Employment Status and Sustainability of Work among Haemodialysis Patients in Saudi Arabia

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Abstract

Background**:** Unemployment and reduced work capacity among people managing Chronic Kidney Disease (CKD) receiving haemodialysis (HD) treatment is high. Whilst we know the treatment is time consuming and patients experience numerous symptoms which hinder their ability to work, there is limited research on how work is sustained and what strategies would retain people with CKD in the labour market. ***Aim:*** The thesis examines employment status, and sustainability of work among HD patients in Kingdom of Saudi Arabia (KSA). ***Methods*****:** A mixed method sequential explanatory approach was used. Phase one (quantitative) administered the Work Productivity Activity Impairment Tool, demographic questionnaire and SF-12: to examine employment status, functioning and wellbeing, work productivity and activity impairment. Phase two (qualitative) adopted semi-structured interviews to generate a deeper understanding of who, what, why and how HD patients continue to work, or not, alongside managing a long-term condition. The research was conducted across two study sites in Riyadh province, targeting a population of people of working age (aged 18-65 years) receiving HD. ***Results*****:** 130 patients completed phase one, 51% male with a mean age 42 years. Only 25% of participants were in employment, predominantly men (91%), reflecting the male dominated labour market of KSA. Physical condition, age and gender were significant predictors for unemployment. For those people employed, 74% reported lost work productivity, and 57% reported activity impairment (employed and unemployed). A convenience sample of 16 patients were interviewed in phase two. Health condition, absence of work ethic, discrimination and policy abuse, social and cultural norms, lack of understanding and support were directly related to a person's impaired activity and ability to sustain employment. ***Conclusion***: This innovative study tested a measure that generated an evidence base to expose the impact of CKD on the labour market. The methodology was useful and replicable across similar countries at identifying productivity reduction and activity impairments among HD patients. In the context of KSA the study exposed unique cultural discrimination and policy abuse, highlighting the need for policy reform and introduction of alternative strategies to enable people with a long-term condition to sustain employment.

Chapter One

Introduction

The PhD thesis presents original research exploring the employment status and sustainability of work among Chronic Kidney Disease (CKD) patients undergoing Haemodialysis (HD) in Saudi Arabia. The study used a mixed methods sequential explanatory design which incorporated both quantitative and qualitative data to gain in-depth understanding of the topic of interest. This chapter provides a fundamental outline and an introduction to the study. It gives a brief description of the topic, the aim and objectives of the study as well as its significance. At the end of this chapter, an overview of how the thesis is structured will be provided.

Background of the Study

Hospital treatment and nursing are often necessary in patients with chronic kidney disease (CKD), which gradually worsens and becomes incapacitating. Undergoing a kidney transplant or dialysis are the only options once failure of the kidneys occur, which is the irreversible final phase of kidney disease. In Saudi Arabia over the past thirty years, final stage CKD has significantly increased in terms of incidence and prevalence (Tolkoff-Rubin, Goldman, & Ausiello, 2007; American Kidney Fund, 2008; MedlinePlus, 2011). This is reported in detail in Chapter Two alongside causes, treatments, and effects of CKD.

It is anticipated that within the next two decades, there will be a 3.5 times increase in the population of Saudi Arabia, which is likely to contribute to increased prevalence of CKD, with numbers expanding yearly (Alsuwaida, Farag, Al Sayyari et al., 2010; Al-Sayyari & Shaheen, 2011). Accurate data is often difficult to extrapolate but it was reported in 2008 that out of 10,203 CKD sufferers receiving haemodialysis (HD), 29.2% were new cases, which accounted for 2976 individuals (Al-Sayyari & Shaheen, 2011).

It is common that, co-morbidity increases and general standard of living decreases for those who are receiving HD as a result of CKD (Curtin, Sitter, Schatell et al., 2004; Barnett, Li Yoong, Pinikahana et al., 2008; Ramani, Dholakiya, Patel et al., 2009; Bağ & Mollaoğlu, 2010; Lingerfelt & Thornton, 2010). This is as a consequence of various related morbidity factors for CKD, that medical practitioners are both aware and unaware of, as well as HD being a complicated procedure, patients often face numerous obstacles in their life. People managing CKD are expected to follow a strict treatment plan of maintaining fluid and diet restrictions, alongside regularly taking prescribed drugs and attending dialysis sessions often at least three times a week (Curtin et al., 2004; Barnett et al., 2008; Bağ & Mollaoğlu, 2010; Lingerfelt & Thornton, 2010). For those patients who struggle to manage their treatment regime, not maintaining their diet and fluid limits, they face an increased risk of co-morbidity, complexities arising from CKD, and the gradual worsening and diminished success of the treatment (Tsay, 2003).

As a previous dialysis nurse, most of the patients I cared for were suffering from many issues related to their medical condition. However, we often did not know anything about their social life; their life outside the dialysis unit or what barriers people faced to sustain and adhere to the treatment plan, their symptoms and how this impacted on their social and personal life. One key factor for a health quality of life among adults is to have productive and sustained employment. Employment is significant for a person’s well-being, to provide the essential resources for living and engagement in society (Mansour, 2009). However, during my work experience as a nurse at the dialysis centre the topic of employment was often never discussed by the patients, social worker, occupational therapists or rehabilitation team. I had the impression that most of the patients in the centre were not working anymore as they were considered too old (above 50 years old). At that time my only awareness that people had continued to work was when some patients asked for a medical report to be sent to their employers indicating that they have been diagnosed with CKD and HD had been initiated in the centre. Indeed, we simply do not know whether CKD patients in Saudi Arabia are working or not, and what may hinder or enable them to sustain employment and maintain a productive work life.

Evidence across different countries reinforces that an individual with CKD wherever they live often has their job or career deeply affected by their illness, alongside their standard of living and day-to-day life being detrimentally influenced (Goldberg, Satow, & Bigwood, 1973; Ferrans & Powers, 1985; Gerhardt, 1990; Curtin et al., 2004; Lingerfelt & Thornton, 2010; Murray, Dobbels, Lonsdale et al., 2014). Employment conflicts with their HD treatment, while tiredness and employees’ lack of toleration of absenteeism from work may result in the career and jobs for people managing CKD being undermined as a consequence of their diagnosis and treatment. Evidence suggests employers have pressured vast numbers of CKD sufferers to resign, or have stopped them from progressing or improving in their chosen employment, and manual work in particular poses a problem to individuals with CKD, often leading to redundancy (Ferrans & Powers, 1985; Murray et al., 2014).

Once an individual with CKD begins HD, their jobs and careers may be detrimentally affected due to various non-medical and medical issues. For instance, there may be issues such as discrimination at work or a lack of compassion, or the individual may have reduced stamina and negative conceptions of oneself. Individuals who have CKD and are treated by HD often have the physical and mental effects overlooked by their place of work, as there is little comprehension of CKD. Murray et al. (2014) suggests that individuals with CKD who have no work usually have problems in obtaining it, while those who do have work commonly lose it as a result of such issues. In Saudi Arabia we have no evidence base as to the extent of the problems people with CKD receiving HD treatment face in sustaining employment. There are no national databases; indeed internationally the evidence on employment for people managing a long term condition (LTC) is not reported or collated at a national level. Information regarding employment and career progression is important when caring for individuals on HD to be able to provide appropriate social and psychological support to people to sustain their quality of life after diagnosis and whilst receiving treatment.

This PhD thesis explores the issues and factors related to sustained employment in a cohort of CKD patients in Saudi Arabia. The wider aspect of employment for people managing a long term conditions is critically analysed, and in particular within the culture and context of Saudi Arabia. The theoretical perspectives and models that may influence the way society views and manages people with a disability, and the perceptions of work and employment among those patients who are considered disabled. Indeed, how these perspectives influence whether people with long term conditions actually pursue or sustain a working career. There is an overwhelming view and demonstrable evidence that working adds a positive element to someone’s quality of life (Mansour, 2009), but for Saudi Arabia there is no evidence that this perspective is supported in society or by the culture and whether people managing a long term condition actually have the opportunity or wish to work.

Significance of the Research

Whilst there is wider evidence that employment has been researched in the field of CKD or long term conditions within other countries (Munir, Jones, Leka et al., 2005; Fisher, Emerson, Firpo et al., 2007; Van der Mei, Kuiper, Groothoff et al., 2011; Julián-Mauro, Molinuevo-Tobalina, & Sánchez-González, 2012; Koolhaas, van der Klink, Vervoort et al., 2013; Shaw, Tveito, & Boot, 2013; Murray et al., 2014), no study has been located to date that has been generated from Saudi Arabia. The lack of a national database as to who works and who does not, suggests that an understanding as to the extent of whether employment or lack of employment is a problem for this cohort of people is unclear. The lack of evidence within this specific cultural context is a concern; often findings are not translatable across different cultures without understanding what is actually happening and the nuances of society and health policies pertinent to Saudi Arabia. For example, dependency and family support were major factors influencing employment within several North American and most European studies (DeGenova, 1997; Bengtson, 2001; Al-Balad, 2014). Whereas, culture and family in Saudi Arabia are “collectivist”, which means that family members, friends, neighbours, and the entire community are all about caring and supporting each other (Al-Balad, 2014).

In addition, the employment system in Saudi Arabia is different to other countries (explained in more detail in Chapter two). The majority of end stage CKD patients work for the government where there is more flexibility, support, and understanding for the employment of a person with a chronic disease. Although, the current employment system in Saudi Arabia does not offer the option of part-time work; workers are hired for full-time positions only across both the private and public sectors. Therefore, the available evidence whilst useful to gain a wider understanding may not be directly applicable to the context of Saudi Arabia, reinforcing the need for this study. Exploring the effect of these and other factors drawn from the literature and the underpinning theory will provide a platform for this study to generate a unique contribution to the knowledge in Saudi Arabia that will inform the management and support provided to people with CKD and potentially other long term conditions.

I worked before for the Ministry of Health. Understanding how we can rehabilitate people managing a long term condition into and contributing to society is important; sustaining employment provides such an opportunity. There is limited understanding about whether health and social care policies in Saudi Arabia facilitate or inhibit employment for this group of people and whether there are additional interventions the Ministry of Health could help get people back into or sustain employment. We first need to explore who is working, the barriers and issues that prevent work, to better understand whether policies, and/or society, and the culture of Saudi Arabia facilitate or hinder this process. The thesis interrogates the current international evidence and experience within the context of CKD and long term condition management and sustained employment before focusing on examining the experiences of people managing CKD on HD within Saudi Arabia. Most significantly the research provides robust new research evidence derived and applicable to Saudi Arabia that informs future health and social care policy.

Purpose of the Research study

Aim of the Research

This study examines the employment status, and sustainability of work among HD patients in Saudi Arabia. The research generates a deeper understanding of who, what, why and how HD patients continue to work, or not, alongside managing a long term condition.

Objectives

Five key objectives include:

1. To identify the employment status, work productivity and activity impairments of HD patients;
2. To understand the impact of CKD on employment achievement and sustainability of work of HD patients;
3. To understand how employed HD patients manage to sustain work, and identify the issues that threaten employment;
4. To understand the barriers that prevent people, receiving HD, to continue to or sustain employment alongside treatment and what enabled them to work;
5. To extend knowledge and understanding of the application of the Capabilities Approach theory and concepts, within health.

Structure of the Thesis

The thesis consists of nine chapters and is structured as follow:

Chapter One: provides a fundamental outline of the thesis structure and brief introduction of the exploration of the research topic, the issues of employment and sustainability of work among CKD patients undergoing HD. It introduces the researcher their background and rationale for focusing on the specific study topic, both to their previous and current role. The study aims and objectives are presented at the outset to provide clarity of focus and a brief overview of the study significance (discussed in further detail in subsequent chapters).

Chapter Two: describes an overview of Saudi Arabia, the context and culture of the country where the study was located, the Saudi Arabian health system, employment data, society challenges, and health and social care strategies. A background context of CKD and HD treatment is offered, such as prevalence and effects. The chapter provides a comprehensive overview of the study key components, CKD, employment and Saudi culture, to facilitate an informed baseline on which to interpret the study findings.

Chapter Three: presents a review of current evidence on the topic of interest, employment and CKD. A search of the literature informed and refined the research question, exposing appropriate methods and was used as a platform from which to compare and validate the study findings. The literature review developed by locating current evidence using a systematic search strategy, critically appraising retrieved literature, identified key themes, gaps in the evidence generating a clear justification for the PhD research.

Chapter Four: examines the theories surrounding the concept of 'disability' often a classification used for people managing a long term condition unable to continue to support themselves through sustained employment due to health issues. The 'social' and 'medical' models of disability, and the International Classification of Functioning, Disability and Health (ICF) are explored in relation to the study context. The chapter introduces the Capability Approach a theoretical framework to consider as a tool to assess the potential for people managing CKD to sustain employment which informs the study outcomes.

Chapter Five: presents the study methodology, a detailed plan of the research design, how the research was conducted the proposed sample, recruitment, approach, ethical issues and systematic steps in the research process. The chapter contains detailed information on the mixed methods design, the research instruments, data collection and analytical methods, and underpinning philosophical assumptions.

Chapter Six: presents the study quantitative findings (Phase one). The chapter focuses on the results from the tools used in the first phase of this study: the Work Productivity Activity Impairment Tool, Health Survey SF-12, alongside participant personal and clinical data. The data measures the self-assessment of research participants with CKD as to their ability to sustain work, and the impact of their chronic disease on their work related achievements, as well as highlighting issues faced by people seeking to continue employment (objectives 1 and 2).

Chapter Seven: presents the integrated data and results from both quantitative and qualitative data (Phase one and two). Incorporating a qualitative approach in this study alongside quantitative data generates a deeper understanding of the employment experiences of people managing a long term illness (objectives 3 and 4). Findings are corroborated and explained reinforcing the value of using the mixed method approach.

Chapter Eight: the discussion chapter draws together and interprets the findings of both phase one (presented in chapter six) and two (presented in chapter seven). The capability approach framework is used to structure the chapter and in order to achieve study objective number five. The chapter closes with the strengths and limitations of the undertaken study.

Chapter Nine: The Conclusion and Recommendations chapter is the last chapter in this PhD thesis. The chapter presents a conclusion of the study findings, theories, discussions and contributions. A dissemination plan and recommendations are also listed in this chapter.

Chapter Two

Background

Introduction

Chronic Kidney disease (CKD) is a serious health condition which can lead to death or disability among many patients especially those undergoing Haemodialysis (HD) treatment. HD treatment is time consuming and patients experience numerous symptoms which could reduce their work capacity and their ability to work and sustain employment. However, there could be other factors than health status contributed to disability among HD patients such as cultural, social, and environmental factors. Identifying and discussing the background of such factors in the context of Saudi Arabia will help for better understanding of the study outcomes, and for better strategies to overcome the issue of unemployment among those groups of patients.

This chapter presents a discussion about CKD and employment in general, an overview of Saudi Arabia including health system, HD treatment and socio-cultural aspects of Saudi Arabia, and the employment and labour market in Saudi Arabia.

Chronic Kidney Disease (CKD) and Haemodialysis (HD)

The kidney is one of the most important organs as it maintains homeostasis in the body (Habibzadeh, 2013). CKD refers to *“any alteration in the kidneys which persists for three months or more resulting in any degree of kidney damage and/or decline in kidney function, regardless of the diagnosis of disease*” (Almutary, Bonner, & Douglas, 2013, p. 17). There are five stages of CKD that can be determined by the rate of the glomerular filtration. End Stage Renal Disease (ESRD), or End stage Kidney Disease, is the most serious stage, stage five CKD and is defined as "*irreversible decline in kidney function, when renal replacement therapy (RRT) is needed for survival*" (Hassanien, Al-Shaikh, Vamos et al., 2012, p. 2).

RRT is vital for patients with kidney failure and has two types: dialysis and kidney transplantation. The gold standard therapy for the majority of patients is a kidney transplant; enabling people with CKD to live longer with a high quality of life, and is more cost-effective compared to long-term dialysis (Hassanien et al., 2012). HD is the most common therapy for kidney failure patients in KSA (Hassanien, Majeed, Watt et al., 2013). In this type of treatment, CKD patients are connected to the dialysis machine for, in most cases, three times a week for three to four hours, a complex and expensive treatment. In KSA, the amount expended on dialysis, per year, is 25 times the per capita annual budgets of the MOH, and the cost of one patient on dialysis, per year, is about five times the individual gross national product ($8,849.05). RRT is available free to all citizens, regardless of age, sex, employment status, or level of education (Subramanian, Jamal, & Shah, 2001).

CKD has been a source of concern for many countries in the world due to the incremental rise in its prevalence and incidence (Hassanien et al., 2013). To reduce the prevalence and delay the progression of such a disease requires a combined effort by many different parties including the government, individuals, families, and society in addition to medical care, and financial support is necessary (Habibzadeh, 2013; Hassanien et al., 2013). Educating people about the risk of obesity and the importance of managing diabetes effectively and other risk factors will have a major positive impact on the prevalence and progression of CKD (Hassanien et al., 2013).

According to the Saudi Centre for Organ Transplantation (SCOT), formerly known as the National Kidney Foundation, the dialysis programme in KSA started in 1970.

SCOT is responsible for setting up a national registry, formulating policies, and monitoring and evaluating procedures for ESRD and organ transplantation. Since 1970 the dialysis services and facilities have increased rapidly in the country (SCOT, 2013). Today, there are 184 dialysis centres with 5086 dialysis machines serving 13160 ESRD patients – 55% male patient and 45% females (Figure 2 & 3). Furthermore, the number of dialysis patients expected to reach 20,000 by the end of 2018, with an incidence of 136 new cases per million population (pmp) (Alsuwaida et al., 2010; SCOT, 2013). Latest statistics show that the majority of CKD patients receiving HD in KSA are in the working age (Figure 4), 18 to 65 years (Almutary et al., 2013; SCOT, 2013; Ministry of Health, 2015).

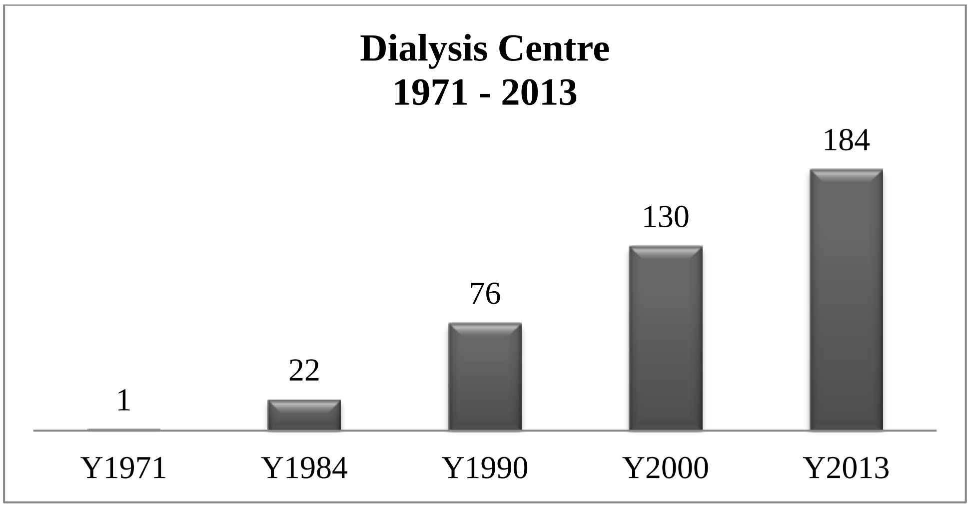

Figure 1: Dialysis Centres in Saudi Arabia 1971 - 2013 (SCOT, 2013)

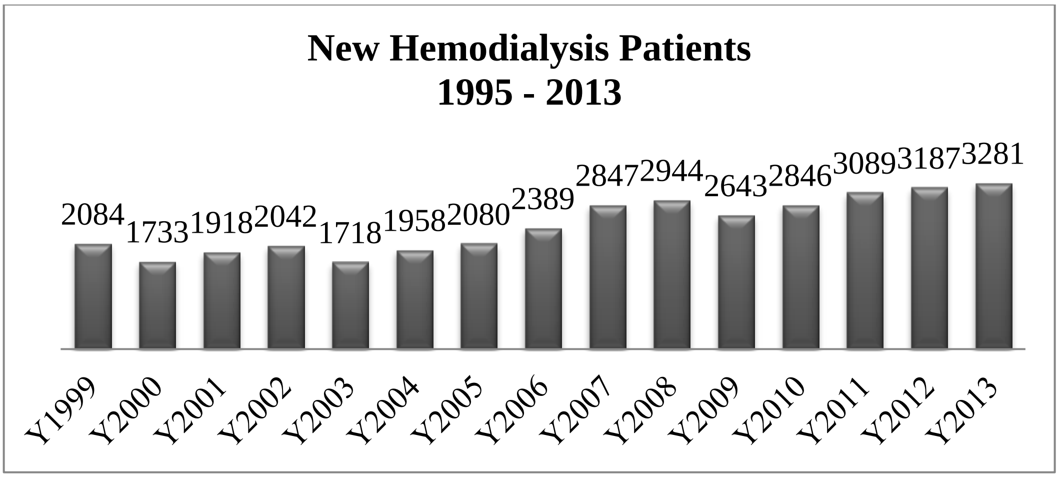

Figure 2: HD patient statistics 1995-2013 (SCOT, 2013, p. 39)

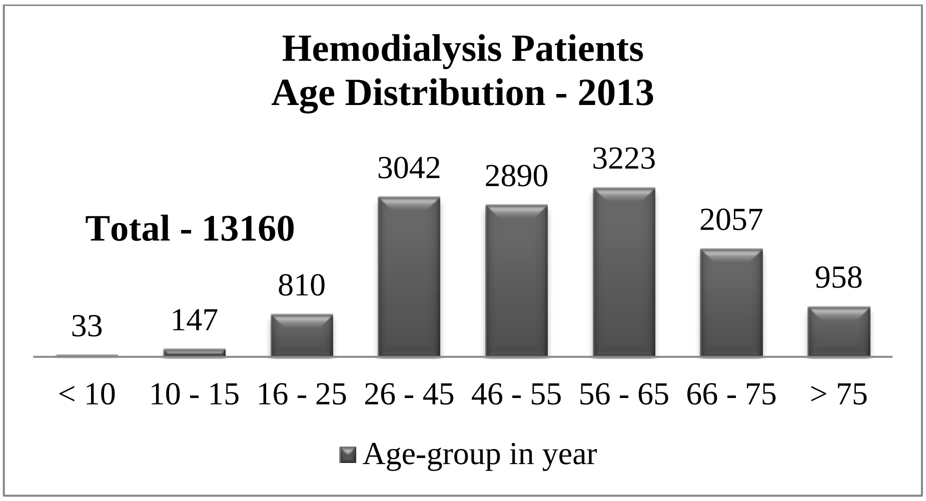

Figure 3: HD patient Age Distribution 2013 (SCOT, 2013, p. 41)

The total number of CKD patients is increasing significantly in the gulf region as well as mortality and morbidity rates among these patients, despite the advancement of health care services and dramatic improvements in technology (Al-Homrany, 2003). However, comprehensive and reliable data on the causes, prevalence and mortality rate of CKD in the gulf region remain limited (Shaheen & Al-Khader, 2005; Hassanien et al., 2012).

According to Hassanien et al. (2012), the main cause of CKD in these countries is diabetes. Whereas, the main cause of death among patients with kidney failure in the Arabic gulf countries is cardiovascular disease and sepsis. Ageing of the population and obesity are other factors contributing to the increment of the prevalence of CKD. Obesity is associated with the rapid growth in the economy of the gulf countries. The prevalence of diabetes in the gulf countries is one of the highest rates in the world (IDF, 2010; Hassanien et al., 2012) and one of the prominent causes of CKD in Saudi Arabia HD patients (SCOT, 2013) (Table 2).

Table 1: Causes of CKD in HD patients in Saudi Arabia (SCOT, 2013, p. 44)

Cause of Kidney Failure	**Number of Cases**	**Percentage %**
Diabetic Nephropathy	5156	39.3
Hypertensive Nephropathy	4690	35.6
Unknown Etiology	1129	8.6
Primary Glomerular Disease	650	4.9
Obstructive Uropathy	313	2.4
Hereditary Renal Disease	283	2.2
Congenital Malformation	242	1.8
Primary Tubulo - Interstitial Disease	187	1.4
Vasculitis	175	1.3
Pregnancy Related	93	0.7
Others	231	1.8
Total	**13160**	**100**

Hassanien et al. (2012) conclude that the accuracy of data on ESRD incidence and prevalence in the gulf region is poor and needs to be updated on a regular basis; there is a need for a national strategy to address such issue. Therefore, it is very important to establish registries for renal diseases in Middle East countries (Habibzadeh, 2013). Moreover, early detection of CKD is very important. The National Kidney

Foundation Kidney Disease Outcomes Quality Initiative (NKF KDOQI) has recommended that an arteriovenous fistula should be placed for at least 65% of CKD patients before initiating dialysis in order to decrease access complications and enhance patients' quality of life. However, in KSA this seems to be an issue (similar to other countries) and additional strategies are required to achieve such a quality standard. Many CKD patients in KSA are referred for urgent HD from the hospital emergency room. This usually results in a catheter being inserted to initiate HD, which increases hospitalization and mortality rates among patients (Hassanien et al., 2013).

Furthermore, renal care and services are not provided to the majority of HD patients in KSA until initiation of dialysis treatment; and some patients receive less than six months of renal care; 41.7-53.5% and 23.5-34.2 % respectively. As a result, most patients are not able to effectively participate in decision-making regarding RRT options. Moreover, educating and preparing patients for dialysis, such as a placement of a permanent vascular access, is a challenge due to insufficiency of time (Hassanien et al., 2013).

Ineffective strategies for early detection of CKD until it becomes an urgent need for treatment will lead to more humanistic, clinical, and economic burdens including the effect on patient’s educational achievement, employment status, social life, and overall quality of life (Gorodetskaya, Zenios, Mcculloch et al., 2005; Chin, Song, Lee et al., 2008). For example, early detection could help potential HD patients to get CKD-related education and have a choice of dialysis before it is needed which will directly impact on their employment and being able to develop strategies over time to sustain employment rather than being faced with the shock of all of a sudden needing dialysis. Indeed, early detection of CKD could delay the progression of the disease and allow for early management, and productive and healthier lives (Braun, Sood, Hogue et al., 2012).

Chronic Kidney Disease and Employment

Chronic illnesses can lead to work disability and can negatively affect an individual’s work ability and productivity (Lerner, Allaire, & Reisine, 2005; Schultz, Chen, & Edington, 2009; Koolhaas, van der Klink, Groothoff et al., 2012). Diabetes, cancer, depression and cardiovascular heart disease, for instance, can reduce employees’ presenteeism (lost in work productivity), and increase absenteeism and work limitations (Burton, Conti, Chen et al., 1999; Kessler, Greenberg, Mickelson et al., 2001). In 2003, absenteeism cost the USA economy $127 billion dollars, and $828 billion dollars for presenteeism (Alliance, 2009).

Many people managing a chronic disease want to retain employability and work productivity (Mancuso, Paget, & Charlson, 2000). However, availability of accommodating work, and flexibility in the work environment are influencing factors for such goals to be realised (Daly & Bound, 1996; Baanders, Andries, Rijken et al., 2001). For example, reducing work hours or shifting to a less demanding role could help employees with health conditions to maintain employment, although such actions could increase the progress of the illness and lead to workforce departure (Allaire, Niu, & LaValley, 2005).

Kidney failure, a major health threat, is a chronic disease and considered to be the most severe form of CKD. In the US, for instance, CKD is the 17th leading cause of disability and 12th leading cause of death (WHO, 2008). End-stage kidney disease (ESKD) means that the kidneys do not function as they should and a renal replacement therapy (RRT) is needed to sustain life (Van der Mei et al., 2011; Murray et al., 2014). Individuals with such disease encounter many challenges including the constant threat of death, reduced mental and physical functioning, diet and fluid restrictions, and many other complex symptoms associated with such disease (Panagopoulou, Hardalias, Berati et al., 2009). Health related quality of life of CKD patients undergoing HD is extremely affected, especially in patients who are on HD treatment long term.

Moreover, those patients are more likely to encounter reduced social, physical, and mental capacity and functioning; as well as other symptoms such as lack of energy and fatigue (Laupacis, Muirhead, Keown et al., 1992; Merkus, Jager, Dekker et al., 1999; Polaschek, 2003; Molsted, Aadahl, Schou et al., 2004; Helanterä, Haapio, Koskinen et al., 2012). Indeed, HD patients have the lowest physical functioning compared to other patients with different chronic diseases (Mittal, Ahern, Flaster et al., 2001; O'Sullivan & McCarthy, 2007). Many consequences could result from managing such a disease including low physical capacity, high mortality rate, and difficulties to retain employment (Altintepe, Kurtoglu, Tonbul et al., 2004; Bayliss, Bayliss, Ware et al., 2004; MacDonald-Wilson & Nemec, 2005).

CKD is a major issue facing many countries all over the world, especially in Saudi Arabia. One significant reason is that the majority of individuals suffering from this disease receive HD treatment and they are predominantly working age, 18 to 65 years old. This is more than 70% of the entire HD population of Saudi Arabia (a total number of 13100 cases) (SCOT, 2013). As a result, many aspects of the lives of HD patients', especially young adults, will be negatively affected by the disease including their ability to work or sustain work (Murray et al., 2014).

CKD patients undergoing HD are considered ‘disabled’ in many countries including Saudi Arabia (ECRI, 2000; Julián-Mauro et al., 2012), and individuals with a ‘disability’ usually experience stressful situations in the workplace (Takaki & Yano, 2006). There is a positive correlation between the increment in disability and the loss of employment (O’Connor, Cano, i Torrenta et al., 2005; Townsend, 2008). Level of education, physical capacity, duration of HD treatment, and co-morbidities are some other factors affecting the employment status and ability of HD patients to work (Gutman, Stead, & Robinson, 1981; Van Manen, Korevaar, Dekker et al., 2001; Takaki & Yano, 2006). Indeed, the loss of work is often a result of a combination of social, medical, and environmental factors rather than the presence of the chronic illness alone (Roessler, Fitzgerald, Rumrill et al., 2001; Johnson, Amtmann, Yorkston et al., 2004). Nevertheless, specific symptoms will have a greater impact on a person’s work productivity and sustainability than general disability (Roessler, Rumrill, & Fitzgerald, 2004).

Unemployment among these patients can have a serious effect on their quality of life in addition to other consequences such as the employer costs which result from high absenteeism, low productivity, and work lost (Lopes, Bragg, Young et al., 2002; Shaw et al., 2013). Employment and meaningful work for patients with chronic illness are important and will positively reflect on their functioning and well-being (Reynolds, 2003; Waddell & Burton, 2006). Employment is also crucial among CKD patients undergoing HD; not only does it provide economic stability and social life, it has a positive effect on a person’s self-esteem, emotional condition and other capacities that they usually lose after initiating dialysis treatment (ECRI, 2000).

There is little known why the employment rate and achievement among HD patients are considerably low (Murray et al., 2014). Evidence on employment and sustainability of work of CKD patients is scarce and further research is needed to better understand who, what, why and how HD patients continue to work, or not, alongside managing a long term condition. Therefore, barriers and facilitators related to work retention and productivity as well as the needs of worker with chronic illnesses need to be identified and explored (Koolhaas et al., 2013).

There is also a need for more research, and adapting and applying theories to better understand this issue and the factors causing employees with chronic disease to lose productivity or/and leave work (Shaw et al., 2013). Although some research has been conducted to explore worker experiences, exploring factors encountered in the workplace, these studies did not examine the experiences of CKD patients or provide any understanding for this cohort (Detaille, Heerkens, Engels et al., 2009; Varekamp & Van Dijk, 2010; de Vries, Reneman, Groothoff et al., 2012).

It is not only the health condition, the experience of treatment complications and/or the management of symptoms that can increase the obstacles to sustain employment, and accelerate work disability among CKD patients. Health policies, society norms and the cultural context in which people find themselves can influence the support or lack of support, people receive to continue working. Therefore, this chapter predominantly focuses on Saudi Arabia as the context for the study; critically analysing the health system, religion and cultural norms to generate a contextual awareness for the prevalence of CKD and uptake of HD, employment and the labour market of Saudi Arabia.

Overview of Saudi Arabia

Demography

Islam originated in KSA and has two of Islam's holiest places 'mosques' located in Mecca and Medina. The legitimate title of the King of Saudi Arabia is 'the Custodian of the Two Holy Mosques'. In 1932, the Kingdom of Saudi Arabia was established, and the majority of the Arabian Peninsula was unified by King Abdul Aziz bin Abdul Rahman Al Saud (Ibn Saud) (Central Intelligence Agency, 2016). The Kingdom of Saudi Arabia (KSA) is one of the largest countries in the Middle East and one of the largest producers of oil and gas in the world (Aldossary, While, & Barriball, 2008; Ministry of Economy and Planning, 2010). KSA is part of the gulf region, and a member of the Gulf Cooperation Council (GCC) with the other five countries: the United Arab Emirates, Kuwait, Qatar, Bahrain, and Oman, and they all share a similar culture, ethnicity, and socio economy (Hassanien et al., 2012). The population of Saudi Arabia was estimated in 2015 to be about 28 million, which includes expatriates who make up at least 30% of the total population (Central Intelligence Agency, 2016) (Table 1).

Table 2: Demographic Data and Indicators of Saudi Arabia (Central Intelligence Agency, 2016)

Indicators (2015 est.)	**Values**	**Notes**
Population:	27,752,316	(about 30% immigrants)
Urbanization:		
Urban population:	83.1%	Of total population (2015)
Rate of urbanization:	2.1%	Annual rate of change (2010-15 est.)
Age structure:		
0-14 years:	27.07%	(male 3,850,992 / female 3,661,194)
15-24 years:	19.11%	(male 2,839,161/female 2,463,216)
25-54 years:	45.9%	(male 7,244,386/female 5,495,284)
55-64 years:	4.68%	(male 710,827/female 587,281)
65 years and over:	3.24%	(male 460,209/female 439,766)

Population growth rate:	1.46%	country comparison to the world: 81th
Birth rate:	18.51 births	/1,000 population
Death rate:	3.33 deaths	/1,000 population
Education expenditures:	5% of GDP (2008)	country comparison to the world: 68th
Health expenditures:	3% of GDP (2013)	country comparison to the world: 178th
Literacy:		
total population:	94.7%	age 15 and over can read and write
male:	97%	
female:	91.1%	

The culture, society, education system, and most aspects of day-to-day activities and life are mostly governed by Islamic law (Sharia) given that Islam is the main religion of Saudi Arabia (Al-Shahri, 2002; Central Intelligence Agency, 2016). The family structure in Saudi Arabia differs considerably from North America and most European countries. The culture and family in Saudi Arabia are “collectivist”, which means that family members, friends, neighbours, and the entire community care and support each other (Al-Balad, 2014). Men control public life in Saudi Arabia, and the family is also controlled by a man (a husband or a father), who is often the main provider for his family; while the woman is responsible for her children and the house (Al-Shahri, 2002).

Due to social and cultural aspects, conservative religious beliefs and practices, and a degree of misinterpretation of both religion and the ‘Quran’, women have been negatively affected in many aspects of life such as education and employment (Mobaraki & Söderfeldt, 2010). The cultural and religious norms, in particular the inequality of gender may influence directly the notion of seeking employment and sustaining employment within the Saudi society.

Religion and Socio-Cultural Aspects of Saudi Arabia

The KSA was transformed by the discovery of oil in 1938, both from an internal perspective and in an international context. The structure of society changed dramatically as people left their traditional earth dwellings and tents in the deserts to move into brick-built houses in the cities, leading to radical changes in lifestyle. As Al-Rasheed (2010) observed, many people were moving to take advantage of the new sources of income created by employment opportunities in the oil companies.

By the mid 1960s Saudi Arabia was in an almost unique situation, with infrastructure and social development lagging far behind the country's significant wealth (Al-Rasheed, 2010). Transportation systems, housing, electricity distribution and the education system all required significant upgrading to meet the needs of the changed society. When Prince Faisal ascended to the Saudi throne in 1964 one of his first acts was to implement significant social, political, economic and education reforms to improve all strata of society, through a series developmental plans. The first developmental plan for example centred on upgrading infrastructure and building the fundamental social needs of education and healthcare. Lacking the necessary skills and workforce to develop these services effectively, Saudi Arabia brought in overseas workers, both skilled and unskilled, to provide the required manpower. According to Ministry of Economy and Planning (2010) Saudi Arabia became increasingly dependent on an expatriate workforce source from other Arab and non-Arab countries, including Pakistan, Philippine, India, Syria, Egypt, Yemen, and Sudan.

