysis. The denial expressed by individuals with ESKD has been caused by feeling asymptomatic, engaging in normal daily activities, and experiencing an overall sense of well-being, which caused conflicts with the treating physicians.

The participants-built assumptions that undergoing haemodialysis would restrict their lives by attending the dialysis session three times a week, which would restrict their ability to roam around and perform their normal daily activities, believing that haemodialysis would cause them tiredness and might result in their death.

Therefore, some of the individuals affected by ESKD sought a second opinion either within Oman or travelled abroad, hoping for a misdiagnosis or an alternative treatment option other than haemodialysis. Meanwhile, others completely denied their kidney failure status and chose to persist with their orally prescribed medication, believing that nothing would happen until obvious complications appeared and their condition deteriorated.

Asghari and Arabi (2019) highlighted that once the barrier of denial falls down, it is replaced by emotions such as anger, jealousy, and hatred. An ill individual's anger seems to be directed toward the environment without any regular pattern.

In this study, some individuals affected by ESKD expressed anger toward their treating physicians when informed about their kidney failure status and the necessity of initiating haemodialysis during their follow-up visit. They felt that their treating physician did not adequately justify the reason for initiating the dialysis procedure, as they lacked knowledge about the haemodialysis process. Instead, they sought information about haemodialysis through their family members and friends. Frustrated, they subsequently refused to undergo haemodialysis.

Some other individuals affected by ESKD were annoyed and denied being involved in discussions about their treatment plans with their treating physician because the physicians preferred to engage with their family members, such as daughters, sons, spouses, and parents, who were deemed more educated and able to comprehend the physician's discussions effectively. Consequently, they did not seek clarification about their health condition, specifically the eGFR level, and relied on their family members with a medical background, assuming that these family members better understood the medical terminology.

According to Germain (1980), when individuals face illness, they realise that time is limited. They begin to pray and seek compromises with any divine entity that may listen, making promises like, 'If you grant me one more year, I will commit to attending church.

In this study, most of the individuals affected by ESKD, upon receiving their informed kidney failure diagnosis, requested their treating physicians to maintain their health condition through a balanced diet and prescribed medication. They believed that continuing with prescribed medication would prevent the development of kidney complications and help maintain their kidney function, as their primary focus was to undergo kidney transplantation.

Individuals with incurable diseases frequently experience a range of emotions and behaviours, encompassing sensations of injury and loss, failure, despair, helplessness, confusion, and isolation. It also involves pessimism about the future, diminished self-esteem, and a feeling of worthlessness and inefficiency. The individuals' families and significant others typically encounter increased challenges as well. (Asghari & Arabi, 2019).

Some individuals with ESKD in the present study experienced stress and fear upon learning from physicians that haemodialysis was the only treatment option given their current kidney failure status. The pronouncements by these physicians induced anxiety and apprehension among the ESKD participants, leading to feelings of stress. Consequently, some of these individuals chose to leave the hospital and refrain from further interactions with healthcare professionals. Moreover, As mentioned in section 6.6.2, individuals with ESKD engaged in conversations about their health condition and possible interventions with family members or friends. These confidants harboured reservations about the reality of end-stage kidney disease and the necessity of haemodialysis. Some family members believed that the individuals affected by ESKD were too young for haemodialysis and, as a result, encouraged them to consider alternative treatments, such as traditional treatment or kidney implantation.

These results are in agreement with those obtained by Silva et al. (2018), who found that individuals diagnosed with diabetes mellitus often have varied emotional responses, such as despair, preoccupation, unrest, and even panic, upon learning about their chronic condition through diagnostic tests or from healthcare providers.

Furthermore, in this study, individuals with ESKD were influenced by the social environment in which they live, as well as the nature of the disease symptoms and their self-experiences. For example, their kidney failure diagnosis and the requirement for haemodialysis led to stigmatisation consequences in the community, creating a negative impact on the diagnosis and intervention. Consequently, they withdraw socially and isolate themselves as they grapple with the profound pain and meaning associated with the disease (Carrillo-Alarcón et al., 2015). These individuals with ESKD experienced stigma from the community due to being identified as kidney failure individuals requiring haemodialysis. Frustrated and unwilling to accept pity and sympathetic perceptions linked to their health condition, they chose to isolate themselves and steer clear of community social gatherings, avoiding criticism of being close to dying due to kidney failure stage and undergoing dialysis. As well as, some other individuals with ESKD in this study felt a sense of injury and conveyed that they could not tolerate the idea of others seeing the haemodialysis catheter on their forearm. These results further support the idea of Alvani et al. (2012), that individuals with chronic illness and disability unveil a spectrum of disruptions in their life stories prompted by the onset and progression of chronic conditions; for example, they do not prefer to be perceived as weak. (Alvani et al., 2012).

Some individuals affected by ESKD in this study showed fatalistic behaviour, where they accepted the disease diagnosis to some extent and suggested continuing their orally prescribed medication, but they refused to undergo haemodialysis. They aimed to search for alternative treatments or to ignore the recommended intervention and wait till the condition deteriorates and the actual day of haemodialysis reaches. However, some of the individuals affected by ESKD who commenced haemodialysis accepted and surrendered to undergo the procedure as it became a tangible necessity when their condition deteriorated and serious complications arose, leaving them with no choice but to undergo haemodialysis. As these individuals embraced their condition, they felt regret for not initiating haemodialysis sooner and allowing the condition to worsen.

These findings are contrary to the Carrillo-Alarcón et al. (2015) study, which suggested that individuals with type 2 diabetes who face illness regain their emotional well-being, embrace the disease as a part of life, and integrate treatment into their daily activities and functions. They also had a higher likelihood of enhancing their knowledge and glycaemic control.

Finally, it was noted that individuals with ESKD had a limited understanding of their disease condition, with fewer insights into the complications associated with it. Therefore, to ensure knowledge efficiency and effectiveness, it is important to evaluate the quality and method of information delivered to the ESKD population, considering their value, beliefs, and preferences.

Chapter 8 Conclusion

This chapter presents a concise overview of the results of the research study, indicating the impact that this study has on expanding knowledge. Moreover, it critically examines the rigour of the study, evaluates its strengths and limitations, and offers recommendations for clinical practice and health policy regarding chronic kidney disease. In addition, this chapter explores potential areas for future investigation.

8.1 Overview of the research study findings

This study aimed to fill a gap in the literature by focusing on the reasons that led individuals affected by ESKD to refuse medically advised haemodialysis.

A literature review was conducted to explore the perceptions of individuals regarding treatment non-adherence, non-concordance, and treatment refusal decision-making across various health conditions in adults. Limited information on individuals who refuse haemodialysis was identified by the review, with the existing literature mainly focused on conservative interventions in chronic kidney failure chosen by Western ageing populations. The decision-making process behind the refusal of medically advised haemodialysis in Oman, Gulf, and Arab countries is thus investigated for the first time in this study. The primary aim of the research is to identify factors influencing the refusal of medically recommended haemodialysis among individuals with ESKD in Oman from the perspective of those with ESKD.

This Grounded theory research study was undertaken with Omani individuals suffering from ESKD who opted not to undergo haemodialysis. As the interviews progressed, individuals affected by ESKD contributed both novel and confirmatory findings related to their refusal of haemodialysis. The analysis of research data disclosed that the decision-making process, central to the study, is influenced by various interconnected factors that contribute to the refusal of haemodialysis by individuals with ESKD. This refusal is integrated into the decision-making process, which is associated with the core category of balancing benefits and risks.

The analysis was carried out using coding and constant comparative techniques to achieve a deeper understanding of the social process of decision-making. A framework comprising five overarching categories emerged: self-conceptualisation, acquiring knowledge, influencers, fear, and self-control. These categories illustrated the decision-making process of the individuals and its impact on their overall health status (refer to Figure 6.9). Although the decision-making process related to haemodialysis refusal was experienced differently by each individual and at various stages in their journey, almost all exhibited almost the same influencing factors.

In the self-conceptualisation category, the rejection of haemodialysis treatment is observed by individuals with ESKD who deny having reached the end-stage of kidney failure.

In the category of acquiring knowledge, ESKD demonstrated a complex interplay of factors through three interconnected sub-categories: information provided by the treating physician, information gathering, and knowledge gaps. Despite being provided with medical advice by their treating physicians, some individuals chose to refuse medically advised haemodialysis, as documented in their medical records. Various justifications were offered for the refusal. Waiting until obvious kidney complications were experienced, doubting the physicians' explanations regarding the eGFR level, and opting for alternative treatment options over hemodialysis were among the reasons provided. Reassurances from physicians and prescribed oral medications were interpreted as indications that haemodialysis was not immediately urgent. The refusal was further contributed to by fear of the procedure, including concerns about death or lifelong dependency.

Diverse methods were employed by participants to gather information and avoid haemodialysis, with reliance on internet searches, primarily utilising Google, to access information about kidney failure signs, symptoms, and treatment. Discrepancies between online information and that provided by physicians led to the rejection of medically advised haemodialysis by some participants. Information-seeking was delegated to family members, particularly those with health professional backgrounds, using WhatsApp messages and videos to learn about the procedure and experiences of haemodialysis users. Knowledge gaps arose from participants' interpretations of their health conditions, often influenced by denial and a lack of education, making it challenging for them to grasp the significance of eGFR markers or seek clarification from physicians. Fear and reluctance to undergo the treatment were further fueled by misconceptions about the haemodialysis procedure.

The influencers category in this study exhibits two sub-categories. Initially, some participants chose to reject haemodialysis under the influence of negative experiences shared by other haemodialysis users. These individuals discouraged accepting haemodialysis and advocated for exploring alternative treatments. Additionally, observing fatigue in fellow haemodialysis users led some individuals with ESKD to believe they could maintain their well-being without haemodialysis, continuing their daily activities without hindrance. The witnessing of deaths among certain haemodialysis users further persuaded participants to decline medically recommended haemodialysis. In contrast, others based their decision to decline haemodialysis on anecdotes from individuals with ESKD who delayed the initiation of dialysis and eventually experienced recovery.

Secondly, another set of participants in the study was swayed by the influence of family members and friends. Upon learning about their kidney failure condition, most participants sought advice from these individuals, whose opinions significantly shaped the decision to decline haemodialysis. Trust was placed in family members or friends who either witnessed the experiences of different haemodialysis users or worked as healthcare professionals. As a result, some individuals shared negative haemodialysis experiences and encouraged rejecting haemodialysis in favour of exploring alternative treatments such as kidney transplantation or herbal remedies.

The fear category, identified as a significant motivator, played a pivotal role in the widespread refusal of haemodialysis among nearly all participants in this study. Participants expressed reluctance to undergo the haemodialysis procedure, driven by the fear of adverse consequences and the potential stigma associated with it.

Consequently, these individuals believed they were asymptomatic, lacked interest in learning about haemodialysis, and wished to extend their lives. Furthermore, concerns about the lifelong commitment and regular attendance required for haemodialysis sessions led some participants to decline, fearing restrictions on their mobility and disruptions to daily routines. Influenced by the experiences of other haemodialysis users, additional fears included becoming bedridden, having foreign bodies implanted, and being hospitalised. Feeling stigmatised, certain participants refrained from participating in community social gatherings due to discomfort with the sympathetic perception tied to their health condition. The fear of being labelled as 'near death' or 'too young to develop kidney disease' added to their vulnerability.

The self-control category is characterised by participants who were sought after for alternative treatment options and exhibited fatalistic behaviour. Future plans in the event of health deterioration were envisioned by these individuals, and a commitment to managing their condition through measures such as a balanced diet, prescribed oral medications, or seeking second medical opinions locally or abroad was expressed. Despite their proactive approach, the haemodialysis decision-making process was significantly influenced by spirituality and religion, with a recognition that ultimate control rested in God’s hands. The possibility of delaying haemodialysis for as long as possible was believed by some, who would surrender if the need arose and acknowledge their limited power in the face of God’s will. For others, acceptance of haemodialysis, if deemed necessary by God, was accompanied by the understanding that they were no better than those who underwent the procedure, continuing to pray for healing.

The decision-making process, centralised around balancing benefits and risks, is supported by five main categories, each interconnected and displaying interactions forming a spiral. Drawing from the grounded theory approach in this study, the ongoing and revisited nature of the haemodialysis refusal decision-making process is reflected. Continuous engagement in evaluating and balancing the benefits and risks, revisiting triggering factors, and reflecting on feelings toward influencing factors characterises this dynamic decision-making process, which is not fixed, highlighting the consideration of emotions and evolving perspectives by the individuals on different influencing factors.

8.2 Study contribution to knowledge.

A substantial contribution is made by the findings of this study to the growing body of evidence, enhancing the understanding of the decision-making process related to the refusal of haemodialysis among individuals with ESKD. This study makes six main contributions.

This study presents a distinctive model using constructivist grounded theory to describe the decision-making process of individuals with ESKD who refuse haemodialysis. This represents the first conceptual framework of its type, available for utilisation and enhancement by researchers in many contexts to expand our comprehension of the reasons and mechanisms behind the choices made by individuals with end-stage kidney disease to decline medically recommended haemodialysis.

The model outlines and connects the steps in the decision-making process of haemodialysis, therefore underlining the main considerations individuals with ESKD encounter when refusing this treatment. This conceptual model integrates multiple research projects focusing on end-stage renal disease and haemodialysis, introducing a novel conceptual model within it. Nephrology medical experts can now utilise it to predict the primary elements that lead to rejection in individuals with ESKD under their care and intervene in a suitable and constructive manner.

This study enhances comprehension of the complexities associated with denial in ESKD cases and provides a distinctive examination of how individuals manage ESKD. This can be utilised by researchers and healthcare providers specialising in nephrology in their various professional endeavours. This study significantly contributes to the existing understanding of the decision-making process for haemodialysis refusal among individuals with ESKD in the Middle East. It complements the research conducted by

Anees et al. (2014); Shafi et al. (2018); Saeed et al. (2020), and Mohamed Hussin and Syed Jamaludin (2023).

This study contributes a novel perspective on the experience of ESKD by providing information on the attitudes, behaviours, and practices of individuals affected by ESKD in Oman. The evidence has the potential to be transferred to Gulf and other Middle Eastern countries due to their similar characteristics, such as religion and culture.

This study is a specific real-life example of how the Dual process model of coping with bereavement Kübler-Ross grieving model is used in the decision-making process of individuals affected by ESKD who refuse to undergo haemodialysis. This study is the first to apply this model to ESKD and dialysis. It provides a comprehensive analysis of how ESKD persons' decision-making regarding haemodialysis refusal might be aligned with the components of the model. Furthermore, this study provides empirical data supporting the effectiveness of the Kübler-Ross grieving model in explaining denial and fatalism behaviour associated with the decision to refuse haemodialysis treatment.

The process of balancing aids in comprehending how individuals affected by ESKD navigate the decision-making process concerning the benefits and risks of haemodialysis. Moreover, this research underscores the significance of high-quality nephrology care for individuals affected by ESKD. Furthermore, it underscores the need for further efforts to enhance the attitudes towards ESKD and haemodialysis among certain healthcare professionals.

The findings of this research must be considered within the context of Omani culture, which deeply influences participants' decision-making, especially in ESKD and haemodialysis phenomenon. Oman is a society where religious beliefs, particularly Islamic principles, play a significant role in shaping attitudes toward illness, life-sustaining treatments, and end-of-life care (Al Harbi, 2018). The strong emphasis on family involvement in health decisions, as well as the importance of spiritual acceptance of illness and interventions, are distinctive factors that may not be as prominent in secular or non-Islamic societies (Al Harbi, 2018; McLaren et al., 2021).

These cultural and religious dimensions are central to understanding the perspectives of Omani individuals, particularly in the context of the decision-making process regarding ESKD and haemodialysis.

However, despite these cultural distinctions, the core themes of this research—such as denial of ESKD, reluctance to undergo haemodialysis, and fatalism—are not unique to Oman. Similar factors have been reported in other countries, especially in those where religion and spirituality are significant components of daily life. Studies conducted in other Muslim-majority countries, as well as those in regions with strong spiritual traditions, often report comparable findings regarding the influence of religious beliefs on health choices (Kisa & Kisa, 2024).

Furthermore, the broader implications of the research, such as the balance between medical recommendations and individuals' preferences, transcend cultural boundaries. The tension between medical intervention and personal beliefs, as observed in the Omani context, is a universal issue faced by healthcare providers and ill individuals worldwide. Therefore, while the findings are deeply rooted in Omani culture, they may be applicable in other settings where religious or spiritual considerations play a pivotal role in healthcare decision-making.

Nonetheless, it is important to acknowledge the limitations of generalising these findings to all cultural contexts. In countries with more secular health systems, or where individual autonomy is emphasized over family or religious considerations, the dynamics observed in Oman may not be as relevant. Therefore, the extent to which these findings can be applied in other cultural or religious contexts requires further investigation.

8.3 Study strengths and limitations.

8.3.1 Strength of the study

This study is believed to be the first study to be conducted in Gulf countries, specifically Oman, that explores the experiences of individuals with end-stage kidney disease at stage five who refuse HD. This study offers a unique perspective on how individuals perceive the decision-making process while declining haemodialysis and becoming ESKD. There is a significant lack of knowledge regarding the personal experiences of individuals with ESKD in Oman and the Middle East region in general. Therefore, the study contributes to the body of knowledge.

The study is geographically and disease-condition-focused; the study was conducted in Oman, aiming to identify the decision-making process of individuals with ESKD regarding haemodialysis. The findings of the study could be transferred to other Gulf and Arab countries with similar cultures and to individuals with other chronic diseases who refuse medically recommended treatment.

One of the merits of this study was the application of grounded theory to accomplish its aim. Grounded theory is widely acknowledged for its efficacy in producing novel discoveries and has been recognised for its substantial contribution to current knowledge (Corbin & Strauss, 2008). The study enabled a comprehensive analysis of the experiences of individuals affected by ESKD who declined haemodialysis. Additionally, it advanced my comprehension of the emotional, cultural, social, and religious factors that influence their experiences with ESKD and refusal of haemodialysis.

The study was conducted using rigorous research methodologies to achieve reliable results and guarantee its credibility. The grounded theory methodology and its rigorous approach encouraged the emergence of the data, resulting in a level of resonance that is valuable for practice, policy, and research.

Finally, the results would be valuable for guiding clinical practice in nephrology departments in terms of different elements of care for individuals affected by ESKD, potentially resulting in the formulation of strategies or guidelines to improve the quality of care delivered.

8.3.2 Limitations of the study

The study was conducted on a small scale, with a specific focus on a limited number of participants within a particular setting and timeframe. The generalisability of the study may have been restricted due to the small sample size, which included a maximum of four and a minimum of two participants from the nine nephrology clinics and kidney dialysis units in the chosen governorates. Nevertheless, this constraint is deemed inevitable in qualitative research, where the focus lies on the quality rather than the quantity of data. A more extensive study might have been conducted to examine a wider demographic throughout different governorates of Oman, including additional rural regions. Furthermore, the research was limited by time constraints and the involvement of a single researcher, as it was carried out for the purpose of academic qualification. However, the researcher took steps to ensure that the study sample included a diverse variety of experiences and perspectives, as mentioned in section 5.3.

Purposive sampling enabled me to capture the experiences of individuals from two different groups at stage five of ESKD in Oman: those living with ESKD who refused haemodialysis and others who underwent haemodialysis. Reflecting on decisions made over the course of the illness was inherently challenging and susceptible to recall biases.

All recruited participants were adult Omani Muslims. Consequently, it is possible that the findings may not be representative of other individuals with ESKD from diverse age groups and cultures or with different religious backgrounds. Haemodialysis refusal was the common factor among the participants. Consequently, if the study had included individuals who refused peritoneal dialysis or kidney implantation, distinct results might have been obtained. The adult Omani population was the primary focus of the study, with an emphasis on individuals with ESKD.

The study sample was relatively small and comprised Omani individuals with ESKD who had made the decision to refuse medically advised haemodialysis and who received free treatment. It is unclear whether the findings will apply to non-Omani individuals with ESKD and whether they are financially insured or not. Studying other groups is warranted to assess generalisability.

The interviews were conducted in a hospital setting by a researcher with medical expertise. This factor may have influenced the participants' narratives of their experience with ESKD and their decision-making process regarding haemodialysis refusal. The hospital atmosphere may have hindered the participants' responses. Nevertheless, the participants themselves took the option to conduct the interviews in a hospital setting and to provide comprehensive data.

The timing of the interviews may present limitations. Each interview took place during the waiting period for blood investigation results. Some concerns from participants might not have been fully communicated due to their urgency to review laboratory results and consult with their treating physician. However, efforts were made to utilise the waiting time by conducting the interviews immediately after the collection of blood investigations and before the dispatch of the results.

Upon completing this study, I recognise that the use of the term refusal may have inadvertently introduced bias, as it can imply a value judgment on the decision-making process of individuals. Moving forward, more neutral terminology may better reflect the complexity of individuals' choices without suggesting a particular stance or evaluative tone.

8.4 Study implications.

8.4.1 Implications for practice

This study established that all CKD individuals denied reaching ESKD and chose not to undergo haemodialysis because they perceived themselves as 'fine' and 'healthy' as they did not experience noticeable symptoms of end-stage kidney disease. In this context, a personalised and patient-centred approach to care may provide more benefits compared to a conventional disease-oriented strategy for individuals affected by ESKD. For example, empowering individuals affected by ESKD involves negotiation, wherein healthcare professionals engage in a thoughtful, empathetic, truthful, and inclusive manner. This approach customises patient-centred decision-making to align with the individuals’ preferences and values throughout the disease trajectory (Wakefield et al., 2018).

Additionally, strategising early interventions to improve haemodialysis acceptance among CKD individuals requires multidisciplinary teamwork to establish effective and continuous interventions. This would enable a comprehensive approach to understanding and encouraging a problem-solving process for treatment acceptance and better health outcomes, considering both the biomedical aspects and the social dimensions of individuals' health and well-being (Mohamed Hussin & Syed Jamaludin, 2023).

Furthermore, the clinical team should routinely reassess the symptoms and consequences of CKD, and specifically inquire about them during individuals’ follow-up. The pre-dialysis education for this group of individuals with CKD should provide clearer information regarding the normal course of CKD and, the significant time gap between starting pre-dialysis education and the following requirements to make a shared decision on ESKD care.

The National Institute for Health and Care Excellence guidelines for KRT in the UK emphasise that the decision to initiate dialysis should involve shared decision-making between individuals affected by ESKD, their families, and healthcare teams. This collaborative approach fosters realistic expectations, aligns treatment options with individual values, and reduces unnecessary interventions. Furthermore, decision-making in kidney care should be holistic and comprehensive to optimise health outcomes and allocate resources effectively. Future research should focus on pathway-based cost studies that map expenses to data from extensive care networks to better represent the resource utilisation in kidney care.

The data uncovered a prevalent lack of understanding regarding the prognosis and treatment of ESKD among both individuals with ESKD and their families and friends. This outcome is likely linked to the pervasive challenge of evaluating the benefit-risk equilibrium of medical interventions, which is prevalent across various healthcare domains, especially affecting individuals striving to make well-informed treatment decisions. Recognising the pivotal role of the benefit-risk balance in decision-making, healthcare professionals bear the responsibility of improving communication about treatment benefits and risks. This emphasis on communication is crucial for eliciting the perspectives of individuals with ESKD and fostering transparent, rational, and defensible decision-making processes that contribute to overall improvement. However, it is crucial to empower individuals affected by ESKD and their families in the process of treatment planning and decision-making. (Coplan et al., 2011).

The participants in this study reported that they did not know about their disease progress reaching ESKD to accept haemodialysis. The role of physicians as educators is crucial in supporting individuals affected by ESKD in addressing their informational needs while making decisions regarding haemodialysis. In addition, physicians should collaborate with individuals affected by ESKD to ensure that they are adequately prepared to make informed and shared decision-making without exerting influence on them to make final decisions considering the possible fluctuations in their health condition.

This study suggests that there is a potential for inadequate health literacy among individuals affected by ESKD in Oman. This limited health literacy may result in a lack of comprehension regarding the nature of kidney disease and the necessity for intervention. Almost all individuals affected by ESKD had a tendency to avoid seeking comprehensive information regarding their condition and treatment, potentially due to a state of denial over their progression to ESKD and the need for haemodialysis. In this study, individuals with ESKD were not persuaded by the treating physician's opinion in their role as advisors or authoritative figures in making decisions. However, their perspectives were shaped by the experiences of their relatives, acquaintances, and other individuals undergoing haemodialysis. Achieving the desired outcome in a situation necessitates effective communication in healthcare. Physicians play a crucial role in helping individuals understand and accept their own preferences regarding various choices or options available to them. While supporting ill individuals' autonomy, clinicians must discern when to provide direct and clear professional advice, ensuring a comprehensive and patient-centred approach.

During the diagnosis phase, beyond making the language of ESKD accessible and allowing time for individuals to process information, effective communication requires healthcare professionals to adopt a listener role. It is essential to recognise that effective communication is not one-size-fits-all; hence, healthcare professionals should continuously assess individuals’ needs throughout their trajectory rather than assuming what will constitute effective communication.

Given the importance of nuanced communication, additional training for healthcare professionals will contribute to a more comprehensive solution. This training will enhance their ability to navigate diverse communication scenarios, fostering improved individuals affected by ESKD understanding and collaboration in decision-making processes.

The results of this study highlight the necessity to change perspectives regarding ESKD and its management, not just on an individual basis but also within family and societal contexts. Addressing inaccurate cultural beliefs and dispelling various rumours about ESKD and its management that are prevalent in Omani culture is crucial, and this can be achieved through community campaigns or workshops. Enhancing public education through the media in Omani society can play a pivotal role in rectifying misconceptions about ESKD and its treatment and concurrently diminishing the existing stigma associated with haemodialysis. For example, promoting open dialogue through storytelling campaigns, where survivors of ESKD or individuals managing their condition through dialysis share their experiences in public forums and media.

Individuals with ESKD hesitated to undergo haemodialysis due to a fear of early death associated with its initiation. Their decision was influenced by witnessing negative experiences, including fatalities, among other haemodialysis users. This noteworthy finding could be attributed to the implementation of innovative and comprehensive multidisciplinary counselling designed to alleviate the fear of haemodialysis among individuals with ESKD and their family members or friends while also enhancing their understanding. This involved strategies such as showcasing informative videos, distributing handout materials, and facilitating interactions with dialysis users and staff through visits to dialysis facilities. It can be suggested, therefore, that healthcare professionals recognise the fears and elements of grief of individuals with ESKD regarding both kidney failure and haemodialysis and foster open communication about these fears.

The findings of this study indicate that nearly all individuals affected by ESKD did not fully comprehend the severity of their condition or the necessity of undergoing haemodialysis. This lack of understanding can result in delayed or refused treatment, potentially worsening health outcomes. It underscores the need for healthcare providers to communicate prognosis and treatment options in a way that aligns with individuals' cultural and religious beliefs. In Oman, this may involve integrating religious concepts, such as the notion that medical treatment does not conflict with faith in divine healing, and that seeking treatment is part of fulfilling one's religious duties.

A multidisciplinary group consisting of nephrologists, nephrology nurses, social workers, psychologists, dieticians and religious leader is essential to provide ongoing education to individuals with ESKD and their families regarding the challenges of kidney failure and dialysis. This would enable timely interventions to be implemented at an early stage. Incorporating religious leaders into individuals affected by ESKD education initiatives may prove beneficial. Religious figures can help bridge the gap between medical recommendations and religious beliefs, addressing misconceptions and emphasizing that seeking treatment does not conflict with trust in divine will. Ultimately, it would ensure that individuals affected by ESKD receive holistic care, addressing both their medical and spiritual concerns.

The presence of a sufficient number of training sessions for nephrology nurses, as well as nephrologists, will facilitate the provision of efficient care to individuals in a timely manner by ensuring the availability of informed and extensively qualified professionals. These medical professionals need to receive training on how to navigate sensitive discussions around ESKD at different staging and treatment options. This includes fostering open dialogues with individuals and their families, addressing concerns about prescribed treatment in the context of religious and spiritual beliefs, and involving religious leaders when necessary.

In Omani culture, families play a pivotal role in decision-making. A lack of understanding about ESKD and its treatment often extends to family members, who frequently influence the decision to undergo haemodialysis. Since families are integral to decision-making, healthcare education should involve both the individuals affected by ESKD and their relatives. Family discussions can help clarify the medical benefits of treatments like haemodialysis and dispel misconceptions about prognosis. By harnessing family involvement positively, healthcare providers can create a support system that encourages individuals to comply with recommended treatments.

Moreover, there are significant societal implications regarding the understanding of ESKD and its treatment options. Many individuals may hold fatalistic views or misconceptions about the effectiveness of medical interventions, shaped by cultural and religious beliefs. National or regional campaigns could play a crucial role in promoting awareness of chronic illnesses like ESKD. These campaigns should be culturally relevant, addressing misconceptions about treatments like dialysis by framing them not as challenges to faith, but as medical necessities. Such initiatives could involve religious scholars to explain the permissibility of treatment within Islamic teachings.

Community involvement is essential, and leaders, religious figures, and healthcare professionals should collaborate on initiatives to raise awareness of diseases like ESKD. Involving mosques, local communities, and public institutions in educational outreach ensures that the message reaches a wide audience.

The participants with ESKD in this study used traditional remedies, believing that this treatment enhanced kidney function and potentially reduced the necessity for haemodialysis. The level of support individuals affected by ESKD receive significantly impacts their decision to reject haemodialysis and prompts consideration of alternate options, such as traditional treatment methods. These findings highlight the significance of healthcare providers caring for individuals with ESKD to actively question the usage of traditional treatments and inquire about individuals' expectations for such treatments. Recording this information in their health record system can augment healthcare practitioners' understanding of traditional therapies for improved development of educational and awareness programs. It might help avoid delays in seeking medical treatment, prevent further complications, and encourage individuals to report the side effects of the traditional treatment.

The Gagani et al. (2016) quantitative study exclusively employed the Renal Care Readiness Scale (RCRS) to construct a reliable and valid testing instrument for assessing the stages of acceptance and denial among CKD individuals. They suggested its applicability to other illnesses to facilitate comparisons across different individual groups. Therefore, to assess denial and decision-making refusal in individuals with ESKD, adapting an assessment tool to gauge the level of acceptance and denial regarding kidney replacement therapy is crucial. This process is essential for identifying the readiness of individuals affected by ESKD to accept such treatment and for addressing their psychosocial needs through tailored counselling programs. The Renal Care Readiness Scale (RCRS) serves as the foundation for evaluating stages of acceptance and denial in individuals with chronic kidney disease before implementing CKD course modules. The gathered data aim to equip physicians with insights to develop counselling programs that specifically cater to the psychosocial needs of individuals undergoing stages of denial. Moreover, the RCRS scale, encompassing factors like appreciation, adherence, assumption, awareness, anticipation, and affective aspects, provides a comprehensive understanding. It helps identify individuals requiring more intervention and counselling while predicting future medical adherence—an essential element in managing CKD.

These findings also suggest that a decision-making process model could be added to the nephrology nursing program curriculum to enhance communication and decision-making skills, addressing the communication and decisional needs of individuals with

ESKD to help them accept their health condition and undergo kidney replacement therapy.

The findings also indicate the presence of numerous misperceptions and misleading beliefs regarding ESKD and haemodialysis, underscoring the importance of healthcare providers addressing them. Education is necessary, extending beyond merely the haemodialysis procedure. It's crucial to address individuals affected by ESKD apprehensions about undergoing kidney replacement therapy by exploring and rectifying their sources.

The interview findings reveal significant gaps in individuals' understanding of ESKD, its prognosis, and treatment options, particularly haemodialysis. These gaps suggest that many individuals affected by ESKD do not fully comprehend the seriousness of stage five ESKD or the irreversible nature of kidney failure, which may lead to the refusal of life-saving treatment. Additionally, haemodialysis is often misunderstood as an optional rather than a necessary intervention, while insufficient communication about the prognosis of ESKD with or without haemodialysis further complicates decision-making. Family members, though heavily involved in these decisions, frequently lack the information needed to support informed choices. To address these issues, it is essential to implement targeted educational programs that are both culturally and religiously sensitive, emphasizing the severity of ESKD and the life-sustaining role of haemodialysis. Improved communication regarding prognosis is also crucial to facilitate informed decision-making. Furthermore, providing family members with accurate and comprehensive information is vital to ensure they can effectively support individuals in making informed treatment decisions.

To address the knowledge gaps identified in this study's findings, a comprehensive approach that integrates educational content, communication strategies, and mechanisms for family involvement is essential. This educational content should provide clear and detailed explanations about ESKD, including the basic functions of the kidneys and the consequences of kidney failure. Specific information on stage five ESKD should be included, highlighting its severity, the irreversible nature of the condition, and the life-threatening risks associated with a lack of treatment. Additionally, educational efforts should cover the progression of ESKD, emphasizing its physical, emotional, and quality-of-life impacts when left untreated. A thorough explanation of haemodialysis, detailing its function in replacing kidney activity and its necessity for sustaining life, is crucial for individuals affected by ESKD understanding. Information on alternative treatment options, such as kidney transplantation and peritoneal dialysis, should also be provided, with clarification on when these options are appropriate and why haemodialysis may be the most viable choice for many individuals affected by ESKD. Lastly, it is essential to clearly communicate the consequences of refusing haemodialysis, including the worsening of symptoms and the eventual fatality due to kidney failure.

To ensure that individuals affected by ESKD make informed decisions about their care, particularly regarding haemodialysis and other treatment options, there is a critical need for targeted interventions in both primary and secondary care to improve individuals' understanding and awareness of the disease and its management. In primary care, general practitioners and primary care nurses, often the first point of contact for individuals with chronic CKD, play a pivotal role in early education. These providers should be trained to deliver clear, accessible information about the progression of CKD to ESKD, emphasizing the importance of monitoring kidney function, making lifestyle adjustments, and understanding available treatment options. Early education can help prevent misconceptions about ESKD and its treatments. In secondary care, nephrologists and nephrology nurses must offer detailed, tailored education based on the individual’s stage of illness. Structured, individualised education sessions, incorporating visual aids, interactive discussions, and decision-making support tools, could further enhance understanding. For example, a pre-dialysis education clinic could provide CKD individuals with an opportunity to explore treatment options in a supportive environment, bridging the knowledge gap.

A multidisciplinary approach to individuals affected by ESKD education is crucial. Involving nephrologists, nephrology nurses, dietitians, social workers, and psychologists ensures that information about the disease and treatment options is communicated holistically, addressing the physical, emotional, and social aspects of ESKD. Given the integral role family members play in decision-making, they should also be included in educational sessions. Providing family members with the same information as individuals affected by ESKD empowers them to support informed decisions. Additionally, support groups, family counselling, and joint decision-making sessions could help families contribute positively to care planning.

Developing digital resources, such as online platforms, apps, or telemedicine programs, can make information more accessible, particularly for those unable to attend in-person consultations. These resources should be designed to be simple and user-friendly, offering multimedia options such as videos, infographics, and interactive question-and-answer sessions. Printed materials in multiple languages should also be available for non-native speakers or those without digital access. Lastly, hiring or training nephrology educators specialising in ESKD education can ensure individuals affected by ESKD consistently receive high-quality, accurate information throughout their care journey.

8.4.2 Implication for policy

This study will provide insights for developing decision aids and clinical guidelines that incorporate the preferences, autonomy, and desire for active involvement of individuals with ESKD in their healthcare planning as empowerment and engagement.

There is a need for an accessible database for individuals with ESKD who refuse kidney replacement therapy within the Ministry of Health Al Shifa health system, as it would aid in creating or updating nephrology care policies and guidelines in Oman.

8.4.3 Implications for future research

The decision-making process model of individuals with ESKD in Oman, as explored in this study, could be expanded to encompass similar groups or contexts and should be subjected to testing through qualitative, phenomenology approach to observe the decision- making process itself, quantitative, or mixed-method studies.

Conducting research to explore strategies for addressing the factors identified in this study is essential to improving the capacity of individuals affected by ESKD to make well-informed decisions regarding their care.

Conducting a similar study in other Gulf countries and analysing the similarities and differences within the regional context would provide valuable insights into the shared and unique factors influencing decision-making in individuals with ESKD across the Gulf region.

Additional research involving nephrologists or treating physicians and the family members of individuals with ESKD would contribute significantly to the field of nephrology decision-making research.

The theoretical model in this study focused on individuals with ESKD who declined medically advised haemodialysis. Further longitudinal research or research involving individuals affected by ESKD who chose to undergo haemodialysis will provide an additional dimension to ESKD-related research. Additionally, it proposes further research on the real and projected survival rates of individuals with ESKD who have refused haemodialysis. This research could yield significant and advantageous outcomes for future communication with individuals affected by ESKD and their families.

8.5 Reflexivity and the rigour of the study

Putting aside methodological problems, the practical reason for addressing reflexivity in qualitative studies is its importance as a fundamental criterion in assessing and evaluating quality and in following research reporting guidelines specific to qualitative research (Gentles et al., 2014). The primary objective of reflexivity is to augment the clarity and trustworthiness of the study findings (Gentles et al., 2014). Reflexivity, as characterised by Charmaz, involves promoting a thoughtful strategy that clearly directs researchers in their study conduct, interactions with research participants, and portrayal of them in written reports (Charmaz, 2006). To aid in establishing standards related to reliability and validity, Charmaz offered a framework for rigour and authenticity strategies in constructivist grounded theory, which consist of credibility, originality, resonance, and usefulness (Charmaz, 2006; 2014).

8.5.1 Creditability

Credibility is essential in qualitative research for conducting naturalistic inquiry. Employing techniques to establish credibility ensures that the researcher accurately represents the experiences and meanings of the phenomenon, making the findings credible to participants. Establishing credibility involves conducting the inquiry in a manner that reinforces the believability of the findings, ensuring these steps are evident in the research outcomes (Dyar, 2022).

This study was supported by a literature review and thematic analysis of the literature, namely in Chapter 3. Performing the literature review yielded a thorough comprehension of the context and subject matter. However, I continued to pay close attention to how pre-existing notions could potentially impact my research. Through consistent self-awareness, I saw different methods of decision-making regarding treatment non-adherence and non-concordance without forcing them onto the data.

In order to ensure credibility, I adhered to the fundamental principles of grounded theory, which encompass systematic and continuous collection and analysis of data. Data collection procedures resulted in a variety of observations among individuals affected by ESKD who declined to undergo haemodialysis and who had undergone haemodialysis. The observations covered a range of experiences and attitudes during the decision-making process, which contributed to the development of the final theoretical model. A saturation point was achieved at approximately 23-25 interviews.

Supervision discussions enhanced my presentation of work and the examination of the emergent codes and categories formed by the data. This discussion refers to the additional gathering of data and subsequent analysis. This procedure also served as a means of quality control for my study of the data, ensuring its richness. Also, it assisted me in revisiting the quality of the processes and results of the study.

The concepts of constant comparison are supported by a process that involves composing memos, reflective diaries, reading and re-reading, and coding, which is carried out using data matrices and diagrams to compare the similarities and differences within categories across all cases. This comparison originated from the preceding interviews and coding. The constant comparative approach was employed to analyse and compare codes and incidents to establish the point at which emergent categories and concepts formed a theoretical model. Furthermore, the constant comparative strategy was employed in conjunction with theoretical sampling to boost theoretical sensitivity and meet the criteria of the emerging categories.

The credibility of the generated data was enhanced by incorporating several settings and including individuals affected by ESKD with various eGFR levels, thus reinforcing the trustworthiness of the data.

Additionally, engaging in peer debriefing with two academic supervisors to enhance the credibility and reliability of the study findings assisted me in revisiting the quality of the processes and ensuring the analysis remained closely aligned with the data. Supervision discussions enhanced my presentation of the work and the examination of the emergent codes and categories formed by the data. This discussion refers to the additional gathering of data and subsequent analysis. This procedure also served as a means of quality control for my study of the data, ensuring its richness.

8.5.2 Originality

The existing research lacks a comprehensive theoretical model that explains the social processes influencing the decision-making of individuals affected by ESKD who refused haemodialysis. Hence, the identification of categories and sub-categories provides fresh insights into comprehending the decision-making process about haemodialysis refusal among individuals affected by ESKD.

The development of these categories involved rigorous coding and drawing from experiences with ESKD. The utilisation of line-by-line and open coding methodologies on transcripts confirmed the truthfulness of the procedure. In addition, the use of a bilingual translator (back translation) to verify bilingual transcriptions enhanced the credibility and originality of the data. Furthermore, the theory of the haemodialysis refusal decision-making process provides a conceptual framework that enhances our understanding of the examined experience.

Moreover, this study is the first instance of applying grounded theory concepts in Oman to gather data on the experiences of adult Omani individuals with ESKD who have chosen not to undergo medically recommended haemodialysis.

8.5.3 Resonance

Resonance is heightened when there is a powerful mix of credibility and uniqueness, as both credibility and originality contribute to enhancing resonance (Charmaz, 2006). This is achieved by applying the constant comparative approach to assessing credibility and originality.

During the study, this research was disseminated to external audiences to confirm that the categories appropriately represented the experiences being investigated. The emergent and changing topics were subjected to scrutiny by presenting them to a varied audience (Involve Hull) in 2022. As the theory development neared its end, the final step involved sharing the model of the haemodialysis refusal decision-making process with nursing professionals interested in nephrology at the RCN International Nursing Research Conference in 2023. Academic supervisors provided ongoing feedback on the evolving theory during the data collection phase. The successive modifications and enhancements to the theory ultimately resulted in the theoretical framework outlined in Chapter 6.

8.5.4 Usefulness

Usefulness is a measure of how effectively the analysis of a study offers an interpretation and solution that individuals can apply in their daily lives (Charmaz, 2014). The findings of this study are expected to be valuable in the treatment of individuals with ESKD who have chosen not to undergo medically recommended haemodialysis. Gaining insight into the decision-making process they went through will aid in informing clinical practice and policy to advance the experience of Omani individuals with ESKD who refuse haemodialysis. Additionally, it can be utilised to provide insights for future research.

8.6 Dissemination plan.

It is important to disseminate the findings of this research to a wider audience. So, my plan for dissemination would include:

1. I plan to publish a paper on the individuals affected by ESKD denial and fatalism behaviours towards ESKD condition and haemodialysis, and I intend to submit it to the International Journal of Nephrology or the Saudi Journal of Kidney Diseases.
2. I also plan to publish a paper on misconceptions about haemodialysis among Omani adult individuals affected by ESKD.
3. I am also interested in writing a paper on how the Kubler-Ross model reflects on the experience of adult Omani individuals affected by ESKD haemodialysis refusal decision-making process. The two highlighted papers are intended to be published in the BMC Nephrology journal.
4. Furthermore, I plan to summarise the main findings of this study into a concise presentation for healthcare professionals, specifically those who work with individuals with kidney disease in MOH health institutions in Oman at primary healthcare, secondary, and tertiary levels.
5. I also intend to present the findings of this study in community workshops during the annual World Kidney Day. Additionally, I plan to collaborate with the dean of the Higher Institute of Health Specialties to share these study findings with students in the nephrology nursing program.

8.7 Conclusion

The chapter has presented a summary of the thesis and examined how the standards of rigour can be employed to evaluate its technique and results. This study is the first extensive study to examine the decision-making process among individuals affected by ESKD who refused haemodialysis in Oman and internationally. The approach has advanced from providing background for the research and creating research questions to utilising the grounded theory technique to construct a theoretical model of the challenges experienced by these individuals while making decisions. As a result, it provides a unique perspective on this particular phase of their lives, adding to the existing knowledge in the field of nephrology-related healthcare and service provision.

Reference

Abfalter, D., Mueller-Seeger, J. & Raich, M. (2021) Translation decisions in qualitative research: a systematic framework. *International journal of social research methodology*, 24(4), 469-486.

Adams, A. M. N., Chamberlain, D. & Giles, T. M. (2019) The perceived and experienced role of the nurse unit manager in supporting the wellbeing of intensive care unit nurses: an integrative literature review. *Australian Critical Care*, 32(4), 319-329.

Adefris, M., Abebe, S. M., Terefe, K., Gelagay, A. A., Adigo, A., Amare, S., Lazaro, D., Berhe, A. & Baye, C. (2017) Reasons for delay in decision making and reaching health facility among obstetric fistula and pelvic organ prolapse patients in Gondar University hospital, Northwest Ethiopia. *BMC women's health*, 17(1), 64.

Aditama, L., Athiyah, U., Utami, W. & Rahem, A. (2020) Adherence behavior assessment of oral antidiabetic medication use: a study of patient decisions in long-term disease management in primary health care centers in Surabaya. *Journal of basic and clinical physiology and pharmacology*, 30(6).

Agarwal, R. (2016) Defining end-stage renal disease in clinical trials: a framework for adjudication. *Nephrology Dialysis Transplantation*, 31(6), 864-867.

Ahmed, S., Autrey, J., Katz, I. T., Fox, M. P., Rosen, S., Onoya, D., Bärnighausen, T., Mayer, K. H. & Bor, J. (2018) Why do people living with HIV not initiate treatment? A systematic review of qualitative evidence from low-and middle-income countries. *Social science & medicine*, 213, 72-84.

Akben, S. B. (2016) Early stage of chronic kidney disease by using statistical evaluation of the previous measurement results. *Biocybernetics and Biomedical Engineering*, 36(4), 626-631.

AL-ALAWI, M. & JAWARNEH, M. (2023) The Role of Sustainable Development in Oman's Economy in the Context of Oman Vision 2040.

Al-Azri, M. & Al-Awaisi, H. (2022) Exploring causes of delays in help-seeking behaviours among symptomatic Omani women diagnosed with late-stage breast cancer-A qualitative study. *European Journal of Oncology Nursing*, 61, 102229.

Al-Barwani, T. A. & Albeely, T. S. (2007) The Omani family: strengths and challenges. *Marriage & family review*, 41(1-2), 119-142.

Al-Hajje, A., Awada, S., Rachidi, S., Zein, S., Bawab, W., El-Hajj, Z., Bou Zeid, M., Yassine, M. & Salameh, P. (2015) Factors affecting medication adherence in Lebanese patients with chronic diseases. *Pharmacy Practice (1886-3655)*, 13(3), 1-9.

Al-Kindi, R. M., Al-Mushrafi, M., Al-Rabaani, M. & Al-Zakwani, I. (2011) Complementary and alternative medicine use among adults with diabetes in Muscat region, Oman. *Sultan Qaboos University Medical Journal*, 11(1), 62.

Al-Marhuby, H. (1998) Renal replacement therapy in Sultanate of Oman. *Saudi journal of kidney diseases and transplantation*, 9(4), 459.

Al-Riyami, H., Al-Maskari, A., Nadar, S. K. & Almaskari, M. (2023) Knowledge, Attitudes and Practices Regarding Traditional and Complimentary Medicine in Oman. *Sultan Qaboos University Medical Journal*, 23(1), 90.

Al-Saadoon, M., Al-Adawi, M. & Al-Adawi, S. (2021) Socio-cultural constraints in protecting child rights in a society in transition: a review and synthesis from Oman. *Child indicators research*, 14, 239-267.

Al-Za'abi, R. (2018) *Oman's treated chronic kidney failure population in years 1980 to 2015: an epidemiology research.*PhD thesis. University of Glasgow. Available online: http://theses.gla.ac.uk/id/eprint/8630 [Accessed 22.12.2019].

AL ‐ Sawafi, A., Lovell, K., Renwick, L. & Husain, N. (2021) Exploring the experience of relatives living with individuals diagnosed with schizophrenia in Oman: A qualitative study. *Journal of Psychiatric and Mental Health Nursing*, 28(6), 1029-1040.

Al Alawi, I., Al Salmi, I., Al Mawali, A., Al Maimani, Y. & Sayer, J. A. (2017a) End-Stage Kidney Failure in Oman: An Analysis of Registry Data with an Emphasis on Congenital and Inherited Renal Diseases. *International Journal of Nephrology*, 1-7.

Al Alawi, I., Al Salmi, I., Al Mawali, A., Sayer, J. A. & Al Alawi, I. H. (2017b) Kidney Disease in Oman: a View of the Current and Future Landscapes. *Iranian Journal of Kidney Diseases*, 11(4), 263-270.

Al Harbi, N. (2018) *End-of-life care practices in two cultures: a comparative ethical analysis and recommendations*Duquesne University.

Al Ismaili, F., Al Salmi, I., Al Maimani, Y., Metry, A. M., Al Marhoobi, H., Hola, A. & Pisoni, R. L. (2017) Epidemiological Transition of End-Stage Kidney Disease in Oman. *Kidney International Reports*, 2(1), 27-35.

Al Rahbi, F. & Al Salmi, I. (2017) Commercial kidney transplantation: attitude, knowledge, perception, and experience of recipients. *Kidney international reports*, 2(4), 626-633.

Al Sharji, A., Alaloul, F. & Al Yazeedi, B. (2022) Coping Strategies in End-Stage Renal Disease Patients on Hemodialysis in Oman: Optimistic, Supportive, Confrontive, and Prayerful. *Journal of religion and health*, 61(3), 2072-2082.

Alrajhi, W. (2018) *Quality of Life and Health Related Quality of Life in Patients with End Stage Renal Disease: an Omani Context*DOCTOR OF PHILOSOPHY THESIS. University of Dundee. Available online: https://discovery.dundee.ac.uk/ [Accessed 16.12.2019].

Alvani, S. R., Hosseini, S. M. P. & Alvani, S. (2012) Living with chronic illnesses and disability. *International Journal of Business, Humanities and Technology*, 2(5).

Alzahrani, N. S., Almarwani, A. M., Alhowaymel, F. & Alharbi, H. F. (2023) The Lived Experience of Middle-Aged Saudi Patients With End-Stage Chronic Renal Disease on Hemodialysis Treatment. *Journal of Transcultural Nursing*, 10436596231166041.

Anees, M., Khan, J. A., Basit, A., Ibrahim, M. & Mumtaz, A. (2014) Refusal of dialysis amongst patients of chronic kidney disease (CKD). *Annals of King Edward Medical University*, 20(3), 228-228.

Arabiat, D., Whitehead, L., Jabery, M. A. L., Hamdan-Mansour, A., Shaheen, A. & Abu Sabbah, E. (2021) Beliefs About Illness and Treatment Decision Modelling During Ill-Health in Arabic Families. *JOURNAL OF MULTIDISCIPLINARY HEALTHCARE*, 14, 1755-1768.

Arghode, V. (2012) Qualitative and Quantitative Research: Paradigmatic Differences. *Global Education Journal*, 2012(4).

Arlinghaus, K. R. & Johnston, C. A. (2018) Advocating for behavior change with education. *American journal of lifestyle medicine*, 12(2), 113-116.

Aromataris, E. & Pearson, A. (2014) The systematic review: an overview. *AJN The American Journal of Nursing*, 114(3), 53-58.

Asghari, B. A. & Arabi, S. (2019) Acceptance of illness in patients with incurable diseases a qualitative study. *Journal of Research and Health*, 9(5), 443-453.

Ashby, M., Hoog, C. O., Kellehear, A., Kerr, P. G., Brooks, D., Nicholls, K. & Forrest, M. (2005) Renal dialysis abatement: lessons from a social study. *Palliative Medicine*, 19(5), 389-396.

Aveyard, H., Payne, S. & Preston, N. (2016) *A post-graduate's guide to doing a literature review in health and social care*. Maidenhead, Berkshire, England: Open University Press.

Aydoğdu, N. G., Çapık, C., Ersin, F., Kissal, A. & Bahar, Z. (2017) The reliability and validity of prostate cancer fatalism inventory in Turkish language. *Journal of religion and health*, 56, 1670-1682.

Baillie, L. (2015) Promoting and evaluating scientific rigour in qualitative research. *Nursing standard*, 29(46), 36-42.

Bartolomé-García, E., Usarralde-Pérez, Á., Sanmartín-Fenollera, P. & Pérez-Encinas, M. (2019) Persistence and adherence to interferon and glatiramer acetate in patients with multiple sclerosis. *European Journal of Hospital Pharmacy: Science & Practice*, 26(1), 23-28.

Beauchamp, T. L. & Childress, J. F. (2019) *Principles of biomedical ethics*, Eighth edition. New York: Oxford University Press.

Ben-Ari, A. & Enosh, G. (2011) Processes of reflectivity: Knowledge construction in qualitative research. *Qualitative Social Work*, 10(2), 152-171.

Ben chmo, M., Matricciani, L., Kumar, S. & Graham, K. (2023) “I know what I'm supposed to do, but I don't do it”: patient-perceived risk factors that lead to their lower extremity amputations. *Journal of Foot and Ankle Research*, 16(1), 79.

Beresford, B. A. & Sloper, P. (2003) Chronically ill adolescents’ experiences of communicating with doctors: a qualitative study. *Journal of Adolescent Health*, 33(3), 172-179.

Berger, R. (2015) Now I see it, now I don’t: Researcher’s position and reflexivity in qualitative research. *Qualitative research*, 15(2), 219-234.

Betegnie, A.-L., Gauchet, A., Lehmann, A., Grange, L., Roustit, M., Baudrant, M., Bedouch, P. & Allenet, B. (2016) Why do patients with chronic inflammatory rheumatic diseases discontinue their biologics? An assessment of patients’ adherence using a self-report questionnaire. *The Journal of rheumatology*, 43(4), 724-730.

Bettany-Saltikov, J. & McSherry, R. (2016) *How to do a systematic literature review in nursing: a step-by-step guide*. Translated from English by, Second edition. London: Open University Press.

Bhojaraja, M. V., Singhai, P., Kumar, M. S. & Sreelatha, M. (2021) Withdrawal from dialysis: why and when? *Indian Journal of Palliative Care*, 27(Suppl 1), S30.

Birkenbeuel, J. L., Lehrich, B. M., Goshtasbi, K., Abiri, A., Hsu, F. P. & Kuan, E. C. (2022) Refusal of surgery in pituitary adenoma patients: a population-based analysis. *Cancers*, 14(21), 5348.

Boateng, E. A., East, L. & Evans, C. (2018) Decision-making experiences of patients with end-stage kidney disease (ESKD) regarding treatment in Ghana: a qualitative study. *BMC Nephrology*, 19(1), N.PAG-N.PAG.

Braun, V. & Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), 77-101.

Brewer, J. (2000) *Ethnography*.McGraw-Hill Education (UK).

Bryant, A. & Charmaz, K. (2007) *The Sage handbook of grounded theory*.Sage.

Bundy, J. D., Mills, K. T., Anderson, A. H., Yang, W., Chen, J., He, J. & Investigators*, C. S. (2022) Prediction of end-stage kidney disease using estimated glomerular filtration rate with and without race: a prospective cohort study. *Annals of internal medicine*, 175(3), 305-313.

Burns, M., Bally, J., Burles, M., Holtslander, L. & Peacock, S. (2022) Constructivist grounded theory or interpretive phenomenology? Methodological choices within specific study contexts. *International Journal of Qualitative Methods*, 21, 16094069221077758.

Byrne, M. M. (2001) Linking philosophy, methodology, and methods in qualitative research. *AORN journal*, 73(1), 207-207.

Carneiro-Leão, L., Amaral, L. & Coimbra, A. (2018) Reasons for Declining Venom Immunotherapy. *Acta medica portuguesa*, 31(11), 618-623.

Carrillo-Alarcón, L. C., López-López, E., López-Carbajal, M. J., Ortiz, M. I. & Ponce-Montern, H. (2015) Level of knowledge in patients with type 2 diabetes mellitus and its relationship with glycemic levels and stages of grief according to Kübler-Ross. *J Diabetes Metab*, 6(495), 2.

Casey, J. R., Hanson, C. S., Winkelmayer, W. C., Craig, J. C., Palmer, S., Strippoli, G. F. & Tong, A. (2014) Patients’ perspectives on hemodialysis vascular access: a systematic review of qualitative studies. *American journal of kidney diseases*, 64(6), 937-953.

Cassidy, B. P., Getchell, L. E., Harwood, L., Hemmett, J. & Moist, L. M. (2018) Barriers to education and shared decision making in the chronic kidney disease population: a narrative review. *Canadian journal of kidney health and disease*, 5, 2054358118803322.

Castellan, C. M. (2010) Quantitative and qualitative research: A view for clarity. *International journal of education*, 2(2), 1.

Ceylan, H. & Yangöz, Ş. T. (2024) Haemodialysis Patients' Experiences on Complementary and Alternative Therapies: A Qualitative Study. *Süleyman Demirel Üniversitesi Sağlık Bilimleri Dergisi*, 15(1), 117-131.

Chan, K., Wong, F., Tam, S. L., Kwok, C. P., Fung, Y. P. & Wong, P. N. (2020) The effects of a brief hope intervention on decision - making in chronic kidney disease patients: A study protocol for a randomized controlled trial. *Journal of Advanced Nursing (John Wiley & Sons, Inc.)*, 76(12), 3631-3640.

Chandaran, M., Yusooff, F. & Loong, L. C. (2021) Decision Making and Self-efficacy in Choosing Renal Replacement Therapy (RRT) Option Among Chronic Kidney Disease Patients Using Individual Cognitive Behavior Therapy (CBT). *International Journal for Studies on Children, Women, Elderly And Disabled*, 12, 36-41.

Charmaz, K. (1990) ‘Discovering’chronic illness: using grounded theory. *Social science & medicine*, 30(11), 1161-1172.

Charmaz, K. (2006) *Constructing grounded theory: a practical guide through qualitative analysis*. London: Sage.

Charmaz, K. (2014) *Constructing grounded theory*.sage.

Charmaz, K. & Mitchell, R. G. (2001) Grounded theory in ethnography. *Handbook of ethnography*, 160-174.

Charmaz, K. & Thornberg, R. (2021) The pursuit of quality in grounded theory. *Qualitative research in psychology*, 18(3), 305-327.

Chiaranai, C., Chularee, S. & White, J. S. (2022) Lived Experience of Breast Cancer Survivors: A Phenomenological Study. *Journal of Nursing Research*, 30(6).

Clavel, N., Paquette, J., Dumez, V., Del Grande, C., Ghadiri, D. P., Pomey, M. P. & Normandin, L. (2021) Patient engagement in care: a scoping review of recently validated tools assessing patients' and healthcare professionals' preferences and experience. *Health Expectations*, 24(6), 1924-1935.

Collard, C. V., Michaut, L., Caillierez, F., Parra, D. & Bonnefoy, M. (2017) Impact of therapeutic education with a written document on treatments knowledge and adherence among elderly patients. Results of a pilot study. *Geriatrie et psychologie neuropsychiatrie du vieillissement*, 15(4), 394-400.

Collins, J. A. & Fauser, B. C. (2005) Balancing the strengths of systematic and narrative reviews. Oxford University Press.

Corbin, J. M. & Strauss, A. (1990) Grounded theory research: Procedures, canons, and evaluative criteria. *Qualitative sociology*, 13(1), 3-21.

Corbin, J. M. & Strauss, A. L. (2008) *Basics of qualitative research: techniques and procedures for developing grounded theory*. Translated from English by, 3rd edition. London;Los Angeles;: Sage Publications.

Couser, W. G., Remuzzi, G., Mendis, S. & Tonelli, M. (2011) The contribution of chronic kidney disease to the global burden of major noncommunicable diseases. *Kidney International*, 80(12), 1258-1270.

Creswell, J. W. (2007) *Qualitative inquiry & research design: choosing among five approaches*. Translated from English by, 2nd edition. Thousand Oaks, Calif;London;: Sage.

Creswell, J. W. & Creswell, J. D. (2017) *Research design: Qualitative, quantitative, and mixed methods approaches*.Sage publications.

Creswell, J. W. & Creswell, J. D. (2018) *Research design: qualitative, quantitative & mixed methods approaches*. Translated from English by, 5th;International student; edition. Los Angeles: SAGE.

Creswell, J. W. & Poth, C. N. (2016) *Qualitative inquiry and research design: Choosing among five approaches*.Sage publications.

Cutcliffe, J. R. (2000) Methodological issues in grounded theory. *Journal of advanced nursing*, 31(6), 1476-1484.

Darawsheh, W. (2014) Reflexivity in research: Promoting rigour, reliability and validity in qualitative research. *International journal of therapy and rehabilitation*, 21(12), 560-568.

Dayapoglu, N., Ayyıldız, N. İ. & Şeker, D. (2021) Determination of health fatalism and the factors affecting health fatalism in patients with epilepsy in the North of Turkey. *Epilepsy & Behavior*, 115, 107641.

Decrop, A. & Snelders, D. (2005) A grounded typology of vacation decision-making. *Tourism management*, 26(2), 121-132.