More recently, due to falls in worldwide oil prices, the instability of the global economy and internal pressures, the Saudi government has sought to minimize the country's reliance on oil revenues by promoting and incentivising the development of other business categories through private enterprises, in order to create a more diversified economic structure. The most recent Saudi government developmental plan focuses on the expansion of the Saudi workforce, through improved education and training programmes. Private sector investment was incentivised with beneficial economic policies and regulatory environments, together with privatization programmes, to build new schools and technical colleges to provide effective vocational training (Ministry of Economy and Planning, 2010). The policy of ‘Saudization’ was then introduced to drive the replacement of expatriate workers with Saudi citizens, particularly in the fields of healthcare, education and other social organizations, to reduce unemployment amongst young people and strengthen the economy (Fataani, 2008).

As a country is founded on Islamic principles, the teaching and practices of Islam have a profound effect on all aspects of Saudi society, including the political, economic and cultural spheres; everything must comply with the traditional Islamic (Sharia) Law. Despite the significant steps made in modernization of infrastructure and services, Saudi Arabia remains firmly entrenched in deeply traditional Islamic principles, and this has a significant impact on the role of women in society (Fataani, 2008).

Yamani and Allen (1996) highlighted that Saudi Arabia had very strict laws governing women and so-called ‘family values’. Even today modern Saudi Arabia is a very wealthy and technologically advanced nation, yet it lags significantly behind other Arab nations in the education and employment of women. The Saudi government is firmly committed to maintaining traditional Saudi customs and the values of Islam, which have strict views on the role of women in society. However, Islamic Law does not prohibit women from gaining an education – indeed it is valued as a fundamental right; women are also permitted to trade and run their own business

(Nasif & Abedin, 1999). Despite this it was Saudi tradition that women were not educated, and thus it was only in the 1960s that the first school for girls was established in Saudi Arabia.

Traditional rules were further relaxed in the late 1980s with a move to encourage Saudi school girls to continue into higher education, to study medicine or education. Doumato (2000) highlighted that although Saudi women were restricted to working in medicine, education and social services, the list of acceptable occupations had now been extended to include banking and financial services, and other businesses with which women have direct interaction. However, Saudi women today have higher aspirations. Some women attend overseas universities, studying subjects such as engineering, petrochemicals, law and geology; even though they are restricted from working in these professions in Saudi Arabia, deemed inappropriate for women (Doumato, 1992).

The developmental plans continue to limit the employment opportunities open to women. Although the Saudi government has increased opportunities for females to attend school, university, or work in a restricted range of business categories, the final decision about whether a woman works rests with the female's designated 'male guardian' (a father, brother or husband). They must provide written consent for education or employment, regardless of the female's age or marital status (Ministry of Economy and Planning, 2010). Because education, employment and most forms of economic activity are dependent on the consent of the male guardian, many women in Saudi Arabia continue to be denied the right to access different opportunities (Almana, 1982).

The education and employment of females is a regular topic of conversation within families in Saudi Arabia today. Nonetheless, a large percentage of male guardians refuse to allow females to undertake education and employment outside the home. In part, this may be a product of the traditional Saudi custom that females must always travel with a male guardian in public, a custom which is supported by the relative lack of public transport services and the continued refusal to allow women to drive. Consequently, even the relatively small numbers of women who obtain written consent for employment are unable to travel to work unless they have access to a car with a driver. Whilst women in the Saudi Arabia of today have the right to be educated and employment, the reality is that their rights remain severely constrained by the government's adherence to traditional patriarchal Saudi customs (Fataani, 2008). This context of gender inequality will be considered when examining the findings of this study on employment even in the context of CKD patients.

Health Care System in Saudi Arabia

The health care system in Saudi Arabia is a national system where the Ministry of Health (MOH) is responsible for all aspects of health care services and facilities (Albejaidi, 2010; Almalki, FitzGerald, & Clark, 2011). MOH was established in 1950 under a royal decree to enhance health care services in terms of quality and quantity (Almalki et al., 2011). It provides and manages health care services in public hospitals and health centres, and supervises health care services in the private sector. This includes formulating, planning, implementing, monitoring, and evaluating health care policies and programmes in Saudi Arabia (Albejaidi, 2010; Almalki et al., 2011). The MOH is the main provider and financier of health care facilities and services in the public sector of Saudi Arabia. All health care services within the public sectors, in accordance with the constitution of the country, are provided for free for all citizens and foreign government workers and their families (Aldossary et al., 2008; Almalki et al., 2011).

The KSA is divided into 13 regions, and each region has at least one regional directorate-general of health affairs (Figure 1). Under the supervision of the MOH, these directorate-generals are responsible for the health care and services in each region. This could include for example: implementing MOH policies and plans, recruiting physicians and other healthcare professionals, building hospitals and primary healthcare centres (PHC), providing medical equipment and medications. They are also responsible for supervising and organizing health care services and facilities in the private sector as well as coordinating with other governmental and non-governmental health care agencies and bodies for the sake of the development of the health care services in the KSA (Aldossary et al., 2008; Almalki et al., 2011).

Figure 4: 13 regions of Saudi Arabia (SCOT, 2013, p. 2)

In addition, the health care structure in Saudi Arabia is divided into three levels: primary, secondary, and tertiary (Albejaidi, 2010; Almalki et al., 2011). Primary health care (PHC) centres provide the essential primary care services, both curative and preventive, for citizens and expatriates working within the government divisions. PHC doctors may also refer some individuals to the public hospitals (the secondary level) for many reasons; particularly those who require the consultation of a specialist, or tests using an advance technology which might be unavailable at the PHC. The tertiary level of care in Saudi Arabia involves university hospitals, central hospitals, and specialized hospital. Usually, these hospitals only accept cases that are transferred from public hospitals and require advanced health care services and technology (Almalki et al., 2011).

Many steps have been taken by the Saudi government in general and the MOH in particular for the betterment of the health care services and the improvement of the overall health status of individuals and communities (Aldossary et al., 2008; Almalki et al., 2011). However, the reform of the health care system in Saudi Arabia, like many others worldwide, faces similar challenges in manpower, expenditure, privatization of the secondary level of care, and implementing electronic health records in public hospitals and across PHC. The workforce is a major barrier for the development of health care services in Saudi Arabia, with a high rate of turnover because most physicians, nurses, pharmacists, and other health care professionals are expatriates (Almalki et al., 2011). Indeed, a shortage of local healthcare professionals is a major problem facing the healthcare reform in Saudi Arabia.

Employment and the Labour Market in Saudi Arabia

Saudi Arabia is one of the fastest growing countries, in terms of population, in the world. The population increased from seven million people in 1975 to 30 million in 2014 although expatriates account for almost 10 million people (Ministry of Labour, 2009; Ministry of Economy and Planning, 2010; General Authority for Statistics, 2016) (Table 3: Compare Saudi Arabia with other countries in G20**).

Table 3: Employment and the Labour Market in Saudi Arabia

	Real GDP growth		GDP per capita (USD terms)		Employment growth		Employment to population ratio	
Economy	8.4	3.8	$24,036	$26,959	3.0	4.1	47.7	51.1
G20 median	1.4	1.9	$25,339	$26,243	1.1	0.9	57.7	57.1
	Unemployment rate		Incidence of long-term unemployment		Youth unemployment rate		Youth unemployment to population ratio	
Economy	5.1	5.7	n/a	n/a	n/a	29.4	5.0	5.3
G20**	6.3	6.1	24.1	31.0	n/a	n/a	6.9	7.8

median								
	Participation rate		Female participation rate		Working age (15 to 64 years) participation rate		Collective bargaining coverage	
Economy	50.3	54.2	17.8	20.1	51.0	55.7	n/a	n/a
G20 median	60.2	60.3	50.0	51.8	70.4	71.2	n/a	28.8
	Informal employment rate		Minimum wage (Per cent of average wage)		Gini coefficient*		School completion rate	
Economy	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a
G20 median	n/a	42.2	34.9	34.9	0.341	0.376	76.5	78.9
	Literacy rate		Year 12 attainment among 25 to 64 Y/O					
Economy	n/a	5.6	n/a	n/a				
G20 median	n/a	n/a	69.8	74.2				

*Note: Percentage figures, except in the case of GDP per capita and the Gini coefficient.**

** Gini coefficient: measure inequality in income distribution (Gini, 1997).*

*** G20: The Group of twenty major economies in the world.*

(Ministry of Labour, 2009; International Labour Office, 2010; General Authority for Statistics, 2016)

During that time, the number of unemployed people increased slightly; however, by looking at the fast growing population, the unemployment rate has decreased in recent years. This was a result of the Ministry of Labour efforts in supporting the creation of work and healthy work environments especially in the private sector (Ministry of Labour, 2009). However, the actual working weekly hours by Saudi worker are less than the average for both male and female employees (Table 4). The documentation of the reasons behind it is very poor (General Authority for Statistics, 2016); however, reliance on foreign co-workers, sick leave, and system flexibility are some of the factors affecting the actual working hours by Saudi citizen.

Table 4: Other Statistical data and indicators on Saudi human resources for 2011 – 2015 (General Authority for Statistics, 2016)

Indicator name	Year 2015	Year 2014	Year 2013	Year 2012	Year 2011
Average Weekly Working Hours	**45.5**	**46.8**	**49.1**	**49.9**	**49.5**
Male	45.7	46.9	49.2	50.1	49.5
Female	44.3	46.0	48.6	48.4	49.6
Average Actual Weekly Working Hours for Citizens	**39.0**	**39.1**	**39.0**	**39.1**	**39.2**
Male	39.5	39.5	39.6	39.7	39.9
Female	36.2	36.3	36.1	35.3	34.9

Employment Challenges for Saudi Arabia

High unemployment rate among youth

Youth unemployment in Saudi Arabia is a major challenge in "school to work transition". Even if the current initiatives, strategies, and programs to address this major issue continue, this issue may well get worse. At least 18% of young Saudis (15 to 24 year olds) are classified as not in education, employment and training (NEET) (Ministry of Labour, 2009; Employment Plan, 2014).

Table 5: Percentage of Unemployed Persons to Population (15 years and above) For Saudi and Non Saudi by Gender in 2005, 2010, and 2015 (General Authority for Statistics, 2016)

Years	Total			Non Saudi		Saudi	
	Total	Female	Male	Female	Male	Female	Male
2005	3.0	2.5	3.4	0.4	0.7	3.0	5.3
2010	2.8	3.2	2.6	0.3	0.3	4.0	4.3
2015	3.0	4.6	1.9	0.7	0.3	5.9	3.3

Despite the percentage per population, the number of unemployed adult Saudi male/females has decreased throughout the last decade (Tables 5, 6, and 7), the unemployment rate is still high among the Saudi population (11.5% unemployed Saudi citizens).

Table 6: Unemployment Rates (15 years and above) For Saudi and Non Saudi by Gender in 2005, 2010, and 2015 (General Authority for Statistics, 2016)

Years	Total			Non Saudi		Saudi	
	Total	Female	Male	Female	Male	Female	Male
2005	6.1	14.1	4.6	1.1	0.8	25.4	8.7
2010	5.5	17.4	3.4	0.8	0.3	30.6	7.1
2015	5.6	21.4	2.4	2.0	0.3	33.8	5.3

Table 7: Unemployed Persons (15 years and above) For Saudi and Non Saudi by Gender in 2005, 2010, and 2015 (General Authority for Statistics, 2016)

Years	Total			Non Saudi		Saudi	
	Total	Female	Male	Female	Male	Female	Male
2005	458,587	163,000	295,541	5,719	25,073	157,327	270,468
2010	518,937	244,876	274,061	5,138	12,539	239,738	261,522
2015	680,176	432,261	247,915	15,829	17,337	416,432	230,578

Saudi and foreign worker imbalance in the private sector

In Saudi Arabia, one third of the labour force is composed of foreign workers (non-Saudi) (Table 8). Almost all foreign residents in Saudi Arabia are employed; 99.5% compared to 88.5% among Saudi people (Table 9). The private sector provides job opportunities with low monthly salary, considered attractive to foreign workers particularly workers from countries such as Egypt, India, Philippines, and Indonesia. The Ministry of Labour is working hard to overcome this issue at the same time ensuring that work in Saudi Arabia continues to be attractive to expatriates. They are working to create new jobs that are specifically designed for Saudi workers (Ministry of Labour, 2009; Employment Plan, 2014).

Table 8: Employed Persons (15 years and above) For Saudi and Non Saudi by Gender in 2005, 2010, and 2015 (General Authority for Statistics, 2016)

Years	Total			Non Saudi		Saudi	
	Total	Female	Male	Female	Male	Female	Male
2005	7,120 m*	995,419	6,125 m	533,618	3,302 m	461,801	2,823 m
2010	8,834 m	1,164 m	7,670 m	621,046	4,258 m	543,406	3,411 m
2015	11,484 m	1,589 m	9,895 m	772,816	5,735 m	816,361	4,159 m

**m=million*

Table 9: Percentage of Employed Persons (15 years and above) For Saudi and Non Saudis by Gender in 2005, 2010, and 2015 (General Authority for Statistics, 2016)

Years	Total			Non Saudi		Saudi	
	Total	Female	Male	Female	Male	Female	Male
2005	47.0	15.3	70.6	40.4	92.7	8.9	55.3
2010	48.4	15.1	72.5	38.0	93.8	9.0	56.5
2015	51.0	16.8	75.7	32.4	93.5	11.6	60.0

Low women participation in the labour market

There are about nine million women of working age in Saudi Arabia and the unemployment rate is considered very low (Table 10). A number of social and cultural factors contribute to this problem as many job opportunities in the country are designed and provided to men only. More recently, the Ministry of Labour implemented initiatives, programs and policies to try to overcome the barriers to women and increase female participation in labour market. Private sector companies are supported in the creation of appropriate jobs for Saudi women taken accommodating the cultural and the social factors of the country. The implementation of the policy “Employment of Saudi women in retail sector” has been used to replace or reduce the addition of foreign workers and encourage increased female employees, with the incentive of reduced working hours within acceptable standards (Ministry of Labour, 2009; Employment Plan, 2014).

Table 10: Employment Rates (15 years and above) For Saudi and Non Saudi by Gender in 2005, 2010, and 2015 (General Authority for Statistics, 2016)

Years	Total			Non Saudi		Saudi	
	Total	Female	Male	Female	Male	Females	Male
2005	93.9	85.9	95.4	98.9	99.2	74.6	91.3
2010	94.5	82.6	96.6	99.2	99.7	69.4	92.9
2015	94.4	78.6	97.6	98.0	99.7	66.2	94.7

The government of Saudi Arabia is aware of the challenges in the Saudi labour market. Despite this, the movement to seriously overcome such challenges over the last decade has been inconsistent. Today, Saudization and creation of new jobs for Saudi citizens is a topic of great interest in Saudi Arabia both among the decision makers as well as the citizens. It is this that has encouraged the Saudi government to introduce the different initiatives and strategies including in 2009 an Employment Strategy (Ministry of Labour, 2009; Employment Plan, 2014).

Employment Strategy in Saudi Arabia

In 2009 the employment strategy of the KSA was adopted by the Saudi Council of Ministers. The strategy was prepared by the Ministry of Labour, with the focus of many objectives and goals to support the national economy of Saudi Arabia.

Enhancement of productivity and employability of Saudi citizens as well as preparing them for the labour market were the main focus of the adopted employment strategy (Ministry of Labour, 2009; Employment Plan, 2014).

The employment strategy comprises different plans, polices, and regulations to ensure that employment opportunities are available and accessible to Saudi citizens (Table 11).

Table 11: General framework of the Saudi Employment Strategy (Ministry of Labour, 2009; Employment Plan, 2014)

Overall objectives	**Short term (2 years)**	**Medium term (3–5 years)**	**Long term (6–25 years)**
Interim targets	Controlling unemployment	Reducing the unemployment rate	Realizing competitive advantage for the national economy depending on national manpower
Realization of full employment	Increasing employment rates	Increasing the pace of growth in employment rates	Realizing full employment
Maintenance of durable increase in national manpower participation	Increasing participation rates	Increasing the pace of growth in participation rates	Achieving the highest possible level of participation rate
Raising Saudi labour productivity to match the standards of productivity in advanced economies	Increasing labour productivity	Increasing the pace of growth in labour productivity	Reaching the highest possible level of labour productivity rate

It will support the countries reputation among non-Saudi workers as an attractive country to work in, continually providing work opportunities for those who have the knowledge, skills, and experience regardless of their nationality. Most Saudi citizens work in public sectors (for many reasons that will be discussed later) however, one of the goals of the employment strategy is to increase job opportunities in the private sector that are more attractive to Saudi people, thus expanding the demographics of the Saudi workforce (Ministry of Labour, 2009; Employment Plan, 2014).

Conclusion

This chapter provided a context to the study; the prevalence of CKD and HD treatment in Saudi Arabia, the health system and problems with the Saudi workforce and labour market. Health care services are provided free to all citizens in Saudi Arabia. Most people receiving HD in Saudi Arabia are in working age of 18 to 65 years old (70% of the entire HD population); often these people are considered ‘disabled’ and face many difficulties to sustain productivity and retain employment once starting treatment. Issues related to unemployment for this group of people are not just health related.

The critical analysis of the context in which the study takes place enables the researcher and the reader to comprehend the issue of employment in the wider society and culture of Saudi Arabia. The dominant male role in society influences whether women can work. The shortage of appropriate job opportunities for Saudi women further expose the socio-cultural and religious aspects of Saudi Arabia that impact on the labour market. The ‘collectivist’ society can both prevent people from seeking work and promoting the ‘sick’ role; or facilitate work, supporting people (women) to travel to work. The implementation of the employment strategy is working towards changing the Saudi workforce and generating greater opportunities for young people and women (summary of society issues affecting employment, Box 1).

Box 1: Society and cultural issues affecting employment in Saudi Arabia

- Many factors including social, environmental, and personal factors increase productivity lost and work disability
- The culture and family in Saudi Arabia are “collectivist”, which means that family members, friends, neighbours, and the entire community are caring and supportive of each other
- Men control the public life in Saudi Arabia, as well as the family which is controlled by a male member
- High unemployment rates among youth and low women participation in the labour market are major employment challenges in Saudi Arabia
- Enhancement of productivity and employability of Saudi citizens is the focus of the Saudi employment strategy

Having reviewed the wider issues of Saudi Arabia society and culture, Chapter three synthesises the current research evidence relevant to employment and LTCs to further explore the factors affecting employment among CKD patients, both individual and health related, and identify gaps in research to inform the focus of the current study.

Chapter Three

Literature Review

Introduction

The previous chapter exposed the societal and cultural issues which impede or influence employment in Saudi Arabia. This chapter synthesises the research evidence of the employment of people managing a LTC. The evidence review critically examines current literature surrounding the well-being of CKD patients to gain a deeper understanding as to their ability to seek and sustain employment. A comprehensive review of the literature is a crucial component to any research study; it expands the researcher’s knowledge, identifies what is already known and exposes the gaps in current evidence (LoBiondo-Wood & Haber, 2014). Interrogating the methods and approaches adopted by other researchers informs the study design, the conceptual and theoretical framework and refines research questions (Polit & Beck, 2013).

The review focused on three core components;

- the well-being of people managing CKD
- their ability to work
- factors influencing the sustainability of work or work ability for people with CKD and other LTCs

To uncover and examine appropriate evidence the review progressed into four stages: development of a search protocol and selection criteria, quality appraisal of studies, synthesis of evidence, and the identification of gaps in knowledge.

Search Protocol and Selection criteria

The search for topic specific evidence was performed using scientific resources, specifically searching electronic databases including thousands of papers from a variety of disciplines; medicine, nursing and social work. The search generated many quality articles exploring employment, ability to work, and functioning and well-being of patients with LTCs. However, the result revealed a lack of information on employment sustainability and work ability among CKD patients.

The inclusion and exclusion criteria for the search retrieved articles from many different settings and different countries. The rationale underpinning the search was to retrieve quality evidence to identify factors and concepts that influence employment sustainability and a persons' ability to work across different contexts, cultures and countries to gain a deeper understanding of the impact of social, economic, and political systems. Publications within Saudi Arabia and other Arab countries were limited reinforcing the importance of strengthening the evidence base on this topic within the Saudi Arabia context.

The search protocol included different search engines and electronic databases; CINAHL, OvidMEDLINE, British Nursing Index (BNI), and PsychInfo. The limited evidence gathered with respect to employment and CKD, resulted in widening the search to include papers related to employment across other LTCs.

Single and multiple key terms and Boolean operators were used with respect to the main areas of interest (Appendix 1). The search was limited by the date of publication (2005 – 2017) and language of published articles (English only) given that the dialysis treatment and care have improved and changed considerably over the past decade (NHS, 2015). Indeed, employment, equality laws and regulations, such as the

Disability Discrimination Act 2005 were considered to influence potential employment sustainability, supporting a 12-year search time span. In Saudi Arabia and many Arab countries English language is adopted as a requirement for publishing medical and nursing literature, thus an English only restriction was applied to the search. An AutoAlert feature was set, to enable a weekly search of new literature to continually retrieve papers with respect to the main topic of research.

Databases such as ProQuest social sciences were also searched, alongside the Saudi Journal of Kidney Diseases and Transplantation to retrieve related evidence. This journal publishes peer-reviewed studies related to kidney disease, RRT, not only transplantation, but unfortunately there were no articles retrieved on the study topic suggesting strongly that from the outset there was a significant gap of context specific evidence.

In total, 545 papers were retrieved and considered relevant based on title, English language and between the dates 2005-2015 (Figure 5). Duplicates were removed and the inclusion/exclusion criteria (Appendix 1) applied to all abstracts, where the focus of the paper was unclear from the abstract full papers were examined, identifying 22 topic relevant studies, 11 specific to CKD, and 11 pertinent to wider LTCs.

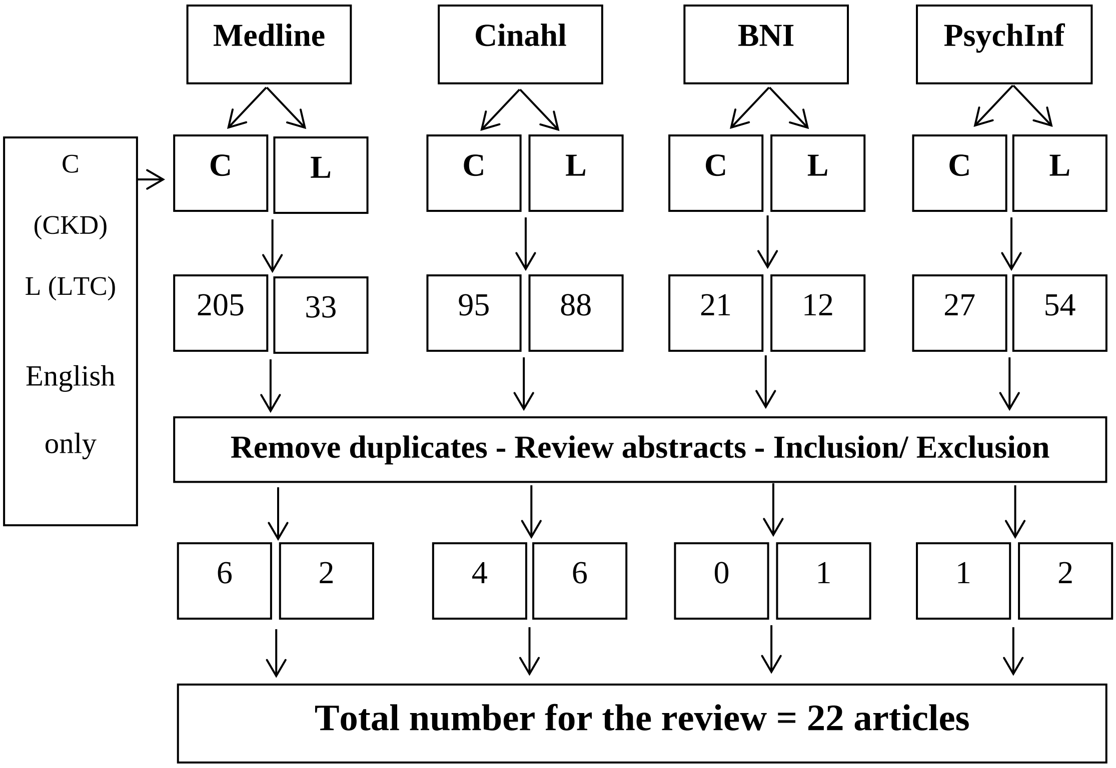

Figure 5: Search Result

All articles that met the inclusion criteria of this study were critically appraised using a defined framework developed by the Health Care Practice Research and Development Unit (HCPRDU). Unlike most other quality assessment tools that are applicable to intervention rather than cross-sectional descriptive studies, this tool can be used on various study designs including quantitative and qualitative studies as well as systematic reviews (Long, Godfrey, Randall et al., 2002).

Overview of the Results

A total of 22 studies were retrieved from the systematic search strategy; 19 were empirical research and three non-empirical research studies. For the empirical studies, 13 used a quantitative approach, five used a qualitative approach, and one study used both quantitative and qualitative approaches (mixed methods design). Most studies originated in Europe including UK (Munir et al., 2005; Munir, Pryce, Haslam et al., 2006; Townsend, 2008; De Souza & Oliver Frank, 2011; Murray et al., 2014), Netherlands (Van der Mei et al., 2011; Koolhaas et al., 2013), Italy (Guerini, Mercieri, & Yavuzer, 2006), Spain (Julián-Mauro et al., 2012), Finland (Helanterä et al., 2012), Ireland (O'Sullivan & McCarthy, 2007), and Greece (Panagopoulou et al., 2009). The remaining studies covered the wider world: USA (Fisher et al., 2007), Canada (Crooks, 2007), Brazil (Cavalcante, Lamy, Lamy Filho et al., 2013), New Zealand (Gilmour, Huntington, & Wilson, 2008), Egypt (Kamal, Kamel, Eldessouki et al., 2013), Saudi Arabia (Al-Jumaih, Al-Onazi, Binsalih et al., 2011), and Japan (Takaki & Yano, 2006). The retrieved studies differed in their purpose, objectives and methodology; although all were relevant to the topic of interest. Five studies assessed the impairment of body functions and structures; limitations in activity (Guerini et al., 2006), and functioning and well-being of CKD patients (O'Sullivan & McCarthy, 2007; Al-Jumaih et al., 2011; Cavalcante et al., 2013; Kamal et al., 2013). Eleven studies explored the impact of CKD and other chronic illnesses on employment status, work ability, and sustainability of work (Takaki & Yano, 2006; Fisher et al., 2007; Gilmour et al., 2008; Townsend, 2008; Panagopoulou et al., 2009; De Souza & Oliver Frank, 2011; Van der Mei et al., 2011; Julián-Mauro et al., 2012; Koolhaas et al., 2013; Shaw et al., 2013; Murray et al., 2014); whereas, employment challenges, work limitations and work adjustments among chronically ill employees were examined by three studies (Munir et al., 2005; Munir et al., 2006; Crooks, 2007).

Three non-empirical studies were identified, and found to be relevant and useful to support or challenge findings, which focused on: sustainability of work (Shaw et al., 2013) and job retention strategies (Koch, Rumrill, Conyers et al., 2013) for people with chronic illness, and the influence of such illness on work occupations (Antao, Shaw, Ollson et al., 2013).

Synthesis of evidence

There were many barriers and factors that affect the employment status and sustainability of work among employees LTCs. These factors were usually related to an individual's personal character, social life, clinical condition, and work environment.

The focus of the thesis was to generate a deeper understanding of who, what, why and how CKD patients continue to work, or not, alongside managing a long-term condition. Therefore, the synthesis of available evidence on what factors impact on the working life of individuals suffering from LTCs was required to provide a platform to focus and build the enquiry of the developing research. The findings of the review were synthesised into core themes and sub-themes (Box 2). Each theme is discussed in turn.

Box 2: Themes and Sub-themes from evidence synthesis

- Functioning and well-being of CKD patients
- Employment status and work-ability of CKD patients
- Factors affecting employment, work-ability, and functioning and well-being
    - *Social and personal factors*
        - Age and gender
        - Perceived health status
        - Knowledge, self-management, and coping strategies
        - Educational level, geography and social legislations
        - Social life and activities
    - *Factors related to the health condition*
        - The nature of the illness
        - Treatment modality
        - Duration of treatment and comorbid physical illnesses
    - *Factors related to work*
        - Effect of employer and managers

- Factors related to work performance and productivity
- Factors related to work environment
- Factors related to job accommodation and work adjustments

Functioning and Well-Being of CKD Patients

Chronic health conditions can interfere with patients' day-to-day activities, social and working life (Munir et al., 2005; Fisher et al., 2007; Shaw et al., 2013). The progress and symptoms of many LTCs can lead to work limitations and low work productivity (Crooks, 2007; Shaw et al., 2013), and affect many aspects of occupation as a result of permanent or temporary disability caused by a chronic illness (Fisher et al., 2007). Diabetes and heart disease, for instance, have been associated with an increase of absence and decreased performance at work, and can lead to many physical and cognitive work limitations (Munir et al., 2005).

Functioning and well-being of CKD patients, measured through Health-Related Quality of Life (HRQoL), is often low, especially among HD patients (Kamal et al., 2013). It means that patients with lower QoL scores are usually impaired and won't be able to function and perform various activities as consistently as healthy individuals because of the impact of various physical, psychological, and environmental factors. (Kamal et al., 2013). Many musculoskeletal complications could result because of the HD treatment such as monoarthropathy and soft tissue calcification. Such complications will disable HD patients physically and socially and limit their ability to function normally (Guerini et al., 2006).

Low QoL draws attention to the need to monitor physical and mental health status of HD patients not only because of its association with mortality and hospitalization but also the association with functioning limitation and disability (Al-Jumaih et al., 2011).

A key goal of a CKD patient treatment plan undergoing dialysis is to enhance functioning and well-being status socially, physically, and psychologically of the patient (Guerini et al., 2006; Kamal et al., 2013). Often, this requires input from a multidisciplinary team such as nurses, physicians, and occupational therapists to enable patients to achieve such a goal and attain a good QoL (Kamal et al., 2013).

Factors such as age, gender, duration of RRT, treatment modality, and comorbid physical disease have been identified to have a major influence of the HRQoL for people with CKD. Kamal et al. (2013) found that the physical functioning (the inability to effectively perform moderate daily work-activities) of HD patients with a longer duration of HD treatment was lower than the physical functioning of those with a shorter duration of HD treatment. They also found that patients in rural areas were more physically impaired than patients living in urban areas; possibly because most people living in rural areas depend on their physical condition to live independently. Whereas, Al-Jumaih et al. (2011) found that there was a positive correlation between employment and high income, and physical condition measured by a QoL questionnaire. Moreover, they found that women were more impaired than men; possibly related to the high employment and income rate of men compared to women. This study was conducted to only measure the QoL of HD patients and not to study the work ability and/or the employment sustainability of those patients. Therefore, it was unclear how and when the physical condition of HD patients influenced work productivity and sustainability. Data drawn from the perspective of the patients themselves may be more helpful to understand better the relationship between employment and functioning and well-being of HD patients.

The reviewed studies measured the physical condition as a subscale of the QoL tool called Physical Component Score (PCS). This questionnaire was designed to measure the physical condition in relation to daily activities, not solely for work life. This raised many questions as it was ambiguous why and how some people with low PCS retained employment; compared to others with high PCS scores who were unemployed. Similar anomalies were also observed in the work productivity and sustainability. Therefore, a more comprehensive approach also using qualitative explanations is required to better understand and accurately interpret the results of quantitative data. The quantitative approach is useful to examine the impact of the illness on QoL alongside work-related measurement tools. Qualitative data however, exposes individual patient experience to generate a deeper understanding of who, what, why and how HD patients continue to work, or not, alongside managing a LTC.

Employment Status and Work-Ability of HD Patients

Unemployment rates among CKD patients undergoing RRT are a serious issue that needs immediate actions from policy and decision makers, employers, and health-care providers. The capacity of CKD patients to sustain employment can be affected significantly by their disease, especially those undergoing HD (Julián-Mauro et al., 2012).

A study conducted in Saudi Arabia among 100 HD patients found that only 28% participants were employed full-time, whereas 43% participants were retired and 38% were unemployed (Al-Jumaih et al., 2011). In another study conducted in the UK to assess employment and education achievement among CKD patient undergoing RRT, the researchers claimed that the unemployment rate among HD patients was at least twice that of the general population (Murray et al., 2014). They found that only 20% of HD patients were in full-time employment, although the sample size was very small (n=8). Certain factors helped them maintain their employment such as the nature of their job: when their job was in line with their capabilities (44%) and accommodating their employment round their illness. Similarly, a study conducted in Italy among 45 HD patients found that those HD patients who were able to sustain their employment, either owned their own business, which allowed them to modify their work schedule and reduce working hours, or *"had a job in a modified and protected environment"* (Guerini et al., 2006, p. 115). Similarly, Van der Mei et al. (2011) indicated that without significant work modifications, and interventions based on empowerment and self-management, HD patients would not be able to sustain employment (Van der Mei et al., 2011).

Among 170 HD patients, where the majority were working-age, unemployed HD patients had more limitations to their physical and mental functioning than employed patients (Kamal et al., 2013). Therefore, for many individuals undergoing RRT, CKD was the main barrier to employment, whereas some believed that employers preferred not to hire young people with a chronic disease (Guerini et al., 2006; Murray et al., 2014). Indeed, the majority of participants agreed that CKD had negatively affected their employment as it reduced their capacity and ability to carry out their job in an efficient and effective manner (Murray et al., 2014).

Van der Mei et al. (2011) examined the pattern of work status and work-ability of 34 kidney recipients during the end stage renal disease trajectory. They found that CKD and HD treatment had negatively affected the work status of many participants over time. Indeed, the number of patients receiving disability benefits increased during periods of dialysis compared to pre-dialysis and after transplantation. On the other hand, the study showed that 74% of the participants were having a paid job at the time they diagnosed with stage 5 CKD. At the start of dialysis, the percentage of employed participants decreased to 72% where 26% of those employees were on a sick-leave. Overtime, more patients continued to leave their jobs which was evident as the percentage dropped to only 50% of employed patients at the time of transplantation. Despite the increased rate of unemployment among HD patients, the researchers believe that the result of their study regarding the number of unemployed patients were less compared to other similar studies which could be because the Dutch social legislation that focus on labour force participation and aims to avoid reimbursement of work loss which differ from country to country (Van der Mei et al., 2011). In the USA, for example, employment of CKD patients could be affected given that return to work could lead to a partial loss of disability benefits received by those groups of patients (Van der Mei et al., 2011). The employment rate among HD patients could also be influenced by the society within Saudi Arabia. Al-Jumaih et al. (2011) identified that HD patients scored high in the patient satisfaction and social interaction domains of the study, which are influenced by the social and clinical environment of the country; such as strong family bonds and social support in addition to well-established dialysis units (Al-Jumaih et al., 2011).

Moreover, examining the patterns of the work-ability of CKD patients in a study conducted in the Netherlands showed that patients physical capability, concentrating ability, and speed of work were all impacted negatively during HD treatment compared to pre-dialysis and after kidney transplantation period (Van der Mei et al., 2011). Factors such as level of education, age and gender, duration of dialysis treatments could also influence the patients’ physical and mental status (Al-Jumaih et al., 2011) and their employment status and work-ability (Julián-Mauro et al., 2012).

Factors Affecting Employment, Work-Ability, and Functioning and Well-Being

The review of current evidence revealed many factors and concepts, in addition to the specific nature of the illness, which contributed the ability to work and sustained employment among patients with CKD or a different LTC. These factors were usually related to an individual’s personal character, social life, clinical condition, and work environment. Literature on employment and work limitations among CKD patients is scarce and does not provide sufficient evidence to fully understand the topic, issues and challenges faced by the CKD population. Most reviewed studies were conducted comparing CKD patient experience across different treatment modality groups, and therefore have a small sample size of HD patients, (Van der Mei et al., 2011; Helanterä et al., 2012; Julián-Mauro et al., 2012). Other studies focused more on other dimensions than employment such as the educational achievement or HRQoL (Guerini et al., 2006; Al-Jumaih et al., 2011; Cavalcante et al., 2013; Kamal et al., 2013; Murray et al., 2014).

A number of different factors were identified from the synthesis of evidence on the impact of other chronic illnesses on patients’ employment and ability to work. All participants in these reviewed studies suffered from a chronic disease and shared many symptoms similar to those experienced by CKD patients, such as fatigue, pain, and depression. These studies were included in the review to inform the context for the developing study and examine the relevance of such factors to the CKD population.

Social and Personal Factors

Age and Gender

Personal characteristics, such as age and gender, play a key role in employment status and sustainability, and work ability of individuals with a LTC (Munir et al., 2006; Gilmour et al., 2008; Koolhaas et al., 2013). It has been reported that men with LTCs are more likely to sustain employment and have a full-time job compared to women (Munir et al., 2006). Unlike men, women with chronic illness were more likely to seek support from managers and colleagues by disclosing their health condition (Munir et al., 2006). Yet, some women with particular chronic disease such as endometriosis found it difficult to disclose and discuss their condition with male co-worker or manager due to the gender-specific nature of such disease (Gilmour et al., 2008).

Ageing can be a major problem for a worker with a LTC compared to healthy workers. Koolhaas et al. (2013) conducted a study to explore workers' (with and without a LTC) perspectives to enhance working-life sustainability among more than three thousand workers across nine different companies in Netherlands. They found that more problems and barriers to carry out work tasks in an efficient and effective manner had been reported significantly by workers with LTCs compared to healthy workers (56 vs 34%).

For CKD patients, it was evident that HD patients' age can significantly affect their functioning and well-being as well as their employment. Among 243 CKD patients undergoing RRT, the older the person, the more likely to be unemployed Julián-Mauro et al. (2012). Al-Jumaih et al. (2011) conducted a study in Saudi Arabia to assess the QOL among 100 HD patients (68% male) and the impact on the QOL of a certain demographic and clinical factors. They found that gender and age, in addition to factors such as duration of HD treatment and level of education, have a major effect on patients' physical and mental functioning. Men were shown to have better physical and mental functioning measured by the physical and mental components score using the KDQOL-SF36 instrument. Furthermore, younger HD patients had a higher physical (Al-Jumaih et al., 2011; Kamal et al., 2013), and mental score compared to elderly patients (Kamal et al., 2013). This could explain the study results of Julián-Mauro et al. (2012) who found that age and gender could affect the employment situation of CKD patients undergoing RRT as men and young participants worked more than women and elderly participants.

Similarly, female HD patients had lower physical functioning conditions than HD male patients although there was no significant difference in their mental functioning in a study conducted among 81 male and 89 female HD patients (Al-Jumaih et al., 2011; Kamal et al., 2013). Whereas gender had no effect on the HRQoL of HD patients based on the total scores of the health survey short form questionnaire (Guerini et al., 2006).

Perceived Health Status

Patients' perceptions and attitudes toward their health condition is a crucial factor that can impact on their employment status and sustainability (Munir et al., 2005; Fisher et al., 2007; Townsend, 2008). Many patients with chronic health conditions lose their confidence to be fit for work and able to perform similar duties to healthy employees (Fisher et al., 2007; Townsend, 2008). This was one of the most critical factors that led people to give up work, identified by 14 participants reporting the effect of Endometriosis on their working their life (Townsend, 2008). However, a change of occupation could alter the perception of health conditions among chronically ill employees. For example employees with chronic pain, engaged in meaningful work or moved to less demanding jobs to decrease the psychological and physical impacts (Fisher et al., 2007). None of the reviewed studies were conducted among the CKD population. Thus, whether this factor is a major indicator for employment sustainability among CKD patients remains unknown and further investigations are required. CKD is a complex health condition and it is unclear how much associated symptoms can affect a person's perception of their health and their ability to work.

Knowledge, Self-Management, and Coping Strategies

The concept of self-management, taking control and managing one’s own condition, has a major positive impact on employment status and sustainability for patients with LTCs (Fisher et al., 2007; Gilmour et al., 2008). Whilst it is a common concept also among the renal community, patients and health care professionals, the relationship between employment and self-management is not clear. The studies in the review provide evidence from people managing similar symptoms but with different LTCs. It would be anticipated that this would be similar for people with CKD but understanding whether self-management fosters sustained employment needs further explication.

It is crucial to help patients know the importance of self-management, most chronic illnesses are incurable but a reduction in disease progression and symptoms can be achieved by following self-management plans (Gilmour et al., 2008). Unfortunately, many patients only recognize the importance of self-managing their own illness when they become unable to tolerate the effect of the disease on their work and social life (Gilmour et al., 2008). Participants with endometriosis, for instance, reported that their health condition reached a point where lifestyle change was crucial and needed to be made immediately, to improve their lives (Fisher et al., 2007). Alongside adhering to the treatment plan and health professional advice, participants used different methods to self-manage symptoms from their illness; such as acupuncture, massage, use of nutritional supplement and herbal treatments (Gilmour et al., 2008).

A lack of disease knowledge and an understanding of different strategies to manage symptoms and complications is often reported by patients with different chronic diseases (Crooks, 2007; Fisher et al., 2007; Gilmour et al., 2008). Health care professionals, especially nurses, educate patients with LTCs about the disease and possible ways and activities to prevent complications and reduce associated symptoms. To do this effectively health professionals need to listen to patients and use simple language and techniques that help patients become knowledgeable about their health condition. Many patients reported that doctors do not listen to them nor treat them appropriately (Fisher et al., 2007) creating an information gap between doctors and patients (Gilmour et al., 2008). Another technique to improve information and knowledge is to introduce patients to various self-management strategies, teaching and training resources: such as support groups, blogs and chat rooms, books, health journals and inspiring success stories from other patients with similar disease or symptoms.

Examples of self-management strategies and adaptions of daily activities used by different people with LTCs to live a better life included: people reducing pain and fatigue by altering their work schedule; keeping busy all the time; and working as much as possible to forget the pain or at least feeling satisfied with what has been achieved (Fisher et al., 2007). Some people accomplished work tasks by adapting simple and creative techniques such as using assistive technologies such as orthotic devices and canes, or taking frequent and short breaks. One patient described how she altered her life to cope with her back pain by purchasing a reaching stick, a low seat for housekeeping, and a higher bed so she didn’t need to bend over when making the bed. These were strategies that most patients could undertake at no cost and be able to sustain a normal and healthier social and working life (Fisher et al., 2007). It would be useful to explore and compare if similar strategies have been adopted by CKD patients in KSA to enable them to effectively manage symptoms, complications, and maintain a content social and work life balance.

Educational Level, Geography and Social Legislations

Educated HD patients have higher physical and mental functioning than uneducated patients (Guerini et al., 2006). The more educated the HD patient the more awareness they are likely to have about the nature of their condition and the importance of self-management and coping (Kamal et al., 2013). It is also more likely that educated patients are employed and have more chance to change their career and sustain work compared to less educated people who may undertake more physical work leading to unsustainable employment (Guerini et al., 2006; Kamal et al., 2013). It is unclear whether education affects employment in countries like Saudi Arabia where less educated people are able to get work that did not require physical strength.

HD patients have increased limitations in activities as they face many challenges coping with CKD, in addition to the physical dysfunction caused by the disease from treatment-related stressors such as fatigue, fluid and food limitation, pain, and discomfort (Guerini et al., 2006). For example, HD patients living in the countryside and/or those who rely more on their physical strength to carry out daily activities and tasks are more affected by HD treatment than urban patients. As exposed in a study conducted by Kamal et al. (2013) where HD patients scored lower in the physical functioning assessment. In addition, Al-Jumaih et al. (2011) found that HD patients with high income had better physical and mental functioning compared to other patients with low income. This was explained as those with a higher income using their financial resources to support them with life difficulties and stress.

Also a factor that affects the employment status of HD patients is social legislation. In Spain, for instance, most HD patients are eligible to receive social security protection benefits which reduces employment rates, although Spanish CKD patients faced challenges to return to work after they had undergone kidney transplantation, as the social security benefits were only received for dialysis patients (Julián-Mauro et al., 2012). The impact on employment of such social policy in developing countries, such as Saudi Arabia, is unclear as the social security services are poor and usually leave patients to face the burdens of their health condition unaided (Winchester, Jacobs, Kjellstrand et al., 2008).

Social Life and Activities

Social life and activities have been identified to have a major influence on the employment and work productivity of patients suffering from chronic diseases such as musculoskeletal pain, arthritis, heart disease, and other LTCs (Munir et al., 2006; Fisher et al., 2007; Townsend, 2008). Many patients stop playing sports, going to parties, and attending social events because of pain and fatigue (Gilmour et al., 2008). Such withdrawal and reduction in social interaction has been found to be associated with a reduction in working hours (Gilmour et al., 2008).

Townsend (2008), explored the reasons that led patients with Multiple Sclerosis to give up work. The level of support required to continue working was one of the most frequent identified elements that caused patients to leave their jobs. Indeed, the influence of family and home in stopping working has been identified by 17% of the participants (Townsend, 2008).

Evidence suggests that many patients experiencing chronic pain who worked have altered relationships with their family and friends (Fisher et al., 2007). Patients, especially those who need increased emotional support, rely more on family rather than their friends, because family members are more sensitive to their needs. The perception of receiving such support is actually one of the reasons why patients with a chronic disease do not often disclose their illness to their employer and co-workers (Munir et al., 2006).

Factors Related to the Health Condition

The Nature of the Illness

The specific nature, associated symptoms and complications of many chronic diseases have a significant effect on the performance of employed patients (Munir et al., 2005; Munir et al., 2006; Crooks, 2007; Townsend, 2008). Many patients with LTCs believe that fatigue and increasing physical disability, as a result of their illness, are the main reason for losing their job (Crooks, 2007; Townsend, 2008). A study conducted to examine the experience of women at work with musculoskeletal disease reported that six participants lost their jobs whereas the other eight participants had experienced difficulties entering the labour market, and finding work with a flexible work schedule (Crooks, 2007).

In addition, the more severe the symptoms the more likely work performance of employees with LTCs is affected (Munir et al., 2006). It is the degree of disease severity that forces the employee to disclose their condition and ask for support such as work accommodation, extra time off or a flexible work schedule. However, fear of discrimination or a reduced level of understanding from colleagues and employers prevents many people suffering from other chronic illness such as depression, to reveal their condition and ask for support (Munir et al., 2005; Crooks, 2007).

Treatment Modality, Duration of Treatment, and Comorbid Physical Illnesses

The treatment modality of CKD patients has a major influence on their employment and work ability (Helanterä et al., 2012; Julián-Mauro et al., 2012). HD, for example, will increase the functioning limitations of a patient and reduce patient activity, especially on the day of dialysis treatment (Guerini et al., 2006). HD therapy is an expensive and time-consuming treatment that has many negative impacts on CKD patients' physical, psychological, environmental, and socioeconomic life (Kamal et al., 2013). Patients undergoing HD are required to limit their fluid and dietary intake. Moreover, the HD shift-schedule is a barrier, for many people to maintain employment status; the time required to attend for treatment impinges on available work time forcing HD patient's to leave or lose their work (Van der Mei et al., 2011; Julián-Mauro et al., 2012).

Van der Mei et al. (2011) examined the pattern of work status during the end stage renal disease trajectory among 34 kidney transplant recipients and found that HD dialysis treatment forced many patients with CKD to leave their work or be on a full sick-leave as the percentage of employed participants decreased during dialysis from 74% to 50% (19% of those were on sick-leave). Work ability was also examined (pre-), during dialysis and after transplantation of the kidney and found that the worst results were during the dialysis period for both time spent at work, concentrating ability, and physical capability.

Similarly, Julián-Mauro et al. (2012) conducted a study to analyse 243 CKD patients' (in working age, 16 to 64 years old) employment status at eight hospitals in Spain. They found that the employment rate among patients undergoing haemodialysis was less than those undergoing automated peritoneal dialysis. Helanterä et al. (2012) reported a similar result examining the association of treatment modality and employment rate among CKD patients undergoing RRT.

Duration of HD treatment has a major impact on patients' well-being and functioning. The longer the duration of HD treatment, the lower the physical functioning condition

(Guerini et al., 2006; Julián-Mauro et al., 2012; Kamal et al., 2013). Furthermore, many HD patients report their self-perceived health has been negatively affected over time (Guerini et al., 2006). As stated earlier, physical condition and health perception among CKD patients have significant impact on their productivity and sustainability at work. Despite this, whether the duration of treatment is considered to be a main indicator for job loss or early retirement for CKD patients is still unknown.

Moreover, according to Murray et al. (2014), low energy levels and the time of the dialysis session were significant issues for many HD patients leading to either reduced work-time or unemployment. They found that self-esteem of RRT patients' was absent for 50% of the participants *"compounded by lack of understanding and support"* (Murray et al., 2014, p. 508).

Moreover, functioning and well-being of HD patients can be affected by CKD related diseases such as diabetes (Guerini et al., 2006; Kamal et al., 2013) as well as their employment (Helanterä et al., 2012). HD patients with diabetes, anaemia, hepatitis C, and sleep disturbance have more limitations in their physical functioning (Guerini et al., 2006; Kamal et al., 2013). Although some of these diseases may also affect HD patients' mental functioning, Kamal et al. (2013) found no difference in the mental functioning of hepatitis C HD patients. One explanation was that HD patients were more likely to adapt to their condition overtime which will positively affect their mental functioning.

Furthermore, 46% of the participants in the study by Van der Mei et al. (2011) reported that CKD was the leading cause for their disability whereas, 36% reported that their disabilities were a result of both CKD and other chronic illness such as visual impairment and chronic fatigue.

Factors Related to Work

Effect of Employer and Managers

It has been reported across studies examining the effect of different chronic illnesses on occupation, that the lack of understating and support from managers and employers is a critical factor that leads people to give up work or at least causes limitations at work (Munir et al., 2005; Crooks, 2007; Gilmour et al., 2008; Townsend, 2008; Koolhaas et al., 2013). Research conducted by Koolhaas et al. (2013) studying the perspective of workers to enhance employment sustainability, highlighted that more workers with LTCs reported that continued support was needed to be able to sustain their employment compared to healthy workers (Koolhaas et al., 2013).

Nevertheless, there were many patients who indicated that not all managers are aware of their conditions nor supportive (Gilmour et al., 2008; Townsend, 2008). Workers with chronic health conditions, for instance, needed the employer and co-worker support to leave work frequently for treatment or medical appointment (Crooks, 2007). However, this could be a problem with unsupportive managers as it may *"impact on the person's finances and pension: Reduced pension if reduce hours*" (Townsend, 2008, p. 107). One participant identified that she was able to have frequent sick leave from her manager who was fully aware of her condition and was very supportive. However, when a new manager came over he asked why she took so much sick leave and when she disclosed her condition he tried to force her to leave the job (Gilmour et al., 2008). This reinforced the importance of helping employers and managers understand the health conditions of their employees and how to overcome barriers that may affect their work performance and employment status.

Factors Related to Work Performance and Productivity

Chronic health conditions affect the employment status and/or work performance and productivity of patients (Munir et al., 2005; Crooks, 2007; Gilmour et al., 2008; De Souza & Oliver Frank, 2011). In New Zealand, a study among 18 women suffering from endometriosis, three women left their jobs whereas seven other women identified not being able to do a full-time work (Gilmour et al., 2008). In another study, among 2420 employees, with at least one chronic illness, work limitation was reported by over a third of participants (Munir et al., 2005). Other studies have showed, frequent requests to leave during work for treatment (Crooks, 2007), "*limited sick leave provisions*" (Gilmour et al., 2008, p. 445), and negative impact on colleagues due to absence (De Souza & Oliver Frank, 2011).

Factors Related to Work Environment

Patients identify work limitations and issues due to the nature of their workplace (Crooks, 2007; Townsend, 2008; De Souza & Oliver Frank, 2011). Some people, report that the nature of their job and required tasks causes them chronic back pain (De Souza & Oliver Frank, 2011). In one study, out of 70 people managing Multiple Sclerosis, 44% reported physical barriers in the work environment as a reason for leaving their employment (Townsend, 2008). Transportation problems and the difficulties to get to work, identified by 28.6 % of respondents was also a barrier. Whereas, 25 out of 70 of the respondents reported that inability to shift from full-time to part-time job or obtain a flexible work schedule was the main reason that prevented them sustaining their employment (Townsend, 2008). Everyday tasks such as managing doors, climb stairs, or walking within the building forces people with LTCs to leave work (Crooks, 2007; Townsend, 2008). Hence, the work environment can play a significant role in maintaining employment of employees, including those with LTCs.

Factors related to Job Accommodation and Work Adjustments

Work adjustments and accommodation is an important factor that can influence employment status and sustainability of patients with chronic health disease (Munir et al., 2005; Crooks, 2007; Gilmour et al., 2008). However, many patients are not fully aware of how, when, and what adjustments could be sought from their employers (Crooks, 2007). People report that work adjustments are unlikely to be provided for less visible non-physical conditions such as cognitive impairment unless disclosure of the disease has taken place. Whereas, physical conditions are more easily identified and therefore physical work adjustments and support such as lifting devices can be made available in the workplace (Munir et al., 2005).

Unfortunately, lack of knowledge among many employees with chronic health conditions about their rights to have a safe work environment and work adjustments enable unsupportive managers to force them to accept the situation as is or give up work (Crooks, 2007). Where employees with LTCs are knowledgeable and fully aware of their rights they receive appropriate work accommodation; however, often due to the symptoms of their illness such as pain and fatigue, they struggle to manage the time and energy required to seek and establish such rights. Consequently, many patients cannot perform as expected and many others leave their place or work (Crooks, 2007).

Quality Appraisal of the Studies

Quantitative Studies Analysis

Most studies reviewed adopted a quantitative approach (n=13), each study was comprehensively critically appraised (see Appendix 2 for quantitative study appraisals). The quantitative approach is mostly used to describe a specific phenomenon among large numbers of subjects. Given there was a lack of literature surrounding the employment of people managing a long term condition in Saudi Arabia a quantitative approach would be an effective way to gather data related to employment and work productivity among a large number of CKD patients undergoing HD. The advantage of using a quantitative approach is that it will provide an overview of the current context, the numbers of Saudi people whose employment is affected and how but the limitation is that often the detail of why they are affected is not captured.

The most frequently used instrument, in quantitative studies, assessed the functioning and well-being of patients with chronic disease (Guerini et al., 2006; O'Sullivan & McCarthy, 2007; Al-Jumaih et al., 2011; Van der Mei et al., 2011; Kamal et al., 2013). Often this was completed in conjunction with the general Short-Form 36-item health status questionnaire or the Kidney Disease Quality of Life-36 (KDQOL-36) survey. The aim of the tools was to measure the physical and mental functioning of individuals with a long term condition. This tool gives a score for the participant’s physical and mental condition which would be useful to give an indication of their work ability. However, these instruments together can be lengthy to complete which may be more suitable to use on a small sample size (Ware, Kosinski, Turner-Bowker et al., 2009).

Although there were many research papers, having already examined quality of life (QoL) of CKD patients in the literature, it could still be useful to simultaneously examine the QoL of HD patients when conducting research on employment and the ability to work. The newer shorter version (SF-12v2) can be used in large surveys, and doesn’t take as long to complete (Ware, Kosinski, Turner-Bowker et al., 2002). This tool could help identify the relationship between the score of the patient’s physical or mental condition, and their employment status or the degree of their work ability. It would enable the researcher to understand how patients with low physical or mental scores could maintain sustainable employment and vice versa, particularly if the research adopts a mixed method approach. To do this would require a further measure to identify the work ability and productivity of employees with chronic disease.

Only one study used a specific tool to examine the employment status and work ability among CKD patients (Van der Mei et al., 2011). The Work Ability Index (WAI) was developed to evaluate the work ability of employed participants. The instrument examined seven items: current work ability compared with the best in life, the work ability in relation to the job demands, the number of current diseases diagnosed by a physician, the estimated work impairment due to diseases, the occurrence of sick leave during the past 12 months, the person’s own prognosis of work ability two years in the future and the mental resources (Silvia Monteiro, Maria Costa Alexandre, Ilmarinen et al., 2009). Similar to the health survey questionnaire, the WAI takes a long time to complete; raising concerns about the accuracy of responses and the reliability of the results. Some participants may lose interest and begin to select answers at random. Another drawback of the use of this tool in the developing study is that the tool was designed to examine the work ability of currently employed patients so not relevant to unemployed people, and in turn many CKD patients. Identifying a shorter valid tool that measures participants work productivity and activity impairments for both employed and unemployed subjects would be beneficial, particularly on the reliability of the findings.

Non-probability sampling methods (i.e. purposive and selective sample) were adopted by all empirical studies, which is often found within nursing and social research studies (Polit & Beck, 2013). Having a large sample size would help to overcome the limitation of such methods of sampling and more robust findings. However, the small sample size (34 to 100 participants) identified in four appraised quantitative studies was a limitation to both the representativeness of the sample population and the ability to generalize findings (Guerini et al., 2006; O'Sullivan & McCarthy, 2007; Al-Jumaih et al., 2011; Van der Mei et al., 2011). Sampling across a single site (in eight reviewed studies) also limited the quality of the study findings (Munir et al., 2005; Guerini et al., 2006; Munir et al., 2006; O'Sullivan & McCarthy, 2007; Panagopoulou et al., 2009; Al-Jumaih et al., 2011; Van der Mei et al., 2011; Kamal et al., 2013).

Therefore, conducting a study in a large sample of subjects within two or more dialysis centres strengthened the quality of the research findings and allowed for comparable and reliable data that was representative of the population of patients undergoing HD. This method requires a scientific technique using a sample size calculation formula to determine the effective sample size for survey studies taking into consideration gender, age, and employment status. A stratified sampling method would prevent potential bias and ensure repressiveness. The calculation of the sample size was explained in detail by only two reviewed studies (O'Sullivan & McCarthy, 2007; Julián-Mauro et al., 2012), and for the other studies there was no mention to the application of a formula.

Qualitative Studies

Five qualitative studies were identified and critiqued to inform the developing research (Crooks, 2007; Fisher et al., 2007; Gilmour et al., 2008; Townsend, 2008; De Souza & Oliver Frank, 2011), please see (see Appendix 3 for qualitative study appraisals). The qualitative method was found to be valuable in explaining detailed issues related to employment and work-ability, although in the qualitative papers reviewed the participants were not CKD patients but people managing a different LTC. With the subjects were not considered representative of HD patients, concepts of generalizability and transferability were not initially considered to be applicable. However, reviewing this group of qualitative studies revealed similar core factors experienced by patients with different chronic disease that influenced their employment and work productivity. This suggested that a qualitative approach may be useful to inform the depth of the research and explore theoretical components relevant to all LTCs.

Incorporating a qualitative approach in the developing study may help in gaining a deeper understanding of employment challenges experienced by CKD patients undergoing HD. Due to the nature of CKD and its treatment a qualitative approach would add valuable information to the existing knowledge, particularly on the effect of such disease on employment and productivity. Unlike other patients with chronic illness, CKD patients receiving HD are required to attend 4-hours dialysis sessions three times a week; which considerably impacts on many aspects of their lives including employment and work-ability.

In-depth face-to-face semi-structured interviews were the most common approach used in qualitative studies (n= 3) (Crooks, 2007; Fisher et al., 2007; De Souza & Oliver Frank, 2011). Whereas, Gilmour et al. (2008), used an unstructured approach, and Townsend (2008) a structured approach. Both structured and unstructured interviews require the researcher to have a well-developed understanding of the setting and the topic of interest. These methods are often more suitable when the participants are available to be interviewed on multiple occasions by the same researcher (Cohen & Crabtree, 2006); whereas, a semi-structured interview is more useful, especially when the participants may not be available or able to be interviewed more than once. A partial structure guides the researcher to develop meaningful questions to explore the area of interest before and during the interviews, and achieve comparable and reliable data (Cohen & Crabtree, 2006). Therefore, the use of the semi-structured interviews was considered to be a valuable approach to explore the work and employment experiences of HD patients.

Within Saudi Arabia, for cultural and religious reasons, unnecessarily private meetings between a man and a woman who are not legally related to each other should be avoided. The culture inhibits the potential of repeated interviews between a male researcher and female research participants, although if it was the most appropriate approach it would not be impossible, just difficult to organise. With this in mind, an interview guide will support a one off meeting and ensure the discussion remains focused on the aim of the study. Conducting a semi-structured individual face-to-face interview would be considered a respectful way of communication by the Saudi population

All five qualitative studies used a thematic analysis method, one of the most common analytic approaches in qualitative research across many disciplines including social and health sciences (Braun & Clarke, 2006). This method would potentially be suitable for the developing research given that it is theoretically-flexible. It complements various theories and frameworks, and works efficiently with questions related to the experiences and views of the participants (Braun & Clarke, 2006).

Mixed Methods Studies

There was a shortage of studies that had used a mixed methods approach to examine employment and work ability among CKD patients. In this review, only one study was located that used this mixed design aimed to examine the impact of CKD on vocational and educational achievement (see summary appraisal, Appendix 4). The study was conducted by Murray et al. (2014) and used a sequential explanatory design, where the qualitative phase depended on the quantitative phase in terms of sampling and expanding findings.

The quantitative phase of the study was descriptive in nature and aimed to understand the spread of the employment and educational achievement among patients undergoing RRT. Generalizing the study findings was difficult particularly for women and patients undergoing HD as the whole sample consisted of only 57 CKD patients, with women and HD patients comprising less than 13% of the total sample. In addition, the study focused on young adults only (>30 years were excluded). Therefore, employment status and the ability to work among other older patients remains unexplored and unknown, the gap supporting the notion that further research is needed to capture the experiences of middle aged and older people, women, and those people managing HD treatment.

For the qualitative phase, semi-structured interviews were conducted using a piloted interview framework; although, the use of a theoretical framework during data collection and/or data analysis was not indicated. The sample for the qualitative phase was only fourteen patients and whilst stratified technique according to age, gender, ethnicity, and treatment modality, the number in the groups was small, for example the interviewees with HD could not be more than three or four people. The reduced number of HD patients whilst useful to identify some issues was limited in the both generalizability and transferability of concepts uncovered. Given this sample size problems careful consideration is needed to capture a sample of sufficient size to bridge the knowledge gap of why and how people with CKD have problems sustaining work.

Within this mixed method study the researchers chose to analyse the research data manually with no aid of any statistical software or computer programs. This was a concern given the amount of data gathered by the researchers especially for the first phase of the study. For this study the type of methodology is quantitative-oriented and the qualitative data was used as a complementary phase to explain or add to the findings of the quantitative stage (Creswell & Clark, 2007). Despite the limitations of this particular study, it provides an insight into a potential effective methodology to facilitate the use of both qualitative and quantitative data, enable theory testing, which seemed appropriate for the developing study given the gaps in available literature (discussed further in the methodology chapter) (Creswell, 2013).

Evidence Gaps

Functioning and well-being of CKD patients, referred to as Health-Related Quality of Life (HRQoL), is often low, especially among HD patients (Kamal et al., 2013). Therefore, it is crucial to monitor the physical and mental status of people managing CKD, not only because of its association with mortality and hospitalization but also for its association with functioning limitation and disability (Al-Jumaih et al., 2011). The progress of the disease and associated symptoms for many chronic health conditions can lead to work limitations and low work productivity (Crooks, 2007; Shaw et al., 2013), and affect many aspects of occupation as a result of permanent or temporal disability (Fisher et al., 2007).

The capacity of CKD patients to sustain employment could be affected significantly by the disease, especially with those undergoing HD (Julián-Mauro et al., 2012). There are many barriers and factors that can affect the employment status and sustainability of work among employees with a LTC. These factors are usually related to an individual’s personal character and social life (e.g. age, gender, educational level, and social life), clinical condition (e.g. nature of the disease, treatment modality, and duration of treatment), and work environment (e.g. employer support, work flexibility, and job accommodations).

Many themes and concepts drawn from the systematic review of the literature are important, and relate closely to the developing study. The review indicates clear evidence of factors, enablers and barriers, such as nature of the illness, that influence the employment status and sustainability of work among employees with CKD or people managing a LTC.

The research evidence does not however provide an understanding of how factors and barriers are related, whether one factor influences another, and what were the most disabling factors, as well as what strategies help people overcome or manage such issues. The lack of research in CKD patients was a limitation of the evidence but similarities of symptoms such as fatigue and pain with other chronic disease populations, enabled comparisons to CKD patients to be extrapolated. The gap in evidence reinforced the need for the developing study, with little being known of the factors that affect work status of CKD patients, especially those undergoing HD.

Research is needed to not only understand factors that may affect individuals' work ability and employment sustainability, but also to apply and adapt theories and tools to better measure and examine the relationships between employment factors (Shaw et al., 2013). There is limited research that examines employment and CKD using a validated tool, in particular the measurement of work ability and productivity of CKD employees. The studies reviewed provided limited evidence of theory application, with no defined theoretical framework or no evidence of a theory guiding the research process. There is a need to connect this research topic with theories and models of disability to generate a deeper understanding of who, what, why and how HD patients continue to work, or not, alongside managing a LTC.

No research to date has been found that explores employment within CKD patients in Saudi Arabia or other Arab countries. Given the unique culture, research performed outside of Saudi Arabia may not be transferrable or applicable to this context. As mentioned previously, the culture and family in Saudi Arabia are known as "collectivist", which means that family members, friends, neighbours, and the entire community care for support each other. This could identify a different type of support model for HD patients that may be transferrable and of interest internationally. Therefore, conducting the proposed research in Saudi Arabia would add to the limited evidence base and theories surrounding the capability of people to work, from the perspective of a different culture than existing studies undertaken in North America and most European countries.

The literature review revealed gaps in both the amount and the quality of the research available exploring employment status and sustainability of work among CKD patients undergoing HD. When examining the methods it was clear that comprehensive research that integrates both quantitative and qualitative approaches would be useful. Indeed, using valid and reliable instruments designed to examine the work ability, productivity, and activity impairment among employed and unemployed individuals with chronic illnesses, combined with in-depth interviews to understand patient experience would offer a deeper perspective of how to sustain employment and advance in the workplace.

Conclusion

Whilst the evidence suggests sustaining employment is difficult for people managing a LTC there is limited understanding of the extent, how and in what way CKD patients are affected. The data on how many people are employed or unemployed with a LTC or in particular CKD is not collated or accurate, particularly in KSA. The experiences of CKD patients in particular HD patient is limited within the body of employment and health literature and research evidence within the society and culture of KSA.

There is no understanding about whether the health and social care polices and legislation in KSA promote or hinder sustained work for people with ill health and what support in society exists or the strategies people adopt to continue working. The gap in evidence reinforces the need for a study in the employment practice and experiences of CKD patients undergoing HD treatment in KSA (Box 3).

Unemployment among CKD patients undergoing RRT is a serious issue that needs immediate action from policy and decision makers, employers, and health-care providers.

Box 3: Key points and gaps in the review evidence

- The unemployment rate among HD patients is at least twice the general population rate

- There are many barriers and factors that can affect the employment status and sustainability of work among employees with long term conditions (LTCs). These factors are usually related to individual’s personal characteristics, social life, clinical condition, and work environment
- Functioning and well-being of CKD patients is often low, especially among HD patients who cannot function and perform various activities consistently as healthy individuals
- It is unclear how and when the physical condition of HD patients influences work productivity and sustainability
- It is ambiguous why and how some people retain employment whereas others are unemployed
- It is unclear whether or how work productivity and sustainability of employment are related
- The lack of theory in the literature is a concern. Theories of disability, social policy, society and sustained employment need to be explored, expanded and understood better for people managing a LTC
- A mixed methods approach would uncover what is happening with respect to employment in CKD patients and will capture a deeper understanding of the patient experience

Chapter four examines and synthesises the different theories and models to understand the concepts that may influence employment sustainability for people managing ill health.

Chapter Four

Conceptual Framework

Introduction

Previous chapters reinforce through the presentation of evidence that CKD patients undergoing HD are more likely to have a reduction in their ability to work in an effective and efficient manner. Helping workers sustain their employability and maintain productivity is a challenge (Williams, Schmuck, Allwood et al., 2007; Nieuwenhuijsen, Franche, & van Dijk, 2010; Abma, 2012). Research has shown a positive correlation between individuals' health condition and work performance (Lerner, Amick III, Rogers et al., 2001; Abma, 2012). For example, the work schedule can interfere with dialysis sessions for CKD patients. However, the review of current evidence shows that employment of CKD patients could be affected by various personal, social, and medical factors. Some factors may relate to patient characteristics and health condition (age, gender, physical impairment), others may relate to social context (acceptance, discrimination) and employment system such as flexibility and readiness to accommodate those groups of individuals (Bakhshi & Trani, 2006). Individuals with limitations in their ability to work are often viewed as "disabled" in many countries (Haveman & Wolfe, 2000; Mitra, 2006). The US Social Security Administration (SSA) considers patients with ESRD undergoing HD as "disabled" as they cannot sustain and carry out valuable tasks or activity for at least twelve consecutive months (ECRI, 2000).

Whilst the comprehensive review in the previous chapter identified employment issues common to people managing LTCs which resonated with symptoms and physical limitations placed on CKD patients there remains gaps in the evidence base.

This makes it more difficult to determine what factors are the most significant that affect HD patients' employment sustainability or ability to work. Therefore, it is important to explore a theoretical and conceptual framework that incorporates various models and concepts to help understand the topic of employment among HD patients and other individuals with disabilities in a given context. This developing research focuses on the exploration of employment in CKD patients in Saudi Arabia. Within the earlier chapters the wider world of employment in the context of LTCs has been exposed and the applicability of the evidence to the culture and context of Saudi Arabia discussed. This chapter draws on existing models and approaches to identify ways in which the topic can be theorised through the societal perspective of disability and the way we think about work and employment among those patients who are considered disabled. Defining and understanding such issues results in positive social, economic, and political implications (Altman, 2001). By doing this, policy makers, for instance, will be able to develop measures and strategies to address such a problem (Mitra, 2006).

The most common 'models' of disability, which have been defined over the last few years, are the Social and the Medical models as well as the International Classification of Functioning, Disability and Health (ICF) model (Mitra, 2006). Indeed an alternative theory to be considered in this context of ill health and employment is the Capability Approach (Bakhshi & Trani, 2006), which combines the different concepts of both the Medical and the Social models of disability, gaining an understanding of whether people are capable of working. Given the unique cultural and religious context of Saudi Arabia, the raft of symptoms and treatment restrictions imposed on HD patients, and the impact of the disease on their physical condition, combining social and medical concepts is crucial to fully understand the context which people find themselves.

To be able to apply the theories and models within the context of KSA the laws on employment and disability, and societal perceptions and support is first presented.

Saudi Arabian Laws on Disability and Employment

Disabled people in Saudi Arabia are characterised as individuals who have reduced ability to undertake and retain employment due to a mental or physical incapacity, according to Article 51 of the Labour and Workman Law (The Economic Bureau, 2002). Individuals who are disabled in Saudi Arabia have a right to exist without ignominy and with recourse to assistance from the state, in accordance with Sharia Law that guarantees individual rights. For 20 years, the Societal and Economic Reform Strategy implemented by Saudi Arabia included policies to support disabled individuals. Disabled people’s mental, physical, cognitive and employment issues were all factored in to the Saudi state’s approach in order for the individuals to better adjust in their communities, while the state also introduced a benefits programme that was contemporary and appropriate (The Economic Bureau, 2002).

Around 4% of Saudi Arabia’s citizens are considered to have disabilities that impact on function that consequently diminish their freedom of activity, although estimates vary (Elsheikh & Alqurashi, 2013). Disability incidence in Saudi Arabia is well researched, thus established data could be utilised more effectively (Al-Turaiki, 2000; Al-Gain & Al-Abdulwahab, 2002; Al-Jadid, 2013). Moreover, information regarding the characteristics of disabilities should be sought out where data is lacking, while the requirements of individuals with disabilities should also be adequately met through assistance initiatives (Al-Turaiki, 2000; Al-Gain & Al-Abdulwahab, 2002; Al-Jadid, 2013).

Diminished output and creativity, reduced standard of living, vulnerability, reliance on others and being restricted to one’s home are all basic assumptions that are prevalent within Saudi Arabia in relation to disabled individuals (Al-Gain & Al-Abdulwahab, 2002). Some of the young people who have disabilities are enrolled, along with their parents, on minor initiatives such as educational programmes, in order to mitigate misconceptions. The Ministry of Social Affairs supports initiatives that are often run by charities, while disabled children and their guardians may benefit from the TV and radio series that are run specifically to assist them (Al-Gain & Al-Abdulwahab, 2002; Ministry of Social Affairs, 2012). However, there is no clear evidence generated as to the utility of such initiatives towards shifting societal conceptions of disability, as well as assisting families and society in mitigating the deleterious consequences of disabilities (Al-Gain & Al-Abdulwahab, 2002). Consequently, research investigating disability in Saudi Arabia in terms of psychosocial factors, economic consequences, features and incidence would assist with disability comprehension, the instigation of educational programmes and an evidence base for legislation (Al-Gain & Al-Abdulwahab, 2002; Al-Jadid, 2013).

According to Elsheikh and Alqurashi (2013), around 100,000 adults with disabilities in Saudi Arabia have the potential to be employed following adequate vocational training, while around 183,000 are currently seeking employment. Around 4% of Saudi Arabia’s entire population, amounting to 720,000 individuals, are considered to have a disability according to Medina’s Social Affairs Representative. However, an alternative approximation suggests it to be 8%, or 900,000 individuals (Elsheikh & Alqurashi, 2013). A more conservative estimate is 0.8 percent, or 135,000 individuals, obtained through a demographic study (Al-Jadid, 2013). Clearly there is a wide discrepancy in these figures. Researching the aetiology and occurrence of disabilities within Saudi Arabia has been the common goal of such research, through locally-orientated epidemiological research and cross sectional study population (Ansari & Akhdar, 1998; Al-Shehri & Abdel-Fattah, 2008). The growth of technology and rapid development provides a pressing need to tackle learning disabilities with a concerted and long-term strategy, something which existing research has overlooked (Elsheikh & Alqurashi, 2013).