Dennis, T., Meera, N., Binny, K., Sekhar, M. S., Kishore, G. & Sasidharan, S. (2011) Medication adherence and associated barriers in hypertension management in India. *CVD Prevention and Control*, 6(1), 9-13.

Denzin & Lincoln (1994) Introduction: Entering the field of qualitative research. *Handbook of qualitative research*.

Denzin, N. K. & Lincoln, Y. S. (2000) *Handbook of qualitative research*, 2nd edition. London: Sage.

Denzin, N. K. & Lincoln, Y. S. (2011) *The Sage handbook of qualitative research*.sage.

Denzin, N. K. & Lincoln, Y. S. (2017) *The Sage handbook of qualitative research*. Translated from English by, Fifth edition. Los Angeles: Sage.

Di Tosto, G., Hefner, J. L., Walker, D. M., Gregory, M. E., McAlearney, A. S. & Sieck, C. J. (2023) Development of a conceptual model of the capacity for patients to engage in their health care: a group concept mapping study. *BMC health services research*, 23(1), 846.

Dias, L. M., Bezerra, M. R., Barra, W. F. & Rego, F. (2021) Refusal of medical treatment by older adults with cancer: a systematic review. *Ann Palliat Med*, 10(4), 4868-4877.

Dijkers, M. P. (2009) The value of “traditional” reviews in the era of systematic reviewing. *American Journal of Physical Medicine & Rehabilitation*, 88(5), 423-430.

Duma, N., Idossa, D. W., Durani, U., Frank, R. D., Paludo, J., Westin, G., Lou, Y., Mansfield, A. S., Adjei, A. A. & Go, R. S. (2020) Influence of sociodemographic factors on treatment decisions in non–small-cell lung cancer. *Clinical lung cancer*, 21(3), e115-e129.

Dunne, C. (2011) The place of the literature review in grounded theory research. *International journal of social research methodology*, 14(2), 111-124.

Dyar, K. L. (2022) Qualitative inquiry in nursing: Creating rigor. *Nursing forum (Hillsdale)*, 57(1), 187-200.

Easton, K. L., McComish, J. F. & Greenberg, R. (2000) Avoiding Common Pitfalls in Qualitative Data Collection and Transcription. *Qualitative health research*, 10(5), 703-707.

Ellison, C. G. (1991) Religious involvement and subjective well-being. *Journal of health and social behavior*, 80-99.

Engels, N., van der Nat, P. B., Ankersmid, J. W., Prick, J. C., Parent, E., The, R., Takahashi, A., Bart, H. A., van Uden-Kraan, C. F. & Stiggelbout, A. M. (2022) Development of an online patient decision aid for kidney failure treatment modality decisions. *BMC nephrology*, 23(1), 236.

Essack, S., Bell, J., Burgoyne, D., Eljaaly, K., Tongrod, W., Markham, T., Shephard, A. & López-Pintor, E. (2023) Addressing Consumer Misconceptions on Antibiotic Use and Resistance in the Context of Sore Throat: Learnings from Social Media Listening. *Antibiotics*, 12(6), 957.

Faruque, L. I., Hemmelgarn, B. R., Wiebe, N., Manns, B. J., Ravani, P., Klarenbach, S., Pelletier, R. & Tonelli, M. (2013) Factors associated with initiation of chronic renal replacement therapy for patients with kidney failure. *Clinical Journal of the American Society of Nephrology: CJASN*, 8(8), 1327.

Farzandipour, M., Sheikhtaheri, A. & Sadeqi Jabali, M. (2015) Perceived Quality of Informed Refusal Process: A Cross-Sectional Study from Iranian Patients' Perspectives. *Developing World Bioethics*, 15(3), 172-178.

Finlay, L. (2002) Negotiating the swamp: the opportunity and challenge of reflexivity in research practice. *Qualitative research*, 2(2), 209-230.

Fiore, J. (2021) A systematic review of the dual process model of coping with bereavement (1999–2016). *OMEGA-Journal of Death and Dying*, 84(2), 414-458.

Fossey, E., Harvey, C., McDermott, F. & Davidson, L. (2002) Understanding and evaluating qualitative research. *Australian & New Zealand Journal of Psychiatry*, 36(6), 717-732.

Franklin, M. D., Schlundt, D. G. & Wallston, K. A. (2008) Development and validation of a religious health fatalism measure for the African-American faith community. *Journal of Health Psychology*, 13(3), 323-335.

Fraser, S. D. & Blakeman, T. (2016) Chronic kidney disease: identification and management in primary care. *Pragmatic and observational research*, 21-32.

Fung, V., Graetz, I., Reed, M. & Jaffe, M. G. (2018) Patient-reported adherence to statin therapy, barriers to adherence, and perceptions of cardiovascular risk. *PloS one*, 13(2).

Gadallah, M. A., Boulos, D. N., Dewedar, S., Gebrel, A. & Morisky, D. E. (2015) Assessment of rheumatoid arthritis patients' adherence to treatment. *The American journal of the medical sciences*, 349(2), 151-156.

Gagani, A., Gemao, J., Relojo, D. & Pilao, S. J. (2016) The dilemma of denial: acceptance and individual coping among patients with chronic kidney diseases. *Journal of Educational Sciences and Psychology*, 6(2).

Gaitonde, D. Y., Cook, D. L. & Rivera, I. M. (2017) Chronic Kidney Disease: Detection and Evaluation. *American Family Physician*, 96(12), 776-783.

Gajjar, D. (2013) Ethical consideration in research. *Education*, 2(7), 8-15.

Gentles, S. J., Jack, S. M., Nicholas, D. B. & McKibbon, K. A. (2014) Critical approach to reflexivity in grounded theory. *The Qualitative Report*, 19(44), 1-14.

Germain, C. P. (1980) Nursing the Dying: Implications of Kübler-Ross' Staging Theory. *The Annals of the American Academy of Political and Social Science*, 447(1), 46-58.

Ghimire, S., Castelino, R. L., Jose, M. D. & Zaidi, S. T. R. (2017) Medication adherence perspectives in haemodialysis patients: a qualitative study. *BMC nephrology*, 18(1), 167.

Ghimire, S., Shrestha, N. & Callahan, K. (2018) Barriers to Dietary Salt Reduction among Hypertensive Patients. *Journal of Nepal Health Research Council*, 16(2), 124-130.

Gibson, G., Timlin, A., Curran, S. & Wattis, J. (2004) The scope for qualitative methods in research and clinical trials in dementia. *Age and Ageing*, 33(4), 422-426.

Glaser, B. G. (1978) *Theoretical sensitivity*.University of California.

Glaser, B. G. & Strauss, A. L. (1967) The discovery of grounded theory: strategies for qualitative research (grounded theory). *Taylor & Francis eBooks DRM Free Collection*.

Goldsmith, L. J., Kolhatkar, A., Popowich, D., Holbrook, A. M., Morgan, S. G. & Law, M. R. (2017) Understanding the patient experience of cost-related non-adherence to prescription medications through typology development and application. *Social Science & Medicine*, 194, 51-59.

Golub, S. A., Gamarel, K. E., Rendina, H. J., Surace, A. & Lelutiu-Weinberger, C. L. (2013) From efficacy to effectiveness: facilitators and barriers to PrEP acceptability and motivations for adherence among MSM and transgender women in New York City. *AIDS patient care and STDs*, 27(4), 248-254.

Goumenos, D. S., Papachristou, E. & Papasotiriou, M. (2016) RENAL REPLACEMENT THERAPY IN PATIENTS WITH HEART AND KIDNEY FAILURE. *ЗАМЕНСКА БУБРЕЖНА ТЕРАПИЈА КАЈ ПАЦИЕНТИ СО СРЦЕВА И БУБРЕЖНА СЛАБОСТ*, 37(2/3), 43-47.

Green, L. W. & Glasgow, R. E. (2006) Evaluating the relevance, generalization, and applicability of research: issues in external validation and translation methodology. *Evaluation & the health professions*, 29(1), 126-153.

Griva, K., Ng, H. J., Loei, J., Mooppil, N., McBain, H. & Newman, S. P. (2013) Managing treatment for end-stage renal disease – A qualitative study exploring cultural perspectives on facilitators and barriers to treatment adherence. *Psychology & Health*, 28(1), 13-29.

Grootens-Wiegers, P., Hein, I. M., van den Broek, J. M. & de Vries, M. C. (2017) Medical decision-making in children and adolescents: developmental and neuroscientific aspects. *BMC pediatrics*, 17, 1-10.

Guba, E. G. (1990) *The paradigm dialog*. Newbury Park, Calif: Sage Publications.

Guba, E. G. & Lincoln, Y. S. (1982) Epistemological and Methodological Bases of Naturalistic Inquiry. *Educational communication and technology*, 30(4), 233-252.

Guba, E. G. & Lincoln, Y. S. (1994) Competing paradigms in qualitative research. *Handbook of qualitative research*, 2(163-194), 105.

Guldin, M.-B. & Leget, C. (2024) The integrated process model of loss and grief-An interprofessional understanding. *Death studies*, 48(7), 738-752.

Haberer, J. E., Baeten, J. M., Campbell, J., Wangisi, J., Katabira, E., Ronald, A., Tumwesigye, E., Psaros, C., Safren, S. A. & Ware, N. C. (2013) Adherence to antiretroviral prophylaxis for HIV prevention: a substudy cohort within a clinical trial of serodiscordant couples in East Africa. *PLoS medicine*, 10(9).

Håkonsen, H. & Toverud, E.-L. (2011) Special challenges for drug adherence following generic substitution in Pakistani immigrants living in Norway. *European journal of clinical pharmacology*, 67(2), 193-201.

Haldane, V., Li, B. P., Ge, S., Huang, J. Z., Huang, H., Sadutshang, L., Zhang, Z., Pasang, P., Hu, J. & Wei, X. (2022) Exploring the translation process for multilingual implementation research studies: a collaborative autoethnography. *BMJ Global Health*, 7(5), e008674.

Hamdy, S. F. (2009) Islam, fatalism, and medical intervention: lessons from Egypt on the cultivation of forbearance (sabr) and reliance on God (tawakkul). *Anthropological Quarterly*, 173-196.

Han, E., Haldane, V., Koh, J. J. K., Quek, R. Y. C., Ozdemir, S., Finkelstein, E. A., Jafar, T. H., Choong, H. L., Gan, S. & Lim, L. W. (2019a) Perspectives on decision making amongst older people with end‐stage renal disease and caregivers in Singapore: A qualitative study. *Health Expectations*, 22(5), 1100-1110.

Han, E., Haldane, V., Koh, J. J. K., Quek, R. Y. C., Ozdemir, S., Finkelstein, E. A., Jafar, T. H., Choong, H. L., Gan, S., Lim, L. W. W., Shiraz, F. & Legido-Quigley, H. (2019b) Perspectives on decision making amongst older people with end-stage renal disease and caregivers in Singapore: A qualitative study. *Health Expectations*, 22(5), 1100-1110.

Harris, T. (2015) Grounded theory.

Harwood, L. & Clark, A. M. (2013) Understanding pre-dialysis modality decision-making: A meta-synthesis of qualitative studies. *International Journal of Nursing Studies*, 50(1), 109-120.

Health, M. o. (2018) Inaugural speech, *Oman International Nephrology Conference.* Muscat 1/2/2018.

Helen, N., Meyer, J., Kelly, D., Johnson, B. & Bridges, J. (2009) Reasons Renal Patients Give for Deciding Not to Dialyze: A Prospective Qualitative Interview Study. *Dialysis & Transplantation*, 38, 82-89.

Hill, N. R., Fatoba, S. T., Oke, J. L., Hirst, J. A., O'Callaghan, C. A., Lasserson, D. S. & Hobbs, F. R. (2016) Global prevalence of chronic kidney disease–a systematic review and meta-analysis. *PloS one*, 11(7), e0158765.

Hong, Q. N., Pluye, P., Fàbregues, S., Bartlett, G., Boardman, F., Cargo, M., Dagenais, P., Gagnon, M.-P., Griffiths, F. & Nicolau, B. (2018) Mixed methods appraisal tool (MMAT), version 2018. *Registration of copyright*, 1148552, 10.

Horter, S., Thabede, Z., Dlamini, V., Bernays, S., Stringer, B., Mazibuko, S., Dube, L., Rusch, B. & Jobanputra, K. (2017) "Life is so easy on ART, once you accept it": acceptance, denial and linkage to HIV care in Shiselweni, Swaziland. *Social Science & Medicine*, 176, 52-59.

Hu, X., Ye, H., Yan, W. & Sun, Y. (2022) Factors associated with patient's refusal of recommended cancer surgery: based on surveillance, epidemiology, and end results. *Frontiers in public health*, 9, 785602.

Hussain, J. A., Flemming, K., Murtagh, F. E. & Johnson, M. J. (2015) Patient and health care professional decision-making to commence and withdraw from renal dialysis: a systematic review of qualitative research. *Clinical journal of the American Society of Nephrology*, 10(7), 1201-1215.

Jabbal, I. S., Sabbagh, S., Itani, M., Dominguez, B., Mohanna, M., Henry, V., Liang, H., Saravia, D., George, T. & Nahleh, Z. (2023) Factors Associated with the Decision to Decline Chemotherapy in Metastatic Non-Small Cell Lung Cancer. *Cancers*, 15(6), 1686.

Jermini, M., Dubois, J., Rodondi, P.-Y., Zaman, K., Buclin, T., Csajka, C., Orcurto, A. & E. Rothuizen, L. (2019) Complementary medicine use during cancer treatment and potential herb-drug interactions from a cross-sectional study in an academic centre. *Scientific reports*, 9(1), 5078.

Johnston, S. & Noble, H. (2012a) Factors influencing patients with stage 5 chronic kidney disease to opt for conservative management: a practitioner research study. *Journal of clinical nursing*, 21(9‐10), 1215-1222.

Johnston, S. & Noble, H. (2012b) Factors influencing patients with stage 5 chronic kidney disease to opt for conservative management: a practitioner research study. *Journal of Clinical Nursing*, 21(9-10), 1215-1222.

Joseph-Williams, N., Elwyn, G. & Edwards, A. (2014) Knowledge is not power for patients: a systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. *Patient education and counseling*, 94(3), 291-309.

Kalantar-Zadeh, K., Jafar, T. H., Nitsch, D., Neuen, B. L. & Perkovic, V. (2021) Chronic kidney disease. *The lancet*, 398(10302), 786-802.

Kaltenmeier, C., Malik, J., Yazdani, H., Geller, D. A., Medich, D., Zureikat, A. & Tohme, S. (2020) Refusal of cancer-directed treatment by colon cancer patients: Risk factors and survival outcomes. *The American Journal of Surgery*, 220(6), 1605-1612.

Khan, S. N. (2014) Qualitative research method: Grounded theory. *International journal of business and management*, 9(11), 224-233.

Khanal, K. P. (2018) Constructivist grounded theory practice in accountability research. *Journal of Education and Research*, 8(1), 61-88.

Khankeh, H. R., Vojdani, R., Saber, M. & Imanieh, M. (2023) How do cancer patients refuse treatment? A grounded theory study. *BMC Palliative Care*, 22(1), 1-10.

Kim, E. Y. & Son, Y. J. (2022) Developing a conceptual model of older patients’ decision‐making process in choosing dialysis or conservative care using meta‐ethnography. *Journal of Advanced Nursing*, 78(1), 1-13.

Kisa, S. & Kisa, A. (2024) Religious beliefs and practices toward HPV vaccine acceptance in Islamic countries: A scoping review. *PloS one*, 19(8), e0309597.

Kooman, J. P., Katzarski, K., van der Sande, F. M., Leunissen, K. M. & Kotanko, P. (2018) Hemodialysis: A model for extreme physiology in a vulnerable patient population. *Seminars in Dialysis*, 31(5), 500-506.

Kriegbaum, M. & Lau, S. R. (2018) Medication non-adherence and uncertainty: Information-seeking and processing in the Danish LIFESTAT survey. *Research in Social & Administrative Pharmacy*, 14(8), 736-741.

Kromer, C., Schaarschmidt, M.-L., Schmieder, A., Herr, R., Goerdt, S. & Peitsch, W. K. (2015) Patient Preferences for Treatment of Psoriasis with Biologicals: A Discrete Choice Experiment. *PLoS ONE*, 10(6), 1-15.

Kruegel, J., Rubel, D. & Gross, O. (2013) Alport syndrome—insights from basic and clinical research. *Nature Reviews Nephrology*, 9(3), 170-178.

Kübler-Ross, E. (2015) Attitudes toward death and dying, *Disaster Prevention*Routledge, 63-79.

Kustimah, K., Siswadi, A. G. P., Djunaidi, A. & Iskandarsyah, A. (2019) Factors affecting non-adherence to treatment in End stage renal disease (ESRD) patients undergoing hemodialysis in Indonesia. *The Open Psychology Journal*, 12(1).

Laba, T.-L., Brien, J.-a. & Jan, J. (2012) Understanding rational non-adherence to medications. A discrete choice experiment in a community sample in Australia. *BMC Family Practice*, 13(1), 61-70.

Laba, T.-L., Lehnbom, E., Brien, J.-A. & Jan, S. (2015) Understanding if, how and why non-adherent decisions are made in an Australian community sample: a key to sustaining medication adherence in chronic disease? *Research in social & administrative pharmacy : RSAP*, 11(2), 154-162.

Lam, L. W., Lee, D. T. & Shiu, A. T. (2014) The dynamic process of adherence to a renal therapeutic regimen: Perspectives of patients undergoing continuous ambulatory peritoneal dialysis. *International journal of nursing studies*, 51(6), 908-916.

Lam, W. Y. & Fresco, P. (2015) Medication adherence measures: an overview. *BioMed research international*, 2015.

Lamore, K., Montalescot, L. & Untas, A. (2017) Treatment decision-making in chronic diseases: What are the family members' roles, needs and attitudes? A systematic review. *Patient education and counseling*, 100(12), 2172-2181.

LeBlanc, T. W., Fish, L. J., Bloom, C. T., El‐Jawahri, A., Davis, D. M., Locke, S. C., Steinhauser, K. E. & Pollak, K. I. (2017) Patient experiences of acute myeloid leukemia: A qualitative study about diagnosis, illness understanding, and treatment decision-making. *Psycho-Oncology*, 26(12), 2063-2068.

Levey, A., Atkins, R., Coresh, J., Cohen, E., Collins, A., Eckardt, K.-U., Nahas, M., Jaber, B., Jadoul, M. & Levin, A. (2007) Chronic kidney disease as a global public health problem:

approaches and initiatives–a position statement from Kidney Disease Improving Global Outcomes. *Kidney international*, 72(3), 247-259.

Levey, A. S. & Inker, L. A. (2014) Definition and staging of chronic kidney disease in adults. *V: UpToDate, Post TW (Ed), UpToDate, Waltham, MA (Pridobljeno 5 Sep 2014)*.

Levin, A., Tonelli, M., Bonventre, J., Coresh, J., Donner, J.-A., Fogo, A. B., Fox, C. S., Gansevoort, R. T., Heerspink, H. J. & Jardine, M. (2017) Global kidney health 2017 and beyond: a roadmap for closing gaps in care, research, and policy. *The Lancet*, 390(10105), 1888-1917.

Li, P. K.-T., Chan, G. C.-K., Chen, J., Chen, H.-C., Cheng, Y.-L., Fan, S. L.-S., He, J. C., Hu, W., Lim, W.-H. & Pei, Y. (2021) Tackling dialysis burden around the world: A global challenge. *Kidney Diseases*, 7(3), 167-175.

Lincoln, Y. S. & Guba, E. G. (1985) *Naturalistic inquiry*.sage.

Lovell, S., Walker, R. J., Schollum, J. B., Marshall, M. R., McNoe, B. M. & Derrett, S. (2017a) To dialyse or delay: a qualitative study of older New Zealanders' perceptions and experiences of decision-making, with stage 5 chronic kidney disease. *BMJ open*, 7(3).

Lovell, S., Walker, R. J., Schollum, J. B., Marshall, M. R., McNoe, B. M. & Derrett, S. (2017b) To dialyse or delay: a qualitative study of older New Zealanders' perceptions and experiences of decision-making, with stage 5 chronic kidney disease. *BMJ open*, 7(3), e014781.

Lunt, N. & Fung, K. w. (2022) Scoping the literature on patient travel abroad for cancer screening, diagnosis and treatment. *The International Journal of Health Planning and Management*, 37(1), 66-77.

Luyckx, V. A., Tonelli, M. & Stanifer, J. W. (2018) The global burden of kidney disease and the sustainable development goals. *Bulletin of the World Health Organization*, 96(6), 414.

M.O.I (2019) *Ministry of Information.* Available online: https://omaninfo.om/ [Accessed 24 December 2020].

Malayala, S. V. & Raza, A. (2016) Compliance with USPSTF recommendations on aspirin for prevention of cardiovascular disease in men. *International Journal of Clinical Practice*, 70(11), 898-906.

Manouchehri, J., Goodarzynejad, H., Khoshgoftar, Z., Sheikh Fathollahi, M. & Aghamohammadi Abyaneh, M. (2012) Discharge against Medical Advice among Inpatients with Heart Disease in Iran. *The journal of Tehran Heart Center*, 7(2), 72-77.

Marahatta, S. B., Yadav, R. K., Giri, D., Lama, S., Rijal, K. R., Mishra, S. R., Shrestha, A., Bhattrai, P. R., Mahato, R. K. & Adhikari, B. (2020) Barriers in the access, diagnosis and treatment completion for tuberculosis patients in central and western Nepal: A qualitative study among patients, community members and health care workers. *PloS one*, 15(1), e0227293.

Marasine, N. R. & Sankhi, S. (2021) Factors associated with antidepressant medication non-adherence. *Turkish journal of pharmaceutical sciences*, 18(2), 242.

Marcussen, J., Madsen, R., Bonner, A. & Agerskov, H. (2023) Perceptions of haemodialysis nurses regarding patients' and families' loss and grief. *Journal of Renal Care*.

Mason, J. (2002) *Researching your own practice: The discipline of noticing*.Routledge.

Matheson, J. (2015) The Voice Transcription Technique: Use of Voice Recognition Software to Transcribe Digital Interview Data in Qualitative Research. *Qualitative report*.

McAllister, J., Beardsworth, G., Lavie, E., MacRae, K. & Carr, A. (2013) Financial stress is associated with reduced treatment adherence in HIV‐infected adults in a resource‐rich setting. *HIV medicine*, 14(2), 120-124.

McGhee, G., Marland, G. R. & Atkinson, J. (2007) Grounded theory research: literature reviewing and reflexivity. *Journal of advanced nursing*, 60(3), 334-342.

McHorney, C. A. & Spain, C. V. (2011) Frequency of and reasons for medication non-fulfillment and non-persistence among American adults with chronic disease in 2008. *Health Expectations*, 14(3), 307-320.

McKillop, G. & Joy, J. (2013) Patients' experience and perceptions of polypharmacy in chronic kidney disease and its impact on adherent behaviour. *Journal of renal care*, 39(4), 200-207.

McLaren, H., Patmisari, E., Hamiduzzaman, M., Jones, M. & Taylor, R. (2021) Respect for religiosity: review of faith integration in health and wellbeing interventions with Muslim minorities. *Religions*, 12(9), 692.

Meline, T. (2006) Selecting studies for systemic review: Inclusion and exclusion criteria. *Contemporary issues in communication science and disorders*, 33(Spring), 21-27.

Mills, J., Bonner, A. & Francis, K. (2006) The development of constructivist grounded theory. *International journal of qualitative methods*, 5(1), 25-35.

Mkansi, M. & Acheampong, E. A. (2012) Research philosophy debates and classifications: Students' dilemma. *Electronic journal of business research methods U6 - ctx_ver=Z39.88-2004&ctx_enc=info%3Aofi%2Fenc%3AUTF-8&rfr_id=info%3Asid%2Fsummon.serialssolutions.com&rft_val_fmt=info%3Aofi%2Ffmt%3Akev%3Amtx%3Ajournal&rft.genre=article&rft.atitle=Research+philosophy+debates+and+classifications%3A+Students%27+dilemma&rft.jtitle=Electronic+journal+of+business+research+methods&rft.au=Mkansi%2C+Marcia&rft.au=Acheampong%2C+Edwin+Asiamah&rft.date=2012&rft.eissn=1477-7029&rft.volume=10&rft.issue=2&rft.spage=132&rft.epage=140&rft.externalDBID=n%2Fa&rft.externalDocID=368747038&paramdict=en-US U7 - Journal Article*, 10(2), 132-140.

MOF (2019) *Ministry of Foreign Affairs: Foreign policy.* Available online: https://www.mofa.gov.om/?lang=en [Accessed November 13 2020].

MOH (2014) *Health Vision 2050.* Sultanate of Oman:

MOH (2015) *Diabetes Mellitus Management Guidelines*, Third Edition edition.Ministry of Health.

MOH (2019) *Annual Report* [eBook]. Sultanate of Oman.

MOH (2022a) *Annual Health Report*.

MOH (2022b) *Annual Health Report*.

Mohamed Hussin, N. A. & Syed Jamaludin, S. S. (2023) Strategizing early interventions to improve hemodialysis acceptance among chronic kidney disease patients. *Chronic Illness*, 17423953231174466.

Moran, A. (2022) The experiences of grief in patients with end‐stage kidney disease. *Nursing Times*, 118(2), 46-50.

Moriarty, J. (2011) Qualitative methods overview.

Morris, A. M., Doorenbos, A. Z., Haozous, E., Meins, A., Javid, S. & Flum, D. R. (2016) Perceptions of cancer treatment decision making among American Indians/Alaska natives and their physicians. *Psycho-Oncology*, 25(9), 1050-1056.

Morton, R., Tong, A., Howard, K., Snelling, P. & Webster, A. (2010) The views of patients and carers in treatment decision making for chronic kidney disease: systematic review and thematic synthesis of qualitative studies. *BmJ*, 340, c112.

Munn, Z., Peters, M. D., Stern, C., Tufanaru, C., McArthur, A. & Aromataris, E. (2018) Systematic review or scoping review? Guidance for authors when choosing between a systematic or scoping review approach. *BMC medical research methodology*, 18, 1-7.

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. *Patient Education and Counseling*, 76(2), 149-158.

Murtagh, F. E., Addington-Hall, J. & Higginson, I. J. (2007) The prevalence of symptoms in end-stage renal disease: a systematic review. *Advances in chronic kidney disease*, 14(1), 82-99.

Nelson, J. A., Fischer, J. P., Radecki, M. A., Pasick, C., McGrath, J., Serletti, J. M. & Wu, L. C. (2013) Delayed autologous breast reconstruction: factors which influence patient decision making. *Journal of plastic, reconstructive & aesthetic surgery : JPRAS*, 66(11), 1513-1520.

Ngueutsa, R., Tchagneno, C. L., Wassouo, E. & Kouabenan, D. R. (2023) Fatalistic Beliefs, Cultural Beliefs and Socio-Instrumental Control Beliefs: What are the Links? Can We Speak of an Active Fatalism? *Psychological Reports*, 00332941231153799.

Noohi, K., Komsari, S., Nakhaee, N. & Feyzabadi, V. Y. (2013) Reasons for Discharge against Medical Advice: A Case Study of Emergency Departments in Iran, 1, 137-142.

Okaiyeto, K. & Oguntibeju, O. O. (2021) African herbal medicines: Adverse effects and cytotoxic potentials with different therapeutic applications. *International Journal of Environmental Research and Public Health*, 18(11), 5988.

Orb, A., Eisenhauer, L. & Wynaden, D. (2001) Ethics in qualitative research. *Journal of nursing scholarship*, 33(1), 93-96.

Organization, W. H. (2018) Noncommunicable diseases country profiles 2018.

Ormston, R., Spencer, L., Barnard, M. & Snape, D. (2014) The foundations of qualitative research. *Qualitative research practice: A guide for social science students and researchers*, 2(7), 52-55.

Özdemir, T., Şahin, İ., Avcı, İ. İ., Güngör, B., Durmaz, E., Tuğrul, S., Hayıroğlu, M. İ., Kahyaoğlu, S., Karımov, O. & Okuyan, E. (2017) Assessment of factors related to statin non-adherence in patients with established coronary artery disease: A single-center observational study. *Turk Kardiyoloji Dernegi arsivi : Turk Kardiyoloji Derneginin yayin organidir*, 45(8), 723-730.

Palm, S., Doering, B. K., Kubiak, T., Geschke, K., Fellgiebel, A. & Wuttke, A. (2023) Influence of loss-and restoration-oriented stressors on grief in times of COVID-19. *Scientific Reports*, 13(1), 19584.

Parrott, F. R., Mwafulirwa, C., Ngwira, B., Nkhwazi, S., Floyd, S., Houben, R. M. G. J., Glynn, J. R., Crampin, A. C. & French, N. (2011) Combining qualitative and quantitative evidence to determine factors leading to late presentation for antiretroviral therapy in Malawi. *PloS one*, 6(11), e27917.

Patel, P., Gupta, P. K. C., White, C. M. J., Stanley, A. G., Williams, B. & Tomaszewski, M. (2016) Screening for non-adherence to antihypertensive treatment as a part of the diagnostic pathway to renal denervation. *Journal of human hypertension*, 30(6), 368-373.

Patierno, C., Fava, G. A. & Carrozzino, D. (2023) Illness Denial in Medical Disorders: A Systematic Review. *Psychotherapy and Psychosomatics*, 1-16.

Patino, C. M. & Ferreira, J. C. (2018) Inclusion and exclusion criteria in research studies: definitions and why they matter. *Jornal Brasileiro de Pneumologia*, 44(2), 84-84.

Patton, M. Q. (2014) *Qualitative research & evaluation methods: Integrating theory and practice*.Sage publications.

Patzer, R. E., Serper, M., Reese, P. P., Przytula, K., Koval, R., Ladner, D. P., Levitsky, J. M., Abecassis, M. M. & Wolf, M. S. (2016) Medication understanding, non‐adherence, and clinical outcomes among adult kidney transplant recipients. *Clinical transplantation*, 30(10), 1294-1305.

Perico, N. & Remuzzi, G. (2012) Chronic kidney disease: a research and public health priority. *Nephrology Dialysis Transplantation*, 27(suppl_3), iii19-iii26.

Point, S. & Baruch, Y. (2023) (Re)thinking transcription strategies: Current challenges and future research directions. *Scandinavian journal of management*, 39(2), 101272.

Polgar, S. & Thomas, S. A. (2020) *Introduction to research in the health sciences*, Seventh edition. Edinburgh: Elsevier.

Purssell, E. (2020) Can the Critical Appraisal Skills Programme check‐lists be used alongside Grading of Recommendations Assessment, Development and Evaluation to improve transparency and decision‐making? *Journal of advanced nursing*, 76(4), 1082-1089.

Raghunath, S., Hijjawi, R., Hoon, E., Shanahan, E. M. & Goldblatt, F. (2019) Qualitative assessment of medication adherence in patients with rheumatic diseases on biologic therapy. *Clinical rheumatology*, 38(10), 2699-2707.

Rashidi, E., Morda, R. & Karnilowicz, W. (2021) "I will not be defined by this. I'm not going to live like a victim; it is not going to define my life": exploring breast cancer survivors' experiences and sense of self. *Qualitative health research*, 31(2), 349-360.

Rate, I. M. & Rate, T. F. (2008) Addressing the Threat of Chronic Diseases in Oman. *Preventing Chronic Disease*, 07_0086a.

Rezaeipandari, H., Morowatisharifabad, M. A. & Shaghaghi, A. (2023) Religious and spiritual coping elements in dealing with chronic diseases: A qualitative exploration of the perspectives of older Iranian zoroastrians. *Journal of religion and health*, 62(5), 3017-3041.

Ritchie, J., Lewis, J., Nicholls, C. M. & Ormston, R. (2013) *Qualitative research practice: A guide for social science students and researchers*.sage.

Saeed, F., Sardar, M., Rasheed, K., Naseer, R., Epstein, R. M., Davison, S. N., Mujtaba, M. & Fiscella, K. A. (2020) Dialysis decision making and preferences for end-of-life care: perspectives of Pakistani patients receiving maintenance dialysis. *Journal of pain and symptom management*, 60(2), 336-345.

Saidi, S., Milnes, L. J. & Griffiths, J. (2018) Fatalism, faith and fear: A case study of self‐care practice among adults with Type 2 diabetes in urban Malaysia. *Journal of clinical nursing*, 27(19-20), 3758-3767.

Salter, C., McDaid, L., Bhattacharya, D., Holland, R., Marshall, T. & Howe, A. (2014) Abandoned Acid? Understanding Adherence to Bisphosphonate Medications for the Prevention of Osteoporosis among Older Women: A Qualitative Longitudinal Study. *PLoS ONE*, 9(1), 1-7.

Salvador, J. T. (2016) Revisiting the philosophical underpinnings of qualitative research. *International Education and Research Journal*, 2(6), 4-6.

Santos, J. L. G. d., Cunha, K. S. d., Adamy, E. K., Backes, M. T. S., Leite, J. L. & Sousa, F. G. M. d. (2018) Data analysis: comparison between the different methodological perspectives of the Grounded Theory. *Revista da Escola de Enfermagem da USP*, 52.

Saqib, A., Atif, M., Ikram, R., Riaz, F., Abubakar, M. & Scahill, S. (2018) Factors affecting patients’ knowledge about dispensed medicines: A Qualitative study of healthcare professionals and patients in Pakistan. *PLoS ONE*, 13(5), 1-22.

Schut, M. S., Henk (1999) The dual process model of coping with bereavement: Rationale and description. *Death studies*, 23(3), 197-224.

Seah, A. S., Tan, F., Srinivas, S., Wu, H. Y. & Griva, K. (2015) Opting out of dialysis ‐ Exploring patients' decisions to forego dialysis in favour of conservative non ‐ dialytic management for end ‐ stage renal disease. *Health Expectations*, 18(5), 1018-1029.

Searcey, R. (2022) Capturing Accidental Moments: The Self-Reflective Researcher and the Utility of the Research Diary, *Sex Work, Labour and Relations: New Directions and Reflections*Springer, 185-208.

Shafi, S. T., Saleem, M., Anjum, R., Abdullah, W. & Shafi, T. (2018) Refusal of hemodialysis by hospitalized chronic kidney disease patients in Pakistan. *Saudi Journal of Kidney Diseases and Transplantation*, 29(2), 401.

Shahin, W., Kennedy, G. A. & Stupans, I. (2019) The impact of personal and cultural beliefs on medication adherence of patients with chronic illnesses: a systematic review. *Patient Preference and Adherence*, 13, 1019-1035.

Shenton, A. K. (2004) Strategies for ensuring trustworthiness in qualitative research projects. *Education for information*, 22(2), 63-75.

Silva, J. A. d., Souza, E. C. F. d., Echazú Böschemeier, A. G., Costa, C. C. M. d., Bezerra, H. S. & Feitosa, E. E. L. C. (2018) Diagnosis of diabetes mellitus and living with a chronic condition: participatory study. *BMC Public Health*, 18, 1-8.

Sjölander, M., Eriksson, M. & Glader, E.-L. (2013) The association between patients’ beliefs about medicines and adherence to drug treatment after stroke: a cross-sectional questionnaire survey. *BMJ open*, 3(9), e003551.

Soares, P., Rocha, J. V., Moniz, M., Gama, A., Laires, P. A., Pedro, A. R., Dias, S., Leite, A. & Nunes, C. (2021) Factors associated with COVID-19 vaccine hesitancy. *Vaccines*, 9(3), 300.

Sofianou, A., Martynenko, M., Wolf, M. S., Wisnivesky, J. P., Krauskopf, K., Wilson, E. A., Goel, M. S., Leventhal, H., Halm, E. A. & Federman, A. D. (2013) Asthma beliefs are associated with medication adherence in older asthmatics. *Journal of general internal medicine*, 28(1), 67-73.

Solomon, D. H., Brookhart, M. A., Tsao, P., Sundaresan, D., Andrade, S. E., Mazor, K. & Yood, R. (2011) Predictors of very low adherence with medications for osteoporosis: towards development of a clinical prediction rule. *Osteoporosis international : a journal established as result of cooperation between the European Foundation for Osteoporosis and the National Osteoporosis Foundation of the USA*, 22(6), 1737-1743.

Son, Y.-J., Kim, H.-G., Kim, E.-H., Choi, S. & Lee, S.-K. (2010) Application of support vector machine for prediction of medication adherence in heart failure patients. *Healthcare informatics research*, 16(4), 253-259.

St. Clair Russell, J. & Boulware, L. E. (2018) End‐stage renal disease treatment options education: What matters most to patients and families, *Seminars in Dialysis*. Wiley Online Library.

Stack, R. J., Bundy, C. E., Elliott, R. A., New, J. P., Gibson, M. & Noyce, P. R. (2010) Intentional and unintentional non-adherence in community dwelling people with type 2 diabetes: the effect of varying numbers of medicines. *British Journal of Diabetes & Vascular Disease*, 10(3), 148-152.

Stavropoulou, C. (2012) Perceived information needs and non-adherence: evidence from Greek patients with hypertension. *Health expectations : an international journal of public participation in health care and health policy*, 15(2), 187-196.

Stewart, K., Gill, P., Chadwick, B. & Treasure, E. (2008) Qualitative research in dentistry. *British dental journal*, 204(5), 235-239.

Stroebe, M. & Schut, H. (2010) The dual process model of coping with bereavement: A decade on. *OMEGA-journal of Death and Dying*, 61(4), 273-289.

Stroebe, M. & Schut, H. (2021) Bereavement in times of COVID-19: A review and theoretical framework. *OMEGA-Journal of Death and Dying*, 82(3), 500-522.

Strohschein, F. J., Bergman, H., Carnevale, F. A. & Loiselle, C. G. (2011) Patient decision making among older individuals with cancer. *Qualitative Health Research*, 21(7), 900-926.

Suh, Y. S., Cheon, Y.-H., Kim, H.-O., Kim, R.-B., Park, K. S., Kim, S.-H., Lee, S.-G., Park, E.-K., Hur, J. & Lee, S.-I. (2018) Medication nonadherence in Korean patients with rheumatoid arthritis: the importance of belief about medication and illness perception. *The Korean journal of internal medicine*, 33(1), 203.

Tan, S. T., Quek, R. Y. C., Haldane, V., Koh, J. J. K., Han, E. K. L., Ong, S. E., Chuah, F. L. H. & Legido-Quigley, H. (2019) The social determinants of chronic disease management: perspectives of elderly patients with hypertension from low socio-economic background in Singapore. *International journal for equity in health*, 18(1), 1.

Taylor, B. J., Francis, K. & Hegney, D. (2013) *Qualitative research in the health sciences: methodologies, methods and processes*. London: Routledge.

Theofilou, P., Synodinou, C. & Panagiotak, H. (2013) Undergoing Haemodialysis: A Qualitative Study to Investigate the Lived Experiences of Patients. *Europe's Journal of Psychology*, 9(1).

Thorne, S., Hislop, T. G., Kim-Sing, C., Oglov, V., Oliffe, J. L. & Stajduhar, K. I. (2014) Changing communication needs and preferences across the cancer care trajectory: insights from the patient perspective. *Supportive Care in Cancer*, 22, 1009-1015.

Tinkler, L., Smith, V., Yiannakou, Y. & Robinson, L. (2018) Professional identity and the Clinical Research Nurse: A qualitative study exploring issues having an impact on participant recruitment in research. *Journal of advanced nursing*, 74(2), 318-328.

Tremblay, S., Castiglione, S., Audet, L.-A., Desmarais, M., Horace, M. & Peláez, S. (2021) Conducting qualitative research to respond to COVID-19 challenges: Reflections for the present and beyond. *International Journal of Qualitative Methods*, 20, 16094069211009679.

Tumwine, C., Neema, S. & Wagner, G. (2012) Reasons Why High Religiosity Can Co-exist with and Precipitate Discontinuation of Anti-retroviral Therapy among Different HIV Clients in Uganda: An Exploratory Study. *Religions*, 3(3), 817-832.

Turan, G. B. & Çiftçi, B. (2023) Examination of Health Fatalism And Health Literacy In Patients With Heart Failure. *Eastern Journal of Medicine*, 28(2), 211-218.

Unit, O. V. I. F.-U. (2020) *Oman Vision 2040.* Available online: https://www.oman2040.om [Accessed 1].

Vanstone, M., Canfield, C., Evans, C., Leslie, M., Levasseur, M. A., MacNeil, M., Pahwa, M., Panday, J., Rowland, P. & Taneja, S. (2023) Towards conceptualizing patients as partners in health systems: a systematic review and descriptive synthesis. *Health Research Policy and Systems*, 21(1), 1-14.

Wai, K. C., Elley, C. R., Nosa, V., Kennelly, J., Mabotuwana, T. & Warren, J. (2010) Perspectives on adherence to blood pressure-lowering medications among Samoan patients: qualitative interviews. *Journal of primary health care*, 2(3), 217-224.

Wakefield, D., Bayly, J., Selman, L. E., Firth, A. M., Higginson, I. J. & Murtagh, F. E. (2018) Patient empowerment, what does it mean for adults in the advanced stages of a life-limiting illness: A systematic review using critical interpretive synthesis. *Palliative Medicine*, 32(8), 1288-1304.

Winterbottom, A., Bekker, H. L., Conner, M. & Mooney, A. (2014) Choosing dialysis modality: decision making in a chronic illness context. *Health Expectations*, 17(5), 710-723.

Wong, L. P., Wong, P.-F., Megat Hashim, M. M. A. A., Han, L., Lin, Y., Hu, Z., Zhao, Q. & Zimet, G. D. (2020) Multidimensional social and cultural norms influencing HPV vaccine hesitancy in Asia. *Human vaccines & immunotherapeutics*, 16(7), 1611-1622.

Wouters, H., Van Dijk, L., Geers, H. C. J., Winters, N. A., Van Geffen, E. C. G., Stiggelbout, A. M. & Bouvy, M. L. (2016) Understanding Statin Non-Adherence: Knowing Which Perceptions and Experiences Matter to Different Patients. *PloS one*, 11(1), e0146272.

Xi, W., Harwood, L., Diamant, M. J., Brown, J. B., Gallo, K., Sontrop, J. M., MacNab, J. J. & Moist, L. M. (2011) Patient attitudes towards the arteriovenous fistula: a qualitative study on vascular access decision making. *Nephrology Dialysis Transplantation*, 26(10), 3302-3308.

Yodchai, K., Dunning, T., Savage, S. & Hutchinson, A. M. (2017) The role of religion and spirituality in coping with kidney disease and haemodialysis in Thailand. *Scandinavian journal of caring sciences*, 31(2), 359-367.

Yousaf, N., Ghulam, A. a. & Tahir, A. (2022) Covid-19 scenario, Kubler Ross model and the novel "Shehar Khaki, Kocha Khali": A Psychological. *Māk͟hẕ*, 3(2).

Zhang, N., Lai, F., Guo, Y. & Wang, L. (2022) Status of and factors influencing the stigma of Chinese young and middle-aged maintenance hemodialysis patients: a preliminary study. *Frontiers in Psychology*, 13, 873444.

Zhang, Q. L. & Rothenbacher, D. (2008) Prevalence of chronic kidney disease in population-based studies: Systematic review. *Bmc Public Health*, 8, 13.

Ziller, V., Kyvernitakis, I., Knöll, D., Storch, A., Hars, O. & Hadji, P. (2013) Influence of a patient information program on adherence and persistence with an aromatase inhibitor in breast cancer treatment - the COMPAS study. *BMC cancer*, 13(1), 407-407.

Zwikker, H. E., van Dulmen, S., den Broeder, A. A., van den Bemt, B. J. & van den Ende, C. H. (2014) Perceived need to take medication is associated with medication non-adherence in patients with rheumatoid arthritis. *Patient preference and adherence*, 8, 1635.

Appendix 1 Included studies matrix

Author(s)/year	**Country**	**Study Population characteristics**			**Data collection**	**Instruments used**	**Findings**	**Limitation**	**Quality appraisal**	**Themes &** ***Sub-themes***
		Disease type	**Sample size**	**Study Design**						
Parrott et al. (2011)	Malawi	Retroviral disease	60 patients Using purposive sampling (28 Males & 32 Females).	Mixed method	In depth Simi-structured interviews.	No specification mentioned about the tool used for quantitative data collection	1- Men patients presented with advanced diseases and they don't care about treatment plan. 2- Ignorance behaviours to such health promotion programme because they are useless and they don't want to appear weak. 3- waiting to see disease signs on their body. 4- Fear to attend clinic and fear to loss their right	1- Study included those who decided to attend the clinic. 2- Transport costs were not identified as a major contributor 3- Relatively small quantitative dataset 4- Since individuals were sampled retrospectively for interviewing, some of those with the most advanced disease had already died by the time of the study, particularly men.	Moderate	**Main theme** **1- Patients' belief and knowledge of treatment and the potential outcome.** **2- Sociocultural context and influence** ***Sub-Theme*** ***1- lack of knowledge*** ***2- culture*** ***3- Lack of support*** ***4- Financial***

							of respect from of their family members and friends. 5- Responses to marital dissolution and reduced marriage chance 6- Financial problems.	5- Since recruitment was clinic-based, respondents may have tended to emphasise negative community factors over negative health system factors. 6- quantitative data not present		
McKillop and Joy (2013)	UK	Chronic Kidney disease	10 patients using Purposive sampling (5 Males & 5 Females)	Mixed method	Simi-structured Interviews.	No specification mentioned about the tool used for quantitative data	1- ambivalence towards the need for multiple medicines and a desire to be taking as few medicines as necessary. 2- Concern around the potential for interactions between medicines. 3- embarrassment about having to take so	1- The study was undertaken by a novice researcher among patients with CKD attending nephrology clinics and did not recruit patients with CKD managed in primary care. **Their experience of poly-pharmacy and adherence may be different.**	Weak	**Main theme** **1- Patients' belief and knowledge of treatment and the potential outcome.** **2- Sociocultural context and influence** **3- Clinical treatment regimens** ***Sub-Theme*** ***1- Lack of Knowledge***

							many medicines. 4- Influenced feedback about the medication quality from different source such as media. 5- Middle of the day dosages more likely to be forgotten or to interfere with daily routines and activities. 6- Missing out night time medication because of fatigue and the burden of taking medicines throughout the day prior to bedtime. 7- Complex medication prone to running out, causing a			***2- Fear of side effect*** ***3- Lifestyle disruption due to undergo treatment*** ***4- Treatment regimens complexities***

							delay in refill and a period of time when the participant is unable to be adherent. 8- Many pills cause burden. 8- intake of prescribed medicines to combat their experience of side effects. 9- Adverse size, taste and texture of some medicines. 10- Ranking some medication as more important than others.			
Lam et al. (2014)	Hong Kong	ESKD (PD)	**Phase 1:** 173 patients using Maximum variation sampling **Phase 2:** 36 patients	An explanatory sequential design, a two-phase Mixed method design	**Phase 1:** self-reported survey questionnaire. **Phase 2:**	Phase 1: Instrument specification not mentioned.	1- Lack of knowledge 2- Inability to see the importance of adhering to dietary and fluid restriction.	1- patients with severe complications due to non-adherence who required repeated hospitalisations were not	Weak	**<u>Main them</u>** **1- Patients' belief and knowledge of treatment and the potential outcome.**

			taken from the phase 1 using Purposive sampling (18 Male & 18 Female)		Semi-structured one to one interview using interview guide		3- Forgetfulness. 4- Inability to abstain from their desires to eat and drink. 5- Drug type, size	included in this study. 2- it is uncertain whether the patients will revert to the initial stage of strict adherence in order to survive.		**2- Sociocultural context and influence** **3- Clinical treatment regimens** ***<u>Sub-theme</u>*** ***1- Feeling well*** ***2- Lack of knowledge*** ***3- Fear of side effect*** ***3- Culture*** ***4- lifestyle disruption due to undergo treatment*** ***5- Treatment regimens complexities***
Aditama et al. (2020)	Indonesia	Diabetes mellitus type 2	40 patients using purposive sampling (8 Males & 32 Females)	A non-experimental Mixed method (explanatory sequential design)	**Phase 1:** questionnaire survey developed to explore the adherence.	The adherence behaviour domain was adopted from the Pharmaceutical Care Practice:	1- Forgetting to take their medication 2- Patient preferring not to take their medication 3- Non-availability of drug product	1- Only clinical observations have been carried out; no interventions have been implemented.	strong	**<u>Main theme</u>** **1- Patients' belief and knowledge of treatment and the potential outcome.** **2- Sociocultural**

							4- Patient does not understand the instructions 5- Patient cannot swallow or self-administer the drug product appropriately			**context and influence** **3- Clinical treatment regimens** **4- Communication** ***<u>Sub-theme</u>*** ***1- Feeling well*** ***2- Lack of knowledge*** ***3- Fear of side effect*** ***4- Lack of support*** ***5- Lifestyle disruption due to undergo treatment*** ***6- Treatment regimen complexities*** ***7- Drug availability*** ***8- Language barriers***
Wai et al. (2010)	New Zealand	Hypertension	20 participants (9 Males & 11 Females)	Qualitative descriptive study	One to one semi-structured interviews.	The interview questions were informed by a literature search and	1- Lack of transportation 2- Family commitments 3- Feeling well	1- The researcher was the physician of several participants which may have influenced their	Strong	**<u>Main theme</u>** **1- Patients' belief and knowledge of treatment and the**

						previous studies addressing this specific area.		response to the questions. So may limit the findings validity. 2- Only Samoan patients were interviewed. Issues around adherence to taking medications may be different within other Pacific groups. 3- The study was conducted in one Auckland practice, which again may be different from the experiences of Samoan people from other practices or other regions of New Zealand		**potential outcome.** **2- Sociocultural context and influence** ***Sub-theme*** ***1- Feeling well*** ***2- Lifestyle disruption due to undergo treatment*** ***3- Physical environment and Practicalities of access to treatment***
Xi et al. (2011)	UK	End Stage Kidney Disease	13 HD patients (7 Males & 6 Females) using purposive sampling till	A qualitative study with a phenomenological approach	Semi-structured interview	using interview guide based on literature review of VA	1- Negative personal or vicarious experiences with the fistula.	1- The dialysis unit had ahigh prevalence of catheter use, and patient attitudes in this unit may not be reflective as	Moderate	**Main theme** **1- Patients' belief and knowledge of treatment and the potential outcome.**

			saturation reached				2- knowledge transfer and informed 3- decision-making. Acceptance of status quo.	those from a unit with a lower rate of catheter use. 2- There are no major financial barriers to fistula creation in Canada because hospital-related costs do not require out-of-pocket payment from the patient. 3- Patients often have to travel long distances (>200 km) to come for an access procedure or creation.		***<u>Sub-theme</u>*** ***1- Alternate sources of knowledge*** ***2- Fear of side effect***
Johnston and Noble (2012a)	UK	CKD	9 patients (4 males & 5 Females)	Qualitative practitioner research study	Clinical consultations and patients' experiences of their decision-making	Using three questions	1- Age and the inevitable 2- Feeling unable to travel on public transport. 3- feeling well on medication	1- There was the potential problem of researcher bias as the PR has a dual role as the nurse and the researcher. 2- Findings were discussed at the	Strong	**<u>Main theme</u>** **1- Patients' belief and knowledge of treatment and the potential outcome.** **2- Sociocultural**

							4- Being a burden or nuisance. 5- An autonomous decision. 6- discussing the decision with others.	weekly CKD multi-disciplinary meetings that acted as a ‘validation group. 3- The decision not to embark on dialysis appears on the face of it to have been a straightforward process for some patients. Because they attended clinic for many months and informed about their decline in their kidney function at different points along the trajectory of stage 5 CKD, which may had a positive impact on how ready they felt to make the decision.		**context and influence** ***Sub-theme*** ***1- Feeling well*** ***2- Lack of knowledge*** ***3- Culture*** ***4- Lack of support*** ***5- Physical environment and Practicalities of access to treatment***

Tumwine et al. (2012)	Uganda	HIV	39 very religious people living with HIV (6 Males & 33 Females)	Qualitative Purposive Using grounded theory approach	In-depth interviews	Using semi-structured interview guide	1- Unwavering faith in God 2- Supporting Biblical Scriptures 3- Testimonies by the “already healed” peers who had stopped ART 4- Teachings and Prophecies from religious leaders	1- The sample size was small, which may lead to difficulty to generalise the findings to all HIV positive persons receiving care in Uganda. 2- Almost all respondents were Pentecostal Christians, and this sample may not be representative of other religious denominations 3- Religiosity was measured using attendance of religious services; there might be some very religious persons who do not regularly attend religious services	Strong	**Main theme** **1- Patients’ belief and knowledge of treatment and the potential outcome.** ***Sub-theme*** ***1- Faith***

Salter et al. (2014)	United Kingdom	Osteoporosis	30 Women only, but Five participants were unable to participate in the follow-up interview due to death or withdrawal from the study	a longitudinal qualitative study with two in-depth interviews	Two in-depth interviews conducted	Using topic guide	1- Made decision of treatment non adherence without discussion with their general practitioner 2- deliberate not to take medication or forgot 3- complexity of the regimen 4- side effects 5- misunderstood the reasons for taking them long-term 6- scepticism	1- include potential sample bias: women who are keen to help research are potentially more motivated to self-care and take an active part in their own health. 2- Theoretical saturation did not occur due to the study design.	Moderate	**<u>Main theme</u>** **1- Patients' belief and knowledge of treatment and the potential outcome.** **2- Sociocultural context and influence** **3- Clinical treatment regimens** **4- Communication** ***<u>Sub-theme</u>*** ***1- Feeling well*** ***2- Lack of knowledge*** ***3- Fear of side effect*** ***4- Lifestyle disruption due to undergo treatment*** ***5- Treatment regimens complexities***

										6- Trust and empathy ***7- Capacity to choose***
Seah et al. (2015)	Singapore	ESKD	9 patients (5 Male & 4 Male)	Qualitative cross-sectional	Semi-structured interview	using an interview schedule as a guide	1- Personal ownership of decision 2- Age and life completion 3- Financial and physical cost of dialysis 4- Unacceptability of being a burden to the families 5- The stories of suffering and burden inflicted by dialysis 6- Inevitability of death	1- There were recruitment difficulties. A considerable number of patients were deemed not eligible due to dementia. 2- Although we invited all eligible patients irrespective of ethnicity, our respondents were all Chinese. 3- This is a single point cross sectional study.	strong	**Main theme** **1- Patients' belief and knowledge of treatment and the potential outcome.** **2- Sociocultural context and influence** ***Sub-theme*** ***1- Lack of knowledge*** ***2- Alternate sources of knowledge*** ***3- Culture*** ***4- Lack of support*** ***5- financial***
Laba et al. (2015)	Australia	Chronic diseases	21 participants with diverse chronic medications and diseases.	Qualitative	in-depth Semi-structured interviews (face-to-face or telephone).	Using interview guide	1- Trading between perceived treatment inefficacy 2- Unfavourable side effects	1- This study did not target participants from specific cultural background 2- The themes regarding	Strong	**1- Patients' belief and knowledge of treatment and the potential outcome.**

			(6 Males & 15 Females)				3- Unaffordable medication costs 4- Trusting prescriber–patient relationships	intentional medication non-adherence explored can be seen as generic. 3- Self-reported medication-taking behaviour may be vulnerable to recall bias and social desirability bias. 4- Although formal development of the codes and subthemes occurred, independent coding of the data was not conducted. 5- The outcomes of patient-directed medication-taking decisions were not assessed.		**2- Sociocultural context and influence** **3- Communication** ***1- Fear of side effect*** ***2- Financial*** ***3- Trust and empathy*** ***4- Capacity to choose***
Goldsmith et al. (2017)	Canada	Chronic diseases	35 patients from four cities across	Qualitative	semi-structured,	Using interview guide	Due to out-of-pocket costs patients kip or split doses, not	1- The data were collected solely from the patient perspective and	strong	**Main theme** **1- Sociocultural**

			two provinces (16 Males & 19 Females)	Purposive sampling	in-depth interviews		filling prescription and delay filling prescription.	relied on participants' reporting of their health care providers' perspectives on their prescription medication. 2- The interviews conducted in English and with persons who were healthy enough to participate in an interview. 3- The qualitative approach means have limited ability to generalise the study findings to populations although the CRNA understanding is rich and varied as the data collected in four cities across two provinces, with		**context and influence** ***<u>Sub-theme</u>*** ***1- Financial***

								individuals with a variety of demographic characteristics, illnesses, and medicines. 4- The researchers also did not systematically gather information about medications for which patients did not engage in CRNA so the researchers do not have a full picture of the trade-offs patients make between drugs and why patients engage in CRNA with some drugs but not others. 5- The study also only reports on one-time interviews with participants, with some		

								participants recalling past CRNA experiences. And longitudinal work would strengthen the understanding of CRNA variation over medications, illnesses and time		
Lovell et al. (2017a)	New Zealand	CKD	Subsequent purposive sampling used to recruit 17 patients (14 Male & 3 Female)	A Qualitative study using Longitudinal design	semi-structured interview schemas with face-to-face interview		1- Maintaining one's independence and act of self-efficacy and manage own health, due lack of practical and emotional support given by spouse. 2- Not to burden anyone. 3- Worry about burden of travelling for HD. 4- Feared the implication of	1- Study findings are less generalisable to countries with constrained healthcare resources or with significantly.	Moderate	**1- Patients' belief and knowledge of treatment and the potential outcome.** **2- Sociocultural context and influence** ***1- lack of knowledge*** ***2- lack of support*** ***3- Lifestyle disruption due to undergo treatment***

							dialysis on lifestyle including travel and outdoor activities			
Saqib et al. (2018)	Pakistan	No disease specification	Purposeful sampling technique was used in recruiting the 19 patients & 16 healthcare workers	A qualitative study design	In-depth semi-structured interview schemas with face-to-face interview		1- Lack of understanding due to language barrier. 2- Due to Misconception patients expected the medicines to show effects within three days. 3- Due to lack of knowledge, the patients may discontinue therapy if side effects appear.	1- Majority of the patients enrolled were illiterate and come from poor socioeconomic backgrounds. Therefore, factors relevant to educated patients and those living in urban areas could have been missed. 2- The findings cannot be generalised to the entire country or abroad, because of differences in the health care system and basic facilities available in	Strong	**Main theme** **1- Patients' belief and knowledge of treatment and the potential outcome.** **2- Communication** ***Sub-theme*** ***1- Feeling well*** ***2- Lack of Knowledge*** ***3- Language barriers*** ***4- Trust and empathy***

								different hospitals.		
Han et al. (2019a)	Singapore	ESKD	23 participants 16 patients (7 Males & 9 Females) using purposive sampling 7 caregivers using snowball sampling	A qualitative study design,	Semi structured, in depth interviews using interview guide		1- Loss of autonomy in daily life 2- Financial burden 3- Caregiver burden 4- Alternative medicine 5- Symptoms and disease progression	1- Sample was largely dominated by Chinese Singaporeans, who make up more than 75% of Singapore's total population. 2- the underrepresentation of certain patient groups including those taking conservative management for ESKD from community clinics. 3- patient population was also comprised of older patients, who have been found to report higher levels of satisfaction with	Moderate	<u>**Main theme**</u> **1- Patients' belief and knowledge of treatment and the potential outcome.** **2- Sociocultural context and influence** <u>***Sub-theme***</u> ***1- Fear of side effect*** ***2- Culture*** ***3- Lack of support*** ***4- Finance***

								care than younger groups. 4- many patients approached had declined to be interviewed, due to either being too frail to hold a long conversation or not wanting to talk about their treatment choice. 5- Lack of patient-public involvement in this study.		
Raghunath et al. (2019)	Australia	Rheumatic disease	96 participants using purposive (non-random) sampling (34 Males & 62 Females)	A qualitative study design, Using grounded theory approach	Semi structured interviews.		1- The presence and tolerability of active symptoms significantly influence adherence 2- Concern regarding long-term side effects of biologics and methotrexate being	1- The principal researcher is a clinician which could affect her perspective as well as the participants' responses. 2- Care, however, was taken by the researchers to "bracket out" their perceptions and presumptions as	strong	**<u>Main theme</u>** **1- Patients' belief and knowledge of treatment and the potential outcome.** ***<u>Sub-theme</u>*** ***1- Lack of knowledge***

							perceived as particularly "toxic"	is common practice in this study method 3- The study was conducted in a single centre with relatively small sample size (saturation).		***2- Fear of side effect***
Tan et al. (2019)	Singapore	Hypertension	Purposive sampling Total of 20 patient (6 males & 14 females)	A qualitative study design	Face-to-face, in-depth,	guided by a semi-structured interview guide.	1- Patients perceived physical and mental wellbeing, and aspects related to management of their medical condition 2- lack of Community support 3- difficulties of lifestyle modification 4- limited financial ability 5- lack of social support 6- Health services availability and financing	1- sampling strategy may have limited the reach to patients who are marginalised. 2- This sampling bias could potentially constrain the analysis to only the "more general" population without including those who are most in need. 3- This study may be limited by desirability bias as the patients generally presented	strong	**Main theme** **1- Patients' belief and knowledge of treatment and the potential outcome.** **2- Sociocultural context and influence** **3- Communication** ***Sub-theme*** ***1- Lack of knowledge*** ***2- Fear of side effect*** ***3- Lack of support***

								positive interpretations of their experiences, despite some complaints about healthcare professional’s disengagement; similarly, evidence has shown elderly patients are more likely to report greater satisfaction in health care services than younger groups. 4- As the focus of the study was limited to patients’ experiences in terms of hypertension management, we could not do an in-depth exploration of how ethnic differences impact all		***4- Physical environment and Practicalities of access to treatment*** ***5- Financial*** ***6- Language barriers***

								aspects of patient access to and acceptance of health care in Singapore		
Håkonsen and Toverud (2011)	Norway	Chronic diseases (HTN, DM & hypercholesterolaemia)	83 immigrant Pakistanis (32 Males & 51 Females	A qualitative study design, explorative	Personal Face to face interviews	using semi-structured guide	1- Fear about side-effects. 2- Opinion that cheaper generic drugs were fake drugs. 3- Difficult to remember to take their medication every day 4- Running out of medication. 5- Being dispensed nonbranded generics in the pharmacy.	1- The participants were recruited opportunistically in collaboration with two voluntary special interest groups 2- Regarding the representativity of the present study, it must be taken into account that the number of participants is relatively small. 3- These findings are not reflected in larger population-based datasets.	Weak	**<u>Main them</u>** **1- Patients' belief and knowledge of treatment and the potential outcome.** **2- Sociocultural context and influence** **3- Communication** ***<u>Sub-theme</u>*** ***1- Fear of side effect*** ***2- Lifestyle disruption due to undergo treatment*** ***3- Financial*** ***4- Language barriers***