Moreover, factors pertaining to non-disabled and disabled individuals' circumstances should be compared and contrasted, rather than simply investigating frequency of disability incidence (Mont; Simkiss, Blackburn, Mukoro et al., 2011). It was argued in Simkiss et al. (2011) that disability definitions need to relate to background dynamics that result in or enhance obstacles to people with disabilities, rather than being constrained to explaining disability characteristics which results in people's positive attributes, capabilities and significance being reduced. Stucki, Boonen, Tugwell et al. (2007), identified that an individual who has a disability has more contemporaneously been defined based on social context and particular case-by-case aspects.

This suggests that there is clearly an ill-applied estimation of actual numbers of disabled people and how they are defined; the majority of women with disabilities, severely disabled, young and old are rarely if ever included in approximations of the disabled population. Furthermore, it may be the case that certain disabled individuals residing in the city and countryside are overlooked (Elsheikh & Alqurashi, 2013). In order for there to be an effective response to disability in Saudi Arabia from care providers, as well as to give analysts a simple introduction, this chapter aims to emphasise major issues pertaining to disabilities.

Shortcomings of Laws on Disability and Employments

Doctors regard disabilities as putting limitations on function, as from their perspective the human body is a repairable instrument whose operation should reflect standard ideals - this is the medical model definition of disability (Paley, 2002). Whereas, the community is perceived to be the major reason contributing to the disability of individuals in the societal disability model; suggesting the causes of disability are consistent obstacles, social marginalisation and harmful attitudes. The diminishment of individuals' capacities to undertake activities is caused by a combination of material, emotional, cognitive as well as psychological factors. However, incapacity does not necessarily follow from being disabled. Disability factors can only function when people's dissimilarities are not considered and factored into a community's accommodation of disability (Elsheikh & Alqurashi, 2013).

Physical location, number of amputees, disability category and overall amount of disabled individuals are all factors that are under- or inaccurately accounted for in the yearly accounts of the Ministry of Health (The Economic Bureau, 2002; Al-Jadid, 2013). Scant regard has been given to assisting disabled individuals with their work prospects, or with preparation and teaching, rather the provision of medical assistance has been the overarching concern (Al-Jadid, 2013).

There are a number of Saudi royal associations that have been formed, creating organisations and networks of groups assisting disabled people. However, their nascent form and continued expansion means that their work is often overlooked. Although the creation of organisations and structures has been the focus of charitable assistance, the acknowledgement by donors of the role of royal associations' provision for disabled individuals is in a preliminary form. Regardless of whether there are a greater number of disabled people in the rural or urban areas, the infrastructure for disabled people in Saudi Arabia is inconsistent (The Economic Bureau, 2002; Al-Jadid, 2013; Elsheikh & Alqurashi, 2013).

Disability and Gender in Saudi Arabia

When investigating Islamic countries and disability, sex is a crucial issue. For example, no information is available explaining or determining the amount and location of gender-specific rehabilitation centres. Although targets exist for women who are severely disabled or have overlapping disabilities to be reintegrated into society, men comprise most of the individuals enrolled in occupational reintegration training programmes (The Economic Bureau, 2002). Consequently, for these women there may be a lack of occupational learning opportunities, or there may be social norms that deem females should not be employed, or occupational reintegration is a concealed barrier. To enhance provision, gender issues and how this influences or impinges on factors related to disability and employment need to be carefully understood (Al-Jadid, 2013; Elsheikh & Alqurashi, 2013).

Employers' view of Disabled Employees

A myriad of issues related to management, cost, individual, and social, can impact upon a business or organisation's decision to employ and maintain the employment of an individual (Graffam, Shinkfield, Smith et al., 2002), with those issues relating to disabled persons being the focus of this research. If the everyday actions of an individual are detrimentally impacted upon over a significant duration as a consequence of mental or physical injury or illness, then that individual could be considered disabled (Americans with Disability Act 1990). A significant duration is taken to be determined disabled; a disability has to have been endured for over a year, while a detrimental impact has to be anything above slight. In relation to a person's everyday actions, various aspects may be relevant such as reduced awareness of harm, lifting capability, movement, cognitive capacity, focus and comprehension, incontinence, motor function and deftness, vision, sound and talking abilities, alongside the facility to hold and transport normal items (Morin, 1990).

Mansour (2009) identified how disability was a source of acceptable social discrimination in Saudi Arabia, with prospective employers able to openly discriminate regardless of legislation being in place so that disabled individuals can be provided for at work. In fact, anti-discrimination legislation allows a disabled person to take their employer to court if they feel they have been victimised, albeit a rare occurrence for such rights to be exercised (Arab News, 2008). Arab News went on to detail an example whereby, in order to meet the requirements under ‘Saudization’ for a particular proportion of jobs in an organisation to be assigned to Saudi citizens, certain number of Saudi worker including disabled ones were hired by the manager to meet such requirement imposed by the government in order to get the rewards for, or to avoid the penalties, meeting the ‘Saudization’ plan within the organization. Many employers are hiring those people just to fulfil the requirement of the legislation of ‘Saudization’, although they do not need, or expect much from, those workers (Arab News, 2008). For a sustained and significant contribution to be made to a country’s progress by disabled individuals, much more effective chances and assimilation backed by laws and tailored actions is required across the Arab sphere (Arab News, 2008; Mansour, 2009).

Medical and Social Models of Disability

The Medical Model

The medical model considers disability as an issue of the person that is specifically brought on by an infection, damage or other wellbeing conditions. It is seen as a problem that only concerns the affected person, not anyone else (Parsons, 1975; UoL, 2015). Moreover, environmental and social conditions, which might influence individuals' wellbeing and cause disability, are not given any significant attention in this model (Figure 6) (Sandqvist & Henriksson, 2004).

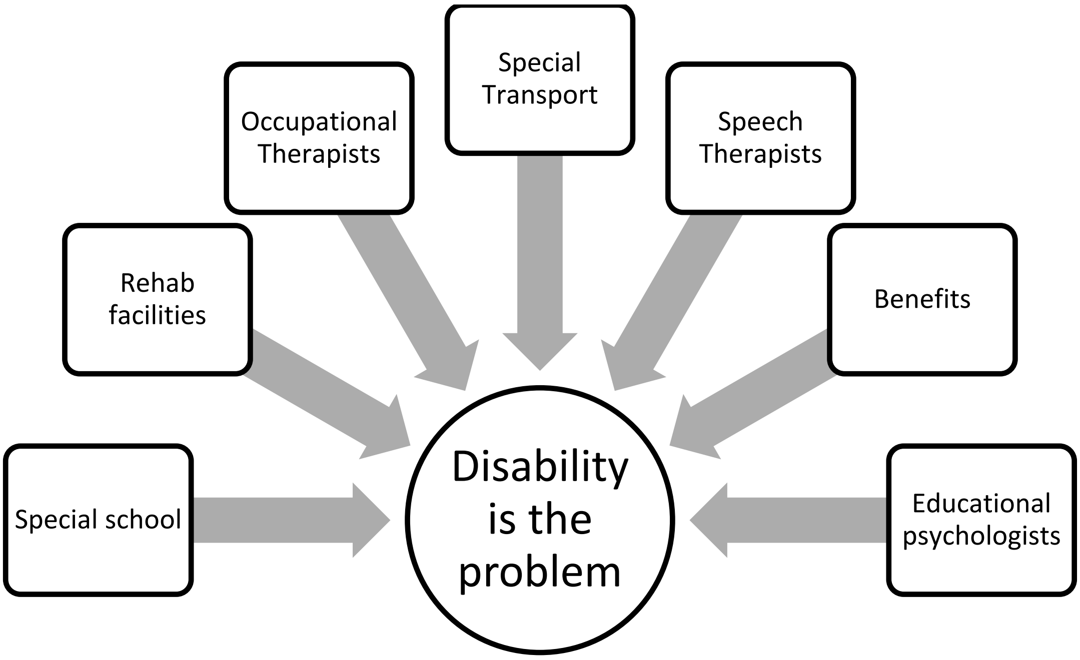

Figure 6: Medical Model of Disability (Ombudsman, 2015, p. 3)

By focusing on the health condition of the person as the main and the only cause of disability, efforts will be taken to cure the disabled individuals and/or provide them with special equipment and services to enhance their life (Table 12) (Ombudsman, 2015).

Table 12: Medical Model in Actions (Ombudsman, 2015, p. 4):

Issue	Medical Model
Transport	For those who are not able access the mainstream transport due to disability, a specialist transport will be provided.
At Home	Health professionals such as occupational health nurses will assess the needs of the disabled people and their homes and will provide special products as well as suggestions in how to adapt the home in order to meet such needs.
Education	Impaired kids attend special schools and get special education. These schools accept only disabled pupils for alternative qualifications.
At work	Workplace environment is made for incapacitated individuals to work close by other impaired individuals in an exceptionally adjusted environment doing particular work.
Communication	Correspondence happens in "standard" ways. For example, if somebody cannot read size 12 font letters, individuals will be asked to approach a non-disabled person to peruse the information on the letter for them.
Language	Dialect normally alludes to a man's health condition, what is "wrong" with them and what they may or may not be able to.
Attitudes	Assumptions are made by non-disabled individuals about what disabled person is equipped for in light of data about their health condition for instance utilizing information from the web.

For example, if a HD person is using a wheelchair and it happened to be unable to access work into some buildings because the building is inaccessible or there is no lift, this model would propose that this is a direct result of the wheelchair, instead of the steps (UoL, 2015). Using this model in this study will only enable the researcher to look at the illness, symptoms, and side effects of HD treatment (medical view only) when assessing employment of HD patients, which are important but cannot be considered in isolation.

In the medical model of disability, individuals are viewed as handicapped on the premise of being unable to function as an "ordinary" individual does (Mitra, 2006). This model is emphatically normative; underpinned by a belief that there is a need to bring disabled individuals closer to the standard norm, usually achieved through the provision of rehabilitation, and healthcare services (Mitra, 2006). Actually, acknowledgment and integrity of the profession of occupational therapists, society and the medical profession reflect the application of this model (Sandqvist & Henriksson, 2004).

This model depends on a conviction that the challenges connected with the disability ought to be borne completely by the disabled individual, and that they ought to try (maybe in time and/or cash) to guarantee that they don't trouble any other individuals (UoL, 2015).

The Social Model

The social model of disability was initially produced by disabled activists and academic writers in response to the medical model of disability (Carson, 2009). They believed that the problem of disability is a result of the society not the disabled individual (Figure 7). Therefore, social change was a key to eliminate such an issue (Oliver, 1996). Using this model in this study, for example, will inform the researcher’s ability to understand the issue of employment among CKD patients taking into account that there are many other factors than the social factors could affect their employment such as personal and cultural factors. Many Saudi female HD patients, for example, could decide to stop going to work if the husband asked them to do so even though they are capable and able to work as other individuals.

Figure 7: Social Model of Disability (Ombudsman, 2015)

There are several versions of the social model of disability such as the oppressed/minority version and the discrimination version and each of these versions use the social model to define certain impairments and disabilities which are believed to be caused by society (Oliver, 1990). For example, within the oppressed minority version of this model, it is assumed that social discrimination faced by disabled individuals is almost the same as those faced by the minorities (Hahn, 2002). The purpose of this section is, however, to give a general overview of the model, not to write about each of its versions in detail.

If everything within the society were made and designed for the majority (non-disabled people) without considering the minority (disabled individuals), then the society is the creator of disabilities (UoL, 2015). In this model, the ideal society would remove or at least reduce any potential social and environmental barriers and factors that could disable individuals with certain needs (Table 13) (Oliver, 1996;

UoL, 2015). Society is required to make adjustments in many social and environmental aspects within the society such as accessible transport and workplaces, which could be costly and time consuming, in order to allow equality among the population, so that impaired individuals will not be excluded (Hahn, 2002; UoL, 2015).

Table 13: Social Models in Actions (Ombudsman, 2015, p. 4):

Issue	Social Model|
Transport	Authorities will take the responsibility to ensure that the mainstream transport and infrastructure are not only for able bodied, but also for and accessible to disabled people
At Home	Mainstream retailers will try to avoid selling special products designed only for disabled people, instead most products such as kitchen, bedroom and bathroom products will be provided for everyone with more options and features such as various measurements taking into account the concept of accessibility when designing such products
Education	Community schools are accessible to all children who wish to attend including disabled kids with same qualifications.
At work	Job accommodations, work adjustments, and accessible work environment are available at workplace, so disabled workers can work together with non-disabled ones.
Communication	Correspondence is customized to address the issues of the people involved and data is accessible and provided in various configurations and formats.
Language	Dialect is all around the boundaries confronted by any person including disabled individuals and what should be possible to reduce or prevent them.
Attitudes	Individuals converse with people about their needs and encounters and the boundaries they confront.

On many occasions, society may not be able to ensure that disabled people are not excluded if the impairment is not obvious to the public i.e. ‘hidden disability’.

Therefore, it is the responsibility of the impaired individuals to disclose and sometimes explain their conditions and needs. Then, the society who adopts this model must respect and accommodate those with less visible conditions causing permanent or temporary disability (Carson, 2009; UoL, 2015).

Despite the fact that medical and social models are the most common models used to define disability, using one or both models within the context of this research study is not appropriate. Neither model incorporates all identified factors and concepts exposed from the literature that could affect employment among CKD patients within the Saudi context. Consequently, there is a need to apply a holistic theoretical framework combining the different concepts that impact on people working. The Capability Approach (CA) may offer such a combined framework; but first it’s important to understand the International Classification of Functioning (ICF) model before such a theory is considered.

The International Classification of Functioning, Disability and Health (ICF)

In 1980s, the World Health Organization (WHO) developed the International Classification of Impairments, Disabilities and Handicaps (ICIDH) which went through several revisions and was recently renamed to be the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001). This model provides a framework with which to describe the disability and functioning of individuals. The situations encountered by people with special needs would be used to classify their functioning and disability.

The ICF model integrates the medical and social models of disability (Chow, Cichocki, & Croft, 2014). While the medical model looks at the biological and health status, and the social model looks at the social conditions that disable individuals, the ICF extends the view of disability to be seen as a result of many factors and concepts including social, biological, environmental, and personal factors (WHO, 2002; Chow et al., 2014) (Table 14).

Table 14: Components and concepts of the ICF (Mitra, 2006; Morris, 2009)

Concepts & Components	**Definitions and examples**
Participation	Individuals' actual involvement and lived experience in society and actual life such as communications, relationships, social life activities, and leisureliness.
Impairments	Abnormality or loss as a result of limitations in the individuals' functioning and their body structure.
Activity	Performed actions and tasks that are carried out by a person.
Contextual factors	These factors refer to the background and current lived context and life of a person such as personal factors and characteristics (e.g. gender, age, and educational level), cultural and social factors (e.g. rules, policies, and attitudes), and environmental factors (e.g. health and social facilities, and transportation).
Functioning and disability	Functioning and disability are two 'umbrella' terms, one being the mirror image of the other. "Functioning covers body functions and structures, activities, and participation, whereas disability includes impairments, activity limitations, and participation restrictions" (Mitra, 2006, p. 238).

The ICF model helps in understanding the employment outcomes of individuals with disability and functioning limitations by assessing the workplace environment as it could be the reason behind hindering those group of people from the achievement of optimal employment outcomes (MacDonald-Wilson & Nemec, 2005; Peterson & Rosenthal, 2005). Co-workers and employers attitude and workplace accessibility are examples of factors that could either facilitate or hinder individuals with special needs.

The ICF consists of two main dimensions: body structures and functions is the first dimension of this model, and the second dimension refers to the individual's activity and participation (Figure 8) (WHO, 2002). The first dimension refers to the body impairment such as a loss of organ and mental disorders; whereas, the second dimension refers to the ability of individuals to carry out tasks and activities and being able to fully participate in a given situation (WHO, 2001).

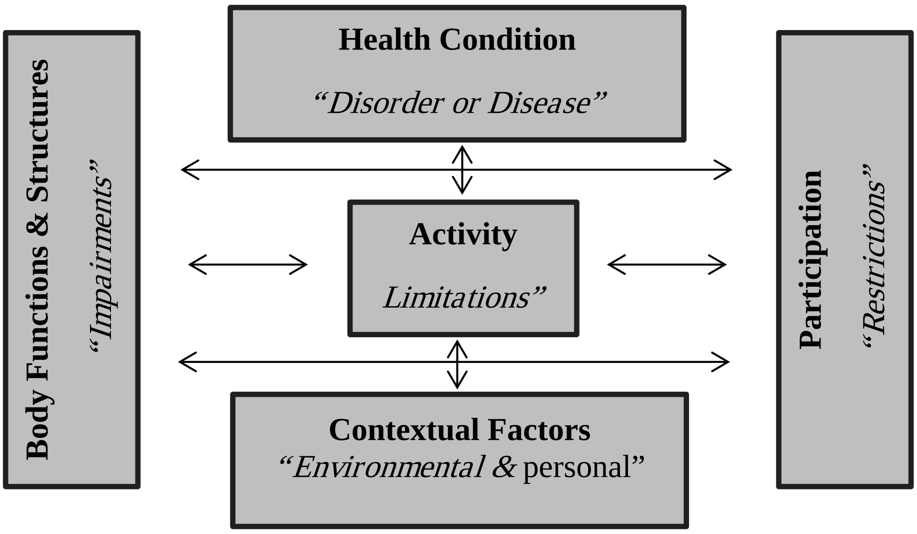

Figure 8: The International Classification of Functioning, Disability and Health (WHO, 2001, p. 18).

ICF provides only two qualifiers for assessing and measuring activities and participation. The first qualifier assesses the individual's capacity by measuring the highest level of functioning the individual can achieve in an ideal environment. Whereas, the second qualifier assesses the individual's performance which refers to the actual activities and functioning of disabled individuals in reality, not in an ideal environment (Hammal, Jarvis, & Colver, 2004; Morris, Kurinczuk, Fitzpatrick et al., 2006; Morris, 2009). As a result, the ICF when used in practice becomes more like a health classification because the socioeconomic conditions of the disabled individuals are not considered when implementing the ICF, limiting the usefulness of the model (Mitra, 2006). The socioeconomic factors are key influencing factors when it comes to studying employment; therefore, the Capability approach and theory may provide a more holistic framework than the ICF to assess and understand employment among HD patients who are considered ‘disabled’.

The Capabilities Approach

The Capability Approach offers a useful tool to understand and respond to various challenges related to employability of CKD patients (Bakhshi & Trani, 2006). It facilitates the assessment of HD patients’ work ability and employment sustainability. Amartya Sen’s Capability Approach is based on the value that a person has to do something (Sen, 2001; Bakhshi & Trani, 2006). It looks at the range of possibilities and choices that an individual can do or take (capabilities), not at what an individual is actually doing (functioning). Many factors at a given time may impede or expand HD patients’ work-ability, and therefore affect their employment status and sustainability (Sen, 2001; Bakhshi & Trani, 2006) (Figure 9).

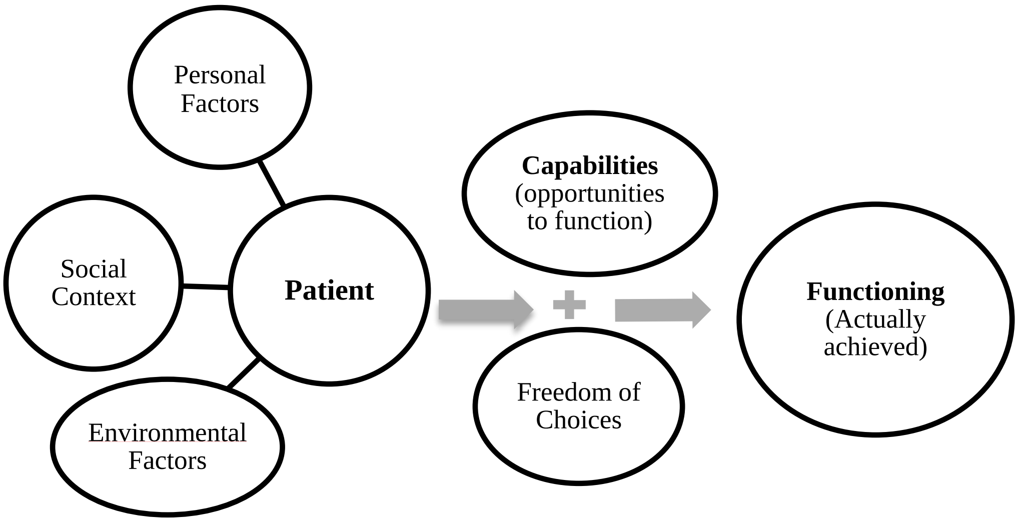

Figure 9: The Capability Approach (Altman, 2001, p. 110)

Employment sustainability has been defined by Van Der Klink, Bultmann, Brouwer et al. (2011) using the capability approach (Robeyns, 2005). First, the concept of ‘capability’ is normative and refers to the potential (‘the opportunity of being able to’) of accomplishing valuable functioning by a person in a given context. Applying this definition within the workplace environment, the ‘capability’ will refer to ‘work’ taking into account that ‘work’ is valuable to individuals. To be able to sustain employment, personal resources such as attitudes, beliefs and values, which significantly affect an individuals’ achievement in the workplace, are considered in the capability approach. It is crucial for individuals to build up and expand their capacities to enable them to take decisions for alternative options when there is a change in their life: a change in their health condition or simply because aging. Applying the capabilities approach to study employment sustainability does not only assess the motivation, skills, and knowledge of the employees, but also the workplace environment and the available opportunities that could either facilitate or hinder the employees from carrying out work tasks in a productive and sustainable way (Van Der Klink et al., 2011).

Defining employment sustainability and the ability or inability to work among HD dialysis patients based on the Capability Approach is important to understand how or whether to rebuild or reform the employment system and policies for the betterment of all (Bakhshi & Trani, 2006). Using this approach to address such an issue will have a significant impact on HD patients living conditions and well-being.

Assessing employability among HD patients using the Capabilities Approach allows different factors to be taken into consideration such as; the inability to work in a given setting or at a given time can be a result of many factors other than just the individual’s health condition. The approach provides a perspective of not only the individual’s capabilities and ability to function, but also the surrounding context, including social, environmental, and political factors (Bakhshi & Trani, 2006). Indeed the Capabilities approach advocates that many individuals who cannot function in a specific society as a result of a disease are able to function in another. Acceptance, availability of policies based on equality of activity and participation, flexibility, and work accessibility are some factors that may increase HD patient’s re-entry to work and/or increase job retention. The hours of treatment three times a week interferes with the flexibility of a work schedule, and physical work is difficult to sustain due to fatigue. In Saudi Arabia some people may need to relocate near a dialysis centre changing their environment and work opportunities. Based on these examples, the Capabilities Approach identifies that it is the resources, work structure and policies that make those groups of individuals “disabled” or unable to work and vice-versa (Bakhshi & Trani, 2006).

The Capability Approach examines the person as a whole, considering many other factors and elements that might affect their quality of life. For example, the individual's "agency" is considered i.e. the person's perception of him/herself, and whether they are able to make meaningful decisions, and set goals (Bakhshi & Trani, 2006). Agency is defined as when "*someone who acts and brings about change, and whose achievements can be judged in terms of her/his own values and objectives, whether or not we assess them in terms of some external criteria as well*" (Sen, 2001, p. 19). This inclusive framework offers a more person-centred approach examining factors which directly impact on an individuals' capability and functioning capacity.

Selecting an appropriate theory

Many health and social agencies consider HD patients "disabled", although it is useful to explore the definition of this term "disability" from both the medical and the social point of view. The medical view is based on individual's physical or mental impairments; whereas the social model argues that the inability of the environment and the society structure to accommodate individuals with impairments is what makes them "disabled" (Bakhshi & Trani, 2006). The social model is now recognized by many disability activists and organizations where they look at the existing barriers that may hinder individuals with special needs to function as if they are nondisabled individuals (Bakhshi & Trani, 2006). Whilst both perspectives highlight key social and physical influences on opportunities for employment and an individuals' ability to physically sustain employment in isolation, neither model encompasses all the influencing factors.

The World Health Organization (WHO) has defined an International Classification of Functioning (ICF) as "*the term functioning refers to all the body functions, activities* *and participation, while disability is similarly an umbrella term for impairments, activity limitations and participation restrictions*” (WHO, 2002, p. 2). However, this definition does not address the interaction between persons with certain limitations, and the environment and society in which they live, even though it's based on both the medical and social models (Bakhshi & Trani, 2006).

Whereas, the Capabilities Approach, highlights the importance of looking at both the tasks that individuals are required to do at work (what they actually do) considering their limitations in functioning, and individuals’ capabilities (what they can do) and the setting where they functioning considering many aspects such as expectation, policies, and flexibility (Bakhshi & Trani, 2006). This also includes assessing the set of capability “choices available” for the person and how the impairment will affect the choice of the available opportunities (“freedoms”) (Terzi, 2005). By doing this, barriers and facilitators related to work-ability and employment sustainability would be identified. This whole approach offers a positive perspective of disability, more what can be achieved and choices available to support people than what issues they have that negatively impact on their ability. Using and exploring these key concepts within the research will enable the researcher to explore wider solutions and strategies with people.

Conclusion

The question the theories on disability generate is whether individuals with limitations in functioning due to chronic illness such as CKD would be considered as having a disability. The evidence suggests that it is the individual’s health condition, personal characteristics, society, and environment that will determine whether a person with certain limitation in functioning is disabled or not, rather than a label being given based on just physical health or social contextual determinants.

This chapter highlighted that the medical, social, and ICF models and definitions offer a limited and narrow perspectives when mapped to employment, as to what is classed as a disability and the factors which may influence a disabled persons ability to work. The Capability approach offers a combined person centred perspective which seems more aligned to the aims of the research study – key theoretical points are summarized (Box 4). It provides a holistic framework to understand the work-ability of a HD patient and enables the determination of facilitators and barriers that may affect employment sustainability within this group of patients.

Box 4: Summary of key theoretical points

- Individuals with CKD undergoing HD are considered “disabled” as they cannot sustain and carry out valuable tasks or activity for at least 12 consecutive months
- The medical model considers disability as an issue of the person that is specifically brought on by a disease or other wellbeing conditions, a problem that only concerns the affected person, not anyone else
- The social model of disability considers the problem of disability is a result of the society not the disabled individuals. Therefore, social change is a key to eliminate such an issue
- The International Classification of Functioning, Disability and Health (ICF) integrates the medical and social models of disability and extends the view of disability to be seen as a result of many factors and concepts including social, biological, environmental, and personal factors.
- The ICF is a health classification but fails to consider the socioeconomic conditions of the disabled individuals.
- The Capability Approach (CA) looks at the range of possibilities and choices that an individual can do or take (capabilities), not at what an individual is

actually doing (functioning).

- CA views not only the individual’s capabilities and ability to function, but also the surrounding context, including social, environmental, and political factors.

The next chapter presents the study methodology and a detailed plan of how the research was conducted, to explore the topic of employment and HD patients in Saudi Arabia.

Chapter Five

Methods

Introduction

The previous chapters have identified many factors and concepts that affect the ability of CKD patients to work and/or sustain employment; including personal factors (educational level, and gender), clinical factors (duration of treatment, and dialysis schedule), social factors (discrimination, and health perception), and environmental factors (work accessibility, and employer flexibility and support). These have been exposed by the review of the literature and additional concepts, theories and models related to disability such as the ICF and the Capability Approach. This chapter draws together the learning to date and presents the research plan to implement a study that comprehensively examines the experiences of HD patients in KSA and their ability to sustain employment.

The study methodology was guided by the employment and health concepts and theories which emerged from the current literature (Crotty, 1998). The methodological approach including the appropriate sample selection, data collection and analytical techniques are discussed and justified. The chapter draws together the study plan starting with the aims and objectives providing a clear and concise overview of the mixed methods study.

Aim of the Study

This study seeks to explore employment status, and sustainability of work among HD patients in Saudi Arabia. The research generates a deeper understanding of who, what, why and how HD patients continue to work, or not, alongside managing a LTC.

Objectives

Five key objectives include:

1. To identify the employment status, work productivity and activity impairments of HD patients;
2. To understand the impact of CKD on employment achievement and sustainability of work of HD patients;
3. To understand how employed HD patients manage to sustain work, and identify the issues that threaten employment;
4. To understand the barriers that prevent people, receiving HD, to continue to or sustain employment alongside treatment and what enabled them to work;
5. To extend knowledge and understanding of the application of the Capabilities Approach theory and concepts, within health.

Methodology

The topic of employment sustainability, work ability and productivity among CKD patients undergoing HD requires further research to measure it both objectively and subjectively. The review of the literature suggested there was merit and strength in a using mixed methods approach to understand employment and work alongside ill health (Murray et al., 2014). Work productivity (presenteesim and absenteeism), activity impairments, health-related quality of life can be measured both objectively and subjectivity. Although objective productivity measurement reduces bias it will limit the generalization and interpretation of the findings (Prasad, Shih, Wahlqvist et al., 2002). Whereas, the subjective measurement tools for health-related work productivity, will be applicable to different populations with various occupations and will increase the transferability and applicability of the findings (Prasad et al., 2002). This means that, in addition to the objective data of the study, CKD patients' perspectives and experiences (from different occupations, age groups, level of education), with respect to their employment and ability to work will inform this study. The findings will lead to a more focused development of strategies to overcome such issues that are patient-centred, evidence based and applicable to real life (Polit & Beck, 2004). Gathering data objectively and/or subjectively in the quantitative phase of this study, such as the use of health-related work productivity measurement tools, does not necessarily make the data fallible, it tells the researcher what is happening. In-depth interviews, however, can add clarity and narrative to explain, the quantitative data. Not all CKD patients, for example, have limitations in workplace as some of them could be working from home using the internet or phone or have accessible, supportive, and healthy work environment.

In essence, subjective evidence is assembled based on individual views from research conducted in the field; hence, input from the participants of the study is essential and will potentially reveal the real life conditions affecting their work status. It is hypothesized that exploring the thoughts and ideas as well as values of the participants of this research would provide a more in-depth description to enable the researcher to answer the objectives of the research. In addition the qualitative exploration provides an opportunity to develop a deeper understanding as to the application of the capabilities approach theory. It will examine whether the theory is useful to explain and offer insights on the parameters of work disability and employment sustainability among HD and other LTC patients. Therefore, collecting and mixed data both quantitative and qualitative data will generate a deeper understanding of who, what, why and how HD patients continue to work, or not, alongside managing a LTC.

Mixed Methods

The mixed methods approach emerged in the 1980s, and has been regarded as a third methodological movement in behavioural social sciences (Tashakkori & Teddlie, 2010). More recently, mixed methods research has become more prolific in fields such as health and medical sciences, social work and nursing (Wisdom & Creswell, 2013). It is described as a methodology which necessitates the collection, analysis and integration (mix) of qualitative and quantitative data to facilitate a deeper understanding of a research problem or issue, so not just what is happening but more often why and how (Johnson & Onwuegbuzie, 2004; Johnson, Onwuegbuzie, & Turner, 2007). Significant definitions of mixed methods are often anchored on Stange, Crabtree, and Miller (2006, p. 1):

> "*Involved integrating quantitative and qualitative approaches to generating new knowledge and can involve either concurrent or sequential use of these two classes of methods to follow a line of inquiry.*"

The value of mixed methods is reflected in its strengths: the meaning of numbers can be enhanced using narrative, words and pictures. It enables the researcher to generate or test theories. By combining qualitative and quantitative approaches, answers to broader and complex questions can be generated, rather than using a single research approach. Indeed, the strength of one research approach can overcome the weakness of the other approach when using a mixed methods approach, offering enhanced generalizability of findings (Creswell, 2013). It is argued that more complete knowledge and evidence to inform practice and theory can be achieved by using mixed methods approach (Johnson & Onwuegbuzie, 2004).

Combining quantitative and qualitative methods often strengthens the validity of the research, allowing variation in data collection and integration of data findings and interpretation. As a result, it reduces the gaps in the collected data/information, and minimizes the researchers' pre-existing assumptions. The use of mixed methods has several advantages and disadvantages (Table 15).

Table 15: Advantages and Limitations of Mixed Methods (Wisdom & Creswell, 2013):

Advantages	***Limitations***
• Allows for a comparison between qualitative and quantitative data: facilitates in-depth understanding of the topic of interest especially when inconsistency between qualitative and quantitative findings • Strengthens the study findings using the point of views of the participants, which support and allow for better interpretation of the study findings • Provides more flexibility in the research methodology, can be adapted to several research designs to collect more data than using one research method • Uses various methods to collect data using both qualitative and quantitative designs which usually results in more comprehensive and rich data	• Difficult to implement: a challenge in complex intervention as it requires careful planning and implementation. This includes, the determination of the study sample for both phases, and stages for the integrations of the data and findings • Requires both qualitative and quantitative experts to ensure high quality, as studies often large and complex • Implementation requires more resources: usually more time and more than one researcher to conduct, including the availability of participants for both study phases especially in the sequential designs

The advantages of the mixed method approach in this study is that it will enable the researcher to use the quantitative strand to determine the employment status, the work productivity and activity impairments, and the quality of life of HD patients in Saudi Arabia.

At the same time, the qualitative strand explores the lived experiences of the participants with respect to their employment status and ability to work, and exposes the barriers and facilitators to sustain employment. This is an innovative way of understanding the topic of interest of this research study. This method will maximize the strengths of both quantitative and qualitative strands and minimize their weaknesses. The data gathered through interviews, will consider the real life context of HD patients, to validate the quantitative data.

With any approach there are limitations. The strategies and steps undertaken to overcome or minimise the limitations of mixed method are considered under the challenges section for the selected mixed methods design.

Research designs have distinct methodology and procedures, and they all provide systematic methods that enable the researchers to gather, investigate, and report data to answer specific questions. Selecting the best possible research design is important to answer the research questions and generate high quality data. Mixed methods approach has four key designs:

1. Triangulation Design: also known as a Convergent Parallel Design (Creswell, 1999), it is a single phase research study where the researchers use both qualitative and quantitative approaches to collect and analyse data in order to achieve different data to answer the same research question (Morse, 1991). Findings from each approach are combined in the interpretation of the results

at the end of the research study (Creswell, 2013). Whilst this is useful, for it to be manageable the sample would need to be small to allow both in-depth and quantitative instrument to be used simultaneously. The combining of phases restricts the researcher from purposively selecting participants for the qualitative element to explore in more detail significant quantitative findings from the collective group. Therefore this design was not considered applicable for this particular study.

2. Embedded Design: similar to the triangulated design it allows the researcher to combine qualitative and quantitative data, but uses one primary qualitative or quantitative approach with the other generating supportive data for the findings of the study (Creswell, Fetters, Plano Clark et al., 2009). An embedded design mixes the different data sets at the design stage with one type of data being embedded within a methodology framed by the other. Whilst this could be useful for this study, merging data at the design stage constrains the freedom of the researcher to follow up theories from one data set to another over time, therefore potentially not the best approach for this study.
3. Exploratory Design: also known as instrument development design (Creswell, Fetters, & Ivankova, 2004) and quantitative follow-up design (Morgan, 1998). It is a two phased sequential design where the researchers start with a qualitative approach to build instrument(s) which will be used in the second (quantitative) phase (Creswell, 2013). This type of design lends itself to a data driven study rather than a theory driven study. The instruments for the study are already developed although not tested or applied within this study context,

which renders the instrument development phase redundant. Therefore this design is not appropriate for the developing study.

4. Explanatory Design: also known as a qualitative follow-up approach (Morgan, 1998). It is a two phased sequential design where the researchers start with a quantitative approach to answer the research questions, and follow-up with a qualitative approach to explain the results of the first phase and/or add to the findings (Creswell, 2013). This was considered the most useful design for this study as it enables the researcher to explore the facts of who and how people are employed then with a select a representative smaller sample explore the individual experienced and intricacies of sustaining employment in real life (Murray et al., 2014). This design will allow for theory testing; the interrogation of the quantitative data followed up by the qualitative phase exploring deeper the questions that arise from theory and findings makes the explanatory design an appropriate choice.

The Explanatory Sequential Design

Mixed methods sequential explanatory design, is a two phased sequential design where the researcher starts with a quantitative approach to answer the research questions, and follows up with a qualitative approach to explain the results of the first phase and/or add to the findings (Creswell, 2013). The use of qualitative data to explain, significant or surprising results of the first phase (quantitative phase) is the overall purpose of the mixed method explanatory sequential design (Creswell, Plano Clark, Gutmann et al., 2003). Researchers are able to select a subsequent group of participants who participated in the first phase to follow up with them based on the results of the quantitative phase (Morgan, 1998; Tashakkori & Teddlie, 1998), or to use the characteristics of the first phase participants to select a purposive stratified sample for the second (qualitative) phase (Creswell, 2013). There are a number of advantages to using such a design and also challenges (Table 16).

Table 16: Advantages and Challenges of Explanatory Design (Creswell et al., 2003)

Advantages:	***Challenges:***
• Most simplistic mixed methods design consists of two separate phases and can be conducted by a single researcher. • Can write the final report in two separate sections which enables the researchers to write a clear description and a high quality study. In this study findings will be presented in two chapters although there will be many points of interaction and integration between the qualitative and quantitative data throughout analysis. • This design is preferred by quantitative researchers, especially when there are instruments to use, and hypotheses and theories to test. This study will utilize two quantitative instruments and will include qualitative interviews guided by the theory of the capability approach to explain, support and add to the findings.	• More time to implement especially when the researcher starts to collect the qualitative phase although this phase could be conducted with a fewer numbers of participants. In this study, no more than 20 patients would be recruited for the qualitative phase which is manageable in the time frame available for data collection. • Selection of the second phase participants challenging: whether to select a representative sample from the same population or to select their sample from the participants of phase one, also availability of participants for phase two. In this research, sampling was performed using a stratified random sampling technique. • Difficulty to secure ethical approval and managerial permissions, due to lack of clarity on how and who will be selected to participate in the second phase. This was not a challenge for this study and was secured within a three month period.

The design is a quantitative-oriented design and consists of two stages (or phases) (Figure 10). It is the most straightforward mixed methods design, although there are challenges to its implementation. Researchers start collecting quantitative data first, analysing, and integrate the findings then use of qualitative data follows. As this design starts quantitatively, the typical philosophical assumption underpinning this design is the post-positivism worldview, however, the philosophical assumptions could change and shift to constructivism worldview for the second phase (qualitative) of the research (Creswell, 2013).

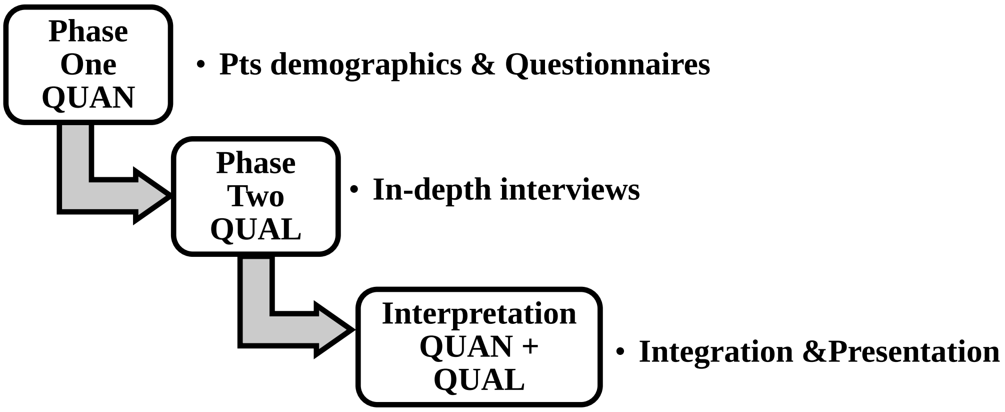

Figure 10: The Explanatory Sequential Design (Creswell, 2013)

Conducting the second phase, in the design, is based on different aspects. There are two models in this approach: (1) the follow-up explanations model (Figure 11) and (2) the selection of participant selection model (Figure 12), although these two models could be used together.

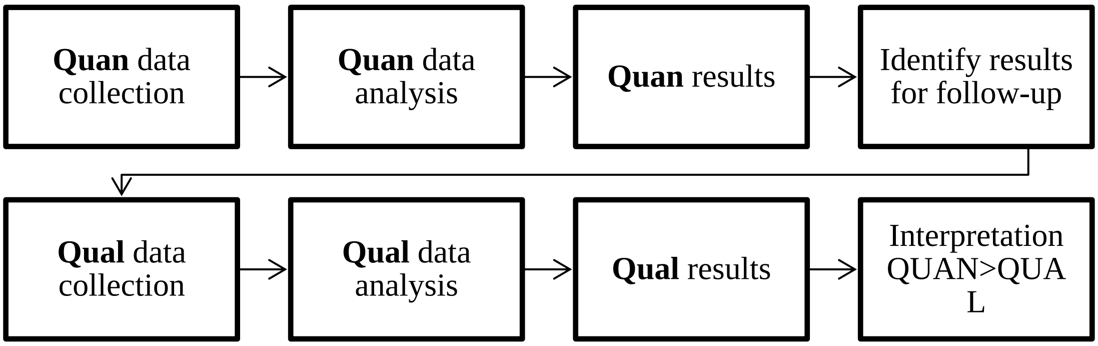

Figure 11: Follow-up Explanations Model (Creswell, 2013, p. 73)

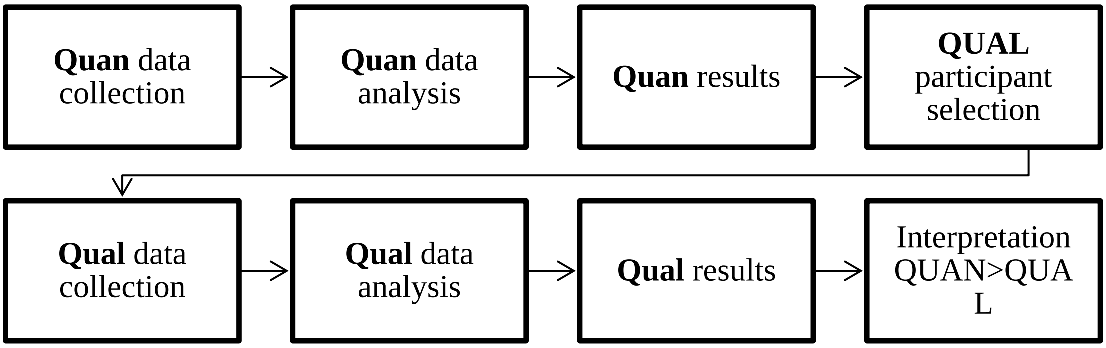

Figure 12: Participant Selection Model (Creswell, 2013, p. 73)

For the explanations models, the aim of the second phase is to explain (or expand) the results of the first one. Therefore, the researchers need to analyse the quantitative data before conducting the qualitative phase in order to set the interview guide aimed to find explanations for phase one significant results, for example. On the other hand, the participant selection model does not necessary require the researcher to analyse the quantitative data first. For example, this model is useful when the researchers want to form a group of participants (representative participants of different groups) for the second phase based on the participants’ demographics and characteristics (e.g. gender, age, employment status). If the strata used to form a group of participants for the second phase contains measurable items (such as subjects with extreme scores), the researchers must analyse the data of phase one first (Creswell, 2013). In this study, the researcher used both models by ensuring a representative sample for phase two using a stratified sampling technique based on patients’ age, gender, employment status, and geographic area. Also, the interviews contain questions related to the results of phase one to explain and validate the findings.

The implementation of this design for this research study will be explained in more details and step by step throughout this chapter starting from the plan of investigation through to data analysis and integration.

Plan of Investigation

The study used a cross-sectional mixed-methods sequential explanatory design, combining the qualities of both quantitative and qualitative approaches to uncover the best available data to gain a better understanding of the research problem (Giddings, 2006; Ivankova, Creswell, & Stick, 2006). The study progressed in two phases (Figure 13).

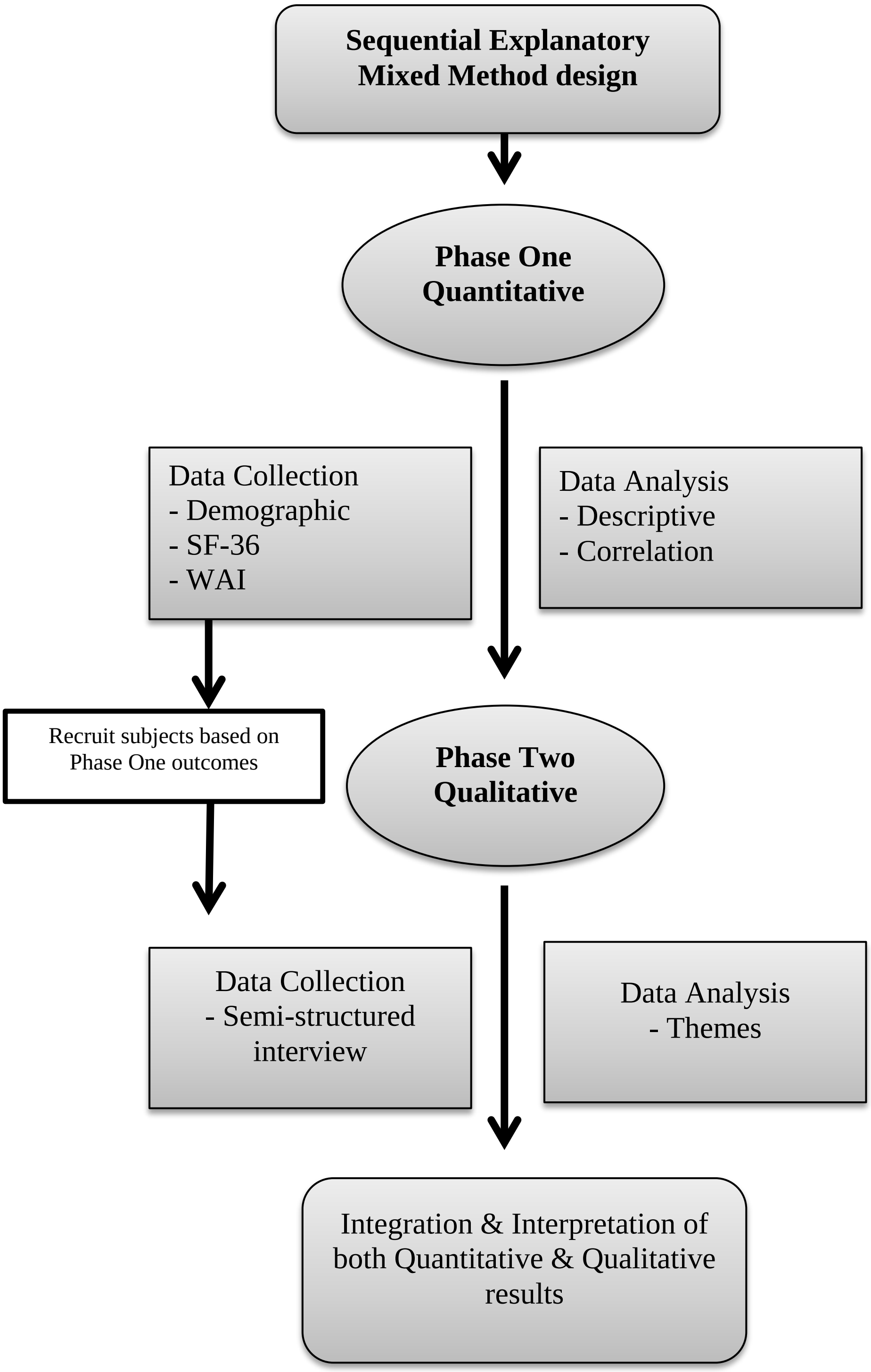

Figure 13: Plan of Investigation

Phase One

The first phase used a quantitative questionnaire to identify the employment status, work productivity and activity impairments of HD patients (objective no 1); and to understand the impact of CKD on employment achievement and sustainability of work of HD patients (objective no 2) (HD patients between 18-65 years). Firstly, data was collected to capture patients’ employment status alongside other demographics such as level of education, occupation, and duration of work (full-time/part-time shifts). Secondly, two valid and reliable questionnaires (SF-12 v2 and WPAI v2) were used for this study alongside questions capturing patient demographic characteristics (Appendix 5, 6, and 7). Permission to use these questionnaires was obtained from the original authors prior to data collection.

In the reviewed quantitative studies, the most frequently used instruments aimed to assessed the functioning and well-being of patients with chronic disease (Guerini et al., 2006; O'Sullivan & McCarthy, 2007; Al-Jumaih et al., 2011; Van der Mei et al., 2011; Kamal et al., 2013). This was completed using a health survey, a QoL measurement tool such as SF-36, and KDQOL-36. The tools measured the physical and mental functioning of individuals with a LTC. Whilst these tools give a score for the participant’s physical and mental condition which is useful to give an indication of their work ability, the instruments take time to complete, which implies a need for a small sample size (Ware et al., 2009).

Therefore, this study measured the perceived health related QoL among participants using the SF-12v2 the shorter version of SF-36v2 often used in large survey samples, taking less time to complete (Ware et al., 2002). This tool helps to identify the relationship between the score of the patient’s physical or mental condition, and their employment status or the degree of their work ability. However, this requires another tool that aims to identify the work ability and productivity of employees with chronic diseases.

In the reviewed studies, only one study used a specific tool to examine the employment status and work ability among CKD patients (Van der Mei et al., 2011). The Work Ability Index (WAI) was developed to evaluate the work ability of employed participants (Silvia Monteiro et al., 2009). This instrument, similar to the health survey questionnaire, takes a long time to complete, raising a concern about the accuracy of the responses and the reliability of the results as some participants my select answers randomly if the questionnaire becomes laborious. Another drawback is that the WAI tool was designed to examine the work ability of employed patients so not relevant to those unemployed, and many CKD patients. A more applicable tool was the Work Productivity and Activity Impairment Questionnaire (WPAI), which also consider unemployed participants by measuring their total activity impairments.

Study Instruments

Short-Form Health Survey SF-12 v2

All participants were asked to complete the short-form health survey (SF-12v2), a valid and shorter version of SF-36v2 (OPTUM, 2014). Unlike the older version of the SF-12 which was recommended to be used in large surveys, the SF-12 v2 can estimate eight health domains of functional health and wellbeing: Physical Functioning, Role-Physical, Bodily Pain, General Health, Vitality, Social Functioning, Role-Emotional, and Mental Health (Ware et al., 2002). The SF-12 v2 was a more versatile alternative to the SF-36 health survey (Ware et al., 2009). An illustration of the outcomes of physical and mental component summary scores of the SF-12 questionnaire is presented in Table 17.

Table 17: Outcomes of physical and mental component summary scores (Ware et al., 2002, p. 22)

Component Summary	**Score**	**Indications**
Physical Component Score (PCS) measure	Low score	1. limitations in physical functioning 2. limitations in role participation due to physical problems 3. high degree of bodily pain 4. poor general health
	High score	1. little or no: physical limitations; disabilities; decrements in well-being 2. high energy level 3. good general health
Mental Component Score (MCS) measure	Low score	1. frequent psychological distress 2. social and role disability due to emotional problems 3. poor general health
	High score	1. frequent positive affect 2. little or no: psychological distress; limitations in usual social/role activities due to emotional problems 3. good general health

The aggregates of the eight domains are used to score the physical component summary (PCS) and the mental component summary (MCS) to achieve many advantages. First, it reduces the scores of the eight health domains into two component summary scores without losing any substantial information. As a result, the validity of the survey outcomes has been improved when distinguishing between mental and physical health outcomes (Ware et al., 2002). Moreover, the SF-12 was tested for validity and reliability among a Saudi population with diabetes and found to be valid and reliable (Al-Shehri, Taha, Bahnassy et al., 2008).

<u>Work Productivity and Activity Impairment Questionnaire WPAI v2</u>

All participants were asked to complete a questionnaire that evaluated their work-ability using the Arabic version of the Work Productivity and Activity Impairment Questionnaire (WPAI v2). This measurement tool was validated against health-related quality of life scales such as the SF-12. Also, it can be used in people with various diseases and occupations, and was found to be the most frequently used and well documented tool among many other health-related productivity measures (Prasad et al., 2002). The main objective of this tool is to examine the effect of CKD on the patient’s ability to work and perform regular activities. This instrument explores four items (Reilly-Associates, 2004) and yields four types of scores:

1. Absence (work time missed)
2. Presence (impairment at work / reduced on-the-job effectiveness)
3. Work productivity loss (overall work impairment / absenteeism plus presenteeism)
4. Activity Impairment

The questionnaire (Arabic or English version) was free to use without permission (Reilly-Associates, 2004). The approved Arabic version of this questionnaire was translated by a professional translation corporation (CorporateTranslations, 2015), to ensure its validity, using harmonization, independent translations, back-translation, as well as experts and local language users’ reviews, and was available for researchers to use at no charge. Moreover, the Arabic version of the questionnaire was used among Saudi Patients with rheumatoid arthritis disease and found to have both content and face validity (Janoudi, Almoallim, Hussein et al., 2013; Hussain, Janoudi, Noorwali et al., 2015). The tool was also reliable and responsive within different populations with different chronic illness (Reilly, Gerlier, Brabant et al., 2008; Reilly, Gooch, Wong et al., 2010).

Phase Two

The second phase draws on qualitative methods to explore the experiences of HD patients of both those working and those who are not, identified with good, moderate, and poor work productivity and activity impairments. The sampling of participants also ensured an equal spread of males and females, different age ranges, and a range of different high/low health status, based on the outcome of the questionnaires of phase one. The main goal of this phase was to generate a deeper understanding of who, what, why and how HD patients continue to work, or not, alongside managing a LTC. This aspect of the study followed up using in-depth questioning to explore how employed HD patients managed to sustain work, and overcome issues that threatened their employment, understanding barriers and influencing factors that enable them to work or not alongside managing their treatment regime (objectives 2, 3 & 4).

Qualitative data enhances the study, particularly useful to check what is reported in phase one is actually what is experienced in real life, using a triangulating technique to interrogate data (more detail on this technique will be presented later in this chapter). More importantly, reinforced from several reviewed studies, this phase helps to explore and understand the patient context and their social and family situation and the barriers and facilitators that enhance or impede sustained employment when faced with managing the LTC (Munir et al., 2005; De Souza & Oliver Frank, 2011; Koolhaas et al., 2013).

In-depth Interviews

Semi structured interviews were used to investigate and explore the patients' perception to their work-ability based on the four dimensions of the WPAI. The interview discussion explored the barriers that prevented them from working and potential facilitators that helped them return to work and/or increase their work-ability and sustain employment. The patient perspective provided a deeper understanding of how employees maintain employment correlated against factors such as age, gender, health status, compared to unemployed subjects. In addition, the interview questions were guided by the theoretical concepts identified in the Capabilities Approach Theory (Sen, 2001) and the topics identified in the review of the literature (Appendix 8). All interviews took place in the dialysis centre, in the Arabic language as preferred by all participants, were digitally recorded and lasted no more than 45 minutes.

Sampling Method and Sample Selection

Study Sites

The study site location was Riyadh province, Saudi Arabia. The province of Riyadh is the second largest province in the country. The region covers about 412,000 km2 of area with a population of about 7 million people (MOI, 2014). The dialysis centres in Riyadh city and the cities surrounding it serve more than 1400 HD patients (almost 11% of the HD population in the entire country) (SCOT, 2013). The study took place in two public dialysis centres operated by the Ministry of Health. The first dialysis centre was located in King Saud Medical City in the centre of Riyadh city. This dialysis centre is the largest centre in the region of Riyadh serving more than 300 HD patients, and the referral centre for all CKD patients across the whole region (KSMC, 2015). The second centre was located in Dawadmi hospital. The dialysis centre in Dawadmi hospital is the largest centre located outside Riyadh and serves HD patients living in rural areas. There are approximately 60 permanent HD patients attending this centre, alongside an unknown number of temporary and referred patients from the surrounding small dialysis centres. The Dawadmi centre is considered the main referral centre for dialysis centres in the west of Riyadh region (RiyadHealth, 2015).

These two centres were approached to be involved in the study because they were the largest centres in the region and potentially provided a good representation and access to the largest HD population in the region. Although this was the primary reason for site selection there were other influencing factors considered such as travel costs, resources, time limit, ethical approval procedures, and geography.

Target Population

The target population included Saudi patients within the working-age of 18-65 years and receiving HD in the study dialysis centres. All patients eligible for work were invited to take part in the first phase of the study; to complete the demographic data, WPAIv2 and SF-12v2 questionnaires. A total of 183 patients met the inclusion criteria and were available during the data collection period. According to the head nurses in the two centres, the remaining patients were either less than 18 or more than 65 years of age, having cognitive or mental disorders, non-Saudi, or unwilling to participate or to give informed consent.

Sample Size and Method

There are several methods that can be used to determine the effective sample size of a research study, the choice of method is linked closely to the study purpose and methodology, alongside the practical availability of subjects, and available resources such as time and cost.

Phase One Sample Size

For the quantitative elements of the research, recruiting 10 participants per item, when using an instrument, is recommended and appropriate for generalizing the results of statistical tests such as factor analysis (Tinsley & Tinsley, 1987; Roberts, 2008; Pekala, 2013). Alternatively, five participants per item were considered sufficient

(Tinsley & Tinsley, 1987; Knapp & Brown, 1995; Pekala, 2013). A previous study conducted in Saudi Arabia and used a QoL questionnaire recruited 100 HD patients only (Al-Jumaih et al., 2011). However, the researcher decided to go for the largest possible number recommended by the literature and the sample calculation techniques, explained in the next paragraph, to enhance representation and generalization. The QoL questionnaire ‘SF-12’ used in the first phase of this research has 12 items; therefore, requiring a minimum of 120 participants recommended for this phase of the study.

Another effective method for calculating sample size is the use of a statistical power equation. However, according to Hulley, Cummings, Browner et al. (2013), the concept of power does not apply in this type of study which is not comparing different groups. Instead, an adequate sample size based on the desired confidence interval level should be recruited. A total of 183 patients met the inclusion criteria (Box 5) and were available during the data collection period.

Box 5: Participant Inclusion Criteria

- Patients with CKD undergoing HD
- Patients who have been on HD for at least six months
- Patients with no mental disorders or cognitive deficits
- Saudi patients only
- Patients in working age of (18-65 year olds)
- Patients who are able to give written or verbal consent to participate in the study

For a 95% confidence level and 5% margin of error, the minimum recommended sample size would be 123 participants. However, more participants were invited to participate to allow for potential participant withdrawal and/or missing data. This was calculated using the following formula designed for survey studies (Raosoft, 2004, para 22):

$$x = Z(\mathrm{c}/100)^2 r(100 - r)$$

$$n = N\,x/((N - 1)E^2 + x)$$

$$E = \mathrm{Sqrt}[(N - n)x/n(N - 1)]$$

Sample size n

margin of error E

N is the population size

r is the fraction of responses that we are interested in

Z(c/100) is the critical value for the confidence level c

Phase Two Sample Size

For phase two, a subset of phase one participant's were selected for individual in-depth interviews, after completion of the phase one instruments. The purpose of this phase was to gain an in-depth understanding of the patient perspective, explain individual results of the quantitative phase, and their experiences of factors that affect their employment and ability to work. To ensure a representative sample for this phase, a stratified random sampling was originally planned by using a predetermined criteria; of age, gender, employment status and patients geographic area. A similar mixed method study achieved rich qualitative data with a small sample of 14 CKD patients (Murray et al., 2014).

Therefore it was anticipated that no more than 20 patients would be recruited ensuring an equal spread of male and females, employed and unemployed patients, different age ranges, and a range of different high/low work ability and health status, based on the outcome of the questionnaires of phase one. A number of 14 to 18 participants were considered appropriate as this number is manageable in the time frame available for data collection. Also it will allow for a stratified selection of different characteristics.

Sample Recruitment

The first stage of participant recruitment involved providing the Head Nurses in both dialysis centres with the ethical approval letter and the permission letter issued by the University of Salford and the Ministry of Health in KSA (Appendix 9, 10, and 11). The Head Nurses assisted the researcher to identify eligible patients and provided a schedule of dialysis treatment for those eligible patients. All eligible patients were approached face-to-face by the researcher with the presence of a female staff nurse in the waiting room before starting the dialysis treatment. The presence of a female staff nurse was particularly important when approaching female patients (discussed in detail within the ethical issues section). Patients had the opportunity to talk directly to the researcher about the study. This type of face to face approach is considered a more respectful way to communicate between people in the Saudi culture, rather than sending out recruitment information (Kaynak & Herbig, 2014). Before making a decision to participate, patients could take the information away and take time to consider their involvement; each patient was provided the following documents:

- Patients’ information sheet explaining the purpose of the study and answering the most frequent asked questions (Appendix 12).
- Consent form which needs to be signed if the patient agrees to participate in the study (Appendix 13).
- Copy of the study questionnaires in Arabic.

The majority of patients agreed to participate during the first visit of the researcher; whilst some stated that they preferred to read the documents at home and think about it first. What was important was that patients had a choice and were not pressured to make a decision immediately. Contact information of the researcher, researcher supervisor, and a staff nurse were provided in the information sheet to answer any enquiries regarding the study. Those patients who required more time to make a decision were approached a week later by the staff nurse to confirm if they wished to be involved in the study.

Ethical Issues

There were a number of ethical issues that needed to be considered in the planning stages of the study, these included cultural and religious gender issues, gaining informed consent, data protection, confidentiality and participant anonymity when reporting and presenting data findings.

A lone researcher policy was developed in order to be used during the data collection of the second phase to reduce any potential risk to the researcher if a participant chose to be interviewed at home or in a remote location off the study site. The plan was to provide a nominated person the address of the interview location and participant’s contact details. The researcher would be required to telephone prior to attending the interview and on leaving to report that they were safe, no more than 90 minutes later. In the event that the communication was not received, the nominated person would contact the researcher, the participant and/or the site to confirm the researcher was at no risk. If this could not be confirmed they would contact the authorities for support.

Cultural and Religious Gender Issues

The ethical issue of interviewing a female participant by a male researcher needs to be considered carefully in Saudi Arabia. Saudi Arabia is a Muslim country and, therefore, the relationship between different genders must be maintained and treated according to Islam’s teachings. For example, unnecessary private meetings between a man and a woman who are not legally related to each other should be avoided.

To address this issue, the study questionnaires for the female respondents were completed only when a female staff member was present in the room, acknowledging the religion and cultural implication of gender sensitivity in the locale of the study. Moreover, all female participants, selected for the second phase of the study, were asked whether they prefer to have a female staff member, their spouse or relative present during the individual interview to avoid any potential cultural issues. Although the interview did not include any discussions that were considered sensitive, it was stressed to the participant (female or male) that at any time they felt distress or discomfort during an interview they could ask for it to be stopped and withdraw from the study without having to provide an explanation.

Informed Consent

All potential participants were provided with a patient information sheet written in Arabic and English, if preferred, to ensure that they have the appropriate information to make an informed decision as to whether they wish to take part in the research. In Saudi culture, people prefer to have personal face-to-face communication; considered a more respectful way of communication. Therefore, the questionnaires for this study were distributed by the researcher himself face-to-face in the HD centres, allowing potential participants the time and opportunity to ask questions, meet the researcher, and decide whether they want to be involved. The participants were told that they did not have to complete the questionnaires the same day but could take them home if they wish and take an extra time to think and make a decision regarding their participation in the research. The researchers contact details were on the information sheet, so any person wanted to be involved or had a question they could contact the researcher directly.

Participants who were selected for the interview (Phase two) were contacted and their consent to be involved in the second phase was confirmed, alongside time provided to answer any questions regarding the interview. Written consent was obtained from each participant prior to each interview, asking them to confirm they had read and fully understood the information provided and were happy to volunteer for the research, prior to any data being collected.

Data Protection, Confidentiality and Anonymity

All participants approached and recruited for the study were recorded on a sample master list and their data were kept confidential and non-identifiable (anonymous) using a research code in a database that was password protected and accessible only by the researcher. The study participants' names were anonymised through codes and pseudonyms on all questionnaires, interview transcripts, and data analysis files, at the same time maintaining consistency between questionnaire and interview codes to facilitate data triangulation. This was achieved using a research code placed on each information sheet administered and the corresponding code placed on questionnaires and interviews by the same participant. This enabled study data to be withdrawn easily at the request of a participant, using the corresponding code on their information sheet.

Digital recordings of interviews, questionnaires, notes and the data analysis database were stored electronically in a password protected folder, on a password protected computer, known only to the researcher. USB devices used to carry electronic data were encrypted. Hard copies were kept in a locked filing cabinet in a safe room at the university, the combination code known only by the researcher. Five years after the study is completed, to allow for data verification if challenged once peer reviewed papers are published; all hard copies will be shredded and disposed of as confidential waste.

Data Analysis Process

Managing Quantitative Data

All quantitative data from this study were analysed using the Statistical Package of Social Science software for analysis IBM SPSS (v.20). While frequency distributions were used to highlight the demographic characteristics of the sample population, descriptive and inferential statistics were employed to analyse and present the research data. The data entries into the SPSS software as well as the statistical tests used in this study were checked by a statistician and an expert professional during the analysis process.

Several statistical tests were to be combined to interrogate the qualitative data (if the distributions of the analysed data were non-normal) which included: Mann-Whitney-U test to compare differences between two independent variables, Kruskal-Wallis test to compare differences between more than two variables (educational level, duration of treatment, age group, and productivity lost and PCS), Fisher exact test and Chi-squared were used to determine the association between two categorical variables (e.g. employment status and gender), whereas the t-test was used for parametric variables (e.g. gender and PCS or activity impairments score), and ANOVA test for more than two groups (e.g. educational level, duration of treatment, age group, and productivity lost and PCS) (Norusis, 2008; Coakes & Steed, 2009; Field, 2013). Last but not least, multivariable regression analyses will be used for personal and clinical variables, and the scores of the SF-12 and the WPAI questionnaires (lr1).

To determine the relationship between participants’ physical components score and their work productivity and activity impairments score (if these scores are normally distributed) the Pearson product-moment correlation coefficient was used (Chok, 2010). If the scores were not normally distributed, Spearman’s correlation would be used to interrogate the data (Norusis, 2008; Coakes & Steed, 2009; Field, 2013). To determine the physical and mental components score, and the work productivity and activity impairments score, a specific computation and special software designed and provided by the original authors of the Health Survey SF-12v2 and the Work Productivity and Activity Impairments questionnaires were adopted.

Managing Qualitative Data

During the data analysis process, researchers need to be close to and familiar with qualitative data, in order to successfully formulate an overall rich picture of the emerging concepts, theories and insights (Polit & Beck). Researchers report the usefulness of computer software when managing large qualitative data sets reducing the manual work time (Polit & Beck, 2010). However the researcher preferred a manual method to code and organize the qualitative data, a decision taken after exploring and trialling qualitative data analysis software and programs, but not finding them particularly helpful to stay close to the data. Indeed, the qualitative strand in the explanatory sequential design was used to complement, explain or expand the quantitative strand, and involved a small sample size which reinforced the appropriate selection of a manual analysis method for this particular research study and effective data management (Creswell, 2013).

Seven steps approach for themed analysis was systematically applied to analyse the qualitative data Chesler (1987, pp. 9-12):

1. underline key terms in the text
2. carried out concurrently with underlining of key terms, restate key phrases in the margin of the text
3. reduce the phrases and create cluster
4. compare, reduce, and group generated clusters to form ‘meta-clusters’
5. generalizing statements in all generated clusters
6. theory generation and prose explanations
7. integrate mini-theories into an explanatory framework

The initial analysis was conducted in the language used for the interviews ‘Arabic’ to reduce the possibility of meaning loss if the analysis was performed using different language. Then, translation and transliteration techniques were performed using scientific methods including forward and back-translation. Finally, each interview transcript was transcribed, read and re-read by the researcher to gain a deeper understanding of the patients’ experiences and perspectives. Themes and codes were checked in a subset of four interviews by an independent researcher (supervisor) to reduce bias and confirm trustworthiness of key themes and findings drawn from the data.

Triangulation of Quantitative and Qualitative Data

Triangulation is usually used when two or more research approaches are adopted in a research study (e.g. the use of quantitative and qualitative strands in one study) (Rothbauer, 2008). It is considered a powerful tool that increases the accuracy and validity of study findings by verifying the results using data obtained from two or more sources. For example, researchers can cite and add quotations from the participants’ in-depth interviews to validate, challenge, or explain the quantitative results. Triangulation was used with both qualitative and quantitative data findings and enhanced the interpretation of data. Moreover, this technique has become an alternative method for credibility (in qualitative data analysis), and validity and reliability (in quantitative data analysis) (Bogdan & Biklen, 2006).

Quantitative and Qualitative Data Integration

The determination of the interaction level between the quantitative and qualitative data is vital in a mixed methods approach (Creswell & Plano Clark, 2010). The researcher decides how and when the quantitative and qualitative data will be integrated in the study. There are two methods or options on how the interaction between the two strands could occur within the research study: the (1) independent level and (2) interactive level (Greene, 2007; Creswell, 2013).

In the independent level of interaction the researcher will only integrate the quantitative and qualitative strands in the interpretation phase at the end of the research study. It means that the qualitative and quantitative data will be collected, analysed, and reported separately from each other, and will only be combined at the end of the study. However, in the interactive level of interaction, the researcher will integrate the qualitative and quantitative strands in many ways and this could happen in any part of the research process (Greene, 2007; Creswell, 2013). For instance, the interaction could occur during the data collection of the qualitative strands when the researchers select their sample based on the results of the quantitative strands. It could also happen when the researchers report their findings using, for example, the integration and/or triangulation technique explained in the previous section of this chapter. In this study the data from the qualitative and quantitative phases is conceptually inter-twinned and may lend itself to a more interactive level of interaction at many points in the analytical process for many reasons including the following identified by Greene, Caracelli, and Graham (1989):

- ***Triangulation:*** the work productivity and activity impairments as well as the physical and mental components scores will be analysed and presented in the findings chapter of the phase one. However, data from the qualitative strands (phase two) will be utilized when possible to validate, challenge, and explain the quantitative data. For example, qualitative data from female participants will be utilized to explain why women undergoing HD are more likely to be unemployed compared to men participants.
- ***Complementary:*** the qualitative data, could be useful when the researchers were not able to capture or identify specific variables using the traditional quantitative approach, such as the impact of the Saudi Arabian culture and society on employment.
- ***Expansion:*** in addition to triangulation and complementary analytical processes, qualitative data could be used to expand the findings of the research (and test out theory) such as exposing new data regarding the facilitators and barriers to sustaining employment among HD patients presented qualitatively in a separate findings chapter.

It is believed that triangulation, complementary, and expansion approaches will strengthen the findings of this study and create new knowledge to facilitate a better understanding of the issues affecting the work life of CKD patients.

Conclusion

This study seeks to explore employment status, and sustainability of work among HD patients in Saudi Arabia. The plan of investigation, adopting a mixed method design, will generate a deeper understanding of who, what, why and how HD patients continue to work, or not, alongside managing a LTC. Mixed methods enable the researcher to identify the best potential data sources available without being constrained by one single method (Giddings 2006), and reduce uncertainty in research findings and to strengthen any generalizations (Robson & McCartan, 2016).

This research study uses both quantitative and qualitative research design. Quantitative research design will be used in identifying the employment status, work condition and quality of life of the patients. The qualitative research design will explore the lived experiences of patients undergoing HD in Saudi Arabia with respect to the employability and the ability to work as well as the barriers to sustain employment. Moreover, this study design provides an explanatory level of quantitative data analysis (Rogers, Day, Randall et al., 2003).

Therefore, the quantitative and qualitative strands will be implemented sequentially using the explanatory sequential mixed methods design, starting with the quantitative strand and follow-up with the qualitative strands. The rationale for using this type of mixed methods design is that the quantitative (phase one) and the consequent qualitative (phase two) data analysis will provide a broad comprehension of the explored topic employment and sustainability of work among HD patients in Saudi Arabia. By exploring the perspectives of the participants in more depth, the qualitative data analysis will be utilized to validate and explain the quantitative results as well as expanding the findings of the study (Rossman & Wilson, 1985; Tashakkori & Teddlie, 1998; Creswell et al., 2003) (Box 6 Summary points).

Box 6: Summary Points

- Identifying employment status, and work ability and productivity among CKD patients as well as exploring the impact of CKD on employment achievement and sustainability of work from the patient perspective requires both quantitative and qualitative data.

- The first phase of this research uses a quantitative questionnaire to determine the employment status work, and productivity and activity impairments alongside demographic characteristics
- The second phase draws on qualitative methods to explore the experiences of HD patients of to generate a deeper understanding of who, what, why and how HD patients continue to work, or not, alongside managing a long-term condition (LTC) as well as the application of the Capability Approach
- Combining quantitative and qualitative methods strengthens the validity of the research, allowing variation in data collection and integration and deeper interpretation of data findings
- The Explanatory Sequential Design is the most effective design for this study as it enables the researcher to explore the extent to which people receiving HD work and then explain why and how work is sustained or not, for whom and what strategies help people remain or re-enter in the labour market
- Triangulation, complementary, and expansion approaches will strengthen the findings of this study and will enable for a better understanding of the issues affecting the work life of CKD patients creating a new body of knowledge
- The theory driven data interrogation facilitates the understanding of the application of the Capability Approach theory within the data

Chapters six and seven present the findings of the study, initially for this paper presented separately as phase one and two but as the themes of the phase two data emerge the findings are integrated under more abstract themes to better use the advantages of the mixed approach to add depth and understanding to the data, to answer the objectives of the study.

Chapter Six

Quantitative Results

Introduction

The study findings are presented in two parts (chapters six and seven). Chapter six focuses on the results from the tools used in the first phase of this study: the WPAI, SF-12, alongside participant personal and clinical data. The chapter aim is:

- to identify the employment status, work productivity and activity impairments of HD patients (objective 1)
- to understand the impact of CKD on employment achievement and sustainability of work of HD patients (objective 2)

Whilst the results presented are predominantly quantitative data sets, data is then triangulated with qualitative in-depth interview data in the subsequent chapter. The qualitative data is used to support, challenge, or explain the findings to gain a deeper understanding of the impact of CKD on employment achievement and sustainability of work from the patient perspective.