Ghimire et al. (2017)	Australia	End-stage kidney disease.	30 haemodialysis patients (23 Males & 7 Females)	Qualitative exploratory study design.	One-on-one semi-structured interviews during dialysis session using interview guide.	Self-reported adherence measured using 4 items Morisky Levin Scale.	1- Patient-related factors 2- Knowledge and belief about medicines 3- Awareness and attitude towards medicines 4- Self-efficacy 5- Action control 6- Lack of family support 7- Health system/HCT-related. Quality of interaction 8- Therapy-related factors	1- This is a single centred study that may limit the generalisability of the findings. 2- Interviews were conducted with English speaking patients only, thus, the findings may not be generalisable to non-English speaking patients. 3- The access barrier gained attention in our themes, which may only be true for patients living in rural areas and they travel to tertiary care metropolitan hospital. 4- interviews were conducted during dialysis sessions; patients may	strong	**Main them** **1- Patients' belief and knowledge of treatment and the potential outcome.** **2- Sociocultural context and influence** **3- Clinical treatment regimens** **4- Communication** ***Sub-theme*** ***1- Lack of knowledge*** ***2- Fear of side effect*** ***3- Lifestyle disruption due to undergo treatment*** ***4- Physical environment and Practicalities of access to treatment***

								have been hesitant in responding freely while sharing their experiences. 5- interviews for research purpose may have facilitated social desirability response.		***5- Financial*** ***6- Treatment regimens complexities*** ***7- Language barriers*** ***8- Trust and empathy***
McHorney and Spain (2011)	USA	Chronic disease	19830 participants selected from the Harris Interactive Chronic Illness Panel (CIP).	A quantitative study design	An internet based Self-reported survey.	Instrument specification not mentioned.	1- Financial hardship. 2- fear or experience of side effects. 3- Generic concerns about medications. 4- Lack of perceived need for the medication. 5- Change in health insurance or drug benefits. 6- Did not believe that	1- Relative to the US adult population, our internet-based sample had a slight under-representation of adults with an income less than $25 000 annually, an under-representation of adults with less than a high school education, an over-representation	strong	**<u>Main theme</u>** **1- Patients' belief and knowledge of treatment and the potential outcome.** **2- Sociocultural context and influence** ***<u>Sub-theme</u>*** ***1- Lack of knowledge*** ***2- Financial***

							their condition was life threatening.	of adults with a college education, and over-representation of Caucasians**.** So, it is plausible that the slight income bias would provide a lower-bound estimate on observed results for financial hardship as reasons for nonfulfillment and non-persistence**.** 2- Social desirability may also have influenced the frequency of reported reasons.		
Solomon et al. (2011)	USA	Osteoporosis.	142 Female patients Only prescribed Osteoporosis medication.	A quantitative cohort study design	Questionnaire survey and follow up for one year	Instrument specification not mentioned.	1- Sociodemographic and health care factors. 2- Osteoporosis factors, and	1- Study sample was relatively small and consisted of white women who were all insured. It is unclear if the	Moderate	**Main theme** **1- Patients' belief and knowledge of treatment and the potential outcome.**

							osteoporosis beliefs.	rule will apply to other groups of patients; testing in other groups is warranted to assess generalisability. 2- The group of potential predictors that we studied was broad but not all inclusive. Psychological factors, such as depression or anxiety, were not queried. 3- Complexity of medication regimens might play a role in very low adherence, but the researchers did not inquire it. 4- All women in the sample had osteoporosis, and researchers had incomplete information		***<u>Sub-theme</u>*** ***1- Fear of side effect***

								about prior fractures 5- Patient followed for only 1 year, and non-adherence may occur beyond 1 year. 6- Some of the non-adherence may have been recommended by physicians		
Laba et al. (2012)	Australia	non-disease specific medication	161 participants. Using non-probability-based sampling methods (72 Male & 89 Female)	A cross-sectional.	online survey	A discrete choice experiment (DCE) through a web-enabled	**influenced by** 1- long-term medication benefits 2- current severity and future risk of medication side effects 3- reduced out-of-pocket costs 4- short-term medication benefits, and	1- The use of an online panel provider has precluded description of non-responders and potential responder bias and may limit the generalisability from web-panels based on strictly demographics-based weighting schemes. 2- An MMNL model was used to account for the	strong	**Main theme** **1- Patients' belief and knowledge of treatment and the potential outcome.** **2- Sociocultural context and influence** **3- Clinical treatment regimens** ***Sub-theme***

							fewer doses per day.	unobservable preference heterogeneity in the sampled population, other background medical information, particularly the number, type and experience with chronic conditions and medications, including psychiatric conditions, as well as cultural/ethnicity **information were not accounted for.** 3- The sample was not matched to the national Australian census on other potentially important variables such as education and income.		***1- Lack of knowledge*** ***2- Fear of side effect*** ***3- Financial*** ***4- Treatment regimens complexities***

								4- This study has been conducted within one health system. It may limit the generalisability of the findings. 5- Respondents were given generic descriptions of disease and treatment. Whilst it could be argued that there are significant challenges in responding to this type of abstraction, it was felt that this was necessary to mimic decisions across multiple diseases and medications and thus address the main study question. 6- The respondents are evaluating hypothetical		

								medications; that is what respondents declare they will do may be quite different to what they would actually do when they experience the consequences of a choice.		
Manouchehri et al. (2012)	Iran	Heart disease	943 patients (643 Male & 300 Females)	A Cross-sectional	Self-reported survey Study and Other information filled out by nurses from the patients file in the hospital database.	Instrument specification not mentioned.	1- lack of consent to surgery or other invasive procedures 2- Personal or family issues 3- Feeling well 4- Financial problems 5- Desire to be transferred to another hospital	1- lack of a control group to compare DAMA patients with those who are discharged normally. 2- The comparisons between men and women are also undercut by the absence of multivariable adjustment and a denominator. 3- Using self-report forms is often biased due to a tendency	Moderate	**Main them** **1- Patients' belief and knowledge of treatment and the potential outcome.** **2- Sociocultural context and influence** ***Sub-theme*** ***1- Lack of knowledge*** ***2- Lifestyle disruption due***

								among people to give socially desirable answers. 4- researchers were unable to follow up all the patients to determine the outcome of DAMA 5- Some of the reasons cited for DAMA by our patient population, e.g. transfer to another hospital or seeking consultation elsewhere, seem to overlap with the others.		***to undergo treatment*** ***3- Financial***
Noohi et al. (2013)	Iran	DAMA from ED, non-disease specific medication	121 cases	Cross-sectional study. A case study	Self-constructed questionnaire interview	Developed questionnaire, but instrument specification not mentioned.	1- Patient's related factors: (Feeling better and Economic status) 2- Medical environment factors:	1- The EDs are considered as stressful and extremely busy wards that might have influenced patients and their companion's response.	Moderate	**<u>Main theme</u>** **1- Patients' belief and knowledge of treatment and the potential outcome.**

							(Patients lacked enough information about the side effect and consequences of DAMA and lack of medical staff attention to the problem.) 3- Medical staff related factors: (Physician and nurse’s inadequate medical services and patient’s lack of trust to medical staff and having bad experience of hospitalisation)	2- This study included both single specialty and general teaching hospitals, so the referral patterns can differ from a hospital to other hospital.		**2- Sociocultural context and influence** **3- Communication** ***Sub-theme*** ***1- Lack of knowledge*** ***2- Lifestyle disruption due to undergo treatment*** ***3- Trust and empathy*** ***4- Trust and empathy***

Nelson et al. (2013)	USA	Breast reconstruction	709 Female patients underwent autologous free flap breast reconstruction.	A quantitative design a retrospective cohort study. Between 2005 & 2009	Mailed a survey questionnaire.	A specific tool was developed to address specific questions and topics, but Instrument specification not mentioned.	1- Past medical history evaluation 2- patients living >100 miles away from the central institution 3- Delayed reconstructions were unilateral as compared to bilateral cases. 4- Not offered the choice of immediate reconstruction neither before mastectomy nor after. 5- Patient were not offered a choice in their reconstructive timing. 6- Not had a discussion regarding the advantages or disadvantages	1- Reviewer bias can certainly exist with regard to the retrospective nature of this project. 2- The idea of the socioeconomic picture of delayed reconstruction was drown from the applying the flaws utilising population-based census data on the study sample. Which may lead to information bias based on assumptions. 3- given a not atypical response rate of 40%, the results must be interpreted with caution as the respondents may not be representative	Strong	**Main theme** **1- Sociocultural context and influence** **2- Communication** ***Sub-theme*** ***1- Physical environment and Practicalities of access to treatment*** ***2- Financial*** ***3- Capacity to choose***

							to reconstructive options. 7- Patients did not have a discussion about different options for subsequent breast reconstruction	of the overall group of delayed reconstruction patients 4- The survey administration, as it was performed at time-points between 6 months and 5 years from the initial surgery, created a setting were recall bias could be prevalent.		
Anees et al. (2014)	Pakistan	Chronic Kidney Disease	150 patients (92 Males & 58 Females)	A quantitative Cross-Sectional study	History taken, Blood test collected for routine Biochemical and Haematological profile.	A predesigned Performa used to collect the demographic data.	Reason for HD refusal: 1- Fear of HD. 2- Patient followed by treatment by spiritual and alternative medications. 3- Death of relatives with CKD on HD. 4- Non availability of nearby dialysis centre	1- Most of patient diagnosed late as ESKD (for less than three months. 2- weak referral system. 3- Poor nephrology system. 4- No trained physicians-Nephrologists. 5- Dialysis units run by	Weak	***Main theme*** **1- Patients' belief and knowledge of treatment and the potential outcome.** **2- Sociocultural context and influence** ***Sub-theme***

								technician and without physicians		***1- Lack of knowledge*** ***2- Alternate sources of knowledge*** ***3-Fear of side effect*** ***4- physical environment and Practicalities of access to treatment***
Al-Hajje et al. (2015)	Lebanon	Chronic diseases	148 patients Randomly selected. (72 Males & 76 Females)	A quantitative study design, Cross-sectional	A structured self-reported questionnaire administered face-to-face by interviewer	using MMAS-8 items questionnaire.	1- Experience a previous drug related side effect 2- Drug cost 3- Forgetting to take their medications 4- Felt better or worse 5- Doubt in medication efficacy	1- The method of drug adherence was self-report which suggests a possibility of recall bias. 2- The influence of the interviewer on patients' answers. 3- The study did not compare between patients according to disease severity, disease type, or drug class. These factors were	Strong	**1- Patients' belief and knowledge of treatment and the potential outcome.** **2- Sociocultural context and influence** ***1- Feeling well*** ***2- Lack of knowledge*** ***3- Lifestyle disruption due to undergo treatment*** ***4- Financial***

								recently believed to be less significant when compared to other patient related factors such as patient attitudes or beliefs		
Farzandipour et al. (2015)	Iran	Non- disease specification	284 patients, (158 Males & 126 Females) using convenient sampling method.	A quantitative study design, Cross-Sectional	interviewing patient at home or calling them after discharge using survey questionnaire	Developed and validated Questionnaire survey,	1- Patient perceptions of Informed refusal process: 2- Information disclosure before any treatment 3- Voluntariness in taking decision of treatment refusal 4- Communication with patients at the time of decision-making	1- The study was conducted only in one province of the country and thus may not be generalised to the whole country or other communities. 2- The study was based mainly on patients' perceptions; therefore, more studies are needed to confirm our results (information bias).	strong	**Main theme** **1- Patients' belief and knowledge of treatment and the potential outcome.** **2- Sociocultural context and influence** **3- Communication** ***Sub-theme*** ***1- Lack of Knowledge***

								3- The patient capacity for their decision-making and their real comprehension was not measured. 4- Study was conducted on patients with a range of diseases, and data about the patients' diseases not collected. 5- Due to the sample size, researchers could not analyse the data by the patients' diagnoses.		***2- Lack of support*** ***3- Capacity to choose***
Kromer et al. (2015)	Germany	Psoriasis	200 participants with moderate to severe psoriasis (115 Males & 85 Females)	An open Cross-sectional study	Computerised survey	Instrument specification not mentioned.	1- **Age (**Older participants judged the probability of 50% and 90% improvement less important than younger ones and older participants	1- findings will have to be verified in larger cohorts and in a multi-centric setting. 2- It is likely that preferences can be influenced by further factors	strong	**Main theme** **1- Patients' belief and knowledge of treatment and the potential outcome.** ***Sub-theme***

							worried more about severe AE).	such as comorbidities and treatment experience. 3- A major limitation of conjoint analysis is that the discrete choice experiments are theoretical and actual patients may choose actual medications differently. 4- Average preferences presented here do not allow direct conclusions for each individual. because, treatment decisions for a particular patient are based on his or her individual preferences.		***1- Lack of knowledge***

Malayala and Raza (2016)	USA	Cardiovascular disease in Men	1001 Men	A quantitative cross-sectional study design.	The survey combines interviews and physical examinations conducted in a mobile examination clinic	National Health and Nutrition Examination Survey (NHANES).	1- drug side-effect. 2- Patient Lack of knowledge regarding the importance, dose and frequency of drug.	1- The data are completely based on self-reporting and studies have shown that such data varies in reliability.	Moderate	**1- Patients' belief and knowledge of treatment and the potential outcome.** ***1- Fear of side effect***
Morris et al. (2016)	USA	Cancer	49 Patient (17 Males & 32 Females)	A quantitative study design,	A survey questionnaire	Using Collaboration and Satisfaction about Care Decision scale (CSACD).	1- Income (Couldn't afford it and poverty). 2- Culture affiliation (tribal affiliation) 3- Everyday discrimination. 4- personal thinking it wouldn't help 5- Intolerable side effects	1- Available sample was small which limited statistical power. 2- Data regarding AI/AN patients are scant because of their very small population size and because of a reluctance to participate in research studies 3- Study also focused on patients obtaining surgical care in the state of Washington; thus, generalisability	Strong	**Main theme** **1- Patients' belief and knowledge of treatment and the potential outcome.** **2- Sociocultural context and influence** ***Sub-theme*** ***1- Fear of side effect*** ***2- Financial***

								to other areas of the United States is limited 4- Provider response rate was low which limited the statistical power of dyadic pairing. 5- An alternative research design would be a descriptive correlational study. This design, however, would not provide the insight into both the patient and the provider cancer treatment experience.		
Patel et al. (2016)	UK	Hypertension (Kidney denervation)	Total of 34 (21 Males & 13 Females)	A quantitative retrospective analysis.	Through different diagnostic Screening steps: clinic BP measurements, HPLC-		1- knowledge provided about the procedure (pain)	1- The data comes from a retrospective single-centre analysis 2- A single biochemical screening for	Moderate	<u>**Main theme**</u> **1- Patients' belief and knowledge of treatment and the potential outcome.**

					MS/MS-based urine analysis, magnetic kidney angiography and biochemical screening		2- Forgetfulness 3- Polypharmacy.	non-adherence to treatment as reported here cannot confirm that the patient is non-adherent (or adherent) in the long-term 3- Some patients may improve their adherence directly prior to attending a clinic (so called 'toothbrush effect').		**2- Sociocultural context and influence** ***Sub-theme*** ***1- Fear of side effect*** ***2- Lack of support***
Wouters et al. (2016)	Netherlands	Cardiovascular disease	229 patients (146 Male & 123 Females)	A quantitative cross-sectional study design	Self-reported Online questionnaire and face-to-face interviews	using the Tailored Medicine Inventory (TMI) & 8-item Medication Understanding, Use Self-efficacy (MUSE) scale, Medication Adherence Rating Scale (MARS) & new	1- patients doubted the necessity of statins and lacked information about and knowledge of the efficacy of statins 2- Worry about and experience of side effects 3- Logistical problems (Getting	1- Researchers relied on self-report to assess clinical characteristics and the findings could be liable to recall bias. 2- although researchers could infer non-adherence from refill data, we had no medical data of patients. Therefore, we could not assess	Strong	**Main theme** **1- Patients' belief and knowledge of treatment and the potential outcome.** ***Sub-theme*** ***1- Fear of side effect***

						Morisky Medication Adherence Scale (MMAS).	insufficient statin tablets).	to what extent non-adherence reflected non-acceptance on legitimate grounds. 3- Because of patient anonymity issues and because patients were only informed by mail about the study, we decided not to record non-response although response bias may have played a role.		
Adefris et al. (2017)	Ethiopia	Obstetric fistula and pelvic organ prolapse	384 patient patients	A quantitative, a hospital based Cross-sectional study design.	Structured Self-reported questionnaire.	Using a developed and pretested questionnaire	1- Social issues (Unavailability of roads, Lack of transportation, Fear of disclosure, Financial constraint. 2- Marital status (Un-married	1- Based on self-report which make it subject to recall bias. 2- A cross-sectional design which might not show temporal relationships and thus making the observed associations not	Strong	**1- Sociocultural context and influence** ***1- Culture*** ***2- Physical environment and Practicalities of access to treatment***

							patients experienced stigma) 3- Age (Older women may believe that the symptom or the problem is a part of aging)	necessarily causal. 3- Small sample size		***3- Financial***
Özdemir et al. (2017)	Turkey	Coronary artery disease	300 patients (203 Males & 97 Females)	A quantitative Cross-sectional study design.	Self-reported Questionnaire & patient medical records to trace patients' clinical details.	Instrument specification not mentioned.	1- medication Stopped by the physician during follow-up. 2- Misguidance in media broadcasts, that long-term treatment used may be harmful to the liver. 3- Patient's discretion (does not like taking pills).	1- The sample size was relatively small, and as patients were recruited from a single centre, findings may not be representative of the overall population of CAD patients in Turkey. 2- The reasons for statin discontinuation are highly subjective. Because this study was conducted in a region with a low socioeconomic	Strong	**Main theme** **1- Patients' belief and knowledge of treatment and the potential outcome.** ***Sub-theme*** ***1- Feeling well*** ***2- Alternate sources of knowledge***

								status where the level of educational achievement and use of the Internet and social media are low		
Shafi et al. (2018)	Pakistan	CKD	125 patients. Nonprobability consecutive sampling used 43 patient refused HD	A quantitative cross-sectional	Patient's history, medical records, and laboratory data reviewed to obtain patient demographic information.	Using developed and piloted survey questionnaire. Instrument specification not mentioned.	1- Unable to afford HD 2- Fear of HD catheter 3- Fear of AV fistula needles 4- No HD center near residence 5- Permanent and lifelong HD is unacceptable 6- Frequency of HD per week is unacceptable 7- Poor health and functional status of patient 8- Old age of patient 9- Perception of poor quality of life on HD	1- This is a single-center study with limited number of patients. 2- Quantitative rather than qualitative assessment of reasons for acceptance or refusal by patients was assessed. 3- There was no follow-up on patients who either accepted or refused HD	Moderate	<u>**Main theme:**</u> **Patients belief/knowledge on treatment and the potential outcome & Sociocultural context and influence** ***<u>Sub-theme:</u>*** ***1- Lack of knowledge*** ***2- side effect*** ***3- Family influencing factors*** ***4- lifestyle disruption caused by undergo treatment***

							10- Fear of complications on HD 11- Fear of death with HD 12- Adverse outcome in friend or family member with HD 13- Advised by family member or friend not to do HD 14- Patient desires second opinion 15 Patient desires to undergo pre-emptive kidney transplant			***5- Financial*** ***6- Physical environment and Practicalities of access to treatment*** ***7- Alternate sources of knowledge***
Ghimire et al. (2018)	Nepal	Hypertension	180 patients (90 Males & 90 Females)	A quantitative study, using a barrier analysis following methodologies	self-reporting questionnaire.	Using the Health belief model (HBM) and the theory of planned behaviour (TPB)	1- Family type (only females): Living in joint family 2- Perceived self-efficacy: 3- Perceived social acceptability	1- The potential for misclassification of cases and controls as Compliant and non-Compliant due to self-reported data	Strong	**<u>Main theme:</u>** **1- Patients belief/knowledge on treatment and the potential outcome**

							(only for females): 4- Reminder to action (only males): Forgetting to eat low salt food.	2- Adherence to recommended dietary salt reduction may be overestimated in order to please the Researchers 3- All the barriers reported are perceived and may not objectively reflect reality.		**2- Sociocultural context and influence** ***<u>Sub-theme:</u>*** ***1- Culture*** ***2- family influencing Factors*** ***3- lifestyle disruption caused by undergo treatment***
Kriegbaum and Lau (2018)	Denmark	cardiovascular disease	3050 Participants (1501 Males & 1549 Females)	A quantitative Cross-Sectional study design	LIFESTAT project: online survey and telephone interviews.	using developed and validated online surveyXact tool	1- The cholesterol level was back to normal 2- It was the doctor's decision 3-The medicine was too expensive 4- The medicine did not help 5- Experienced side effects	1- participants were recruited from the general population. Hence, participation was independent of contact with a particular clinic, which could lead to selection bias. 2- The cross-sectional design is limited with	Strong	**<u>Main theme</u>** **1- Patients' belief and knowledge of treatment and the potential outcome.** **2- Sociocultural context and influence** ***<u>Sub-theme</u>*** ***1- Feeling well***

								respect to causal relations.		***2- Fear of side effect*** ***3- Financial***
Bartolomé-García et al. (2019)	Spain	Multiple sclerosis	224 patients (78 Males & 146 Females)	A quantitative design using an observational retrospective study	Clinical data were obtained from the review of electronic clinical records as well as from the forms requesting treatment initiation.		Clinical decision due to lack of efficacy and adverse effects.	1- Retrospective and single-centre design and the limited size of the series analysed. 2- For the adherence calculation we have assumed that all doses dispensed have been administered, which could lead to an overestimation of our results. 2- we cannot claim that the differences found in adherence and persistence between the four treatment arms can be assigned only to those factors identified due to	Weak	**Main theme** **1- Patients’ belief and knowledge of treatment and the potential outcome.** ***Sub-theme*** ***1- Lack of knowledge*** ***2- Alternate sources of knowledge***

								the limitations of our study and because there is a likely impact on adherence and persistence by other variables such as socioeconomic level, patient/healthcare staff relationship, disease denial, perception of lack of treatment benefit and adverse effects, motivation or family/social support.		
Son et al. (2010)	Korea	Heart failure	76 patients with HF (21 Male, 55 Female)	A Quantitative Cross-Sectional study design.	self-reported questionnaire survey.	Developed questionnaire	1- A longer duration of HF diagnosis	1- Small sample size, which made it very difficult for any of the endpoints to achieve statistical significance	Moderate	<u>**Main theme:**</u> **Patients' belief and knowledge of treatment and the potential outcome** <u>***Sub-theme:***</u>

										1- Lack of knowledge
Stack et al. (2010)	UK	Type 2 diabetes	480 patients	A quantitative study design, A cross sectional survey	Self-reported postal questionnaire and patients' medical records	using Morisly Medication Adherence scale (MMAS)	1- Because medicines for type 2 diabetes are more likely to be prescribed as multiple doses	1- The participants were from a narrow range of ethnic backgrounds, limiting the generalisability of these findings. 2- The sample was drawn from a population of largely elderly people (mean age 66.3 years) who had a range of long-term conditions. 3- The focus of this investigation was type 2 diabetes and CVD but the people who participated may have been taking other medicines 4- The use of Self-report	Moderate	**1- Patients' belief and knowledge of treatment and the potential outcome.** **2- Clinical treatment regimens** ***1- Lack of knowledge*** ***2- Treatment regimens complexities***

								measures to examine adherence; over-reporting of non-adherence may have been a problem. 5- Some participants may have felt threatened by the way that questions on the Morisky adherence scale are phrased and the potential for questionnaire items to generate negative feeling among participants may have led to underreporting of non-adherence on some questionnaire		
Stavropoulou (2012)	Greece	Hypertension	743 individuals Gender not specified	A quantitative study design	A questionnaire survey through	using Morisly Medication Adherence	1- lack of information regarding medication	1- The sample studied was mostly adherent to the	Moderate	**<u>Main theme</u>** **1- Patients' belief and**

					telephonic interviews	scale (MMAS	2- Media and magasines	medication. A possible explanation may be hidden in the fact that the sample was taken from a specialised centre.		**knowledge of treatment and the potential outcome.** ***Sub-theme*** ***1- Alternate sources of knowledge***
Carneiro-Leão et al. (2018)	Portugal	Hymenoptera venom allergy.	83 patients (55 Males & 28 Females)	A quantitative cross-sectional study design	A medical record review followed with phone interviews using structured questionnaire	Instrument specification not mentioned.	1- Cost of the hospital visit 2- Working hours lost 3- Reimbursement	study was limited by its retrospective design, the inability to contact all patients refusing VIT and by the small sample size. Which may affect the finding generalisability	Moderate	***Main theme*** **1- Sociocultural context and influence** **2- Sociocultural context and influence** ***Sub-theme*** ***1- Lifestyle disruption due to undergo treatment*** ***2- Financial***

Dennis et al. (2011)	India	Hypertension	Random selection of 608 patients. (312 Males & 296 Females)	A qualitative study design observational study. December 2008 to Mat 2009	A questionnaire-based survey through interview by the investigator.	Using a validated questionnaire named Brief Medication Questionnaire (BMQ)	1- Medication effectiveness 2- Unwillingness and difficulty to pay for medication. 3- Difficult to get refills on time. 4- Difficult to remember all prescribed doses due to multiple drugs.	1- study did not assess the financial status of patients or the cost of medications prescribed information bias due to self-reporting and personal believes. 2- Availability of prescribed medications at patients' locations was also not recorded in this study. 2- These limitations might have contributed to the access barrier observed in this study. 3- This was designed as an observational study and we did not try to include patients with equal educational	Strong	**1- Patients' belief and knowledge of treatment and the potential outcome.** **2- Sociocultural context and influence** **3- Clinical treatment regimens** ***1- Fear of side effect*** ***2- Financial*** ***3- treatment regimens complexities***

								status to balance out the chance of education backgrounds influencing adherence to treatment. 4- This study was not conducted as a prospective study and hence the effect of visit schedule on adherence could not be ascertained. 5- Since this study was conducted in a hospital where people belonging to different economic strata avail medical care in a metropolitan city in India, these results are applicable only to the scenario in Indian cities		

Golub et al. (2013)	USA New York	Negative HIV (MSM & Transfer gender Women)	184 participants. (177 Men & 7 transgender Women)	A quantitative study design, Cross-sectional	Self-reported Computerized survey.	Instrument specification not mentioned.	1- PrEP acceptability 2- PrPE efficacy aside effect:	1- The cross-sectional nature of the data does not allow us to infer causality. 2- Participants were asked to respond to hypothetical scenarios, which may not be generalisable to their actual behaviour. 3- While our sample was diverse in terms of race/ethnicity, age, and socioeconomic status, the limited number of transgender women in our sample limits our findings for this group	Strong	**Main theme** **1- Patients' belief and knowledge of treatment and the potential outcome.** **2- Sociocultural context and influence** **Sub-theme** ***1- Fear of side effect*** ***2- Financial***
Haberer et al. (2013)	Est Africa Kenya & Uganda	HIV-Uninfected members	1147 HIV serodiscordant couples using convenience sampling	A quantitative study design, A randomised, placebo-controlled,	Self-reported questionnaire.	Instrument specification not mentioned.	1- Incident of pregnancy. 2- Abuse (verbal, physical and economic).	1- Although UPC and MEMS are significantly correlated and both indicate high adherence,	strong	**Main theme** **1- Sociocultural context and influence**