This chapter is structured in three sections. The first section provides an overview of response rates, participant characteristics and data collected for both phases. The second presents clarification of the quantitative data analysis processes used in the study, and the distribution of the data. Finally, the findings of phase one, employment status, work productivity and activity impairments, are presented in section three.

Response Rate and Sample Characteristics (Phase One)

A total of 183 patients met the inclusion criteria and were available in the target population during the data collection period; previous sample calculations highlighted that the minimum recommended sample size was 123 participants In total 131 patients agreed to take part of the first phase of this study, although one patient chose to withdraw from the study at phase two. As a result 130 CKD patients (103 from the dialysis centre in Riyadh, and 27 from the dialysis centre in Dawadmi) were involved in phase one of this study. Their characteristics are presented in Table 18.

Of the total number of participants (n=130), 51% were male and 49% female, with a mean age 42 years. The majority of the patients, 55 (42.3%), were aged 51-65, 48 (36.9%) were aged 36-50, 18 (13.8%) were aged 26-35, and 9 (6.9%) were aged 18-25 years. Only 25% (33) of the participants were employed, and of those only three were female.

Most of the patients, 103 (79.2%) lived in the city, with less than a quarter 27 (20.8%) coming from rural areas. Descriptive analysis of the sample characteristics indicated that 100 (76.9%) of the patients were married, compared to 30 (23.1%) single. For married participants, one female patient was aged between 18-25, nine patients were aged between 26-35 (2 female), 39 patients were aged between 36-50 (27 female), and 51 patients were aged between 51-65 (24 female); whereas, for single participants, eight patients were aged between 18-25 (2 female), nine patients were aged between 26-35 (3 female), nine patients were aged between 36-50 (2 female), and four patients were aged between 51-65 (3 female).

Table 18: Participant Characteristics and Data (phase one):

Items		**Frequency**	**Percentage**
Geographical area	Urban area	103	79.2
N = 130	Rural area	27	20.8
Gender	Male	66	50.8
N = 130	Female	64	49.2
Age Group	18 – 25 year olds	9	6.9
N = 130	26 – 35 year olds	18	13.8
	36 – 50 year olds	48	36.9
	51 – 65 year olds	55	42.3
Marital Status	Single	30	23.1
N = 130	Married	100	76.9
Educational Level	≤ High school	133	86.9
N = 130	Undergraduate level	17	13.1
Employment Status	Employed	33	25.4
N = 130	Unemployed	97	74.6
When HD starts	≤ One year	19	14.6
N = 130	1 to 2 years	19	14.6
	3 to 4 years	17	13.1
	≥ 5 years:	75	57.7
Job Physical Demand	Heavy	5	15.15
N = 33	Moderate	21	63.6
	Not heavy	7	21.2
Form of Employment	Full time job	30	91
N = 33	Part time job	3	9
HD Frequency	Twice a week	1	0.8
N = 130	3 times a week	129	99.2
HD Duration	Three hours	31	23.8
N = 130	≥ Four hours	99	76.2
Mobility	Ambulance / bed	2	1.5
N = 130	Wheel chair	25	19.2
	Walk	103	79.3

The results also showed that 113 (86.9%) of the patients had a high school level educational (60 female), whereas only 17 (13.1%) had an undergraduate level education (four female – two aged between 26-35, one aged between 36-50, and one aged between 51-65).

More than half, 75 (57.7%) of the patients had been receiving HD for five years or more; compared to 17 (13.1%) who had started HD within 3-4 years, 19 (14.6%) within 1-2 years, and a further 19 (14.6%) patients who had been on HD treatment for less than a year. Apart from one, all the patients 129 (99.2%) had HD three times a week. The duration of the HD treatment differed from patient to patient. The majority 99 (76.2%) had HD treatment lasting four hours, whereas 31 (23.8%) had three hour HD sessions. For 26 (20%) patients it took less than 15 minutes to travel from home to the HD centre; for 58 (44.6%) 15-30 minutes, 39 (30%) 30 minutes to an hour, and 7 (5.4%) over an hour travelling time. The majority of patients 103 (79.2%) walked to the HD centre, 25 (19.2%) arrived in a wheelchair, and only 2 (1.5%) by ambulance/bed.

Employed patients (33) were asked whether they needed to change their occupation as a result of their long-term condition and treatment regime. There were mixed responses: 22 (66.7%) patients indicated they did not make any change to their occupation, whereas 11 (33.3%) highlighted that they did make changes to their occupation as a result of their health condition and after starting HD. Only a small number of the patients 6 (18.2%) were thinking of retiring due to ill health, however the majority of those employed 27 (81.8%) were not.

The purpose of this study is not to address the gender inequality of employment but to expose the issues men and women face with a long term illness. It is therefore important to be mindful of the increased difficulties faced by women than men within the study context. The reason of including these women whilst it was never to do them justice is to expose issues alongside employment of women that they face within the context of Saudi Arabia. The researcher wanted to include women right from the outset to expose the barriers they are facing when it comes to employment due to social and cultural reasons, so by taking those women out we are not doing them any favour. However, by keeping them in, the researcher is actually raising their profile and it is really important in the context of Saudi Arabia to do this in order to battle gender inequality in terms of education and employment. If studies left out women then we do them no favour at all.

Quantitative data analysis and Normality of data

Data analysis

Descriptive statistics such as frequencies, percentages, tables, mean, standard deviation, minimum, and maximum were used to describe the data and results. The data was tested for normality using Kolmogorov-Smirnov (K-S) and histograms (Cohen, Cooper, Piersall et al., 2011; Field, 2013). The parametric independent samples t-tests was used to compare means of normally distributed data, whereas the non-parametric Mann-Whitney U tests was used to compare means of data that deviated from normality. The following classifications were used to interpret Cohen's *d* effect sizes; d=0.1 (small), d=0.5 (medium), and d=0.8 (large) (Cohen, 1988). Also, logical regression was conducted to assess the impact of gender, age, physical component summary score (PCS), mental component summary score (MCS), activity impairment, marital status, education, HD frequency, HD duration and HD distance, on employment status. Prior to this, the assumptions of multicollinearity and outliers were assessed. The logical regression results are presented in words and tables, with various statistical parameters. These include odds ratio, 95% confidence interval (CI), and probability (*p*) values.

The relationship between work productivity loss of the patients who were employed and the HRQOL total PCS was investigated using the non-parametric Spearman's rank correlation coefficient (rho). Similarly, the relationship between the total PCS and MCS was investigated using the parametric Pearson product-moment correlation coefficient (r). For both correlations, preliminary analyses were performed to ensure no violation of the assumptions of normality, linearity, and homoscedasticity. Scatterplots indicating the linear relationship between the variables were also drawn. The following interpretation of *r* and rho were used to interpret the strength of the correlation; r=0.1-0.29 (small), r=0.30-0.49 (medium), and r=0.50-1.0 (large) (Cohen, 1988).

Normality of data

Prior to statistical analysis, the data was tested for normality using Kolmogorov-Smirnov (K-S) tests (Table 21) and histograms (Figures 14-19). Results from normality tests indicated PCS and MCS were normally distributed because these variables had non-significant p-values; $p \geq 0.05$. However, all the other variables (absence, presence, work productivity loss, and activity impairment) were deviated from normality ($p \leq 0.05$).

Normality distribution of data was performed in order to ensure the appropriateness of the selected descriptive and inferential statistical tests. It is not always possible to have the data distributed normally using, for example, transformations techniques such as the use of square root (Osborne & Waters, 2002), especially when there are some data equal to 0% or 100%.

The WPAI questionnaires results included several data equal to 0% or 100%. Therefore, more appropriate statistical tests, more effective when data was not distributed normally (or did not assume normality of the distributions when performed) were used. For example, central tendency can be measured using both mean and median; however, when the data are not normal the median will be more effective than the mean as it will not be influenced by skewed values (Laerd, 2016).

Table 19: Results of normality tests

Variables	**Kolmogorov-Smirnov test**	
	Statistic	P value
PCS	0.06	0.20
MCS	0.06	0.20
Absenteeism	0.23	0.00
Presenteeism	0.18	0.01
Work productivity loss	0.22	0.00
Activity Impairment	0.16	0.00

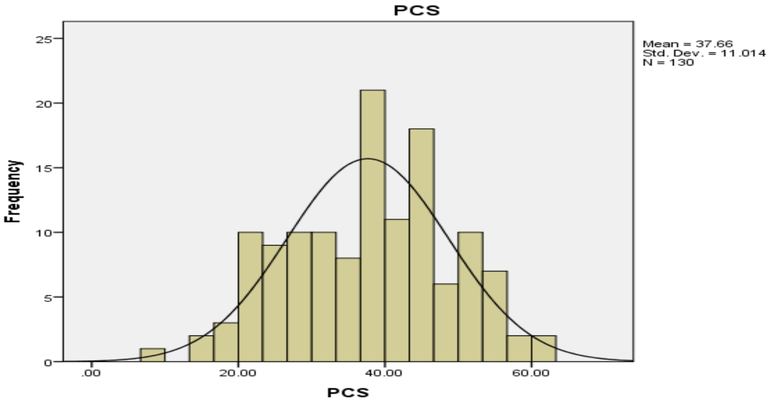

Figure 14: Histogram distribution of the PCS

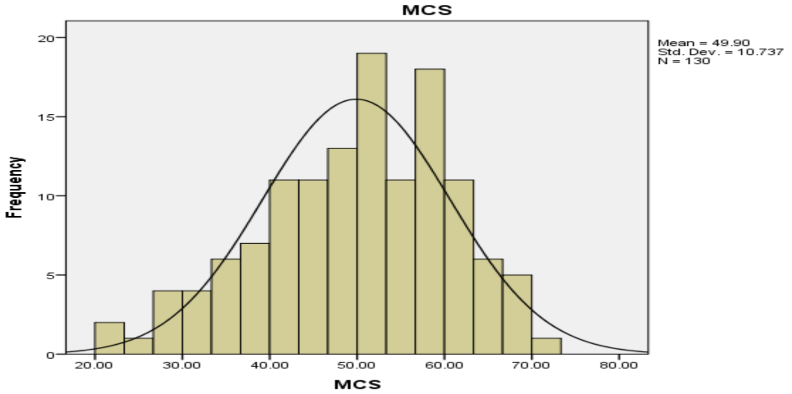

Figure 15: Histogram distribution of the MCS

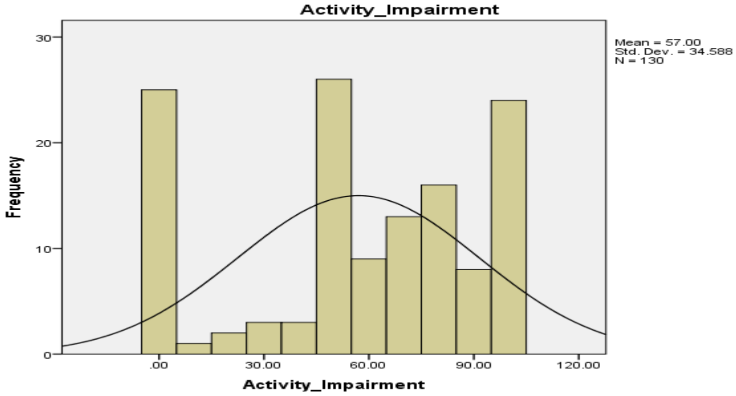

Figure 16: Histogram distribution of Activity Impairment

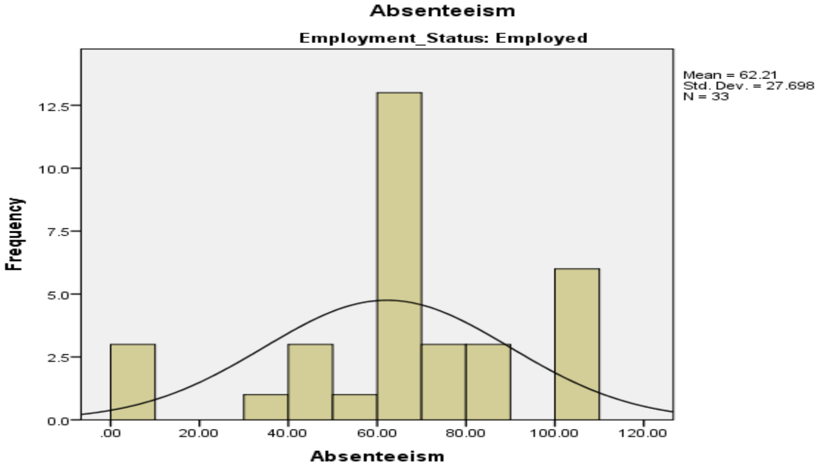

Figure 17: Histogram distribution of Absenteeism

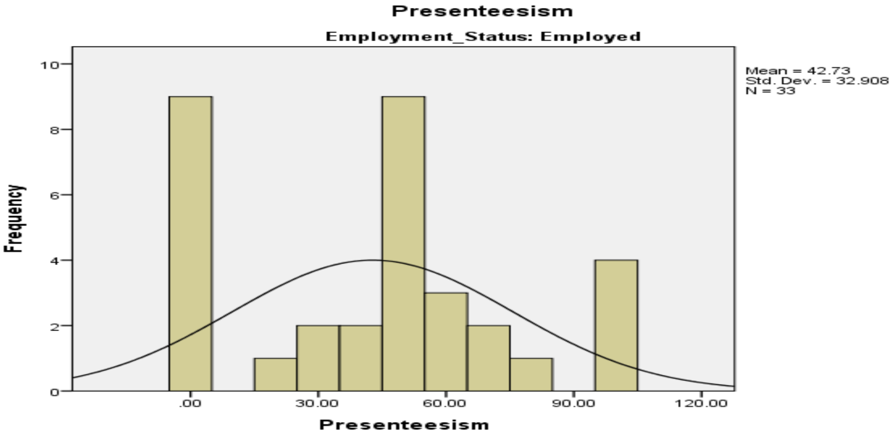

Figure 18: Histogram distribution of Presenteeism

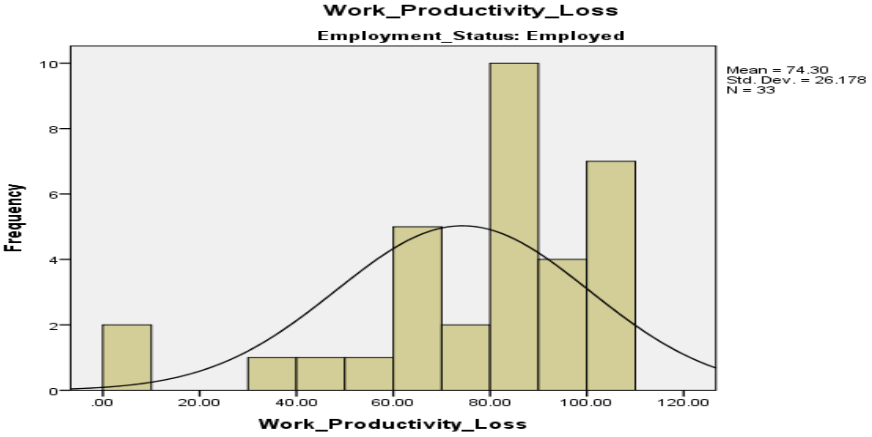

Figure 19: Histogram distribution of the Work Productivity Loss

Employment status

Identifying employment status among HD patients in Saudi Arabia is one of the main objectives of this study. From the total number of participants (n=130), 51% were male and 49% female, with a mean age 42 years. There was an unemployment rate of 75% (male 37%, female 63%); compared to only 25% in employment (Figure 20). The majority of which were male (91%) employed in full-time jobs, reflecting the male dominated working environment of KSA.

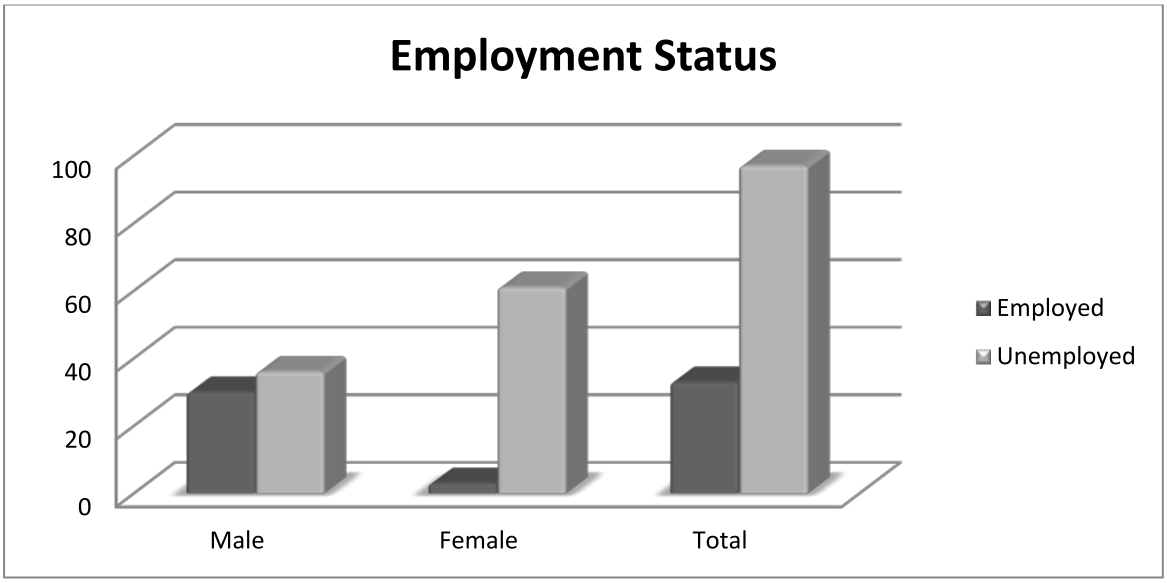

Figure 20: Employment status (female and male)

When the demographic data of the patients were analysed, the results indicated that 97 (74.6%) of the patients were unemployed, but 33 (25.4%) were employed. Out of the patients who were employed, 30 (90.9%) worked full time but 3 (9.1%) worked part-time. When asked why they worked part-time, two of the patients indicated that they were ill or disabled, whereas one indicated that he preferred part-time job because he did not want to work full time. Twenty one (63.6%) of the patients who were employed indicated that their work did not involve heavy physical activities. A small number of the patients 7 (21.2%) and 5 (15.2%) indicated that their job involved moderate and heavy physical activities respectively.

Logical regression on employment status

Understanding the impact of CKD on employment achievement is another main objective for this study. As a result, direct logical regression was conducted to assess the impact of numerous factors on the likelihood of employment status. The model contained 10 variables (gender, age, PCS, MCS, activity impairment, marital status, education, HD frequency, HD duration and HD distance). The full model containing all predictors was statistically significant, X^2 (14, N=130) = 76.4, p=0.000, indicating that the model was able to distinguish between patients who were employed and those who were not employed. The model as a whole explained between 44.4% (Cox and Snell R square) and 65.5% (Nagelkerke R square) of the variance in employment status, and correctly classified 86.9% of cases.

Three variables made a unique statistically significant contribution to the model (gender, PCS, and age) shown in Table 22. The strongest predictor of reporting unemployment among HD patients was gender, recording an odds ratio of 67.6. The physical component score (PCS) was directly related to the CKD which was evident in the literature; however, the other two predictors were related to other factors including personal, cultural and social factors which are explored further in the next chapter (qualitative data). Finally, to answer the question whether CKD has an impact on employment achievement among HD patients, the results section suggest that the answer is positive (Yes) although there are other factors than CKD that contributed to unemployment among this group of patients.

Table 20: Logistic regression predicting unemployment

	B	**S.E.**	**Wald**	**df**	***p***	**OR**	**95% CI / OR**	
							Lower	Upper
Gender	4.2	1.0	16.1	1	0.00	67.6	8.6	528.3
PCS	-0.1	0.0	4.5	1	0.03	0.9	0.8	0.9
MCS	-0.0	0.0	0.4	1	0.54	0.9	0.9	1.1
AI	-0.0	0.0	0.0	1	0.8	0.99	0.97	1
Age								
18-25	-1.9	1.4	1.9	1	0.16	0.1	0.0	2.2
26-35	-1.7	1.4	1.5	1	0.23	0.2	0.0	2.8
36-50	0.5	1.4	0.1	1	0.7	1.6	0.1	23.5
Marital status	1.1	0.9	1.6	1	0.2	3.1	0.5	18.2
Education	-1.5	0.9	3.2	1	0.1	0.2	0.0	1.2
HD duration	-0.0	0.8	0.0	1	0.9	0.9	0.2	5.1
HD frequency	-14.3	40192.9	0.0	1	1.0	0.0	0.0	0.0
Constant	17.8	40192.9	0.0	1	1.0	55136653.1		

AI = activity impairment
OR = Odds ratio

Work productivity, activity impairments, and HRQoL

Identifying the work productivity and activity impairments of HD patients, alongside the physical and mental condition of patients enables the researcher to assess the impact of CKD on employment achievement and sustainability of work (objective 2).

With HRQoL, the mean PCS and standard deviation of the patients was 37.7±11.0, with minimum and maximum values of 9.88 and 61.58 respectively. Also, the mean MCS and standard deviation was 49.9±10.7, with a minimum value of 21.55 and maximum value of 71.58. For the employed patients, the mean score and standard deviation for absenteeism, presenteeism, and work productivity loss are shown in Table 23. For all the patients, the mean total score for activity impairment and standard deviation was 57.0±34.6.

Table 21: HRQoL, and WPAI

Items	Employment Status	Mean	Median	SD	*p value*	Min/Max
Absenteeism	Employed	62.21	60.00	27.70	N/A	0.00 – 100
Presenteeism	Employed	42.73	50.00	32.90	N/A	0.00 – 100
Productivity Loss	Employed	74.30	80.00	26.18	N/A	0.00 – 100
Activity Impairment	Employed	43.33	50.00	33.42	$P<0.05$	0.00 – 100
	Unemployed	61.65	70. 00	33.90		0.00 – 100
PCS	Employed	44.09	43.71	8.42	$P<0.001$	23.91 - 61.33
	Unemployed	35.47	36.88	10.97		9.88 - 61.58
MCS	Employed	48.88	50.43	10.30	$P = 0.5$	26.69 - 64.42
	Unemployed	50.25	50.96	10.91		21.55 - 71.58

Comparing PCS and MCS (male and female)

Parametric independent-samples t-test was conducted to compare the PCS and MCS for male and female patients (Figure 21). There was a statistically significant difference in the total PCS for males M=40.90, SD = 9.86 and females, M=34.32, SD =11.21; t (128) = 3.56, p= 0.001 (two-tailed). The magnitude of the differences in the means (mean difference =6.58, 95% CI: 2.92 to 10.24) is moderate (Cohen's d = 0.63). The Cohen's d is the effect size to compare two means by dividing them with their standard deviations. In the case above, the means differ by 0.63 standard deviations; considering that 0.2 is small, 0.5 is medium, and 0.8 and above is large. In other words, if the effect size is less than 0.2 the difference will be unimportant even though it is statistically significant. Although the result shows that PCS for men and women is statistically significant, this was expected and has been repeatedly proven in the existing literature.

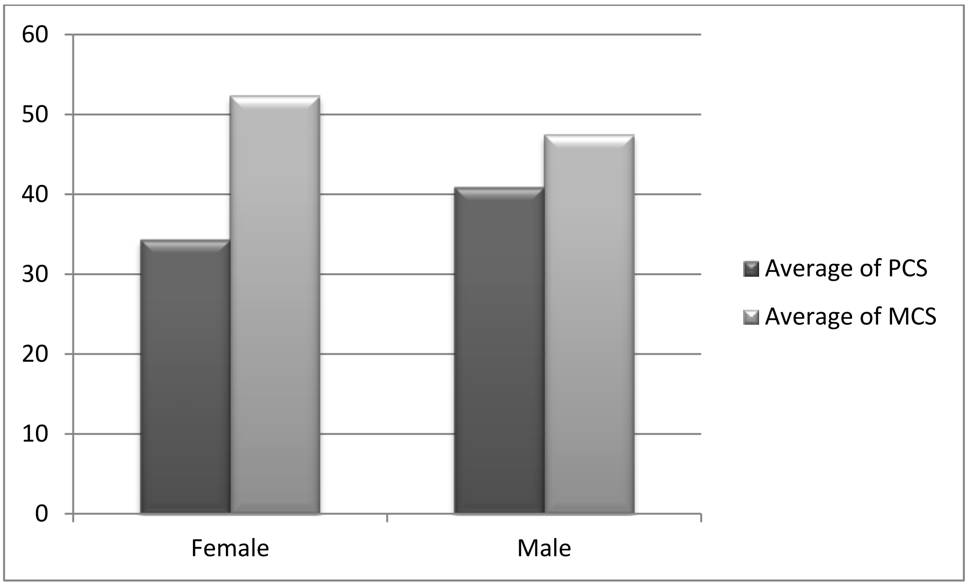

Figure 21: Average of PCS and MCS (male and female)

Similarly, there was a statistically significant difference in the total MCS for females M=52.39, SD= 9.65 and males, M=47.50, SD =11.25; t (128) =2.66, p=0.009 (two-tailed), which was also expected among HD patients. The magnitude of the differences in the means (mean difference =4.89, 95% CI: 1.24 to 8.53) is moderate (the effect size is Cohen's d = 0.5).

Comparing employed and unemployed patients

Parametric independent-samples t-test was conducted to compare the PCS for employed and unemployed patients. There was a statistically significant difference in the total PCS for employed patients M=44.1, SD =8.41 and unemployed, M=35.47, SD= 10.97; t (128) = 4.12, p=0.000 (two-tailed). The magnitude of the differences in the means (mean difference =8.63, 95% CI: 4.48 to 12.77) is large (the effect size is Cohen's d = 0.89). This result suggests that, the negative effect of CKD among HD patients on their physical condition could contribute to their unemployment. It could also means that physical effects of CKD are not as apparent in employed patients as they were in those unemployed. Further exploration in the qualitative phase was needed to validate and understand such a result and this finding was explored within the patient interviews (discussed in next chapter).

However, there was no statistically significant difference in the total MCS for unemployed patients M=50.26, SD =10.91 and employed, M=48.87, SD =10.29; t (128) =0.64, p= 0.52 (two-tailed). The magnitude of the differences in the means (mean difference =1.39, 95% CI: 2.91 to 5.68) is very small (Cohen’s d = 0.1).

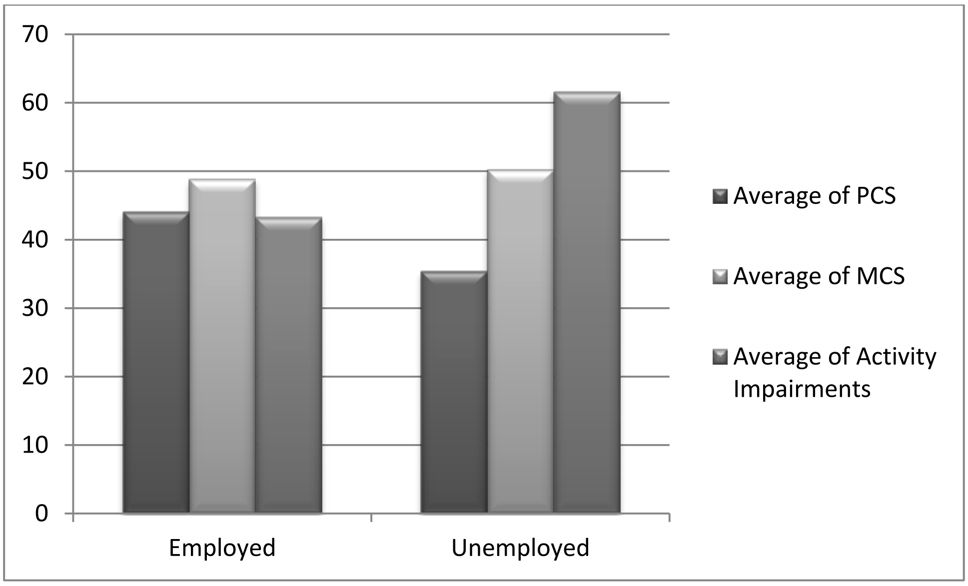

Figure 22: PCS, MCS and activity impairment (employed and unemployed)

As stated earlier, because the data for patients’ activity impairment deviates from normal distribution, a non-parametric statistic was conducted. The results of non-parametric Mann-Whitney U Test indicated that, there is statistically significant difference between activity impairment between unemployed patients (Median =70, n=97) and those who were employed (Median =50, n=33), U=1082, z= -2.81, p=0.005, r=0.25. Taking into consideration that PCS of employed patients is higher than unemployed ones; this result was expected as activity impairment is usually associated with physical conditions.

Comparing lost work productivity (male and female)

The results of non-parametric Mann-Whitney U Test indicated that, there was no statistically significant difference in absenteeism between male employed patients (Median =60, n=30) and female employed patients (Median =60, n=3), U=44.0, z = -0.07, p= 0.95, r= 0.01. However, there was only three employed women compared to 30 employed men, thus, this finding needs more exploration and explanation (qualitatively) which will be presented in the next chapter.

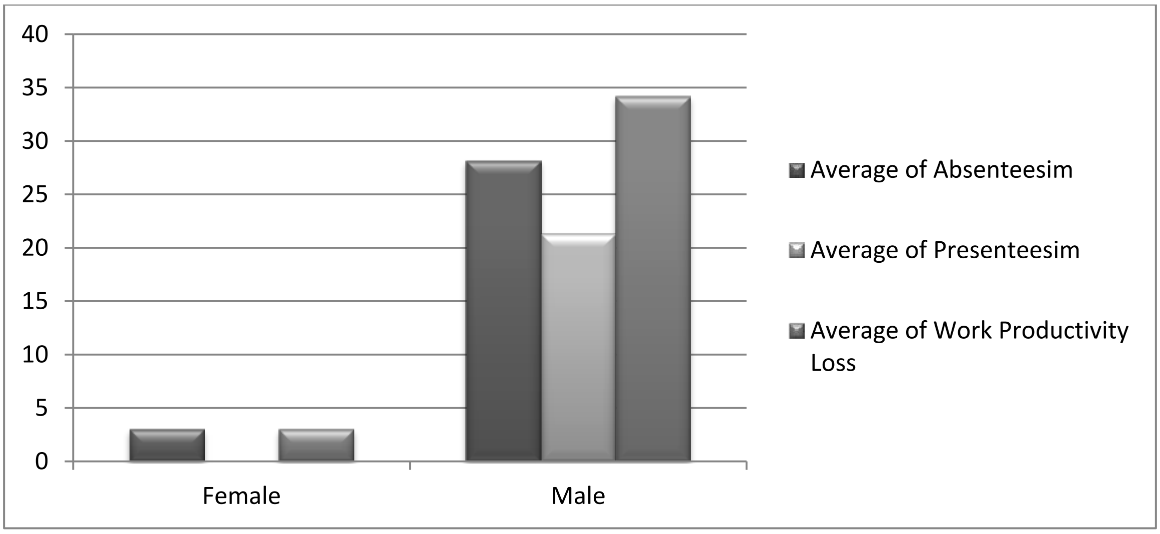

Figure 23: Absenteeism, presenteeism, and work productivity loss

Similarly, the results of non-parametric Mann-Whitney U Test indicated that, there was no statistically significant difference in work productivity loss between male employed patients (Median = 81.5, n=30) and female employed patients (Median = 60, n=3), U = 21.0, z = -1.51, p = 0.13, r= 0.26. However, the results of Mann-Whitney U Test indicated that, there was a statistically significant difference in presenteeism between male employed patients (Median = 50.0, n =30) and female employed patients (Median = 0.0, n =3), U = 9.0, z = -2.3, p = 0.02, r= 0.4. Again, the results above needs more exploration in order to get a clear conclusion as only three women were employed compared to 30 men. The nature of the job available to women in Saudi Arabia could be the reason behind their very low presenteeism as they mostly work in schools where there are many employees doing the same tasks in one school and the absence or low presenteeism of one employee will usually not affect the work.

Conclusion

This chapter presented predominantly the key findings from the analysis of data collated in phase one (quantitative data) of the study, to identify the employment status, overall health condition, and work ability and activity impairments of Saudi CKD patients undergoing HD.

The employment status, work productivity and activity impairments of HD patients' results show that the unemployment rate among HD patients in Saudi Arabia is very high. Unemployment among HD patients was expected and is evident in many countries; however, in Saudi Arabia the number of unemployed patients was high and exceeded the expectations especially among female patients where only three women out of 64 female participants were employed.

Whether CKD had an impact on patients' employment achievement and work productivity was an underpinning objective of the analysis. The results suggested many factors contributed to unemployment including gender, physical condition, and age. It was evident that patients undergoing HD have lower PCS which leads to unemployment or activity impairments. Finally, both absenteeism and work productivity loss were very high among employed participants; which could be because of the flexibility in public sector jobs rather than the disease but will be followed up in the qualitative data in the next chapter.

The key findings of the chapter are summarized (Box 7).

Box 7: Phase one key findings

- Unemployment rate among the CKD patients was very high.
- Gender strongest predictor of unemployment: among 130 participants only 30 men and 3 women were employed. 3 out of 64 women employed – a result of the culture and social norms of a masculine society like Saudi Arabia
- PCS was also a predictor for unemployment - results show a significant difference in the physical component summary score between male and female participants
- The results showed a significant difference in the physical component summary score between employed and unemployed participants. This also supports the previous claim that CKD has a negative impact on HD patients' employment achievement and work productivity and sustainability.
- There is a statistically significant difference between activity impairment between unemployed patients. This result shows that, CKD was not the only factor affecting employment achievement of HD patients, but also their day-to-day activities and social participation.
- The questions remaining of the quantitative findings highlighted that the instruments were not sufficient to explain the impact of CKD on employment as many other factors could have the most significant impacts on employment and ability to work.

Chapter seven interrogates and offers explanations for the quantitative results further through the analysis of the qualitative data (phase two) which aimed to explain and to add to the results presented in this chapter.

Chapter Seven

Qualitative Results

Introduction

Previous studies have drawn on qualitative methods (chapter three), to explain in more detail issues related to employment and people’s ability to work. The advantage of incorporating a qualitative approach in this study alongside quantitative data was that it generated a deeper understanding of the employment experiences of people managing a LTC. The focus was to understand the impact on a HD patient’s ability to sustain work when required to attend a four-hour dialysis session three times a week.

This chapter presents the findings of phase two of the research (qualitative data), with the aim of achieving the following study objectives:

- to understand how employed HD patients manage to sustain work, and understand issues that threatened their employment (objective 3)
- to understand the barriers that prevent people receiving HD to continue or sustain employment alongside treatment and what would enable them to work (objective 4)

Interview Response Rate and Sample Characteristics (Phase Two)

Participants recruited to phase one of the study were provided with the option to be involved in the second phase (a qualitative in-depth interview). Initially it was anticipated sufficient participants would agree to take part to facilitate a stratified sampling frame; enabling recruitment of an equal spread of male/female, employed/ unemployed patients, and spanning the different age ranges and different educational levels.

However, only eleven patients agreed to take part in an in-depth interview, the remaining participants refused to be involved. To better understand the reason for this, the head nurses were asked to allow the researcher to meet the participants once again to enquire, and answer any questions, and try to understand why they didn’t want to be involved in the second phase of the study. Only six participants agreed to meet the researcher once again and after a brief discussion concerning the interview procedures, all six participants agreed to be involved, although one female participant withdrew on the day of the interview. Participants highlighted social and cultural barriers that had made them reluctant to be involved and were probably the reasons why others would not take part in the second phase interviews. For example: the issue of a male researcher interviewing female patients or being afraid that the interview will involve questions that may get them in trouble with the government or their employer. Although the study information sheet explained how these barriers would be overcome, meeting and consenting participants face to face to explain and discuss issues and providing reassurance would have been a better approach to prevent participant drop out between phases.

As a result, in the second phase of the study, a convenience sample of 16 participants were recruited and interviewed. Fortunately, despite the challenges that the researcher experienced during participant recruitment the sample characteristics represented an equal spread of male (n=8) and female (n=8) participants, with varying employment status, educational level, and spanning different age groups.

For the female participants, two were living in rural areas, whereas six were in urban area. Four were single and four were married, and three were employed and five were unemployed. Two were aged between (26 – 35), five were aged between (36 – 50), and one was aged between (51-65). For male participants, one was living in rural areas, whereas seven were in urban area. Two were single and six were married, and six were employed and two were unemployed. Three were aged between (26 – 35), three were aged between (36 – 50), and two were aged between (51-65). The detailed characteristics and data of the second phase sample are presented in Tables 19 (female) and Table 20 (male).