			(608 Males & 539 Females)	clinical trial of daily oral PrEP.				UPC is consistently somewhat higher than MEMS which suggested systematic bias. 2- ely lies somewhere in between the two measurements. Second, due to the small numbers of participants with low adherence as measured by UPC, the power to identify factors associated with that measure of adherence was limited. 3- This sub-study was conducted within a blinded randomised controlled trial and recruitment was performed without regard to study arm.		***<u>Sub-theme</u>*** ***1- Culture*** ***2- Lack of support*** ***3- Financial***

								however, possible that these differences influenced the efficacy estimate. 4- The 80% threshold may or may not reflect the optimal level of adherence for protection against HIV acquisition. 5- This study cannot assess whether non-adherence correlated with HIV infection because no individuals in the treatment groups became infected.		
McAllister et al. (2013)	Australia	HIV	500 patients Gender not specified	A quantitative study design. A cross-sectional	An anonymous survey.	Instrument specification not mentioned.	1- Difficult & very difficult to meet pharmacy dispensing costs and meet the cost	1- This study is a cross-sectional, single-site study, with no a priori sample size calculation.	strong	**<u>Main theme</u>** **1- Sociocultural context and influence**

							of getting to the clinic. 2-	2- The limited size of some subgroups, such as the number with hepatitis coinfection, makes it possible that some additional factors associated with poor adherence may not have been detected. 3- Almost all patients were male; as women generally earn less money than men, financial stress may be of even greater importance in women. 4- Researchers did not record patient socio-economic characteristics. The associations of delayed medication use and of treatment		***Sub-theme*** ***1- Financial***

								interruption with financial stress were not validated independently or prospectively. 5- The reports of financial stress may be an underestimate, as patients were not followed from treatment commencement such that patients previously lost to follow-up were not assessed.		
Sjölander et al. (2013)	Sweden	Stroke	578 patients (346 Male & 232 Females)	A quantitative study design Cross-sectional	Self-reported Survey questionnaire and clinical data from stroke register	using three validated questionnaires: The Brief Illness Perception Questionnaire (Brief IPQ), the Beliefs about Medicines Questionnai	1- Personal beliefs in medication harm and low beliefs in personal need for drugs 2-	1- Validated questionnaires have been used to collect data on a large sample of patients. 2- Although only a minority of patients reported non-adherent behaviour,	Strong	<u>**Main theme**</u> **1- Patients' belief and knowledge of treatment and the potential outcome.** ***<u>Sub-them</u>***

						res (BMQ) and the Medication Adherence Report Scale (MARS).		associations between beliefs and adherence were statistically significant. 3- The cross-sectional design of this study made it impossible to draw conclusions about causality or to measure changes in behaviour.		***1- Feeling well***
Sofianou et al. (2013)	USA	Asthma	242 patients (39 Males & 203 Females)	A quantitative study design, Cross-sectional	Self-reported questionnaire	Using the Medication Adherence Report Scale (MARS)	1- Believed that they would not always have asthma. 2- No symptoms and no asthma belief. 3- Believing that asthma is not chronic disease. 4- A weaker tendency to believe in the ability of	1- A direct causal link between self-reported adherence and the asthma beliefs we examined cannot be assumed since this was a cross-sectional, observational cohort study. 2- The treatment beliefs, in particular, may	Strong	**Main theme** **1- Patients' belief and knowledge of treatment and the potential outcome.** ***Sub-theme*** ***1- Lack of knowledge***

							asthma medication to control their asthma. 5- Concern about side effect and other problems associated with using asthma medications.	be subject to reverse causality since experiences like treatment failure or unpleasant side effects could have caused patients to discontinue use of the medications. 3- A self-reported assessment of medication adherence, where responses could be influenced by social desirability and recall bias. 4- The BMQ and BIPQ have been validated in older populations, no study that we know to date has assessed their performance on		

								adults >80 years old, so there is a possibility that responses of patients >80 years of age may not have the same meaning as those of younger participants.		
Zwikker et al. (2014)	Netherland	Rheumatoid arthritis	580 female patients	A quantitative study design, Cross-sectional	Self-reported questionnaire.	Beliefs about medication were measured using two parts of the validated BMQ: the BMQ "specific" and the BMQ "general"	1- Weaker necessity beliefs about medication 2- A more unfavourable balance between necessity and concern beliefs about medication 3- Having an indifferent attitude toward medication	1- Due to the cross-sectional design of this study, we were not able to assess the causality of associations between beliefs about medication and non-adherence. So, it is unclear if beliefs about medication led to non-adherence or whether non-adherent behaviour influenced beliefs	Strong	<u>**Main theme**</u> **1- Patients' belief and knowledge of treatment and the potential outcome.** <u>***Sub-theme***</u> ***1- Fear of side effect***

								However, there still is insufficient knowledge about the presence (or absence) of longitudinal associations between beliefs about medication and non-adherence.		
Gadallah et al. (2015)	Egypt	Rheumatoid arthritis	140 patients. (9 Males & 131 Females)	A quantitative study design, Cross-sectional descriptive study.	Self-reported questionnaire and Patients' medical records.	Using a licensed Arabic version of the validated 8-item Morisky's Medication Adherence Scale (MMAS-8)	1- Forget taking their medications. 2- Intentionally miss dosage. 3- Forget bringing medications while traveling. 4- Feel hassled sticking to treatment. 5- Fear of side effects of medications. 6- Cost of medications 7- Did not believe that	1- The relatively small sample size is not powered to detect small differences between groups. 2- As study sample is mostly females, our results are only generalisable to women. 3- The cross-sectional study design only permits correlational analyses and causality cannot be inferred.	Strong	**Main theme** **1- Patients' belief and knowledge of treatment and the potential outcome.** **2- Sociocultural context and influence** ***Sub-theme*** ***1- Fear of side effect*** ***2- Lifestyle disruption due***

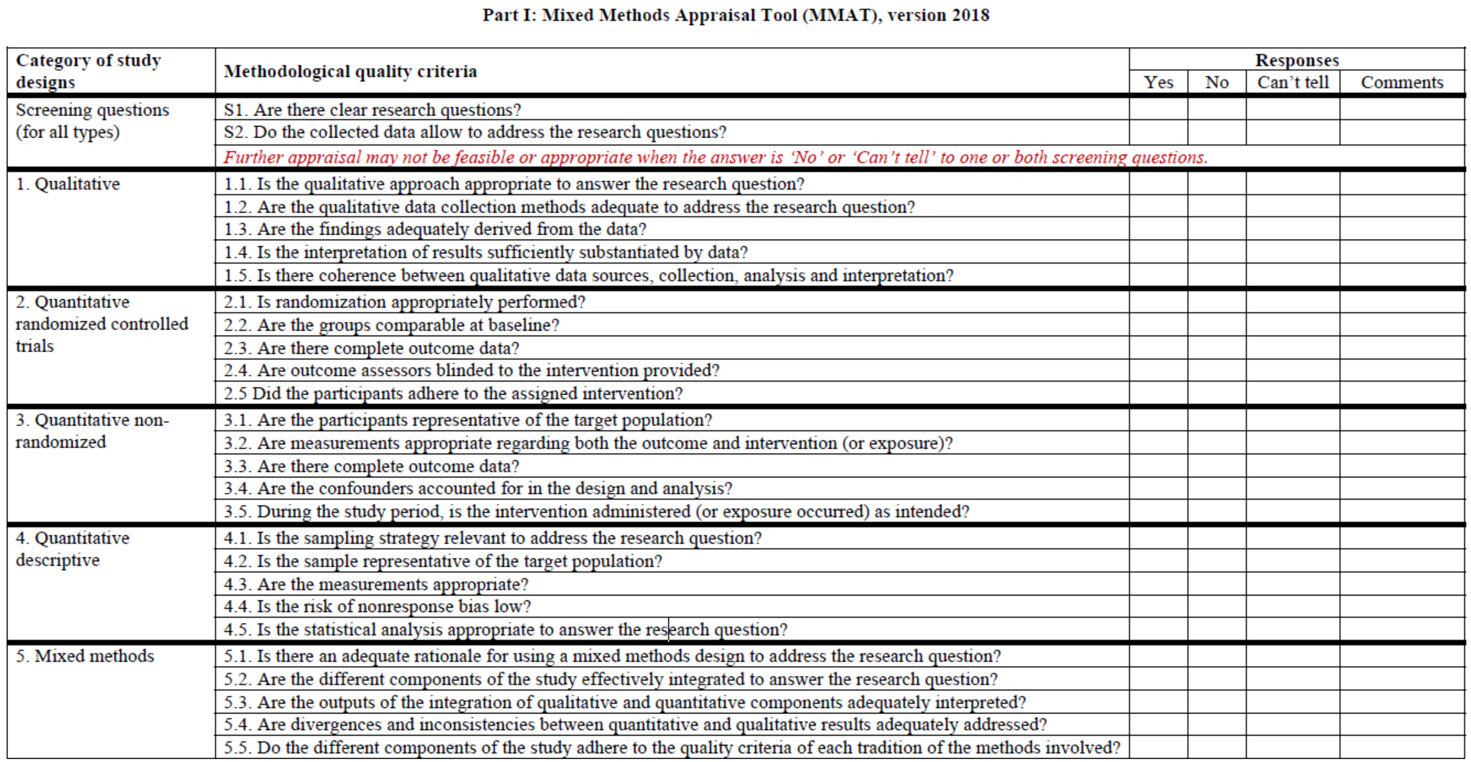
							treatment can make them live longer. 8- Did not think that treatment can prevent future RA complications	4- There is a risk of response bias as the measures rely on self-reporting.		***to undergo treatment*** ***3- Financial***
Betegnie et al. (2016)	France	Chronic inflammatory rheumatic disease.	581 patients. (147 Males & 434 Females)	A quantitative, prospective descriptive study design	Self-reported questionnaire	Using developed and validated Self-reported questionnaire. Internet based	1- Patients' beliefs and perceptions about the efficacy of biologics and side effects 2- Negative beliefs about treatment 3-_Lack of medical and social support	(Questionnaire piloted for validation purpose. a backward stepwise sample size selection was performed to give the final model, with 5 independent SD factors (for a p value < 0.05).	Moderate	<u>**Main theme**</u> **1- Patients' belief and knowledge of treatment and the potential outcome.** **2- Sociocultural context and influence** <u>***Sub-theme***</u> ***1- Fear of side effect*** ***2- Lack of support*** ***3- Financial***

Fung et al. (2018)	USA	Cardiovascular	730 patients using stratified random sampling. (52.1% Males & 47.9% Females)	A quantitative Cross-sectional study design	Through pharmacy data, patient medical record & self-reported questionnaire (telephone interview).	Instrument specification not mentioned.	1- Concerns about the need for or benefits of statins 2- logistical barriers 3- Concerns about side-effects or adverse effects 4- lifestyle preferences	1- The study was not powered to examine interactions between clinical risk categories and perceived risk. 2- The study findings may not generalise to individuals who are newly recommended to receive statins, such as those without elevated LDL-c levels (due to guideline update). 3- Study was also conducted within an integrated delivery system and adherence levels and communication with providers could be lower in other settings. 4- this was a cross-sectional	moderate	**Main theme** **1- Patients' belief and knowledge of treatment and the potential outcome.** **2- Sociocultural context and influence** ***Sub-theme*** ***1- Lack of knowledge*** ***2- lifestyle disruption due to undergo treatment*** ***3- Financial***

								survey and we are not able to assess the causal relationship between actual and perceived risks and adherence		
Suh et al. (2018)	Korea	Rheumatoid Arthritis	292 patients. (52 Males & 240 Females)	Cross-sectional study design	Self-reported questionnaire	Using the Patient Health Questionnaire-2 (PHQ-2), Brief Illness Perception Questionnaire (IPQ), and using the Beliefs about Medicines Questionnaire (BMQ).	1- Beliefs about medication and illness perceptions 2- lower belief in the necessity of medications and a higher emotional response to disease	1- the potential for selection bias was introduced by recruiting patients from tertiary hospitals and enrolling only adult patients diagnosed with RA for at least 6 months and treated with at least one DMARD. 2- The subjective nature of surveys conducted implicates reporting bias as well. 3- 2 weeks might seem to be quite short period to evaluate the	Weak	**Main theme** **1- Patients' belief and knowledge of treatment and the potential outcome.** ***Sub-theme*** ***1- Fear of side effect***

								adherence in patients with RA. 4- other factors that may influence nonadherence, such as patient-doctor relationships, perceived costs, and especially cognitive functions, were not pursued.		

Appendix 2 Critical appraisal checklists



Part I: Mixed Methods Appraisal Tool (MMAT), version 2018

Category of study designs	**Methodological quality criteria**	**Responses**			
		Yes	No	Can't tell	Comments
Screening questions (for all types)	S1. Are there clear research questions?				
	S2. Do the collected data allow to address the research questions?				
	Further appraisal may not be feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.				
1. Qualitative	1.1. Is the qualitative approach appropriate to answer the research question?				
	1.2. Are the qualitative data collection methods adequate to address the research question?				
	1.3. Are the findings adequately derived from the data?				
	1.4. Is the interpretation of results sufficiently substantiated by data?				
	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?				
2. Quantitative randomized controlled trials	2.1. Is randomization appropriately performed?				
	2.2. Are the groups comparable at baseline?				
	2.3. Are there complete outcome data?				
	2.4. Are outcome assessors blinded to the intervention provided?				
	2.5 Did the participants adhere to the assigned intervention?				
3. Quantitative non-randomized	3.1. Are the participants representative of the target population?				
	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?				
	3.3. Are there complete outcome data?				
	3.4. Are the confounders accounted for in the design and analysis?				
	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?				
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the research question?				
	4.2. Is the sample representative of the target population?				
	4.3. Are the measurements appropriate?				
	4.4. Is the risk of nonresponse bias low?				
	4.5. Is the statistical analysis appropriate to answer the research question?				
5. Mixed methods	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?				
	5.2. Are the different components of the study effectively integrated to answer the research question?				
	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?				
	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?				
	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?				

CASP Checklist:
For Cohort Studies

Section A: Are the results valid?	
1. Did the study address a clearly focused issue?	☐ Yes ☐ No ☐ Can't Tell
CONSIDER: *A question can be 'focused' in terms of* • *the population studied* • *the risk factors studied* • *is it clear whether the study tried to detect a beneficial or harmful effect* • *the outcomes considered*	
2. Was the cohort recruited in an acceptable way?	☐ Yes ☐ No ☐ Can't Tell
CONSIDER: • *Look for selection bias which might compromise the generalisability of the findings:* • *was the cohort representative of a defined population* • *was there something special about the cohort* • *was everybody included who should have been*	
3. Was the exposure accurately measured to minimise bias?	☐ Yes ☐ No ☐ Can't Tell
CONSIDER: *Look for measurement or classification bias:* • *did they use subjective or objective measurements* • *do the measurements truly reflect what you want them to (have they been validated)* • *were all the subjects classified into exposure groups using the same procedure*	
4. Was the outcome accurately measured to minimise bias?	☐ Yes ☐ No ☐ Can't Tell
CONSIDER: *Look for measurement or classification bias:* • *did they use subjective or objective measurements* • *do the measurements truly reflect what you want them to (have they been validated)* • *has a reliable system been established for detecting all the cases (for measuring disease occurrence)* • *were the measurement methods similar in the different groups* • *were the subjects and/or the outcome assessor blinded to exposure (does this matter)*	
5. (a) Have the authors identified all important confounding factors?	☐ Yes ☐ No ☐ Can't Tell
CONSIDER: • *list the ones you think might be important, and ones the author missed*	
b) Have they taken account of the confounding factors in the design and/or analysis?	☐ Yes ☐ No ☐ Can't Tell
CONSIDER: • *look for restriction in design, and techniques e.g. modelling, stratified-, regression-, or sensitivity analysis to correct, control or adjust for confounding factors*	

6. a) Was the follow up of subjects complete enough? ☐Yes ☐ No ☐ Can't Tell

CONSIDER:
- *the persons that are lost to follow-up may have different outcomes than those available for assessment*
- *in an open or dynamic cohort, was there anything special about the outcome of the people leaving, or the exposure of the people entering the cohort*

b) Was the follow up of subjects long enough? ☐Yes ☐ No ☐ Can't Tell

CONSIDER:
- *the good or bad effects should have had long enough to reveal themselves*

Section B: What are the results?

7. What are the results of this study? ☐Yes ☐ No ☐ Can't Tell

CONSIDER:
- *what are the bottom line results*
- *have they reported the rate or the proportion between the exposed/unexposed, the ratio/rate difference*
- *how strong is the association between exposure and outcome (RR)*
- *what is the absolute risk reduction (ARR)*

8. How precise are the results? ☐Yes ☐ No ☐ Can't Tell

CONSIDER:
- *look for the range of the confidence intervals, if given*

9. Do you believe the results? ☐Yes ☐ No ☐ Can't Tell

CONSIDER:
- *big effect is hard to ignore*
- *can it be due to bias, chance or confounding*
- *are the design and methods of this study sufficiently flawed to make the results unreliable*
- *Bradford Hills criteria (e.g. time sequence, dose-response gradient, biological plausibility, consistency)*

Section C: Will the results help locally?

10. Can the results be applied to the local population? ☐Yes ☐ No ☐ Can't Tell

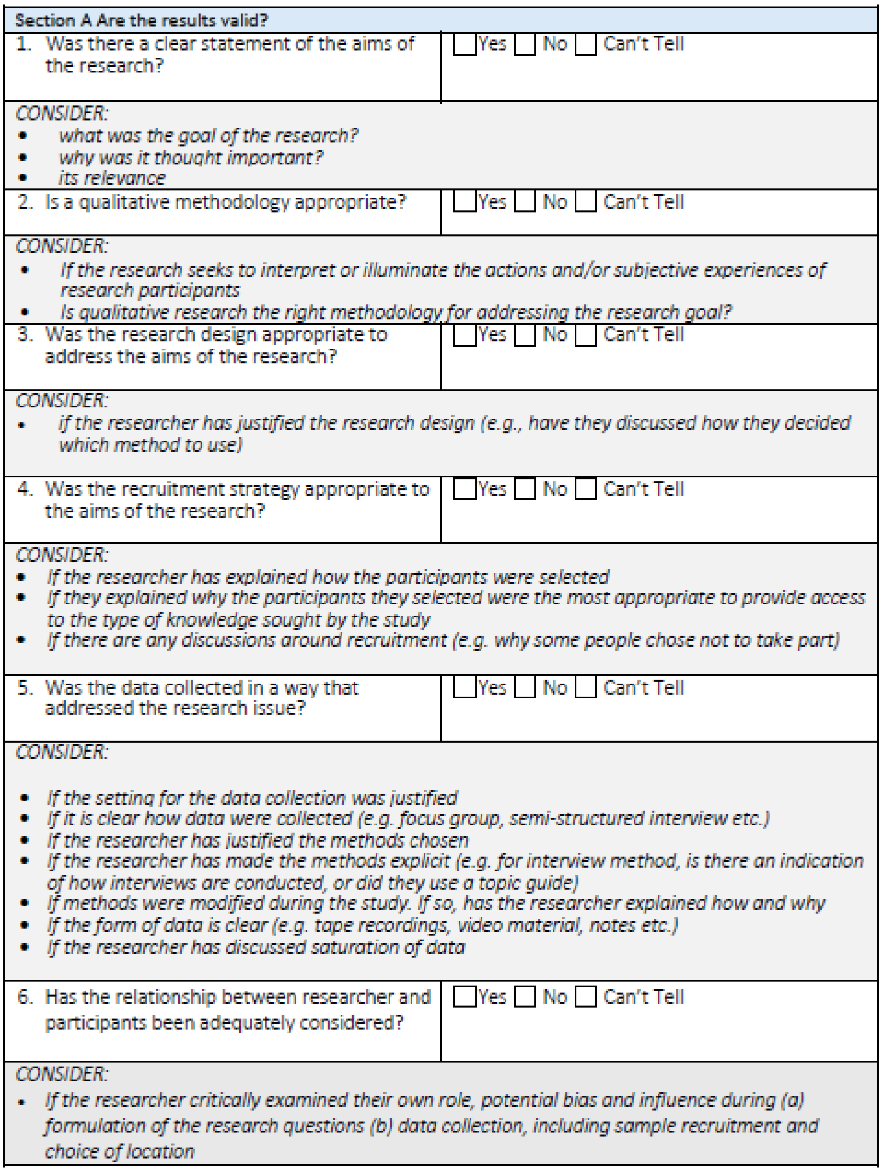
CONSIDER:
- *Is a cohort study the appropriate method to answer this question*
- *If the subjects covered in this study could be sufficiently different from your population to cause concern*
- *If your local setting is likely to differ much from that of the study*
- *If you can quantify the local benefits and harms*

11. Do the results of this study fit with other available evidence? ☐Yes ☐ No ☐ Can't Tell

12. What are the implications of this study for practice? ☐Yes ☐ No ☐ Can't Tell

CONSIDER:
- *one observational study rarely provides sufficiently robust evidence to recommend changes to clinical practice or within health policy decision making*
- *for certain questions, observational studies provide the only evidence*
- *recommendations from observational studies are always stronger when supported by other evidence*

CASP Checklist:
For Qualitative Research



Section A Are the results valid?

1. Was there a clear statement of the aims of the research? ☐ Yes ☐ No ☐ Can't Tell

CONSIDER:
- *what was the goal of the research?*
- *why was it thought important?*
- *its relevance*

2. Is a qualitative methodology appropriate? ☐ Yes ☐ No ☐ Can't Tell

CONSIDER:
- *If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants*
- *Is qualitative research the right methodology for addressing the research goal?*

3. Was the research design appropriate to address the aims of the research? ☐ Yes ☐ No ☐ Can't Tell

CONSIDER:
- *if the researcher has justified the research design (e.g., have they discussed how they decided which method to use)*

4. Was the recruitment strategy appropriate to the aims of the research? ☐ Yes ☐ No ☐ Can't Tell

CONSIDER:
- *If the researcher has explained how the participants were selected*
- *If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study*
- *If there are any discussions around recruitment (e.g. why some people chose not to take part)*

5. Was the data collected in a way that addressed the research issue? ☐ Yes ☐ No ☐ Can't Tell

CONSIDER:

- *If the setting for the data collection was justified*
- *If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)*
- *If the researcher has justified the methods chosen*
- *If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)*
- *If methods were modified during the study. If so, has the researcher explained how and why*
- *If the form of data is clear (e.g. tape recordings, video material, notes etc.)*
- *If the researcher has discussed saturation of data*

6. Has the relationship between researcher and participants been adequately considered? ☐ Yes ☐ No ☐ Can't Tell

CONSIDER:
- *If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location*

- *How the researcher responded to events during the study and whether they considered the implications of any changes in the research design*

Section B: What are the results?

7. Have ethical issues been taken into consideration?	☐Yes ☐ No ☐ Can't Tell

CONSIDER:
- *If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained*
- *If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)*
- *If approval has been sought from the ethics committee*

8. Was the data analysis sufficiently rigorous?	☐Yes ☐ No ☐ Can't Tell

CONSIDER:
- *If there is an in-depth description of the analysis process*
- *If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data*
- *Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process*
- *If sufficient data are presented to support the findings*
- *To what extent contradictory data are taken into account*
- *Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation*

9. Is there a clear statement of findings?	☐Yes ☐ No ☐ Can't Tell

CONSIDER:
- *If the findings are explicit*
- *If there is adequate discussion of the evidence both for and against the researcher's arguments*
- *If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)*
- *If the findings are discussed in relation to the original research question*

Section C: Will the results help locally?

10. How valuable is the research?	☐Yes ☐ No ☐ Can't Tell

CONSIDER:
- *If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g., do they consider the findings in relation to current practice or policy, or relevant research-based literature*
- *If they identify new areas where research is necessary*
- *If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used*

Mixed Method Appraisal Tool (MMAT) version 2018								**Score**
Screening questions								
Author	**Are there clear research questions?**	**Do the collected data allow to address the research questions?**	**Is there an adequate rationale for using a mixed methods design to address the research question?**	**Are the different components of the study effectively integrated to answer the research question?**	**Are the outputs of the integration of qualitative and quantitative components adequately interpreted?**	**Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?**	**Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?**	
Parrott et al. (2011)	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Moderate
McKillop and Joy (2013)	Yes	No	No	No	No	No	No	Weak
Lam et al. (2014)	Yes	Yes	Yes	No	No	No	No	Weak
Aditama et al. (2020)	Yes	Yes	Yes	Yes	No	Yes	Yes	Strong

Modified CASP Cohort study checklist														
Author	Are the results of the study valid?								What are the results?		Will the results help locally?			
	Did the study address a clearly focused issue?	Did the authors use appropriate methods to answer their question?	Was the cohort recruited in an acceptable way?	Was exposure measured to minimise bias?	Was outcome measured to minimise bias?	Have the authors identified all confounding factors?	Have they taken into account of the confounding factors in the design and/or analysis?	Was follow up complete?	Are results presented transparently and precisely?	Are the results plausible?	Can the results be applied to the local population?	Do the results fit with other evidence?	Does this study have direct implications for practice?	Score
McHorney and Spain (2011)	Yes	Yes	Yes	Yes	No	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	>7 strong
Son et al. (2010)	No	Yes	Yes	Yes	Yes	Yes	Yes	No	No	No	Yes	No	No	Moderate
Stack et al. (2010)	Yes	Yes	No	Yes	Yes	Yes	Yes	No	Yes	No	No	No	No	Moderate
Solomon et al. (2011)	Yes	Yes	No	Yes	No	No	Yes	No	No	Yes	Yes	No	Yes	Moderate
Freitas et al. (2012)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	>7 strong
Laba et al. (2012)	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	>7 strong

Manouchehri et al. (2012)	No	Yes	Yes	No	No	Yes	Yes	No	Yes	No	Yes	Yes	Yes	Moderate
Stavropoulou (2012)	Yes	Yes	Yes	Yes	Yes	No	Yes	No	Yes	No	No	No	No	Moderate
Noohi et al. (2013)	No	Yes	No	Yes	No	Yes	No	No	Yes	No	Yes	Yes	Yes	Moderate
Nelson et al. (2013)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	>7 strong
Al-Hajje et al. (2015)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	>7 strong
Farzandipour et al. (2015)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	No	Yes	Yes	Yes	>7 strong
Kromer et al. (2015)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	>7 strong
Wong et al. (2015)	No	Yes	No	Yes	No	Yes	Yes	No	Yes	No	Yes	No	Yes	Moderate
Morris et al. (2016)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	No	Yes	>7 strong
Malayala and Raza (2016)	Yes	Yes	Yes	Yes	No	No	Yes	No	Yes	No	No	Can't tell	No	Moderate

Patel et al. (2016)	No	Yes	Yes	Yes	Yes	No	Yes	No	Yes	No	Yes	Can't tell	No	Moderate
Wouters et al. (2016)	Yes	Yes	Yes	Yes	Yes	No	Yes	No	Yes	No	Yes	Yes	Yes	>7 strong
Adefris et al. (2017)	Yes	Yes	No	Yes	Yes	Yes	Yes	No	Yes	Yes	No	Yes	Yes	>7 strong
Özdemir et al. (2017)	Yes	Yes	Can't tell	Yes	Yes	No	Yes	No	Yes	Yes	Yes	Yes	No	>7 strong
Carneiro-Leão et al. (2018)	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	No	No	No	No	Can't tell	Moderate
Ghimire et al. (2018)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	>7 strong
Kriegbaum and Lau (2018)	Yes	Can't tell	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	>7 strong
Bartolomé-García et al. (2019)	No	Can't tell	No	No	No	No	Yes	No	Yes	No	No	Yes	No	Weak
Dennis et al. (2011)	Yes	Can't tell	Yes	Yes	No	Yes	Yes	No	Yes	No	Yes	Yes	No	>7 strong

Golub et al. (2013)	Yes	Can't tell	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	>7 strong
Haberer et al. (2013)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	>7 strong
MacDonell et al. (2013)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	>7 strong
McAllister et al. (2013)	Yes	Yes	Yes	Yes	Yes	No	Yes	No	Yes	No	Yes	Yes	Yes	>7 strong
Sjölander et al. (2013)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	No	Yes	Yes	Yes	>7 strong
Sofianou et al. (2013)	Yes	Yes	Yes	Yes	Yes	No	Yes	No	Yes	No	Yes	Yes	Yes	>7 strong
Zwikker et al. (2014)	Yes	Can't tell	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	>7 strong
Gadallah et al. (2015)	Yes	Can't tell	Can't tell	Yes	Yes	Yes	Yes	No	Yes	No	Yes	Yes	Yes	>7 strong
Betegnie et al. (2016)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	No	Yes	Yes	Yes	Morerate
Shafi et al. (2018)	Yes	Yes	No	Yes	No	Yes	Yes	No	No	No	No	Yes	Yes	Morerate

Fung et al. (2018)	Yes	Can't tell	No	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Yes	No	Morerate
Suh et al. (2018)	Yes	Can't tell	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	No	Weak

CASP Qualitative Study checklist

Article	**Was there a clear statement of the aims of the research?**	**Is qualitative methodology appropriate?**	**Was design appropriate to address the aims?**	**Was the recruitment strategy appropriate to match aims?**	**Was the data collected in a way that addresses the research issue?**	**Has the relationship between researcher and participants been adequately considered?**	**Have ethical issues been taken into considerati on?**	**Was the data analysis sufficiently rigorous**	**Is there a clear statement of findings**	**Is the research valuable?**	**Score**
Han et al. (2019)	Yes	Yes	No	Yes	Yes	No	Yes	Yes	Yes	Yes	Morerate
Lovell et al. (2017)	Yes	Yes	Yes	Yes	Yes	No	Yes	No	Yes	No	Morerate
Xi et al. (2011)	Yes	Yes	Yes	No	No	Yes	No	No	Yes	Yes	Morerate
Johnston and Noble (2012b)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	>7 strong
Seah et al. (2015)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	>7 strong

Wai et al. (2010)	Yes	Yes	Yes	No	No	No	Yes	No	Yes	No	Morerate
Tumwine et al. (2012)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	>7 strong
Salter et al. (2014)	Yes	Yes	Yes	Yes	Yes	No	Yes	No	Yes	No	Morerate
Laba et al. (2015)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	No	Yes	Morerate
Goldsmith et al. (2017)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Morerate
Hollander et al. (2017)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	>7 strong
Holten et al. (2018)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	>7 strong
Saqib et al. (2018)	Yes	Yes	Yes	No	Yes	No	Yes	Yes	Yes	Yes	>7 strong
Raghunath et al. (2019)	Yes	Yes	Yes	Yes	Yes	Yes	No	No	Yes	No	Morerate
Tan et al. (2019)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	>7 strong
Håkonsen and Toverud (2011)	Yes	Yes	Yes	No	No	No	No	No	No	No	Weak
Ghimire et al. (2017)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	>7 strong

Appendix 3 Approval letters (UOH & MOH Oman)

UNIVERSITY
OF HULL

University of Hull
Hull, HU6 7RX
United Kingdom
T: +44 (0)1482 463336 | **E:** e.walker@hull.ac.uk
w: www.hull.ac.uk

PRIVATE AND CONFIDENTIAL
Sharifa Al Zadjali
Faculty of Health Sciences
University of Hull
Via email

9th February 2022

Dear Sharifa

REF FHS363 - Why do patients with end-stage renal disease decide non- concordance with haemodialysis medical advice when they offered it? Form C

Thank you for submitting your ethics Form C: Notice of Substantial Amendment to the Faculty of Health Sciences Research Ethics Committee.

Given the information you have provided I confirm approval by Chair's action.

Please refer to the Research Ethics Committee web page for reporting requirements in the event of any amendments to your study.

Should an Adverse Event need to be reported, please complete the Adverse Event Form and send it to the Research Ethics Committee FHS-ethicssubmissions@hull.ac.uk within 15 days of the Chief Investigator becoming aware of the event.

I wish you every success with your study.

Yours sincerely

Professor Liz Walker
Chair, FHS Research Ethics Committee

UNIVERSITY
OF HULL

Liz Walker | Professor of Health and Social Work Research |
Faculty of Health Sciences
University of Hull
Hull, HU6 7RX, UK
www.hull.ac.uk
e.walker@hull.ac.uk | 01482 463336
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Sultanate of Oman
Ministry of Health
Directorate General of Planning and Studies

سلطنة عمان
وزارة الصحة
المديرية العامة للتخطيط والدراسات

Ref. : MoH/DGPS/CSR/PROPOSAL_ APPROVED/80/2021

Date : 30/09/2021

الرقم :

التاريخ :

الموافق :

Sharifa Al Zadjali
Principal Investigator

Study Title: Why do patients with end-stage renal disease decide non- concordance with haemodialysis medical advice when they offered it?

Proposal ID: MoH/CSR/21/24954

After compliments,

We are pleased to inform you that your research proposal **'Why do patients with end-stage renal disease decide non- concordance with haemodialysis medical advice when they offered it?'** has been approved by the Research and Ethical Review & Approval Committee, Ministry of Health.

The RERAC should be notified in case of any changes or significant deviation from the approved proposal, otherwise this approval will be deemed invalid. On completion of the study, you are required to provide a copy of the final report within 2 months to the Centre of Studies and Research in Ministry of Health.

Regards,

Dr Halima Qalam Al Hinai
Acting Director General of Planning and Studies
Acting Chairman, Research and Ethical Review & Approval Committee
Ministry of Health, Sultanate of Oman

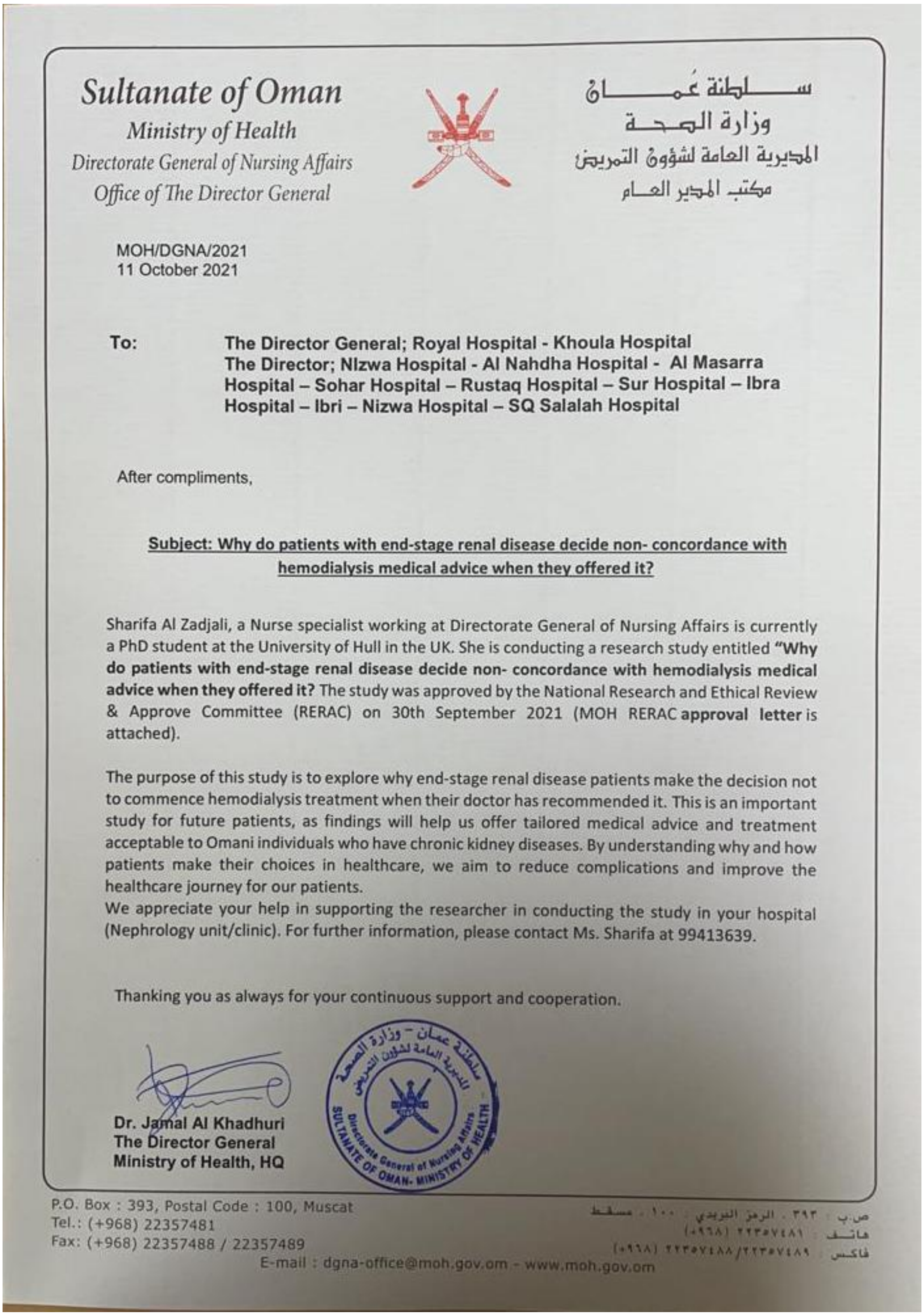
Cc: Day file

P.O. Box : 393, Postal Code: 100, Muscat
Tel.: 22357254, Fax : 22357260

E-mail: dg.plan16@gmail.com

ص.ب : ٣٩٣ ،الرمز البريدي : ١٠٠
مسقط ، هاتف: ٢٢٣٥٧٢٥٤، فاكس : ٢٢٣٥٧٢٦٠

Appendix 4 Directorat General of Nursing Affaires letter



Sultanate of Oman
Ministry of Health
Directorate General of Nursing Affairs
Office of The Director General

سلطنة عمان
وزارة الصحة
المديرية العامة لشؤون التمريض
مكتب المدير العام

MOH/DGNA/2021
11 October 2021

To:
The Director General; Royal Hospital - Khoula Hospital
The Director; NIzwa Hospital - Al Nahdha Hospital - Al Masarra Hospital – Sohar Hospital – Rustaq Hospital – Sur Hospital – Ibra Hospital – Ibri – Nizwa Hospital – SQ Salalah Hospital

After compliments,

Subject: Why do patients with end-stage renal disease decide non- concordance with hemodialysis medical advice when they offered it?

Sharifa Al Zadjali, a Nurse specialist working at Directorate General of Nursing Affairs is currently a PhD student at the University of Hull in the UK. She is conducting a research study entitled **"Why do patients with end-stage renal disease decide non- concordance with hemodialysis medical advice when they offered it?** The study was approved by the National Research and Ethical Review & Approve Committee (RERAC) on 30th September 2021 (MOH RERAC **approval letter** is attached).

The purpose of this study is to explore why end-stage renal disease patients make the decision not to commence hemodialysis treatment when their doctor has recommended it. This is an important study for future patients, as findings will help us offer tailored medical advice and treatment acceptable to Omani individuals who have chronic kidney diseases. By understanding why and how patients make their choices in healthcare, we aim to reduce complications and improve the healthcare journey for our patients.
We appreciate your help in supporting the researcher in conducting the study in your hospital (Nephrology unit/clinic). For further information, please contact Ms. Sharifa at 99413639.

Thanking you as always for your continuous support and cooperation.

Dr. Jamal Al Khadhuri
The Director General
Ministry of Health, HQ

P.O. Box : 393, Postal Code : 100, Muscat
Tel.: (+968) 22357481
Fax: (+968) 22357488 / 22357489
E-mail : dgna-office@moh.gov.om - www.moh.gov.om

ص.ب : ٣٩٣ . الرمز البريدي : ١٠٠ . مسقط
هاتف : (٩٦٨+) ٢٢٣٥٧٤٨١
فاكس : (٩٦٨+) ٢٢٣٥٧٤٨٨/٢٢٣٥٧٤٨٩

Appendix 5 Amendment approval letter

UNIVERSITY
OF HULL

University of Hull
Hull, HU6 7RX
United Kingdom
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w: www.hull.ac.uk

PRIVATE AND CONFIDENTIAL
Sharifa Al Zadjali
Faculty of Health Sciences
University of Hull
Via email

9th February 2022

Dear Sharifa

REF FHS363 - Why do patients with end-stage renal disease decide non- concordance with haemodialysis medical advice when they offered it? Form C

Thank you for submitting your ethics Form C: Notice of Substantial Amendment to the Faculty of Health Sciences Research Ethics Committee.

Given the information you have provided I confirm approval by Chair's action.

Please refer to the Research Ethics Committee web page for reporting requirements in the event of any amendments to your study.

Should an Adverse Event need to be reported, please complete the Adverse Event Form and send it to the Research Ethics Committee FHS-ethicssubmissions@hull.ac.uk within 15 days of the Chief Investigator becoming aware of the event.

I wish you every success with your study.

Yours sincerely

Professor Liz Walker
Chair, FHS Research Ethics Committee

UNIVERSITY
OF HULL

Liz Walker | Professor of Health and Social Work Research |
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Appendix 6 English Invitation letter & partcipant's information sheet

Invitation letter

Dear Patient,

You are invited to participate in a research project designed to understand and explore why end-stage kidney disease patients decide not to start Haemodialysis when medically advised. I will conduct the research project, Sharifa Al Zadjali, a full-time PhD student at the University of Hull in the UK. My research project is supervised by Professor Mark Hayter (M.Hayter@hull.ac.uk) and Doctor Amanda Lee (A.J.Lee@hull.ac.uk).

You are invited to participate in this study if you are an End-Stage kidney failure at stage 5, decided not to start Haemodialysis when medically advised.

If you are interested in this study, you need to understand why the research is being done and why you understand your participation. Therefore, please take the time to read the attached information sheet carefully. Ask me if there is anything that is unclear or if you would like more information and clarification.

Kind regards,

Would you please not hesitate to contact me for further clarification

Sharifa Said Al Zadjali

Faculty of Health sciences

Department of paramedical, Preoperative and Advanced Practice

University of Hull

Phone No: 0096899413639

E.mail: S.S.AL-ZADJALI-2019@HULL.AC.UK

INFORMATION SHEET FOR PATIENTS WITH ESKD

Version 3 23/8/2021

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Title of study

Why do patients with end-stage kidney disease decide non- concordance with haemodialysis medical advice when they offered it?

I would like to invite you to participate in this project which forms part of my research. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

The purpose of the study is to explore why end-stage kidney disease patients make the decision not to commence haemodialysis treatment when their doctor has recommended it. This is an important study for future patients, as findings will help us offer tailored medical advice and treatment acceptable to Omani individuals who have chronic kidney diseases. By understanding why and how patients make their choices in healthcare, we aim to reduce complications and improve the healthcare journey for our patients.

Why have I been invited to take part?

You are being invited to participate in this study because you have unique and valuable experience as a patient. Your views are of considerable interest because we want to determine what things influence your choices and decision making in your care. Sharing your experience may help us clarify the strategies needed to promote nephrology care in Oman.

What will happen if I take part?

Having read this information sheet and had the opportunity to ask questions, you will be asked to sign a consent form if you choose to take part in the study. So, that sections of your medical notes that are relevant to this research project may be accessed by the researcher from the University of Hull and the Research & Ethical Review & Approval Committee (RERAC) Ministry of Health Oman has given permission to access the medical records. Additionally, you can attend one face-to-face discussion with a researcher who has no input into your care. These interviews will take place in the outpatient nephrology clinic, in a private space or a place you prefer. The interview will be digitally recorded and take around 30-60 minutes; this will only be done with your consent. It is not anticipated that the interview will exceed one hour. During the interview, you will be asked to share your experiences with your care in the Omani healthcare system. Please be assured the researcher is interested in your experiences, so there no right or wrong answers. You can be assured the responses will all be anonymous, and at no time will participation affect any of your continuing care and treatment. So, we can analyse responses, interviews will be audio-recorded and transcribed. All records will be anonymised and then securely held. Records will only be accessed by the researcher and her academic supervisory team.

However, If CCOVID19 status hindered face-to-face interviews, you will be interviewed remotely through the Zoom platform, which is accessible in the country through flexible interview scheduling.

Payment/Incentives

you will receive no payment

What are the possible risks of taking part?

It is not anticipated that taking part in the study will cause you any harm. However, If you have concerns about any study aspects, you should speak to the researcher, who will do her best to clarify your concerns, and the contact details are listed below. If you consent to an interview, you are under no obligation to proceed. You do not have to give a reason for changing your mind. If the interview triggered an unpleasant feeling for you or experiencing distress during the interview, the researcher will stop the interview and provide support and reassurance. Then you will be asked whether you wish to continue the interview or not. If you feel to continue then, the interview will resume by the researcher. However, suppose you feel unable to continue the interview, the researcher will stop the interview totally and move you to another quiet area and encourage you to seek assistance, advice and support from your treating physician and nurse or anyone you prefer.

What are the possible benefits of taking part?

It is not expected that taking part in the study will benefit you directly, but findings from this research will be used to inform future patients so that we can support their choices more effectively and help their continuing care.

Data handling and confidentiality

Your data will be processed in accordance with the General Data Protection Regulation (GDPR).

All printed documents that include your detailed information will be stored in a secured cupboard and transcribed audio recording interviews will be stored in a computer that requires a protected password and stored on online Box data repositories password-controlled that fulfils the GDPR guideline at the University of Hull, and all will be accessible to the researcher only. Therefore, all information related to the study will be destroyed after the completion of five years, according to the University of Hull's rules and regulations. Involved researchers in the study will have access to the data in their capacity as the researcher's supervisors but in an anonymised form only.

Your identity will be anonymous throughout the study process, and this includes sharing interview information with other researchers involved in the study, the person checking the transcript translation, study writing up, study publication and academic conferences presentation. It will not be possibly identified from your transcribed audio-recording discussion or from your demographic information or direct quotations used. Because after your permission, you and your treating health institution will be identified by a specific code that is known by the researcher only.

In addition to ensuring your confidentiality, the researcher is responsible for protecting you and providing suitable support. At some certain exceptional circumstance, you mentioned information that prompts concern and relates to your and other individuals' safety. The researcher at this stage may need to take appropriate action such as report this to her supervisors and then to an appropriate authority (health institution director) after discussing this with you first.

Data Protection Statement

The data controller for this project will be the University of Hull. The University will process your personal data for the purpose of the research outlined above. The legal basis for processing your personal data for research purposes under GDPR is a 'task in the public interest' You can provide your consent for the use of your personal data in this study by completing the consent form that has been provided to you. Information about how the University of Hull processes your data can be found at https://www.hull.ac.uk/choose-hull/university-and-region/key-documents/data-protection.aspx

You have the right to access information held about you. Your right of access can be exercised in accordance with the General Data Protection Regulation. You also have other rights, including rights of correction, erasure, objection, and data portability. Questions, comments and requests about your personal data can also be sent to the University of Hull Data Protection Officer [dataprotection@hull.ac.uk]. If you wish to lodge a complaint with the Information Commissioner's Office, please visit www.ico.org.uk.

What if I change my mind about taking part?

You are free to withdraw at any point of the study without having to give a reason. Withdrawing from the study will not affect you in any way. You are able to withdraw your data from the study before interview transcription, after which withdrawal of your data will no longer be possible due to all data collected will have been anonymised. If you choose to withdraw from the study, we will not retain the information you have given thus far

What will happen to the results of the study?

The anonymised study results will be used for a PhD thesis which will be available as a hard copy and electronic Ethesis database held in affiliation with the University of Hull. Results may be used for academic journal publications, academic conferences and to inform discussions with key stakeholders and decision-makers at the governmental level.

Who has reviewed this study?

The Faculty of Health Sciences Ethics Committee reviewed the research study, University of Hull and by the Ministry of Health Oman Research & Ethical Review & Approval Committee (RERAC) to protect your interests.

Who should I contact for further information?

If you have any questions or require more information about this study, please contact me using the following contact details:

Sharifa Said Al Zadjali

E.mail: S.S.AL-ZADJALI-2019@HULL.AC.UK

Phone No: 0096899413639

Faculty of Health sciences

Department of paramedical, Preoperative and Advanced Practice

University of Hull

What if I have further questions, or if something goes wrong?

If you wish to make a complaint about the conduct of the study, you can contact the University of Hull using the details below for further advice and information:

Student project: Why do patients with end-stage kidney disease decide non- concordance with haemodialysis medical advice when they offered it?

In the first instance please contact

Primary supervisor: Professor Mark Hayter, RN, PhD, BA (Hons), Cert. Ed, M.Med.Sci, FEANS, SFHEA, FRCSI, FAAN. Editor-in Chief, Journal of Clinical Nursing

M.hayter@hull.ac.uk

Secondary supervisor: Dr Amanda Lee/ Senior Lecturer

Ass. Editor Nursing Open

a.j.lee@hull.ac.uk

Alternatively, please contact coo@hull.ac.uk

Thank you for reading this information sheet and for considering taking part in this research.

Appendix 7 English interview scheduale

UNIVERSITY OF Hull

Interview schedule

At the start, during and before the interview ends, participants will be reminded about their **confidentiality and withdrawal rights**

S. No	Activities	Time frame	
1-	**Great the participants** **Discuss with the participants** • Research purpose, interview process and time frame. • Ethical principles applied to the study. • Information sheet.	5-10 minutes	
2-	Obtain the informed consent	5 minutes	
3-	**Example of interview guided questions** • Can you tell me about your health condition? • When did you first diagnosed with ESKD and interarticular stage 5? • What did your doctor say about your future treatment? • Why did you decide not to start HD? • In your opinion, what are the factors that might influence your HD refusal decision? • Did you discuss your health issue with anyone who? How? and why? • How have others in your family reacted to your ERSD status and decision made? • Describe your information sources about ESKD and HD? • How do you feel now after the decision made? • Can you describe your future plan concerning your health condition progression?	40-50 minutes	**Example of probing questions** • Could you tell me more about it/ that? • That's interesting, why do you think this? • What did you do about that? • What effect did that have? • What do others think about it? • Can I just take you back to…? • When you say … do you mean …? • Can you explain how this links to what I was asking about in a bit more detail? • Can you give any examples?
4-	**Closing questions** • Do you want to add more information? • Thank you for your participation today.		• Is there anything you think I haven't asked you?

Appendix 8 Arabic interview scheduale

جدول المقابلة

في بداية المقابلة وأثناءها وقبل انتهائها، سيتم تذكير المشاركين بشأن السرية وحقوق الانسحاب

م	ألانشطة	الإطار الزمني	
1-	الترحيب بالمشاركين النقاش مع المشاركين بالاتي • الغرض من البحث وعملية المقابلة والإطار الزمني. • تطبيق المبادئ الأخلاقية على الدراسة. • ورقة المعلومات.	10-5 دقائق	
2-	الحصول على الموافقة	5 دقائق	
3-	**مثال على أسئلة دليل المقابلة** • هل يمكن أن تخبرني عن حالتك الصحية؟ • متى تم تشخيصك لأول مرة بالداء الكلوي بمراحله الأخيرة (المرحلة 5)؟ • ماذا قال طبيبك عن علاجك المستقبلي؟ • لماذا قررت عدم البدء بالغسيل الكلوي الدموي؟ • في رأيك، ما هي العوامل التي قد تؤثر على قرار رفضك للغسيل الكلوي الدموي؟ • هل ناقشت مشكلتك الصحية مع أي شخص؟ كيف؟ ولماذا؟ • كيف كان ردة فعل الآخرين في عائلتك لحالتك الصحية ERSD ولقرارك؟ • صف مصادر المعلومات الخاصة بك حول الداء الكلوي بمراحله الأخيرة وغسيل الكلى الدموي (HD)؟ • كيف تشعر الآن بعد اتخاذ القرار؟ • هل يمكنك وصف خطتك المستقبلية فيما يتعلق بتطور حالتك الصحية؟	50-40 دقيقة	**مثال على فحص الأسئلة** • هل يمكن أن تخبرني المزيد عنها / ذلك؟ • هذا مثير للاهتمام ، لماذا تعتقد ذلك؟ • ماذا فعلت حيال ذلك؟ • ما هو تأثير ذلك؟ • ما رأي الآخرين حيال ذلك؟ • هل يمكنني فقط إعادتك إلى...؟ • عندما تقول... هل تقصد...؟ • هل يمكنك أن تشرح كيف يرتبط هذا بما كنت أسأل عنه بمزيد من التفصيل؟ • هل يمكنك إعطاء أي أمثلة؟
4-	**أسئلة ختامية** • هل تريد إضافة المزيد من المعلومات؟ • شكرا لمشاركتك اليوم.		هل هناك أي شيء تعتقد أنني لم أسألك عنة

Appendix 9 Arabic invitation letter & partcipant's information sheet

خطاب دعوة للمشاركة

عزيزي المريض،

أنت مدعو للمشاركة في مشروع بحثي مصمم لفهم واستكشاف سبب قرار مرضى الكلى في المرحلة النهاية من عدم بدء غسيل الكلى الدموي عندما يتم نصحهم طبيًا. سيجري مشروع البحث، شريفة سعيد الزدجالية، طالبة دكتوراه (بتفرغ كامل) من جامعة هال بالمملكة المتحدة. يشرف على المشروعي البحثي البروفيسور مارك هايتر (M.Hayter@hull.ac.uk).

أنت مدعو للمشاركة في هذه الدراسة إذا كنت تعاني من الفشل الكلوي في المرحلة النهائية تحديدا في المرحلة الخامسة، وقررت عدم بدء غسيل الكلى عندما ينصحك طبيبك بذلك.

إذا كنت مهتمًا بهذه الدراسة، فأنت بحاجة إلى فهم سبب إجراء البحث ولماذا انت مدعوا للمشاركة. لذلك، يرجى أخذ الوقت الكافي لقراءة ورقة المعلومات المرفقة بعناية. اسألني إذا كان هناك أي شيء غير واضح أو إذا كنت ترغب في مزيد من المعلومات والتوضيح.

أطيب التحيات،

أرجو ألا تترددوا في الاتصال بي لمزيد من التوضيح

شريفة سعيد الزدجالية

كلية العلوم الصحية، القسم الطبي، قبل الجراحة والممارسة المتقدمة

جامعة هال

رقم الهاتف: 0096899413639

البريد الإلكتروني: S.S.AL-ZADJALI-2019@HULL.AC.UK

ورقة المعلومات للمرضى الذين يعانون من الداء الكلوي بالمرحله الأخيرة

سوف تحصل على نسخة من ورقة المعلومات هذه

عنوان الدراسة

لماذا يقرر المرضى الذين يعانون من مرض الفشل الكلوي في مراحله النهائية من عدم التوافق مع المشورة الطبية لغسيل الكلى الدموي عندما يعرض عليهم؟

أود أن أدعوكم للمشاركة في هذا المشروع الذي يشكل جزءًا من بحثي. قبل أن تقرر ما إذا كنت ترغب في المشاركة ، من المهم أن تفهم سبب إجراء البحث وما الذي ستشمله مشاركتك. يرجى تخصيص بعض الوقت لقراءة المعلومات التالية بعناية ومناقشتها مع الآخرين إذا كنت ترغب في ذلك. اسألني إذا كان هناك أي شيء غير واضح أو إذا كنت ترغب في مزيد من المعلومات.

ما هو الغرض من الدراسة؟

الغرض من الدراسة هو استكشاف سبب اتخاذ مرضى الكلى في المرحلة النهاية قرارًا بعدم البدء في علاج غسيل الكلى الدموي عندما يوصي الطبيب بذلك. هذه دراسة مهمة للمرضى في المستقبل، حيث ستساعدنا النتائج على تقديم مشورة طبية مخصصة وعلاج مقبول للأفراد العمانيين المصابين بأمراض الكلى المزمنة. من خلال فهم لماذا وكيف يتخذ المرضى خياراتهم في مجال الرعاية الصحية، كما نهدف إلى تقليل المضاعفات وتحسين رحلة الرعاية الصحية لمرضانا.

لماذا تمت دعوتي للمشاركة؟

أنت مدعو للمشاركة في هذه الدراسة لأن لديك خبرة فريدة وقيمة كمريض. تحظى آرائك باهتمام كبير لأننا نريد تحديد الأشياء التي تؤثر على اختياراتك واتخاذك للقرار في رعايتك. قد تساعدنا مشاركة تجربتك في توضيح الاستراتيجيات اللازمة لتعزيز رعاية أمراض الكلى في عمان.

ماذا سيحدث إذا شاركت؟

بعد قراءة ورقة المعلومات هذه وإتاحة الفرصة لك لطرح الأسئلة ، سيُطلب منك التوقيع على نموذج الموافقة إذا اخترت المشاركة في الدراسة. لذلك ، سوف يمكن ذلك الباحثة من جامعة هال الوصول إلى أقسام ملاحظاتك الطبية ذات الصلة بهذا المشروع البحثي ، وقد منحت لجنة البحث والمراجعة الأخلاقية (RERAC) بوزارة الصحة العمانية الموافقة والإذن بالوصول إلى السجلات الطبية . بالإضافة إلى ذلك ، يمكنك حضور مقابلة واحدة وجهًا لوجه مع الباحثة والتي ليس لديها تدخل مباشر في رعايتك الصحية. ستتم هذه المقابلات في العيادة الخارجية لطب الكلى ، في مكان خاص أو في مكان انت تفضله. سيتم تسجيل المقابلة رقميًا وسوف تستغرق المقابلة حوالي 60-90 دقيقة ؛ ولن يتم ذلك إلا بموافقتك. لا يتوقع أن تتجاوز المقابلة ساعة واحدة. أثناء المقابلة ، سيُطلب منك مشاركة خبراتك مع الرعاية الصحية المقدمة لك في نظام الرعاية الصحية العماني. يرجى التأكد من أن الباحثة مهتمة بتجاربك ، لذلك لا توجد إجابات صحيحة أو خاطئة. كما يمكنك أن تتطمئن إلى أن جميع الردود ستكون مجهولة المصدر ، ولن تؤثر المشاركة في أي وقت على أي من استمرار رعايتك

وعلاجك. لذلك ، سيتم تحليل الردود من خلال تسجيل المقابلات الصوتية ونسخها. حيث سيتم إخفاء هوية جميع السجلات ومن ثم الاحتفاظ بها بشكل آمن. لن يتم الوصول إلى السجلات إلا من قبل الباحثة وفريقها الإشرافي الأكاديمي.

ومع ذلك ، إذا أعاقت حالة CCOVID19 المقابلات وجهًا لوجه ، فستتم مقابلتك عن بُعد من خلال منصة Zoom ، والتي يسمح باستخدامها والوصول اليها في الدولة من خلال جدول مقابلات مرن

الدفع / الحوافز

لن تتلقى أي مدفوعات

ما هي المخاطر المحتملة للمشاركة؟

ليس من المتوقع أن تسبب لك المشاركة في الدراسة أي ضرر. ومع ذلك ، إذا كانت لديك مخاوف بشأن أي من جوانب الدراسة ، فيجب عليك التحدث إلى الباحثة ، التي ستبذل قصارى جهدها لتوضيح مخاوفك ، وسيتم سرد تفاصيل الاتصال أدناه. إذا وقعت لأجراء المقابلة ، فأنت لست ملزمًا بالمتابعة ولا داعي لإعطاء سبب لتغيير رأيك. إذا أثارت المقابلة شعورًا غير سار بالنسبة لك أو تعرضت لضيق أثناء المقابلة ، فستقوم الباحثة بإيقاف المقابلة وتقديم الدعم والطمأنينة. ثم سيتم سؤالك عما إذا كنت ترغب في مواصلة المقابلة أم لا. إذا كنت تشعر بالاستمرار في ذلك الوقت ، فستستأنف الباحثة المقابلة. ومع ذلك ، لنفترض أنك تشعر بعدم القدرة على مواصلة المقابلة ، فستقوم الباحثة بإيقاف المقابلة تمامًا ونقلك إلى منطقة هادئة أخرى وسترشدك لطلب المساعدة والمشورة والدعم من طبيبك المعالج والممرضة أو أي شخص تفضله.

ما هي الفوائد الممكنة من المشاركة؟

لا يُتوقع أن تفيدك المشاركة في الدراسة بشكل مباشر، ولكن سيتم استخدام نتائج هذا البحث لإعلام المرضى في المستقبل حتى نتمكن من دعم خياراتهم بشكل أكثر فعالية والاستمرار في مساعدتهم وتقديم الرعاية لهم.

التعامل مع البيانات وسريتها

ستتم معالجة بياناتك وفقًا للائحة العامة لحماية البيانات (GDPR).

سيتم تخزين جميع المستندات المطبوعة التي تتضمن معلوماتك التفصيلية في خزانة آمنة وسيتم تخزين المستندات المكتوبة للمقابلات المسجلة صوتيا في جهاز كمبيوتر يتطلب كلمة مرور محمية وسيتم تخزينها في مستودعات بيانات Box عبر الإنترنت التي يتم التحكم فيها بكلمة مرور والتي تفي بإرشادات GDPR بجامعة هال، وجميعها ستكون متاحة للباحث فقط. لذلك، سيتم إتلاف جميع المعلومات المتعلقة بالدراسة بعد إكمال خمس سنوات وفقًا لقواعد ولوائح جامعة هال. سيتمكن الباحثون المشاركون في الدراسة من الوصول إلى البيانات بصفتهم مشرفي الباحثة ولكن بشكل مجهول الهوية فقط.

ستكون هويتك مجهولة طوال عملية الدراسة، وهذا يشمل مشاركة معلومات المقابلة مع باحثين آخرين مشاركين في الدراسة، وكذلك الشخص الذي سيتحقق من ترجمة النصوص، وعند كتابة الدراسة ونشرها، وأيضا العروض المشاركة فالمؤتمرات الأكاديمية. لن يتم التعرف عليك من خلال التسجيل الصوتي للمقابلات أو من المعلومات الديموغرافية أو الاقتباسات المباشرة المستخدمة. لأنه بعد الحصول على إذن منك، سيتم ترميز هويتك وهوية مؤسستك الصحية المعالجة من خلال رمز محدد يعرفه الباحثه فقط.