Table 22: Female Participant Characteristics and Data (phase two):

Item	**Participants Corresponding Pseudonyms and Codes**							
	RH_F_16	***RH_F_15***	***RH_F_39***	***RH_F_1***	***RH_F_3***	***RH_F_9***	***DH_F_14***	***DH_F_13***
Geographic area	Urban area	Urban area	Urban area	Urban area	Urban area	Urban area	Rural area	Rural area
Age Group	36-50	26-35	51-65	26-35	36-50	36-50	36-50	36-50
Marital Status	Single	Single	Married	Single	Married	Married	Married	Single
Education Level	Undergrad	≤ H School	≤ H School	Undergrad	≤ H School	≤ H School	≤ H School	≤ H School
Employment	Employed	No	No	Employed	No	No	No	Employed
When HD starts	> 5 years	> 5 years	> 5 years	3-4 years	<1 year	> 5 years	> 5 years	3-4 years
Physical at Job	Not heavy	N/A	N/A	Moderate	N/A	N/A	N/A	Not heavy
Work Shift	Full time	N/A	N/A	Full time	N/A	N/A	N/A	Full time
HD Frequency	3x week	3x week	3x week	3x week	3x week	3x week	3x week	3x week
HD Duration	4 Hours	4 Hours	4 Hours	4 Hours	3 Hours	4 Hours	3 Hours	4 Hours
Mobility	Walk	Walk	Walk	Walk	Walk	Walk	Walk	Walk
PCS	43.42	37.32	20.00	46.46	49.34	45.14	40.24	43.71
MCS	62.62	62.27	46.38	50.43	57.62	41.54	43.72	62.32
Absenteeism	60	N/A	N/A	60	N/A	N/A	N/A	72.73
Presenteeism	0	N/A	N/A	0	N/A	N/A	N/A	0
Productivity Loss	60	N/A	N/A	60	N/A	N/A	N/A	72.73
Activity Impaired	50	90	100	40	0	70	100	0

Table 23: Male Participant Characteristics and Data (phase two):

Items	**Participants Corresponding Pseudonyms and Codes**							
	RH_M_26	***RH_M_25***	***RH_M_22***	***RH_M_35***	***RH_M_34***	***DH_M_2***	***RH_M_55***	***RH_M_49***
Geographic area	Urban area	Urban area	Urban area	Urban area	Urban area	Rural area	Urban area	Urban area
Age Group	51-65	26-35	36-50	51-65	26-35	36-50	26-35	36-50
Marital Status	Married	Single	Married	Married	Married	Married	Single	Married
Education Level	Undergrad	Undergrad	≤ High School	≤ High School	≤ High School	≤ H School	Undergrad	Undergrad
Employment	Unemployed	Employed	Employed	Self-Employed	Unemployed	Employed	Employed	Employed
When HD starts	1-2 years	<1 year	> 5 years	> 5 years	> 5 years	<1 year	3-4 years	> 5 years
Physical at Job	N/A	Heavy	Heavy	Not heavy	N/A	Moderate	Moderate	Not heavy
Work Shift	N/A	Full time	Full time	Part time	N/A	Full time	Full time	Full time
HD Frequency	3x week	3x week	3x week	3x week	3x week	3x week	3x week	3x week
HD Duration	4 Hours	4 Hours	4 Hours	3 Hours	4 Hours	4 Hours	4 Hours	4 Hours
Mobility	Walk	Walk	Walk	Walk	Wheel Chair	Walk	Walk	Walk
PCS	50.88	55.80	50.94	33.56	24.78	46.67	50.06	55.57
MCS	51.67	40.37	41.59	48.41	48.09	56.01	36.42	57.85
Absenteeism	N/A	30	100	80	N/A	40	100	0
Presenteeism	N/A	50	100	50	N/A	20	50	0
Productivity Loss	N/A	65	100	90	N/A	52	100	0
Activity Impaired	0	70	50	50	60	50	70	0

Analysis of qualitative data

As stated earlier in the methodology chapter, the data of the semi-structured interviews were analysed using a thematic analysis approach (Chesler, 1987). Using this approach all themes emerging from the data were explored, and also those themes related to a particular area of interest, following up questions that arose from the phase one data (Ball, 2011). Interviews were digitally recorded and lasted between 20 to 45 minutes; then transcribed and independently coded by two reviewers. Then, similar and interrelated codes were grouped into clusters during the analysis process. This was helpful to structure the data and summarize/reduce the findings in a way that can support achieving the research objectives (Ball, 2011). This analysis method sits within a broad family of analysis methods often termed thematic analysis or qualitative content analysis. To accomplish the study goals, the seven steps of Chesler (1987) approach as stated in the methodology chapter were followed. This allowed the researcher to explore all emerging themes by following all seven steps; and also explore specific themes related to a particular question of area of interest by following the first four steps only. The two techniques were both used to achieve the objectives of the study and to generate mini-theories that helped to understand and explain employment and CKD. In addition, an inductive approach was also used before and after the analysis, by repeated reading and listening of the interviews, to ensure that significant findings were not overlooked. This robust approach helped sense check the data and confirm findings.

Five overarching themes emerged: job retention, employment sustainability, loss of jobs, unemployment, and job seeking and will be discussed in turn.

Job retention

The study explored how employees with CKD retained employment alongside undergoing HD treatment. The analysis exposed statements that described the experiences of employed

CKD patients, which were formed into seven clusters (Table 24). Each cluster generated a mini theory as to how people retained and sustained their ability to work and the motivations driving the need to work.

Table 24: Retaining employment alongside undergoing HD treatment

Clusters	Restated key phrases	Mini theory
Availability of jobs	Jobs were available, at least when I was hired. I still have many other job opportunities if I want to change my current one. It was easy for me to find a job opportunity.	The availability of work opportunities in KSA for people managing a LTC was not a barrier to unemployment
Love and enjoy what you doing	I rarely take sick-leave because I love going to work all weekdays, even on the days of HD treatment. I feel comfortable in my current job. I will not leave my job, it is very enjoyable. I love my job. I will not search for another job, simply because I love my current one. Nothing will stop you to work if you love what you do. I cannot see anything bad or negative in my job, I think everything is excellent.	For most of those who remained employed they valued and enjoyed their work although this was only applied to those who work in the public sector
See successful stories	I was about to lose my job until I saw many employed HD patients who were able to maintain employment alongside their health condition. I thought it was the end of life until saw many HD patients able to live a normal life.	Seeing other people cope with work and treatment inspired others to continue working
Self-confidence, self-	I am like any normal human being.	

management and acceptance	Not all tasks are easy but I never complain and don’t feel that I am unable to finish my work. HD patients need to be strong and dependant. If you have faith in God and accept his willing, there will be no issues. I am able to work and continue working like other normal people. I will continue my higher education. I am normal, it’s hurts to be seen as a disabled person. There will be no barriers if I stick to the treatment regimen and look after my health condition. I am a normal person with a kidney dysfunction that’s it. I hate sick-leave, it makes me feel as if I am disabled. I told you, I do not feel that I am sick.	Continuing working made people feel normal Not working made people feel more disabled by their condition
Socialization and positive relationships and thoughts	Working and socializing helped me forget my health concerns. My brothers help me to commute from and to work. Do not surrender, it is all about loving life and being optimistic. I live my life normally and try to not think about the disease ever. If the desire exists, you can make the impossible possible. My family is the reason for my happiness.	Social participation and strong family ties have many positive implication on both health and employment
Support and flexibility	Government decision to grant us official days-off on the day of dialysis	Public sector in Saudi Arabia provide

	helped me retain my employment. Official days-off are very important as I will not be able to work right after the HD treatment, I need some time to rest. My manager and colleagues are very supportive. I have many options in my workplace.	flexibility and support to Saudi employees (that helped them continue in employment “as a status only for many patients” although there work productivity was negatively affected by this)
Work is vital	Having a job is very important to me, both socially and financially. Work is important; it is not all about money. My job is most important to me than many other things in life. Employed person is more respected; I really care about my social situation. My work is the only source for living.	Realizing the importance or working and participating in the community in all aspects of life contribute to retaining employment

Table 25 provides a summary of the patient characteristics related to the job retention sub-themes.

Table 25: Participants' Characteristics

	DH_F_13	***RH_F_16***	***RH_F_1***	***RH_M_49***	***DH_M_2***	***RH_M_35***
Gender	Female	Female	Female	Male	Male	Male
Age Group	36-50	36-50	26-35	36-50	36-50	51-65
Marital Status	Single	Single	Single	Married	Married	Married
Education Level	≤ High School	Undergrad	Undergrad	Undergrad	≤ High School	≤ High School
Employment	Employed	Employed	Employed	Employed	Employed	Self-Employed
PCS	43.71	43.42	46.46	55.57	46.67	33.56
MCS	62.32	62.62	50.43	57.85	56.01	48.41
Absenteeism	72.73	60	60	0	40	80
Presenteeism	0	0	0	0	20	50
Productivity Loss	72.73	60	60	0	52	90
Activity Impaired	0	50	40	0	50	50

Availability of jobs

Patients who were looking for jobs and were willing to work even in jobs that were created for unskilled people such as a guard on a gate or school site observer, found work easily. The finding of the qualitative data showed that, job opportunities were available to all employed participants at least during the time when they were looking for work. To the question as to whether work opportunities were freely available, patients' commented:

> *"I don't know I was hired at a time when jobs were available"* (DH_F_13)

> *"I was able to find a job easily."* (RH_F_16)

Patients with specialist skills and higher education training in professions such as nursing, medicine, and engineering still had many job opportunities.

> *"I have many options… I can work in hospitals or health services departments or in a primary health centre where I am working now."* (RH_F_1)

Indeed, work opportunities were available for everybody but many patients, would not accept or expect to work in unskilled jobs or in low class jobs, reflecting the culture in Saudi Arabia. Unskilled work where minimal training was required or an educational certificate, usually involved roles such as packing in a warehouse or cleaning. People were reluctant to take work outside their speciality or training. A patient described the restrictions placed on people from the Saudi culture and traditions as '*stupid*' preventing people taking work that is deemed beneath their status in society.

> *"If you keep trying and searching you will not fail, especially if you were able to overcome stupid barriers caused by our customs and traditions, you know what I mean. What's wrong if I sell dates or food on the street?!"* (RH_M_49)

The analysis of the data suggested that, in Saudi Arabia jobs were in abundance; however, most of these available opportunities were considered low level work with low wages as well. Available jobs were filled with foreign workers as most Saudi citizens' wouldn't work in such low level work due to cultural reasons unless they lacked financial resources and needed the money. Thus, the availability of work opportunities in KSA for people managing a LTC was not a barrier to employment.

Love and enjoy what you doing

Five participants expressed their love and enjoyment towards their work, it was important to continue working because of the positive benefits work provided.

> *"…for my current job, it is very enjoyable and I do not think that I will leave it one day."* (RH_F_1)

One participant commented in a question regarding whether she thinks to apply for health retirement:

> *"No not even an early retirement. I never thought of that because I love my job and I think I will feel more sick if I leave my job."* (DH_F_13)

The patients who enjoyed work suggested that they would feel more ill with their condition if they did not have work to focus their mind.

See successful stories

Seeing other patients succeed in life and able to maintain their jobs and live a normal life was a motivator to help other patients to retain employment.

> *"Right after I got the CKD and started HD, I was about to leave my job for many reasons …, but … I found … a lecturer at the university and she was on dialysis for long time and … also* [I saw] *a nurse suffering from CKD but still able to retain employment. This gave me the motivation to continue in work and this actually saved my life in many aspects."* (RH_F_1)
>
> *"I saw CKD patients who were able to live a normal life I mean their life did not end after they became CKD patients as I imagined. Before, I thought that CKD will end my life and will makes me a hopeless person but after I saw some patients live normally, my life became more easily to live."* (RH_F_1)

There is a very negative view about CKD among people in Saudi Arabia. They think that this disease is the end of life and the only thing you can do is waiting to die. However, seeing other people cope with life and treatment inspires CKD patients to live a normal life and be an active member in the community.

Self-confidence, self-management and acceptance

Increased self-confidence, self-management and acceptance helped five participants (DH_F_13, RH_F_16, RH_M_49, DH_M_2, and RH_F_1) to sustain working. This was also reflected in their mental component scores that were very high. Being optimistic and feeling like a 'normal' person as well as following the treatment regime were key factors that helped HD patients continue working and maintain a health work life balance.

> *"Sometimes my work tasks increase but, thank God, I never complaint and I never felt that I am not able to finish my work."* (DH_F_13).
>
> *"Thank God I work the same as my healthy colleagues except that I am off on the day of dialysis."* (RH_F_16)
>
> *"I am a normal person with a kidney dysfunction that's it."* (RH_F_16)
> *"I do not want to take any days off from work, simply because I do not want to deal with myself as a patient or feel as if I am disabled."* (RH_M_49)

This suggests that, working will help CKD patients to feel normal and they do not consider themselves to be disabled.

Socialization and positive relationships and thoughts

This cluster was mentioned by almost half of the participants. Socializing and hanging out with friends and colleagues makes you feel as if you are a healthy person and helps you keep and value your job.

> *"Going to work and socializing with customers and colleagues will help me forget my health concerns and feel normal and comfortable."* (RH_F_1)

Maintaining good relationships with people and family was also beneficial in many aspects including employment. One female patient stated that her good relation with her family helped her to go to work. Since women were not allowed to drive in Saudi Arabia, for cultural and social reasons, male relatives supported her and helped her maintain her employment status.

> *"My brothers or sometimes my father helped me to commute to and from work, you could say that they are my means of transportation."* (RH_F_1)

Being positive and optimistic and avoiding negative thoughts about the health condition was another factor that helped employed patients to keep their jobs and maintain a productive healthy life.

> *"I go to work and live my life normally. I do not think about the disease completely, because as I said if I think about it I will be negatively affected emotionally and psychologically. So I consider this disease like any other mild illness, such as flu. Otherwise, if I think a lot of the disease the results will be very negative on me."* (RH_M_49)

> *"It is all about loving life and feeling positive and optimistic. If I surrender to the disease I will be in more trouble. I am a normal person with a kidney dysfunction that's it."* (RH_F_16)

Support and flexibility

Government, employer and co-worker support for CKD patients and the ability for flexible working enabled people to successfully maintain employment. The Saudi government has granted all employed patients with renal failure paid sick-leave on the day of HD treatment, and this was appreciated and important to many patients as they were unable to work effectively on the day of dialysis for reasons such as fatigue.

> *“I will not be able to work right away after the HD treatment, I need sometimes to rest.”* (RH_F_1)
>
> *“I am happy with this decision [paid day-off during HD treatment]; it helped me to keep my job.”* (DH_M_2)

Managers and colleagues support this, for instance, allowing HD patients to rest during work or reducing their work tasks. This was appreciated and was considered an important influencing factor to sustaining employment by HD patients.

> *“Actually they offer me this opportunity [*to be transferred to another department that is suitable for her health condition]*, they were helpful and supportive.”* (RH_F_1)
>
> *“They* [colleagues and managers] *treat me in a great way and actually I feel that they become more supportive with me and I think this is because of my health condition”* (DH_F_13)

Work is vital

Recognizing the importance of being employed is another key factor for job retention. Three patients stated explicitly the importance of work in their life socially and financially.

> *“Employed people are more respected than unemployed ones; I really care about my social situation.”* (RH_F_16)
>
> *“I spend all my day working in farming; it is my only source of living.”* (RH_M_35)
>
> *“employment is important… it is not all about the money”* (DH_M_2)

Employment is a source of living. Being a respected and active member in the community and being responsible are major concepts that help patients to realize the importance of being employed; which also helped them to retain employment.

Employment sustainability

Patients who work were asked to identify what they needed to avoid to enable them to sustain their work career. Comments and statements were organised into five key clusters and mini theories were developed from the meaning within statements (Table 26).

Table 26: How to sustain employment?

Clusters	Restated key phrases	Mini theories
Avoid isolation and negative thoughts	Stay away from bad thoughts related to my health condition. Sitting home leads to isolation and more health issues. Negative thoughts will make me feel unable to work. I don’t miss any chance to socialize and meet people. Surrendering to this disease will cause major problems. Only psychological factors can affect work ability.	CKD could lead to hopelessness and social isolation which could result in work disability and work discontinuity
Avoid unnecessary work absence	Regular absence from work makes me think that I am sick and can’t work. Sick-leave granted by the government could make me isolated. Not going to work and spending all day at home brought negative thoughts. I don’t want unnecessary days-off, I am not sick.	CKD patients need to go to work and avoid time-off in order to feel that they are normal and an active and productive group of the community
Disclosure, information and knowledge	My manager and co-workers are supportive especially after they knew my health condition. I don’t know my rights as a HD patients. We need education, training and rehabilitation to sustain	Employer, community, and patient knowledge and understanding of CKD help patients sustain work.

	employment. I always ask and read about my health status.	
Suitability of work	I do office work, does not require extra efforts. I transferred to another department that required less work demands. I wouldn’t be able to work in my previous department; it was a lot of work. Hard work tasks could damage my vascular access. I am more comfortable now compared to my previous busy job.	CKD patients are able to sustain a healthy work life in jobs that do not require heavy physical demand
Understanding and support	My employer is trying to reduce my tasks as possible. They will always support us as long as they understand our situation. My manager allows me to transfer to another office. If they were unsupportive, I could’ve left my job and stayed home. I feel that they are treating me in a good and a positive way. Employers need to understand our serious condition.	Positive work environment and managerial support are key factors for employment sustainability and ability to work

We cannot work every day, they must understand that and continue supporting us.

They always allow me to take rest when needed.

Table 27 provides a summary of the patient characteristics related to the employment sustainability sub-themes.

Table 27: Participants' Characteristics

	RH_F_16	***RH_F_1***	***DH_F_13***	***RH_M_49***	***DH_M_2***
Gender	Female	Female	Female	Male	Male
Age Group	36-50	26-35	36-50	36-50	36-50
Marital Status	Single	Single	Single	Married	Married
Education Level	Undergrad	Undergrad	≤ H School	Undergrad	≤ H School
Employment	Employed	Employed	Employed	Employed	Employed
PCS	43.42	46.46	43.71	55.57	46.67
MCS	62.62	50.43	62.32	57.85	56.01
Absenteeism	60	60	72.73	0	40
Presenteeism	0	0	0	0	20
Productivity Loss	60	60	72.73	0	52
Activity Impaired	50	40	0	0	50

Avoid isolation and negative thoughts

Isolation and negative thoughts could have major negative impacts on CKD patients' life including employment. Job loss or unemployment is one consequence of such factors alongside many various health and social problems.

> *"If I surrender to the disease I will be in more trouble"* (RH_F_16)

One female participant from being diagnosed with the disease was under the impression she would not be able to work and would need to leave her job.

> *“I basically thought that I would not be able to work with the presence of the disease and then start to feel isolated from the community for a short period of time… but now, thank God, I was able to live normally with the disease”* (RH_F_1).

Socializing and avoiding being lonely for long periods of time had a positive impact on patients’ employment sustainability.

> *"Sitting in the house which leads to isolation and more sickness ...I honestly trying to help myself and I try to stay away from anything that makes me think negatively and feel that [*I am*]... unable to work"* (DH_F_13)

Although those patients were not given any impression that work should stop after starting HD, they knew that if they did their health condition and all aspect of their life will be negatively affected. Isolation, thinking of the disease as a disability, losing hope and negative feelings need to be avoided to continue working.

Avoid unnecessary work absence

Regular absence from work was considered a contributing factor that would have many consequences on a patient’s life. Patients believed that absence from work should be used with caution, including the use of the official sick-leave provided by the government, only to be used when there was good reason. Being absent from work contributed to isolation and increased health issues that potentially could affect work sustainability.

> *“Regular absent from work makes me bored and will have negative impacts on my psychological condition and will let me think negatively- if I stayed home or without work, therefore, I love to go to work even when I have HD session on the same day, simply because I do not want to be isolated”*. (RH_F_1)

One employed patient said that he always goes to work and has never be on sick-leave unless really necessary either due health related reasons or hospital appointment:

> *"I do not want to take any days off from work...sitting at home and absent from work... even if the days off are allowed and granted by the employer, you know inside yourself it is a sick leave and you start to feel that you are sick and you are disabled... I do not want to deal with myself as a patient or feel as if I am disabled"* (RH_M_49)

This suggests that a strong work ethic, reinforced by a positive work environment contributed to patients not taking unnecessary absences from work. However, some patients prefer to enjoy the official paid days-off granted by the government to do the dialysis sessions din the morning even though their work environment is positive.

Disclosure, information & knowledge

Disclosing their illness was mentioned by all employed patients as making a significant contribution to their employment sustainability. Without disclosing the renal failure disease, patients would not be able to take the official paid days-off during the HD sessions. Moreover, many patients believed that their employer and colleagues support increased noticeably after they disclosed their health condition.

> "[My manager and co-workers] *are very supportive especially after they knew about my health condition."* (DH_M_2)

However, this disclosure should be accompanied with the provision of at least a basic knowledge about the disease by the employer, co-workers, and people. They should know that CKD patients with HD can fulfil their work requirements as any other healthy employee but with some work adjustment. Such information, knowledge and understanding is important so employers do not force employees with CKD to leave their job, or prevent them from hiring new workers suffering from such a disease in the future.

> *"Knowledge and education about the disease is very important for HD patients and also for the community and employers they should know that HD patients are not different than other normal people. CKD is similar to any other chronic diseases and*

> *with knowledge and self-management patients will be able to work and sustain work."* (DH_M_2).

Suitability of work

Having a job that was suitable for HD patients is another important factor that contributed to increased employment among patients. Four patients indicated that; for work to be HD patient-friendly, key characteristics were required: (1) reduced work tasks, (2) the ability for regular absence from work when needed or at least having the opportunity to rest during work, (3) reduced heavily physical work demands which could damage a patient's vascular access. One patient, transferred to another department that facilitated work that required less mental effort:

> "[I would not be able to sustain employment if I did not transfer to my current department]. *My previous job required a lot of work, I worked in a very sensitive department where it was also hard to be absent on a regular basis."* (DH_M_2).

Another female patient who worked as a nurse in primary health care centre (PHC) said:

> *"The working system and the tasks are good* [here in the PHC centre]. *I mean if I am working in a hospital I may face some difficulties handling my tasks."* (RH_F_1)

Understanding & support

Both understanding and support were closely related in the context of work sustainability. Employers, managers, and colleagues were found to be more supportive to HD patients when they understood the seriousness of their condition.

> *"Employer should understand that we are having a serious disease"* (RH_F_1)

Those factors are also related to the factors ‘*disclosure, information & knowledge’* discussed above.

> *“Patients cannot go to work every day, they should attend their dialysis treatment, for example.”* (RH_F_16)

Manager support and co-worker collaboration were vital to HD patients. One patient found it difficult to manage HD treatment alongside work, but the administrator was very supportive and he understood the situation and transferred him to another department where he will be able to work and attend his HD treatment sessions.

> *“I did* [request to be transferred for another department], *and they were very supportive ... If they were unsupportive I could had left my job and stayed home.”* (DH_M_2)

Loss of jobs

Understanding the factors that created job insecurity and could contribute or force employed HD patients to leave their jobs was important. Statements were collated into four key clusters (Table 29).

Table 28: Why are HD patients from at risk losing their jobs?

Clusters	**Restated key phrases**	**Mini theories**
CKD related health issues	I cannot do anything especially on the day of dialysis as I feel very exhausted and cannot move the high duration and frequency of dialysis will make it hard to work I cannot move a lot I am sick and tired since I got this disease After got CKD I felt very sick and unable to work, so I lost my job HD is exhausted, time consuming and could cause disability and death. Don't believe anyone who says otherwise.	The time consuming nature of HD and its effect on health is a barrier to sustain employment and functioning
Policy abuse and Fake employment	I have been hired so they can fulfil the government requirement of the Saudization scheme They hired me for doing nothing, they were benefiting from my status as a disabled person Someone from the private sector came to the dialysis centre looking for unemployed disabled patients to hire them The government will provide many facilities and benefits to companies that hire disabled people, but this was abused by most companies My disability status, is actually an advantage, and many companies look for us to get some benefits from the government	Manipulation of employment strategies and initiatives, and policy abuse are serious issues that contribute to unemployment and health work-life

	I don’t go to work at all except if they call when there is inspection or something from the office of labour I worked once under the “Saudization scheme” and they were giving me salary for doing nothing, I don’t even know where is the location of the company Private sectors are searching for unemployed disabled people, because the will be receiving four times more benefits from the government for hiring disabled people than healthy ones	Employment data and processes of disabled people in private sector is unreliable and is a barrier to the government employment strategy
	I am employed in the private sector but I cannot work or even go to work The department of labour will find jobs for us in the private sector, all we need is to apply to the department of labour	Forcing private sector companies to hire Saudi workers with no considerations to their capabilities and qualifications could results in more job loses
Job insecurity	I work in the private sector, but I am planning to continue my studies to be able to find a job opportunity in the government sector There was some support at the beginning, but after they knew that my condition could last forever they ended my contract I want to work in the public sector for job security. The private sector wants profits only I wasn’t able to work effectively so the manager fired me in just two months after starting HD	Work environment and absence of work ethics in private sector, especially for low level workers is a barrier to work continuity

Table 29 provides a summary of the patient characteristics related to the loss of jobs sub-themes.

Table 29: Participants' Characteristics

	RH_M_34	***RH_M_22***	***RH_M_55***	***RH_M_25***
Gender	Male	Male	Male	Male
Age Group	26-35	36-50	26-35	26-35
Marital Status	Married	Married	Single	Single
Education Level	≤ High School	≤ High School	Undergrad	Undergrad
Employment	Unemployed	Employed	Employed	Employed
PCS	24.78	50.94	50.06	55.80
MCS	48.09	41.59	36.42	40.37
Absenteeism	N/A	100	100	30
Presenteeism	N/A	100	50	50
Productivity Loss	N/A	100	100	65
Activity Impaired	60	50	70	70

CKD related Health issues

Three patients believed that the progression of the CKD as well as the HD treatment had a major effect on their physical condition and their ability to work or sustain work. Saudi Arabia is a developing country where '*working-from-home*' jobs are not available for many reasons including lack of infrastructure (poor internet services). Therefore, available work often required some physical activity such as standing for sustained periods (as a cashier) or lifting heavy goods. These jobs could be difficult to maintain especially among patients experiencing physical impairment. Not only job retention was affected by the progression of the disease but also daily activities of life.

> *"I am sick and tired since I got this disease. I cannot do anything especially on the day of dialysis as I feel very exhausted and cannot move"* (RH_M_34)

> *"I am a HD patient for long time and now I need to sit on a chair when I pray, it does affect my physical activity and of course my ability to work. And the doctors here do not help us, they told that this is a normal progression of the disease we can't do anything"* (RH_M_22)

Coming to the dialysis centre for HD treatment three times a week for four hours for most HD patients was both exhausting and time consuming. Many patients failed to manage the possible conflict between the HD schedule and their work or social life. The following comment provided a very interesting opinion regarding those patients who always say that they are fine and need nothing more.

> *"HD is exhausting, time consuming and could cause disability and death. Don't believe anyone who says no, especially elderly patients because they have more faith and they don't need jobs as they have everything they need such as house, wife and kids. For me I always think of future, marriage, travel, real estate, work, accomplishments …I want for example to continue my studies for a better job but I can't because I have to attend the college almost every day and I don't have time for that. You can't be absent and, for me, on the day of dialysis I can't do anything and I really feel tired and exhausted"* (RH_M_55)

One patient recalled how he lost his job in the private sector because of the symptoms of CKD before he was diagnosed. He was living a normal healthy life and working in a company as a security guard. One day he called in sick, exhausted and was ill for a couple of weeks until he visited the hospital and the doctor told him that he needs to start HD as soon as possible. His employer tried to support him at the beginning but after they knew that his condition could be a permanent and he would be unable to work effectively, they chose to fire him.

> *"I was working in a company (private sector) and after I got CKD I felt very sick and unable to work, so I lost my job…. At first I didn't know what was wrong with me, I was tired and sick … I started visiting the hospital for many times … I was not able to*

> *work effectively …. As you know that the private sector employers want their employees to work every single minute …. That’s why they fired me”* (RH_M_34)

Policy abuse and Fake employment

In Saudi Arabia, since the discovery of oil, the country is heavily reliant on foreign workers to fulfil both skilled and unskilled work. Today, the government of Saudi Arabia is moving towards ‘Saudization’, replacing foreign workers with Saudi citizens in many various types of jobs such as teaching and nursing. The employment strategy also encourages the private sector to fulfil their social responsibility obligations and hire Saudi citizens where possible. To achieve this companies are given many incentives and privileges for each Saudi citizen they hired. One of the unique and key findings from this study was uncovering the misuse of the employment strategy policy by the private sector in Saudi Arabia.

To receive the government’s incentives, companies hire Saudi citizens especially those with a registered disability. This has nothing to do with social responsibility expected from private sector companies, but companies are unable to issue a working visa for foreign workers unless they hire certain number of Saudi citizens (reported in the background chapter). Hiring disabled people counts as four non-disabled employees. Indeed all four patients interviewed who worked in the private sector believed they were hired as a result of such misuse of the national employment strategies. This is potentially a serious issue and many people could lose their employment if this policy changed or was amended without careful consideration and evaluation of the widespread implications of such practice.

One patient who worked as a teacher in a private school said that he was the only Saudi teacher in the school even though there were many unemployed Saudi teachers who could replace non-Saudi teachers.

> *“I am the only Saudi teacher in the school among other teachers from different nationalities. My manager and some close colleagues knew about my condition and they are all very supportive… they knew about my condition and that I am disabled when I applied for the job… but I am sure that they rather hire a foreign teacher with low salary than me if they were not forced by the ‘Saudization’ system.”* (RH_M_25)

The salaries of non-Saudi teachers were at least 50% less than Saudi teachers. He believed he was hired because the government had forced the private sector to recruit Saudi citizens, and instead of hiring four Saudi teachers they hired this patient who was registered disabled.

Another patient believed that the company which hired him was “*benefiting from my status as a disabled person*” (RH_M_34); otherwise they wouldn’t have employed him. He was sure because of the way they recruited him which appeared strange, unprofessional, was potentially an illegal practice.

> *“The company representative came to me here in the hospital while I am on dialysis and asked me about my current employment status and whether I have a disability card or not, and then he offered me the job… I agreed, and then he took my phone number, a picture of me, a copy of my national ID, and a copy of my disability card…. I didn’t know that this was illegal.”* (RH_M_34)

One patient did not see any misuse of the employment strategy by the private sector; instead he viewed the policy as a blessing, it helped him and many other patients to gain employment.

> *“Thank God that we have a good government as it gives the companies many incentives and privileges to hire HD patients…. This was a good decision, it forces companies to hire disabled people in order to get many features… [yes] they will benefit from us, actually it is a mutual benefit… our disability status is enough to let you continue in work and receive a monthly salary…. This new policy will create many jobs for patients like me because it is a win-win bargain for many companies, they will be receiving four times more benefits for having disabled employees than normal ones.”* (RH_M_55)

He believed that all unemployed HD patients should be informed about such an opportunity to bring them back into the labour market.

> *"Many patients are not employed because they do not know about this new reform; we should inform them though…. For me, I spend a lot of time not working until I got some information from a friend that my disability status is actually an advantage and many companies look for people like me, in order to get some benefits from the government."* (RH_M_55)

The impact of the policy abuse (discussed in the previous section) could result in many HD patients being hired by the private sector where the only qualification that they required was a disability card. This problem promoted the employment of unqualified workers who were missing the opportunity to be trained and educated in many situations to undertake a suitable role. This was the case for three interviewed patients where their employment was fake and for some patients they could not even identify the location of their work. This was certainly an illegal practice and would in the future, when uncovered, lead to potential increased unemployment within this group of patients.

This was an example of how some companies hired disabled people even if they did not have any qualifications at all:

> *"Even if you do not have a certificate at all, they will hire you in a security department, kitchen, or any other department that do not require you to have a certificate. These new policy "Nitaqat" is very good and helped us find jobs."* (RH_M_55)

Another example was a case where the employee did not go to work unless the company was due for inspection by the department of labour:

> *"A friend of mine offers me this job in his company and I am happy as I don't do anything and actually I don't go to work at all except if they need me, you know, when there is inspection or something from the office of labour.* [How is that?] *I don't know*

> *my friend help me to get this job and I don't care as long as I receive a monthly salary without going to work…* [What if you are not disabled, are they going to hire you?] *Maybe but I have to go and do a full-time job which I cannot do."* (RH_M_22)

This was reinforced by a fake employment for an employee who did not know where the location of his work was:

> *"I worked under the "Saudization scheme" and they were giving me 500 SAR for doing nothing, I didn't even know where the location of the company is. Then my social security benefits stopped as they considered me employed and I didn't know that this will happen, otherwise I will not accept 500 SAR as I was receiving 1000 SAR from the social security department. Then I went to search for the company in the department of labour and I found that the company actually hired me for a salary of 3500 SAR (in the register), so I felt very disappointed and then I realized that they were not helping me they were actually benefiting from my status as a disabled person."* (RH_M_34)

Examining the characteristics of the people employed by the private sector as disabled employees there was considerable variation between them and no clear indicator that appeared to influence this practice by individuals. For example, two were married and two single, they were all young or middle aged, two had undergraduate degrees, two high school certificates, and their physical and mental conditions was rated good. In addition to the quantitative data, the qualitative data revealed that those employed patients (in private sector) were considered unemployed suggesting the quantitative data alone could be misleading. Those patients employed were because they classed as disabled; the companies in the private sector were forced by the government to hire them and other citizens, regardless of their qualification and capabilities.

The quantitative data showed that out of 130 patients who participated in this study, only 33 patients were employed (30 male and 3 female). Of these employed patients (in the private sector) only four agreed to participate in the qualitative interview. In reality the finding indicated that they were employed and at risk of losing their jobs at any time, as they were not considered useful to the employers. We do not know about the remaining employed patients who refused to be involved in the interviews, but the data suggests that there could be more than four patients in the same situation.

Job insecurity

Job security was very important for most people. Employees in the public sector indicated greater job security than those in the private sector, especially in a developing country such as Saudi Arabia. Fake employment and policy abuse were some examples highlighted earlier, that increased job insecurity and eventually led to job loss. Most people in Saudi Arabia, especially those with low educational level, preferred to work in the public sector even with a lower salary to ensure that they are not in danger to losing their jobs.

> *"I want to work in the public sector for job security"* (RH_M_34)
> *"I am a teacher, and can only work in schools … Thank God I got this job [private school] right after my graduation. And I am planning to continue my studies to be able to find a job opportunity in the government sector"* (RH_M_25)

Whilst some companies were exposed as abusing the employment strategy other private companies chose not to violate the policy even though disabled employees could be an advantage to facilitating increased foreign employees. These companies preferred not to hire disabled people and ended the contract of the disabled employees whom ability to work was noticeably affected by their disability. This raises questions over the social responsibility obligations absent within the private sector.

> *"There was some support at the beginning, but after they knew [private sector employer] that I need to visit the hospital several times a week and after they saw that my work ability is reduced, the manager called me and said sorry we cannot help you anymore and you need to leave your job."* (RH_M_34)

> *“I worked in a not-for-profit foundation once and I got a shock actually … I hated the idea of having a job while I am on dialysis, it was very difficult because it required a lot of effort…. I was working full-time and there was no rest…. I wasn’t able to work effectively so the manager fires me in just two months.”* (RH_M_55)

Unemployment

It was important to understand the reason behind unemployment among many HD patients and whether they were able to work or not. The analysis identified many statements which were sorted into four clusters (Table 30):

Table 30: Barriers to employment among HD patients

Clusters	Restated key phrases	Mini theories
Discrimination in hiring	You will not be able to work effectively as long as you are a CKD patient Once the employers know that I am on dialysis they reject my application CKD does not affect my ability to work but does affect employer's decisions to hire me	HD patients are facing discrimination when they apply for jobs in private sector as it was believed that they would not be able to work effectively
Personal factors	I am illiterate, who will hire me?! My educational level will not get me a suitable job The CKD does not have any effect on my decision to leave my job	Education, training and other personal affairs are barriers to employment, especially in a culturally accepted kind of work
Culture and traditions	I wanted to work long time ago but my husband did not agree I am busy at the house and have no time for extra work It is my husband job to go to work and provide for the family, not me	Traditions and culture is the main barrier to employment among female HD patients
Environment and society	I couldn't do anything but to shut down my own business because of the transportation	Society and the environment such as the Saudi Arabia culture and hot weather hinder

	I need a job that is near to my home or a job that provide transportation for employees Transportation not only limited my ability to work, but also forced me to leave the school Most available jobs for me are not suitable	many HD patients from employment especially females

Table 31 provides a summary of the patient characteristics related to the unemployment sub-themes.