بالإضافة إلى ضمان السرية، فإن الباحثة مسؤوله عن حمايتك وتقديم الدعم المناسب لك. في بعض الظروف الاستثنائية، قد تكون ذكرت معلومات تثير القلق وتتعلق بسلامتك وسلامة الأفراد الآخرين. في هذا السياق قد تحتاج الباحثة إلى اتخاذ الإجراء المناسب مثل إبلاغ المشرفين بذلك ثم إلى السلطة المناسبة (كمدير المؤسسة الصحية) بعد مناقشة هذا الأمر معك أولاً.

بيان حماية البيانات

ستكون جامعة هال هي المتحكم في البيانات لهذا المشروع. ستعالج الجامعة بياناتك الشخصية لغرض البحث الموضح أعلاه. الأساس القانوني لمعالجة بياناتك الشخصية لأغراض البحث بموجب اللائحة العامة لحماية البيانات هو "مهمة للمصلحة العامة" يمكنك تقديم موافقتك على استخدام بياناتك الشخصية في هذه الدراسة من خلال استكمال نموذج الموافقة الذي سيتم توفيره لك. يمكن العثور على معلومات حول كيفية معالجة جامعة هال لبياناتك على https://www.hull.ac.uk/choose-hull/university-and-region/key-documents/data-protection.aspx

لديك الحق في الوصول إلى المعلومات المحفوظة عنك. يمكن ممارسة حقك في الوصول وفقًا للائحة العامة لحماية البيانات. لديك أيضًا حقوق أخرى، بما في ذلك حقوق التصحيح والمسح والاعتراض وإمكانية نقل البيانات. يمكن أيضًا إرسال الأسئلة والتعليقات والطلبات حول بياناتك الشخصية إلى مسؤول حماية البيانات بجامعة هال [dataprotection@hull.ac.uk]. إذا كنت ترغب في تقديم شكوى إلى مكتب مفوض المعلومات، يرجى زيارة www.ico.org.uk.

ماذا لو غيرت رأيي بشأن المشاركة؟

أنت حر في الانسحاب من الدراسة في أي وقت دون الحاجة إلى إبداء الأسباب. والانسحاب من الدراسة لن يؤثر عليك بأي شكل من الأشكال. يمكنك سحب بياناتك من الدراسة قبل نسخ المقابلة، وبعد ذلك لن يكون سحب بياناتك ممكنًا نظرًا لأن جميع البيانات التي تم جمعها ستكون مجهولة المصدر. إذا اخترت الانسحاب من الدراسة، فلن نحتفظ بالمعلومات التي قدمتها حتى ذاك الوقت.

ماذا سيحدث لنتائج الدراسة؟

سيتم استخدام نتائج الدراسة مجهولة المصدر لأطروحة الدكتوراه والتي ستكون متاحة كنسخة ورقية وقاعدة بيانات إلكترونية بالاشتراك مع جامعة هال. يمكن استخدام النتائج في منشورات للمجلات الأكاديمية والمؤتمرات الأكاديمية والمناقشات مع أصحاب المصلحة الرئيسيين وصناع القرار على المستوى الحكومي.

من قام بمراجعة هذه الدراسة؟

تم عرض الدراسة البحثية على لجنة أخلاقيات كلية العلوم الصحية بجامعة هال ووزارة الصحة العمانية لجنة البحوث والمراجعة الأخلاقية والموافقة (RERAC) لحماية مصالحك.

بمن يجب علي الاتصال للحصول على مزيد من المعلومات؟

إذا كانت لديك أي أسئلة أو تحتاج إلى مزيد من المعلومات حول هذه الدراسة، فيرجى الاتصال بي باستخدام تفاصيل الاتصال التالية:

شريفة سعيد الزدجالية

البريد الإلكتروني: S.S.AL-ZADJALI-2019@HULL.AC.UK

رقم الهاتف: 0096899413639

كلية العلوم الصحية، القسم الطبي، قبل الجراحة والممارسة المتقدمة بجامعة هال

ماذا لو كان لدي المزيد من الأسئلة ، أو إذا حدث خطأ ما؟

إذا كنت ترغب في تقديم شكوى بشأن إجراء الدراسة، فيمكنك الاتصال بجامعة هال باستخدام التفاصيل أدناه للحصول على مزيد من النصائح والمعلومات:

عنوان مشروع الطالب: لماذا يقرر المرضى الذين يعانون من مرض الفشل الكلوي في مراحله النهائية من عدم التوافق مع المشورة الطبية لغسيل الكلى الدموي عندما يعرض عليهم؟

في المقام الأول يرجى الاتصال

بالمشرف الأساسي: البروفيسور مارك هايتر M.hayter@hull.ac.uk

أو بدلاً من ذلك ، يرجى الاتصال بـ coo@hull.ac.uk

نشكرك على قراءة ورقة المعلومات هذه وعلى الاخذ فالاعتبار بالمشاركة في هذا البحث.

Appendix 10 English consent Form

UNIVERSITY OF Hull

CONSENT FORM

Version 2 24/7/2021

Title of study: **Why do patients with end-stage kidney disease decide non- concordance with haemodialysis medical advice when they offered it?**

Name of Researcher: Sharifa Al Zadjali

Please initial box

1. I confirm that I have read the information sheet dated................... version........... for the above study. I have had the opportunity to consider the information, ask questions and have had any questions answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, ☐
3. I understand that the research interview will be audio-recorded and that my anonymised verbatim quotes may be used in research reports and conference presentations. ☐
4. I understand that relevant sections of my medical notes and data collected during the study may be accessed by the researcher from the University of Hull, where it is relevant to my taking part in this research. I give permission for this individual to have access to my records. ☐
5. I understand that the research data, which will be anonymised (not linked to me), will be retained by the researchers and may be shared with others and publicly disseminated to support other research in the future. ☐
6. I understand that my personal data will be kept securely in accordance with data protection guidelines, and will only be available to the immediate research team ☐
7. I give permission for the collection and use of my data to answer the research question in this study. ☐
8. I agree to take part in the above study. ☐

_____________________ _____________________ _____________________

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

If you have any questions or require more information about this study, please contact me and my supervisors using the following contact details:

Sharifa Said Al Zadjali

E.mail: S.S.AL-ZADJALI-2019@HULL.AC.UK

Phone No: 0096899413639

Faculty of Health sciences

Department of paramedical, Preoperative and Advanced Practice

University of Hull

Primary supervisor: Professor Mark Hayter, RN, PhD, BA (Hons), Cert. Ed, M.Med.Sci, FEANS, SFHEA, FRCSI, FAAN. Editor-in Chief, Journal of Clinical Nursing – M.hayter@hull.ac.uk

Secondary supervisor: Dr Amanda Lee/ Senior Lecturer

Ass. Editor Nursing Open – a.j.lee@hull.ac.uk

Appendix 11 Arabic consent Form

نموذج الموافقة على المشاركة

عنوان الدراسة: لماذا يقرر المرضى الذين يعانون من مرض الفشل الكلوي في مراحله النهائية من عدم التوافق مع المشورة الطبية لغسيل الكلى الدموي عندما يعرض عليهم؟

اسم الباحثة: شريفة الزدجالية

1. أؤكد أنني قرأت ورقة المعلومات المؤرخة 2021/7/24 إصدار 2 الدراسة أعلاه. لقد أتيحت لي الفرصة للنظر في المعلومات وطرح الأسئلة والرد على الأسئلة التي كانت لدي بشكل مرضي. ☐
2. أدرك أن مشاركتي طوعية وأنني حر في الانسحاب في أي وقت دون إبداء أي سبب. ☐
3. أفهم أن المقابلة البحثية سيتم تسجيلها صوتيًا وأن الاقتباسات الحرفية مجهولة المصدر يمكن استخدامها في تقارير البحث وعروض المؤتمرات. ☐
4. أفهم أن الأقسام ذات الصلة من ملاحظاتي الطبية والبيانات التي تم جمعها أثناء الدراسة قد يصل إليها الباحث من جامعة هال، حيث ستكون ذات صلة بمشاركتي في هذا البحث. هنا انا أعطي الإذن لهذا الفرد للوصول إلى سجلاتي. ☐
5. أفهم أن بيانات البحث، التي ستكون مجهولة المصدر (غير مرتبطة بي)، سيتم الاحتفاظ بها من قبل الباحثين ويمكن مشاركتها مع الآخرين ونشرها علنًا لدعم الأبحاث الأخرى في المستقبل. ☐
6. أفهم أنه سيتم الاحتفاظ ببياناتي الشخصية بأمان وفقًا لإرشادات حماية البيانات، وستكون متاحة فقط لفريق البحث الفوري ☐
7. أمنح الإذن بجمع واستخدام بياناتي للإجابة على سؤال البحث في هذه الدراسة. ☐
8. أوافق على المشاركة في الدراسة المذكوره أعلاه. ☐

____________	____________	____________
اسم المشارك	**التاريخ**	**التوقيع**
____________	____________	____________
اسم الشخص الذي أخذ الموافقة	**التاريخ**	**التوقيع**

إذا كانت لديك أي أسئلة أو تحتاج إلى مزيد من المعلومات حول هذه الدراسة، فيرجى الاتصال بي وبالمشرف التابع لي باستخدام تفاصيل الاتصال التالية:

شريفة سعيد الزدجالية

البريد الإلكتروني: S.S.AL-ZADJALI-2019@HULL.AC.UK

رقم الهاتف: 0096899413639

كلية العلوم الصحية، القسم الطبي، قبل الجراحة والممارسة المتقدمة بجامعة هال

المشرف الأساسي: البروفيسور مارك هايتر M.hayter@hull.ac.uk

Appendix 12 English Demographic data form

Participant’s demographic data

Please note that the following demographic information will be used within the interview analysis only. The identifiable data will be removed, each patient will have a unique identifier. it will be stored in SPSS in a password control data repository that fulfils GDPR guidelines at the University of Hull.

Participant’s code: **Institution’s code:** **Interview Date:**

Original Residency: **Current Residency:**

Date diagnosed with ESKD:

1. **Sociodemographic information**

   a. Age:
   b. Gender:

2. **Occupational status, circle the applicable one**

   a. Working what? Where?
   b. Retired/ Pension
   c. Not working

3. **Marital status, circle the applicable one**

   a. Married
   b. Single
   c. Divorce
   d. Widow
   e. Lives with children/ spouse/family

4. **Education level and specify, circle the applicable one**

   a. Illiterate
   b. Read & write only
   c. Primary
   d. Secondary
   e. Higher education (specify)
   f. Others

5. **income status, circle the applicable one**

   a. less than 500 O/R
   b. 500 – 900 O/R
   c. 1000 – 2000 O/R
   d. More than 2000 O/R
   e. Pension or other income
   f.

6. **Nephrology care Mode of treatment**

   a. Non-dialysis care:
   b. Length of kidney follow-up:

   c. Hospitalisations:

7. **Comorbidity, circle the applicable one**

   a. Diabetes
   b. Hypertension
   c. Cardiovascular
   d. Others:
   e. Specify if two or more combined diseases

8. **Stage of kidney disease at the time of research, eGFR:**

Thank you for sharing your views and experiences and valuable contribution, and you are appreciated for your dedicated time and valuable input.

Appendix 13 Arabic Demographic data form.

البيانات الديموغرافية للمشاركين

يرجى ملاحظة أنه سيتم استخدام المعلومات الديموغرافية التالية في تحليل المقابلة فقط. وستتم إزالة البيانات التي يمكن تحديد هويتك من خلالها، حيث سيكون لكل مريض مشارك رمز تعريفي محدد. كما سيتم تخزين هذه المعلومات في منصة برمجيات ال SPSS وفي مستودع البيانات المتحكم به بكلمة مرور والذي يفي بإرشادات اللائحة العامة لحماية البيانات في جامعة هال.

رمز المشارك: رمز المؤسسة: تاريخ المقابلة:

الإقامة الأصلية: الإقامة الحالية:

تاريخ تشخيصك بالداء الكلوي بمراحله الأخيرة (ESKD):

1. المعلومات الاجتماعية الديموغرافية
    - العمر:
    - الجنس:
2. الوضع المهني، ضع دائرة حول الحالة المناسبة
    - يعمل ماذا؟ أين؟
    - متقاعد / معاش
    - لا يعمل
3. الحالة الاجتماعية، ضع دائرة حول الحالة المناسبة
    - متزوج/ة
    - غير مرتبط/ة
    - مطلق/ة
    - أرمل/ة
    - يعيش مع أطفال / زوج / أسرة
4. حدد المستوى التعليمي، وضع دائرة حول المستوى المناسب
    - أمي
    - يقرأ ويكتب فقط
    - ابتدائي
    - ثانوي
    - التعليم العالي (حدد):
    - أخرى
5. حالة الدخل، ضع دائرة حول الحالة المناسبة

- أقل من 500 ريال عماني
- 500-900 ريال عماني
- 1000-2000 ريال عماني
- أكثر من 2000 ريال عماني
- معاش أو دخل آخر

6. أذكر طريقة الرعاية المتبعة لعلاج أمراض الكلى
   - رعاية بدون غسيل الكلى:
   - مدة طويله من المتابعة لأمراض الكلى:
   - التنويم بالمستشفى:

7. الامراض المصاحبة، ضع دائرة حول التشخيص المناسب
   - داء السكري
   - ارتفاع ضغط الدم
   - القلب والأوعية الدموية
   - أمراض أخرى، اذكرها:
   - حدد ما إذا كان هناك مرضان مشتركان أو أكثر

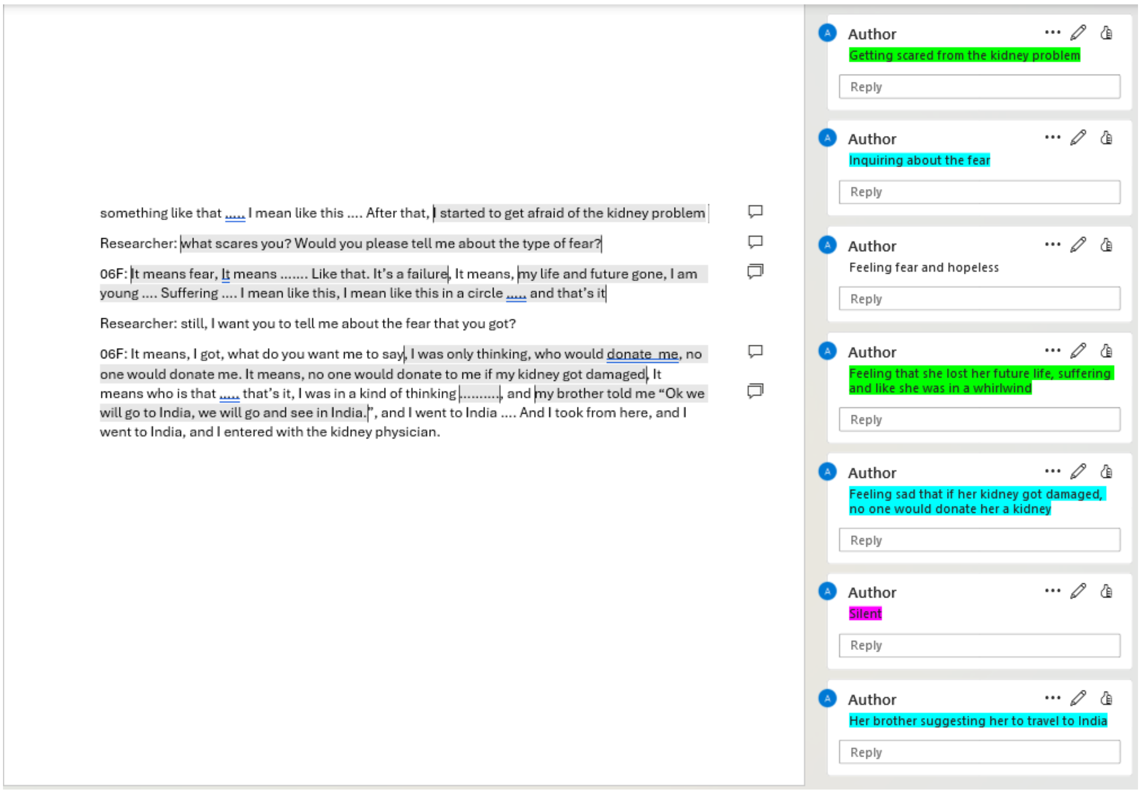
8. مرحلة مرض الكلى وقت البحث، تقدير معدل التصفية (eGFR):

نشكرك على مشاركة آرائك وخبراتك ومساهمتك القيمة، ونقدر لك مشاركتك القيمة ووقتك الذي خصصته للمشاركة.

Appendix 14 Setting of data collection

Figure 8.1 Setting of data collection.

Appendix 15 Line by line coding



something like that ..... I mean like this .... After that, I started to get afraid of the kidney problem

Researcher: what scares you? Would you please tell me about the type of fear?

06F: It means fear, It means .... Like that. It's a failure, It means, my life and future gone, I am young .... Suffering .... I mean like this, I mean like this in a circle ..... and that's it

Researcher: still, I want you to tell me about the fear that you got?

06F: It means, I got, what do you want me to say, I was only thinking, who would donate me, no one would donate me. It means, no one would donate to me if my kidney got damaged, It means who is that ..... that's it, I was in a kind of thinking ...., and my brother told me "Ok we will go to India, we will go and see in India.", and I went to India .... And I took from here, and I went to India, and I entered with the kidney physician.

Author
Getting scared from the kidney problem

Author
Inquiring about the fear

Author
Feeling fear and hopeless

Author
Feeling that she lost her future life, suffering and like she was in a whirlwind

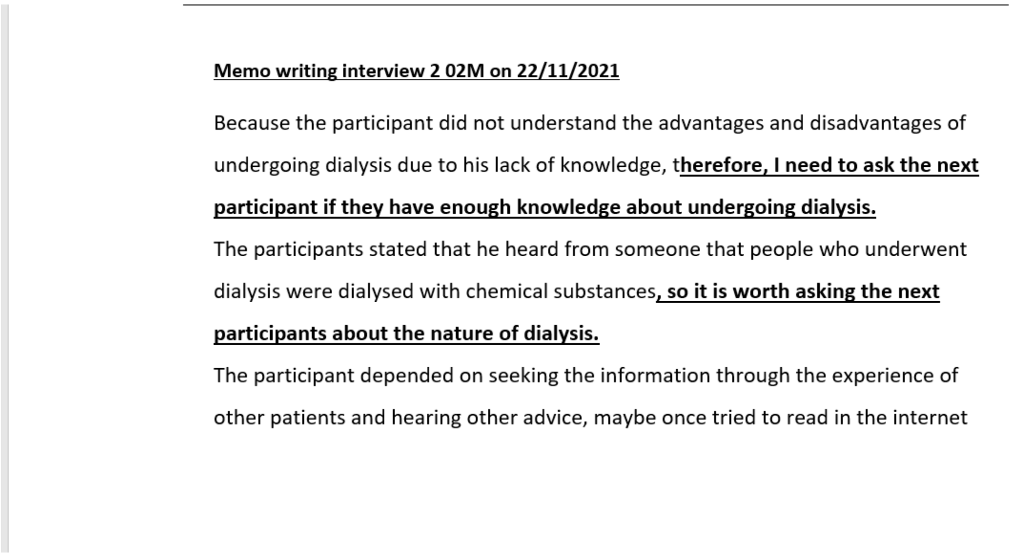
Author
Feeling sad that if her kidney got damaged, no one would donate her a kidney

Author
Silent

Author
Her brother suggesting her to travel to India

Figure 8.2 line by line coding.

Appendix 16 Example of memo writing



Memo writing interview 2 02M on 22/11/2021

Because the participant did not understand the advantages and disadvantages of undergoing dialysis due to his lack of knowledge, t**herefore, I need to ask the next participant if they have enough knowledge about undergoing dialysis.**

The participants stated that he heard from someone that people who underwent dialysis were dialysed with chemical substances**, so it is worth asking the next participants about the nature of dialysis.**

The participant depended on seeking the information through the experience of other patients and hearing other advice, maybe once tried to read in the internet

Figure 8.3 Example of memo writing.

Appendix 17 Axial coding

Initial codes	Axial code
No signs and symptoms, believing young, feeling well and driving a long distance alone, feeling healthy and performing normal life activities, examining own leg and feeling fine, going to bathroom and having nothing and could go and come back normal, and having no pain or other issues.	Feeling asymptomatic
eGFR 15% at a private clinic (normal), eGFR 10% at 02H hospital, then reduced to 7% at (MS) polyclinic without complication signs and symptoms, having normal investigation and believing being young boy and strong.	Having normal investigation
Believing the kidney is fine, passing urine very well, passing normal urine (4-5) times at night, drinking well, eating well & walking, performing sports twice per day, and drinking water all the time, feeling fine and able to perform daily activities & feels strong.	Feeling fine.
Swearing feeling good, no issue of urine burning sensation, urine foam formation & urine delay, having good health, having leg problem only, having normal body, eating well & not feeling tired, looking normal and have the strength to work.	Disbelieving reaching kidney failure.
Missing some hospital follow up appointments, requesting support through medications, believing used medication prevents kidney cysts getting enlarged and increasing urine output, drinking & eating well, physicians stating senility talks, and not having oedema but low haemoglobin and not knowing the cause.	Neglecting/ denying kidney failure complications
Getting surprised and shocked from the news as doing well, refused the treatment and run out of the hospital, getting surprised when informed about kidney problem, not having symptoms proving the sickness, denying that her kidney was in failure, and disbelieving to undergo dialysis one day. not	Disbelieving/ denying reaching kidney failure.

bothering to think about the future since did not reach the dialysis point.	
requesting to continue on medication and emphasising to undergoing dialysis & requesting the physician to have time.	Feeling better

Initial codes	Axial code
Advising not required for HD, advising to performing sport, & Physician planning dialysis when complications becoming obvious, & Kidney functioning at 12% level & having no complication (urine & Oedema)	Hearing what they want to hear
Insuring (in India) that doesn’t require dialysis, having no kidney problem, not to undergo dialysis & continue with medications, & knowing that dialysis initiating at 8% kidney function.	Physicians advise (abroad)
Physician advising and supporting the use of frankincense, reduce weight, avoid taking high quantity and frequency of a specific type of foods.	Information giving
Gaining information through physicians’ discussion, comparing themself with what being informed and what they found, using the mobile phone to trace the information about kidney problem, & sitting with friends (HD users) to gain knowledge, learning through WhatsApp messages, dialysis people complain of pain	Accessing information.
Searching on the internet, using the internet to know about kidney failure signs & symptoms, using Google as main source of searching engine, & searching for symptoms of frequent urination.	Relying on the internet as a source of information.
Discussing the dialysis issue with daughter, believing that daughter knows about the dialysis, relying on daughter to talk to the treating physician because daughter is a medical staff/ having medical background.	relay on daughter’s knowledge.

Working with eGFR 10% (as normal), and heard voice indicates a normal sound, Consulting brothers and sisters about the physician's plan, daughter's friend sharing experience of her mother and providing diet advice to help and stabilised the participants health condition, hearing that undergoing dialysis cause a person to becoming tired and screaming in the hospital, hearing from a neighbour that dialysis is tiring, & Wife hearing from others.	Opinion of others, Hearing from others.
Dialysing with chemical substances, knowing it is machine mixing up blood, believing that blood circulate inside the kidney through tubes put inside the kidney, having no knowledge about dialysis process & Hearing from others, & not interesting to discover about the dialysis, seeing dialysis not good, scaring because it shakes person up and down, feeling that dialysis would hinder attending work, medication discontinuation would cause kidney problem.	Misconception about dialysis
Having no knowledge about the dialysis procedure, believing if starting on dialysis would get sicker & would not end.	Lack of knowledge
Physician talking with daughter in English, and could not understand them, not understanding what the physician spoke to daughter, not informing to have a kidney weakness, Not understanding physician's positions.	Gap of communication
Initial codes	**Axial code**
Taking opinions of HD users about the signs of kidney failure, family not convinced to undergo dialysis, HD users not praising the dialysis, and advising not to undergo dialysis.	Relying on others opinion.
Dialysing experience of sister, dialysis causing tiredness, receiving blood during dialysis causing coma. Hearing the negative experience of father-in-law who undergone dialysis and witnessing the experience of mother-in-law, & not tolerating seeing people connected with oxygen and tubes.	Experience of sister, father-in-law.
Family not wanting him to undergo dialysis as kidney works well, considering dialysis as a burden, building the hope based on family encouragements, believing daughter understands well as educated, wife advising not to undergo dialysis (prohibited), participant's son refusing the catheter creation as it is a metal kept in the participant's flesh. 50% of family refusing HD due to other people's negative consequences,	Influence by family members (wife, mother, sister & brother)

following wife's instruction, wife making the decision for the best choice, relying on wife in everything and following wife's decision and order. Mother requesting to wait and hoping to find a kidney donor.	
Knowing a person who was advised dialysis but travelled to India and did not require dialysis up to tomorrow, comparing themselves with other symptoms kidney failure individuals, football friends saying that dialysis cause tiredness and exhaustion, & people believing that dialysed person would die.	Influenced by others.
Initial codes	**Axial code**
Doing dialysis would cause death, relatives dialysed end up weak, becoming sick after initiating dialysis and health status change, feeling scared to have similar experience of other HD individuals, witnessing dialysed individuals who died after four or five months of their dialysis, refusing dialysis due to the death of his uncle, feeling had enough, and having negative experiences due to death of friends.	Negative experience of others with dialysis
Feeling scared from the disease to become chronic disease, getting scared from dialysis and remaining thinking, feeling scared of the dialysis's blood, it is not an easy procedure, complicated procedure, and person become tired and dizzy. not wanting to be a patient and to be in the hospital daily, dialysis would disturb the life commitment & feeling frightened from the commitment process of dialysis, agreeing that dialysis is a life commitment, dialysis causing too much life disturbance, hindering individuals from going out and travelling in or out of the country. feeling upset and limited freedom. Travelling outside the country challenging and exhausting, hindering a person to go anywhere, having fluid restriction, feeling that they lost their future life, & life would stop, suffering as they were in a whirlwind, feeling life restriction, committed to dialysis and restricted life, not imagining to undergoing dialysis, and word dialysis scaring, & scared to remain on dialysis whole life.	Fearing dialysis procedure.
Scared to leave daughter alone if she died, worrying about his children if he started dialysis, scared not to see her family again, feeling that death might happen faster than with healthy person, witnessing individuals died on dialysis, hearing others' death due to the dialysis start, HD tiring procedure leading to quick death, wishing to live longer.	Feeling scared of death

Family can’t imagine them to undergo dialysis as they would labelled as near to death, could not eat and drink during the social gathering, people discussing the kidney disease topic during social gathering, and feeling pointed by surrounded people.	Community/Social gathering

Initial codes	Axial code
lifting the matter of health condition to his mighty God, trusting in God and would wait for the physician trial results, delegating her affairs to God, having no idea what would happen in the future and accepting whatever comes from God, she would accept dialysis on the day she would become sicker, If developing complications, matters would be at Allah Almighty's hand, Believing God will take over his health matters, Hoping that God may descend some mercy upon her due to the Holy month of Ramadan.	wafering to God.
knowing that he would undergo dialysis if his condition worsened, accepting the dialysis as a last option, If no other solution he would end up doing dialysis, She has no other option because that is her destiny, agreeing for dialysis when time reach, & Having nothing to do at that time only to accept the fact.	Accepting HD as a last option
Faith on God for accepting the fact &having nothing to do with it, accepting what comes from God, believing that God will solve it, What writing by God will happen.	Faith in God.
Accepting to undergo dialysis on the day that God wills, Would agree to undergo dialysis if his condition worsened but he believes that the medication is doing a good job, Waiting to see what would happen till that day, Would undergoing dialysis if no donor found.	Accepting HD at the time of powerlessness & condition worsen.
Evaluating him for couple of months, avoiding dialysis by organising the daily lifestyle.	Requesting delaying the dialysis (bargaining)
Wanting to do kidney implantation, convinced that his health condition would reach to it’s end but he would wait for possible implantation, Waiting for someone to donate money to kidney implantation abroad, Hoping to find association to sponsor her for implantation, Preferring for implantation but not dialysis. not accepting dialysis but will continue on medication till finding donor.	Wanting to go for kidney implantation.

Taking folk remedy and believing it would not harm, using frankincense and pumpkin, believing on pumpkin use as a safe remedy & too beneficial, going for an alternative treatment to avoid HD	Personal practical experience and belief.
Attending private clinic for second consultation, believing might recover if travelled abroad, Seeking second consultation to avoid dialysis, Travelling to Turkey for kidney implantation, discovering doners incompatibility due to physical diseases.	Shopping around.

Appendix 18 Categories formation

Axial code	Sub-category	Category
Feeling asymptomatic	**Not accepting ESKD & HD.**	**Self-conceptualisation**
Having normal investigation		
Feeling fine.		
Disbelieving reaching kidney failure.	**Accepting ESKD but not HD.**	
Neglecting/ denying kidney failure complications		
Disbelieving/ denying reaching kidney failure.		
Feeling better		
Hearing what they want to hear	**Information provided by the Physician.**	**Acquiring knowledge**
Physicians advise (abroad)		
Information giving		
Accessing information.	**Information gathering.**	
Relying on the internet as a source of information.		
relay on daughter's knowledge.		
Opinion of others, Hearing from others.		
Misconception about dialysis	**Knowledge gaps**	
Lack of knowledge		

Gap of communication		
Relying on others opinion.	**Experiences of HD users.**	**Influencers**
Experience of sister, father-in-law.		
Influence by family members (wife, mother, sister & brother)	**Family members and others.**	
Influenced by others.		
Negative experience of others with dialysis	**Fear of HD negative consequences.**	**Fear**
Fearing dialysis procedure.		
Feeling scared of death		
Community/Social gathering	**Fear of feeling stigmatised.**	
wafering to God.	**Fatalism.**	**Self-control**
Accepting HD as a last option		
Faith in God.		
Accepting HD at the time of powerlessness & condition worsen.		
Requesting delaying the dialysis (bargaining).	**Looking for alternatives**	
Wanting to go for kidney implantation.		
Personal practical experience and belief.		
Shopping around.		