Table 31: Participants' Characteristics

	RH_F_15	***RH_F_9***	***DH_F_14***	***RH_M_26***	***RH_F_39***
Gender	Female	Female	Female	Male	Female
Age Group	26-35	36-50	36-50	51-65	51-65
Marital Status	Single	Married	Married	Married	Married
Education Level	≤ H School	≤ H School	≤ H School	Undergrad	≤ H School
Employment	No	No	No	Unemployed	No
PCS	37.32	45.14	40.24	50.88	20.00
MCS	62.27	41.54	43.72	51.67	46.38
Absenteeism	N/A	N/A	N/A	N/A	N/A
Presenteeism	N/A	N/A	N/A	N/A	N/A
Productivity Loss	N/A	N/A	N/A	N/A	N/A
Activity Impaired	90	70	100	0	100

Discrimination in hiring

The qualitative data revealed many factors that led to unemployment among Saudi HD patients including discrimination in hiring. However, two unemployed patients believed that CKD and HD treatment did not have a negative impact on their ability to work, but it does contribute to their employment status. They faced discrimination because they were CKD patients undergoing HD.

> *"The disease does not have an impact on my ability to work but it does influence the decision of the employers when I applied for a job. My application for a job in a private healthcare centre have been rejected after they knew that I am a CKD patient and undergoing HD."* (RH_F_15)

> *"I remember once, a private school were hiring unskilled people and I went there and I met with the manager who was very nice with me and when my daughter told her that I am on dialysis three times a week, she said we will find a suitable job for you and will contact you in three days, but they didn't. And when I called them they said sorry we are no longer looking for workers. And I am sure that they rejected my application because they knew that I am a HD patient. Even though I am physically fit and feel good and able to work. This happened to me several times; once they know that I am on dialysis they reject my application."* (RH_F_9)

Those patients were talking about private sector employers as they believed that HD patients would not be able to work effectively.

Personal factors

Patients' personal situations were also found to be a factor that led to the high unemployment rate among those patients. This was reported by two of the interviewed HD patients who chose to be unemployed for personal reasons that did not have any relation with their current health condition. One female patient was not satisfied with her educational level which she believed she would not get a suitable job,

> *"Even if I want to work my education is very poor and I will not be able to work in a suitable job, the only chance is to work in unskilled jobs which require a lot of physical demands."* (DH_F_14)

Another retired patient was interviewed to see if his decision to apply for early retirement was a result of managing CKD. The patient was mentally and physically fit and his decision was a personal decision and he had planned for this decision a long time before he was diagnosed with CKD.

> *"I had a plan that after I complete 32 years in service I will apply for early retirement which many teachers do because the salary then will not have a much difference, they will only deduct 20% of my salary, and that's why I retired. The CKD does not have any effect on my decision or my ability to work, Thanks to God."* (RH_M_26)

Culture and traditions

The culture and tradition of Saudi Arabia contributed to the increment of unemployment rate especially among women. This applied to most women in the country whether they were healthy or not. This meant that CKD was not the most influencing factor, in many cases, that impacted on the employment status among many CKD female patients. In Saudi Arabian society, women look after the house and children, whereas men are responsible for supporting their families; providing for them, paying bills and any other expenses, and giving family members money when needed.

> *"I got married when I was 15 years old then God blessed me with children and I was busy looking after them and the house. However, one day I wanted to work like many other women but my husband refused and he said that you don't need the job, thanks to God we are fine, just leave it for someone else who is in need; and since then I never thought about searching for job."* (DH_F_14)

When the husband in the quotation said "we are fine", this meant their financial status was sufficient and the husband could continue to provide for his wife and children without a need for another job; a reflection of the usual traditions and culture of people in Saudi Arabia.

> *"I was busy in the house and busy raising my children and I didn't have time for extra work. Yes I was doing some crafts at home, when I have the time, and sometimes I sold them but I do not consider this as a business. My husband worked in the north region of the country and he always sent us money when we needed."* (RH_F_39)

Environment and society

Saudi Arabia is a developing country that lacks infrastructure within many services, including the work environment and society. Most work environments do not accommodate disabled people, lacking disabled parking spaces, ramps to enter buildings, or specially adapted disabled toilets.

> *"I want a job that is suitable for my condition but I am sure nothing is available."* (RH_F_15)

Transportation is another problem that contributes to unemployment especially among women, as they are not allowed to drive in Saudi Arabia and the country does not have public transportation, such as buses or trains. Two female patients indicated this barrier which contributed to them being unemployed.

> *"No one is a round to help commute and I cannot afford a daily taxi fares. Actually I had my own business long time ago but I wasn't able to continue because of the transportation problem."* (RH_F_9)
>
> *"Transportation is a problem for me as a female; I need a job that is near to my house or a job that provides transportation for the employees."* (RH_F_15)
>
> "*No, it was the transportation not the disease, actually I left school before I even become a CKD patient, the school was very far and the transportation was not available."* (RH_F_15)

Job seekers

Seeking employment was an interesting theme among employed and unemployed HD patients. Only four unemployed patients identified looking for appropriate employment although when pressed in the interview they each demonstrated limited effort to seeking work. The findings showed two main elements were behind their desire to have a job: money and satisfaction (Table 32).

Table 32: Motivators to seek employment among HD patients

Clusters	**Restated key phrases**	**Mini theories**
Financial issues	No conditions at all, I will work in any job as our financial situation is bad My husband’s salary is low, I just want to help him My husband died and I need the money for my kids	Poverty or the need for money to provide for the family
Psychological relief	Working will help me forget most of my personal problems Having a job will be good for me and my health Being employed means a longer healthy life and a good citizen	Employment can help patients to achieve their desire to be active members of the community and live a healthy life

Table 33 provides a summary of the patient characteristics related to the job seekers sub-themes.

Table 33: Participants' Characteristics

	RH_F_3	***RH_F_9***	***DH_F_14***	***RH_F_15***
Gender	Female	Female	Female	Female
Age Group	36-50	36-50	36-50	26-35
Marital Status	Married	Married	Married	Single
Education Level	≤ H School	≤ H School	≤ H School	≤ H School
Employment	No	No	No	No
PCS	49.34	45.14	40.24	37.32
MCS	57.62	41.54	43.72	62.27
Absenteeism	N/A	N/A	N/A	N/A
Presenteeism	N/A	N/A	N/A	N/A
Productivity Loss	N/A	N/A	N/A	N/A
Activity Impaired	0	70	100	90

Two unemployed patients who were women had reasons to seek employment: one wanted to help her husband on a low salary, even though Saudi culture expected the male to take full responsibility to provide for his family. Another woman had lost her husband and thus had the responsibility for her house and dependent children.

> *"My husband salary is low; he works as a security guard that's why I want to help him providing for the house and the kids. My only income is now 800 SAR from the social affair department and sometimes I spend it in days. I really want a job as our financial situation is not that good. I searched and I am still looking for any opportunity."* (RH_F_3)
>
> *"I am illiterate I do not read and write. I am also a widow, my husband died 4 years ago that's why I need a transportation to be able to work and provide for*

> *my children. I only receive 800 SAR from the social affair department, it was 1000 SAR a long time ago but they decreased to 800 SAR which is not enough but what can I do."* (RH_F_9)

The psychological relief and feeling of satisfaction was an important factor which led patients to search for job opportunities, indicating that employment would help them to live longer and be a good citizen (RH_F_15) as well as forgetting about their illness:

> *"Working will help me forget my personal problems"* (DH_F_14)
> *"It [what being employed means to her] will makes me feel alive and active in the community. It makes people live longer." (RH_F_15)*

Looking for work for such reasons is common among many women in Saudi Arabia especially middle-aged women, when their responsibilities as a mother decrease.

> *"I prefer to work even if I lose my social benefits because it is better for my health, I love meeting people and socializing. You know what I even feel happy to come here in the dialysis centre so I can meet and talk to the nurses and the patients."* (RH_F_3)

Indeed, for some patients, employment was the influencing factor towards achieving a healthy happy balance.

Conclusion

The thematic analysis of the qualitative data (Phase two) has generated some very interesting results which explain and clarify the quantitative findings but also identify where statistical results need to be considered with caution. This in-depth complementary data has facilitated a deeper understanding of how employed HD patients manage to sustain work, and has exposed unique issues that both enhance and threaten their employment. The barriers that prevent people who are receiving HD to continue or sustain employment alongside treatment are important to understand so that appropriate support, policies and strategies can be developed to enable them to work without discrimination. The summary of the key findings is presented (Box 8):

Box 8: Phase two key findings

- The availability of work opportunities in KSA for people managing long term illness was not a barrier to unemployment.
- For most of those who remained employed they valued and enjoyed their work although this was only applied to those who work in the public sector.
- Seeing other people cope with work and treatment inspired others to continue working.
- Continuing working made people feel healthy.
- Not working made people feel more disabled by their condition.
- Social participation and strong family ties have positive implications for both health and employment.
- The public sector in Saudi Arabia provides flexibility and support to Saudi employees that help them continue in employment, sometimes as a status only for many patients (although there work productivity was negatively affected).
- Realizing the importance or working and participating in the community in all aspects of life contributes to retaining employment.

- CKD can lead to hopelessness and social isolation which could result in work disability and work discontinuity.
- CKD patients need to go to work and avoid time-off as much as possible to feel that they were a healthy people, active and productive group of the community.
- Employer, community, and patient knowledge and understanding of CKD helps patients sustain work.
- CKD patients are able to sustain a healthy work life in jobs that don’t require heavy physical demand, usually available in higher level jobs or in public sector.
- Positive work environments and managerial support are key factors for employment sustainability and ability to work.
- The time consuming HD treatment and its effect on health is a barrier to sustain employment and functioning.
- There is evidence of manipulation of employment strategies and initiatives, and policy abuse; with serious implications for unemployment and health work-life.
- Employment data and processes of disabled people in the private sector is unreliable and a potential barrier to the government employment strategy.
- Forcing private sector companies to hire Saudi workers with no consideration to their capabilities and qualifications could result in more job losses.
- The work environment and absence of work ethics in the private sector, especially for low level workers is a barrier to work continuity.
- HD patients face discrimination when they apply for jobs in the private sector as employers perceive they would not be able to work effectively.
- Education, training and other personal affairs are barriers to employment.
- Traditions and culture are the main barriers to employment among female HD patients.
- Saudi Arabia culture hinders many HD patient from employment especially female patients.
- Poverty and the need for money to provide for the family is a motivator for employees.
- Employment can help patients achieve their desire to be active members of the

community and live a healthy life.

The key findings and theories emerging from the combined quantitative and qualitative data are now discussed in Chapter Eight, alongside the Capability Approach to understand the new knowledge gleaned from the study and subsequent recommendations. The mini-theories and findings are merged and integrated within an explanatory framework to understand and explain who, what, why and how HD patients continue to work, or not, alongside managing a LTC. It is important to understand the capabilities and employability of HD patients using such an approach, to inform appropriate support for social policy reform.

Chapter Eight

Discussion

Introduction

The aim of this explanatory sequential mixed method study was to examine the employment status, and sustainability of work among HD patients in Saudi Arabia. The research generated a deeper understanding of who, what, why and how HD patients continue to work, or not, alongside managing a LTC. Indeed, the study achieved its objectives and revealed interesting and unique findings related to employment and the ability to work among CKD patients receiving HD in Saudi Arabia. Combined, the findings, the systematic review of the literature, the design and the application of developing theories contributes to and extends existing knowledge, theory, and practice. Although, this is the first study of its kind in this group of patients, further research related to employment and work-ability among this group of patients, especially in Saudi Arabia and most Arab countries that share similar culture and social aspects is needed. This chapter draws together the key findings alongside evidence and theory to transform collected data into valuable information and evidence on employability and workability of CKD patients.

It is evident that, both in this study’s findings and the literature, HD patients have a very high unemployment rate, and they encounter many issues that hinder them from seeking employment, or force them to leave their jobs. The robust explanatory evidence from this study indicates that CKD itself has at times little influence on the issue of employment; but it is the environment, social, context, and personal factors that impact on employment among this group of patients. As a result, the Capability Approach proved a useful framework to assess and understand the employment and unemployment of CKD patients. The findings were consistent with the basic ideas and concepts of the Capability Approach Theory and, to some extent, themes that emerged from the systematic review of the literature from experiences reported in other LTC groups.

Key themes that emerged from both the Capability Approach and the systematic review of the literature are used to structure this chapter. This informs the final study objective related to the application of the Capability Approach theory within the domain of health, then concludes with an examination of the limitations and strengths of the study.

Health factors affecting capability and functioning

This section brings the study findings together with the available evidence in the literature to discuss the effect of HD patients’ health status as CKD patients on their ability to work (capability) and their employment (functioning). Four sub-themes emerge: HRQoL, CKD, Haemodialysis, and perceived health.

HRQoL

Statistically, the physical condition of HD patients has been found to be the second significant predictor to unemployment among this group of patients. CKD and HD were the primary causes to the low PCS among the patients. However, female patients were found to have lower PCS than male patients which was not surprising as most employed participants were men. Essentially the study findings showed that employed HD patients had a better physical condition compared to unemployed patients.

These findings are supported by the study of Al-Jumaih et al. (2011) who found that there was a positive correlation between employment and patient's physical condition measured by a QoL survey. Moreover, they found that women were more impaired than men; possibly related to the high rate of employment and income among men compared to women. The study findings were partially consistent with another study conducted by Kamal et al. (2013), who found that limitations in both physical and mental health condition among unemployed HD patients are very high compared to employed ones. However, the literature failed to explain how the physical condition of HD patients affects their employment status and sustainability, and why some patients with limited physical condition were unable to keep their jobs.

The qualitative findings of this study offered an explanation for both employed and unemployed patients, reinforcing the strength of the combined mixed method approach in examining the phenomenon. Employed patients with limited physical condition who managed to sustain employment did so because of: job accommodation, transferring to another department where work did not require heavily physical activity, or continuing a desk-based role. However, physical condition affected some patients finding a suitable job particularly those without a degree or with low level of education, as most available jobs at this level required heavy physical activity (such as working in a warehouse). Thus, physical condition of HD patients could affect their employment in many different aspects unless a healthy work environment and/or employer support was available (discussed in more detail in the work environment and employers section).

CKD and Chronic illness

In a study that examined the patterns of the work-ability of CKD patients, almost half of the participants reported that CKD was the leading cause for their disability (Van der Mei et al., 2011). Similarly a study conducted by Murray et al. (2014) to examine the employment and educational achievement of CKD patients found that the majority of participants agreed that CKD had negatively affected their employment as it reduced their capacity and ability to carry out their job in an efficient and effective manner. Many patients with LTCs believe that fatigue and the increasing of physical disability as a result of their illness were the main cause for losing their job (Crooks, 2007; Townsend, 2008).

This study's findings were consistent with these studies in terms of the negative affect of CKD on physical and mental conditions of the patients which eventually affect many patients' employment and ability to work. However, the study also found that a patients' mental condition had a greater impact on their employment achievement even among those with normal PCS. For example, many patients with good physical condition did not search for a job but simply believed that they would not be able to work as they were CKD patients. Moreover, the findings showed that CKD could lead to hopelessness and social isolation which could result in work disability and work discontinuity. Therefore, to work and sustain employment, CKD patients need to be supported to avoid isolation and reduce negative thoughts, increasing self-esteem and self-efficacy.

Haemodialysis (HD)

In a study conducted by Julián-Mauro et al. (2012), to analyse CKD patients' employment status at eight hospitals in Spain, it was found that the employment rate among patients undergoing HD is less than those undergoing automated peritoneal dialysis. Helanterä et al. (2012) reported a similar result examining the association of treatment modality and employment rate among CKD patients undergoing RRT.

The participants of this study were only HD patients; however, the results were consistent with the literature in terms of the high unemployment rate among HD patients. The quantitative phase findings showed that only 25% of the HD patients where employed. Moreover, the majority of those employed patients were men – 30 employed men compared to only three women. This result could be a shocking for people not familiar with the culture and social context of Saudi Arabia and other Arab countries (discussed later in the chapter alongside personal and social factors). What was clear in this study was that, CKD and HD treatment were not the key contributory factor to very low unemployment among female patients. Again signalling the value of the adopted research design and additional qualitative approach to explain, and enhance understanding the findings of the quantitative phase and from the literature.

A study that examined the patterns of the work-ability of CKD patients showed that patient's physical capability, concentrating ability, and speed of work were all impacted negatively during HD treatment compared to pre-dialysis and after kidney transplantation period (Van der Mei et al., 2011). Duration of HD treatment has a major impact on patient's well-being and functioning. The longer the duration of HD treatment, the lower the physical functioning condition is (Guerini et al., 2006; Julián-Mauro et al., 2012; Kamal et al., 2013). Time spending on dialysis and the low energy level caused by this treatment modality have been found in the literature to be a major issue concerning HD patients as it contributed to their unemployment or reduced their work-time (Murray et al., 2014). It is also found that HD will increase patients' functioning limitation and reduce patients' activities, especially on the day of dialysis (Guerini et al., 2006).

The results of the quantitative phase did not show a significant relationship between the duration of HD treatment and employment or work productivity. It did indicate a significant increase in the productivity loss among employed patients due to HD. However, the questionnaire included absenteeism rate of workers in the calculation of productivity loss, and given that many employed patients in the public sector were granted official sick-leave this result was skewed. This only came to light when patients explained the productivity loss and absenteeism in the qualitative interviews. Similarly to the literature, the interviews also confirmed how the time consumed by the HD treatment and its effect on health was a barrier to sustain employment and work productivity. Many patients felt exhausted and unable to work on the day of dialysis; whereas some of them believed that the high frequency and long duration of the HD treatment was the reason behind their unemployment. Moreover, unnecessary absence from work for many employed patients was found to be a barrier to sustain employment. CKD patients reinforced the need for patients' to go to work and avoid time-off as much as possible to feel that they are healthy, active and productive group within the community.

These finding are also consistent with other studies in the literature. The HD shift-schedule was found to be a barrier for many people to maintain employment as the time required to attend for treatment impinges on available work time. This forced some HD patient's to leave or lose their work, or the HD treatment led to disability or sustained and untenable sickness absence (Van der Mei et al., 2011; Julián-Mauro et al., 2012). Van der Mei et al. (2011), found that HD treatment forced many patients with CKD to leave their work or be on a full sick-leave as the percentage of employed participants decreased during dialysis from 74% to 50% (19% of those were on sick-leave).

Perceived health

Many HD patients believed that their self-perceived health has been negatively affected over time (Guerini et al., 2006). Patients' perceptions and attitudes toward their health condition was a crucial factor that impacted on their employment status and work sustainability (Munir et al., 2005; Fisher et al., 2007; Townsend, 2008). Many patients with chronic health conditions lost their confidence to feel fit for work and able to perform similar duties to healthy employees. This was one of the most critical factors that led people to give up work (Fisher et al., 2007; Townsend, 2008).

None of the reviewed studies were conducted to examine how perceived health could affect employment and how employed HD patients were able to overcome this issue. In the literature, in addition to coping strategies, a change of occupation could be used to alter the perception of health condition among chronically ill employees. Employees with chronic pain, for example, engaged in meaningful work or moved to less demanding jobs to decrease the psychological and physical impacts (Fisher et al., 2007).

The results of this study were broadly consistent with the literature. Whilst some patients lost hope in life once they were diagnosed with renal failure, most employed HD patients felt confident and as normal as other healthy individuals. Acceptance and seeing successful stories from previous HD patients inspired patients to retain employment and actively participate in the society. One patient stated that *"I am a normal person with a kidney dysfunction that's it"* (RH_F_16). Of course, employer support helped employed patients to sustain employment. Two patients were able to change their role at work and moved to another department that was more suitable for them after they became HD patients which helped them to keep their jobs. Acceptance, self-confidence, coping, as well as the managers' support helped HD patients alter their health perceptions and attitudes toward their ability to work and continue to be an active member in the community.

Personal and social factors affecting capability and functioning

On closer inspection of the qualitative data findings, there was a very strong link found between personal and social factors among all patients, but particularly women. In many cases, personal factors were driven by social and cultural factors and beliefs. Therefore, social and personal factors will be presented together to better understand how such factors influence the ability to work ('capability') and employment achievements ('functioning') among HD patients.

Age and gender

Many studies have found that there is an association between patients' age and gender, and their employment status and work ability and sustainability (Munir et al., 2006; Gilmour et al., 2008; Koolhaas et al., 2013). Male patients with LTCs were found to be better able to sustain employment and have full-time job than female patients (Munir et al., 2006). These findings are, to some extent, consistent with this study's findings in that male patients are more likely to be employed compared to female patients. In this study, gender was the most significant predictor of unemployment among HD patients. One reason was that, jobs were more available to men than women due to many factors including environmental, social and cultural norms. The Saudi government has increased efforts to provide job opportunities for women; however where jobs are available many women remain unable to gain employment influenced by Saudi culture and tradition. For example, highlighted in the background chapter, the final decision about whether a woman takes employment is made by the female's designated 'male guardian' (a father, brother or husband). They must provide written consent for a woman to partake in education or employment, regardless of the female's age or marital status (Almana, 1982).

The majority of both employed male and female patients, not only men, were able to sustain employment. This was because most jobs available for Saudi citizens are provided by the public sector which has a very high job security compared to the private sector. The public 'government' sector provides many facilities and services to HD patients including paid sick-leave on the day of dialysis. However, this increased both absenteeism and productivity loss among employed patients which had negative health economic implications for both patients and government.

There was limited evidence of the effect of age on employment achievement among CKD patients in the literature. It was found that the physical and mental condition among CKD patients undergoing HD were negatively impacted by several personal factors including age and gender (Al-Jumaih et al., 2011). Although, the older the CKD patients undergoing RRT, the more likely they were to be unemployed (Julián-Mauro et al., 2012).

In this study, patients' physical condition was the second predictor for unemployment among HD patients. Physical condition was also found to have an impact on workers productivity at work. As age has been proven to affect physical condition, there is an indirect link between age and employment achievement among this group of patients. This study found that age was the third predictor for unemployment among HD patients which meant that there was a significant relationship between age and employment status. A reason for this was that most female participants were not employed due to cultural reasons; and their age could influence the study results. Qualitatively, older women explained that they don’t have the time for full-time jobs because they were busy looking after the children and the house. Indeed, the qualitative findings indicated that tradition and culture was the main barrier to employment among female generally, and older female HD patients.

Educational level and geography

It was found in the literature that educated patients were more likely to be employed and have more chance to change their career and sustain employment; whereas less educated people did more physical work which led to unsustainable employment (Guerini et al., 2006; Kamal et al., 2013). The quantitative data in this study showed no significant relationship between educational level and employment among HD patients; this was due to the small sample size of patients with higher education. Qualified and well-educated patients were able to work in suitable jobs; whereas others were able to change the nature of their work to suit their health condition and to not conflict with their HD treatment schedule which resulted in employment sustainability. Many unemployed patients with no education or with low educational level were unable to find jobs opportunities, or the job available to their education level involved heavily physical activity. CKD patients were able to sustain a healthy work life in jobs that didn’t require heavy physical demand, usually high level jobs or in the public sector.

Al-Jumaih et al. (2011) found that HD patients with high income had better physical and mental functioning compared to other patients with low income. This was explained as that those with higher income use their financial resources to support them with life difficulties and stresses. In this study the findings were partially consistent with the literature with regard to the benefits of employment on health. The quantitative data showed that the physical condition of employed patients was higher than unemployed patients. Although there was no significant quantitative data on mental condition and employment, the interviews with patients revealed that employment is one source of happiness for many patients that made them feel healthy and active members of the community. They believed that unemployment made them feel disabled and led to isolation and feeling depressed. Thus, realizing the importance of working and participating in the community in all aspects of life are contributing factors to retaining employment among HD patients.

However, the quantitative data showed that most patients with a degree or a certificate above high-school level were employed. However, educational level was not a predictor for a person being unemployed. A potential reason for this result is the low number of patients with a college degree in the whole study sample. The study did identify though that all men with such qualifications were employed, retired due to their age, or retired due to other personal reasons; compared to only two educated women in the same situation who were employed. One reason is that most jobs available or suitable were for men only. The available jobs for women in Saudi Arabia are in health and education sectors which require high level of education. Over time opportunities for females to access education to attain these higher levels have expanded; but it was still only from the 1960s that the first school for girls was established in Saudi Arabia (Nasif & Abedin, 1999). Thus, the availability of work opportunities in Saudi Arabia for people managing a LTC was not a major barrier to employment among men but it was a barrier for women.

The findings with regard to the effect of educational level on employment achievements were the same as the geographical factors. The quantitative findings showed no geographical effect on employment among patients. However, all patients with higher educational level lived in urban areas because urban areas had the higher education institutions not present in rural areas. Also, most people in rural areas were considered conservative where going to work and providing for the family was the responsibility of men only. Therefore, many patients in rural areas, particularly women, were uneducated or had a low level of education.

The qualitative findings emphasised that the issue of employment was influenced more by cultural and social aspects. Both urban and rural areas lacked transportation networks such as trains and buses. Cars to date are only to be driven by men. The very hot climate did not allow for riding or walking to the workplace for either men or women. There were taxis in the urban area but it was expensive and unaffordable if employees used them every day to go to and from their workplace. Thus, society and culture, alongside the environment and weather hindered HD patients from being employed, particularly women.

Knowledge and Coping

In the literature, people with LTCs reduced their pain and fatigue by keeping themselves busy and working as much as possible; if they ignored or tried to forget the pain they felt more satisfied with what they had achieved (Fisher et al., 2007). This was also applicable to CKD patients demonstrated by the qualitative findings which showed that patients felt normal when they attend their work. Some patients believed that frequent absence from work could have unpleasant implications such as social isolation and depression allowing patients time to think about their disease and increasing the notion that they were disabled.

Patients' knowledge about the disease was important to help them cope, encourage and support them to live a normal life as possible. However, a lack of disease knowledge and appropriate ways to manage symptoms and complications have been reported by many patients with different chronic diseases in many studies (Crooks, 2007; Fisher et al., 2007; Gilmour et al., 2008). This was applicable to HD patients. One female patient in our study was about to leave her job after being diagnosed with renal failure and start HD treatment. She thought that her role in life was over and she was going to die unless she found a kidney donor. Her perspective altered when she met other employed patients who looked very happy and lived a normal life and were able to sustain employment job. Thus, seeing other HD patients cope with work and treatment inspired others to continue working and led to acceptance. Acceptance was very important as many patients reported that they were fine and able to work as normal, and they chose to perceive CKD and the HD treatment more like a mild health condition.

Social Life and legislation

Social legislation was a factor that affected the employment status of HD patients. In Spain, for instance, most HD patients were eligible to receive social security protection benefits which in turn reduced the overall employment rate amongst HD patients (Julián-Mauro et al., 2012). These study findings were consistent with the literature although, not for all patients. All HD patients in Saudi Arabia were considered disabled and entitled to receive a monthly disability allowance of 800 SAR in addition to a social security allowance of 1000 SAR. However, patients were no longer eligible for social security allowance when they found an official job. Some patients, predominantly single people, with less responsibility, preferred to stay unemployed to continue receiving such benefits without any effort. Whereas, for many this amount of money was considered very low and if the only source of income, patients with responsibilities needed to seek employment with a higher wage, even if the social security allowance stopped. It would appear important to assess each individual for his/her capacity and ability to work on a regular basis, and provide the allowance for those who were unable to work or couldn't find a suitable job.

A patient's social life played a significant role on their employment status. There were no studies identified in the literature that investigated this element among CKD patients undergoing HD. All reviewed studies were conducted among other group of patients suffering from different LTCs that share similar symptoms with CKD. They found that social support, especially from a patient's family, was the most influential factor that facilitated a patient's work life (Munir et al., 2006; Fisher et al., 2007; Townsend, 2008). Similarly, this study findings concurred; support from the employer and co-workers helped both men and women remain in work, and women relied on the support of their family to commute them to and from work. With the lack of transportation means in Saudi Arabia, family support was essential for female patients to sustain employment. The qualitative findings showed that social participation and strong family ties had many positive implications for both health and employment of HD patients. A positive work environment and managerial support were key factors for employment sustainability and ability to work. It’s important to mention that employer support and flexibility in the public sector helped employed patients continue in employment. However, work productivity was negatively affected by some support and flexibility measures such as the eligibility to be absent during the day of HD treatment (discussed in more detail in the next section).

The effect of employers and work environment on capability and functioning

When examining the effect of chronic illness on occupation, a lack of understating the illness and lack of support from managers and employers, is a critical factor that can lead people to give up work or experience many limitations at work (Munir et al., 2005; Crooks, 2007; Gilmour et al., 2008; Townsend, 2008; Koolhaas et al., 2013). The study findings were broadly consistent with literature; however, there were differences between the private and the public sectors in many aspects including understanding, support, and working flexibility. All these differences were found to have a major impact on a person’s employment and work productivity and are discussed with respect to both public sector and private sector employees.

Public sector vs. private sector

Research conducted by Koolhaas et al. (2013) to study the perspective of workers to enhance employment sustainability, highlighted that more workers with LTCs required continued support to sustain their employment compared to healthy workers . The findings were consistent with the literature regarding the influence of understanding, support and flexibility of employers on employment status and sustainability. The availability of these elements in the public sector in Saudi Arabia helped HD patients to sustain employment; whereas, in the private sector these elements were almost absent which forced HD patients to leave work or to accept fake employment status.

Public sector

In the public sector, many patients reported that they received and continued to receive support from both managers and co-workers. Moreover, the government granted them paid sick-leave on the days of HD treatment – three days a week absent for the majority of HD employed patients. Therefore, patients in the public sector who remained employed were found to value and enjoy their work. Of course, the managers' and colleagues' understanding, support as well as employers' knowledge about the health condition of HD patients were key factors that help in retaining and sustaining employment.

However, it's important to acknowledge that the findings of this particular study showed negative side effects of the huge flexibility in the public sector towards HD patients. This study uncovered that there were no regulations or systematic process on how and when HD patients used granted sick-leave during HD treatment. Every HD patient could take the paid sick-leave even if she/he worked in the morning and went for HD treatment in the evening. This led many patients to stay home and think about their health condition which caused many patients to feel disabled and hopeless leading to isolation and feelings of depression. Some patients refused to take the official sick-leave for such a reason and they were worked and lived as other healthy individuals. Furthermore, frequent absence has many negative implications on the economy simply because people were paid for producing nothing in return. Moreover, there was a negative impact on colleagues due to frequent absence, consistent with current literature (De Souza & Oliver Frank, 2011). Statistically, the study found that employed HD patients' absenteeism, presentism, and productivity loss were very high and for some the score was 100% productivity lost. This was not directly related to their health condition but more as a consequence of the negative impact of granted sick-leave (as absenteeism was accounted when calculating productivity loss). The policy of paid sick leave requires reform and a process developed based on need rather than a blanket policy for the collective.

Employer support for the public sector manifested in strategies such as job accommodations. Patients identified work limitations and issues due to the nature of their workplace which effected their employment sustainability as well as work productivity (Crooks, 2007; Townsend, 2008; De Souza & Oliver Frank, 2011). People with LTCs have reported that the nature of their job and required tasks caused chronic back pain (De Souza & Oliver Frank, 2011). Transportation problems and the difficulties getting to work, were identified by participants in this study. In addition, many people with LTCs reported an inability to shift from full-time to part-time job or to obtain flexible work schedules which prevented them sustaining their employment (Townsend, 2008).

Within this study the findings were broadly consistent with the literature except for the flexibility of work schedule in the public sector due to the HD patients' right to take paid sick-leave on the day of HD treatment, as explained earlier. For patients who complained about the nature of their work it generally involved heavy physical or mental activity and they were often able to get their mangers support to transfer to another department and sustain work that was more suitable for their health condition. On the other hand, the transportation problems were mostly reported by female patients, resulting in some women being unable to search for a job or continue to work. This was mainly because the Saudi system does not yet allow women to drive; and for female patients in the urban area, it was very costly to use the taxi transportation daily to and from work.

Private sector

Unfortunately, both work environment and systems in the private sector in Saudi Arabia did not help with the employment issues of Saudi HD patients. The Saudi government employment strategies encouraged and in many cases forced companies in the private sector to help unemployment issues in the country. Companies prefer to rely on foreign workers, as they can be paid considerably reduced wage, compared to Saudi citizens. To tackle unemployment the government decided to only sanction working visas for foreign workers, based on a company's employment rate of Saudi citizens. In addition, if a company employed a disabled Saudi person they were issued with four foreign worker visas. It may be that companies have started to abuse the policy seeking out disabled people to take advantage of their status and to gain the entitlement of work visas for non-Saudi manpower, regardless of their qualification and skills.

This is not explored in the literature particularly in Saudi Arabia concerning chronic ill health and employment. The original contribution of this study identified that many HD patients were recruited by the private sector because they had a disability card regardless of their qualification and skills. Indeed, more concerning was the fact that many patients were asked not to work or come into the company unless they were called, if inspected by the government. Some patients didn’t even know where their employment was physically located. This led to fake employment, which when investigated using quantitative measures was not detected, which raises questions as to the reliability of such tools when asking straight forward questions without allowing an explanation. The value of the mixed method approach used to conduct this research cannot be understated. The findings highlighted that greed and corruption in the private sector represented by the manipulation of the government employment strategies and initiatives, and policy abuse might be a serious hindrance to employment and healthy work-life. Employment data and processes of disabled people in the private sector are unreliable and a barrier to the government’s employment strategy. Forcing the private sector companies to hire Saudi workers with no consideration as to their capabilities and qualifications could result in more job losses if the employment strategy was changed; it therefore requires careful consideration.

One of the major findings of this study is the identification of an absence of the concept of social responsibility for companies in the private sector in Saudi Arabia. Job insecurity in the private sector was frightening for some patients. Employed HD patients in private sector were not happy with the work environment and worried about their future. People kept looking for work in the public sector even with a lower salary because of the security provided with jobs compared to the private sector. Companies that did not rely on foreign workers or were afraid to abuse the employment policy by employing disabled people, forced workers to leave their jobs once they identified they had a chronic illnesses, especially low skilled workers. One patient was forced to leave his job after he was diagnosed with CKD and started HD due to his request to leave early from work to attend his HD treatment session. Lack of support, knowledge, work ethics, understanding, and employer's responsibility towards society did not help reduce the unemployment rate nor facilitate employment sustainability among HD patients.

Patients with no qualifications or skills willing to work were not able to find suitable jobs in the private sector, as most available jobs required heavily physical activity. The findings identified that HD patients were facing discrimination when applying for jobs in the private sector, as perceptions suggested employers believed HD patients would not be able to work effectively. Some patients reported that their applications were rejected once the employers knew that they were HD patients. Of course, this was not the reason provided to the applicants, but they were sure this was the case. Lack of knowledge among employers about CKD, and an understanding that HD patients were capable to work as effective as any other people, with some support and flexibility, could be the reason behind hiring discrimination.

The approach adopted to conduct the study was effective as without the sequential qualitative phase such discrimination and policy abuse of employment in the private sector would not have been uncovered. The study findings, to some extent, are consistent with literature examining employment among people with LTCs. Many patients with LTCs indicated that not all managers were aware of their condition nor supportive

(Gilmour et al., 2008; Townsend, 2008). One participant reported that when she disclosed her condition to her manager and indicated she may need to apply for sick-leave he tried to force her to leave the job (Gilmour et al., 2008). This reinforced the importance of helping employers and managers to understand the health conditions of their employees and how to overcome barriers that may affect their work performance and employment status.

Moreover, some CKD patients undergoing RRT believed that employers preferred not to hire young people with a chronic disease (Guerini et al., 2006; Murray et al., 2014). Unfortunately, a lack of knowledge among many employees with chronic health conditions about their rights to have a safe work environment and work adjustments according to their conditions enable unsupportive managers to force them to accept the situation or give up work (Crooks, 2007). Where employees with LTCs are knowledgeable and fully aware of their rights they receive appropriate work accommodation. Many, however, often due to the symptoms of their illness such as pain and fatigue, struggle to manage the time and energy required to seek and establish such rights. Consequently, many patients do not perform as expected and many others leave their place or work (Crooks, 2007).

Capability and functioning of HD patients

An integral aim of this study was to examine the capability of HD patients (their ability to work), and their actual functioning (their employment status). The concepts of capability and functioning are the two major concepts of the theory of the Capability Approach. These two concepts are unique as they assess a person’s functioning and their capability in the real world and not in an ideal environment. This in turn generates a holistic assessment and view of the employment among HD patients.

Employment among HD patients is an important issue that needs to be considered by health and social care professionals as well as policy makers. A study conducted in Saudi Arabia, among 100 HD patients, found that only 28% of participants were employed full-time, whereas 43% of participants were retired and 38% were unemployed (Al-Jumaih et al., 2011). In another study conducted in the UK to assess employment and education achievement among CKD patient undergoing RRT, the researchers claimed that the unemployment rate among HD patients was at least twice as the general population rate (Murray et al., 2014). The very low rate of employment among HD patients was also mentioned in the study of Van der Mei et al. (2011) who examined the pattern of work status and work-ability of CKD patients. They also found that, over time, HD patients more often left work.

This study concurred, with only 25% of patients employed; and 90% of those employed patients were men. However, the qualitative data revealed that the employment rate of Saudi HD patients was much less than calculated using quantitative tools. Fake employment and policy abuse had a negative impact on both the Saudi economy and people's health. This finding could exist in other developing countries, particularly in the gulf region where most countries rely on cheaper foreign migrant workers. These issues exposed how the work environment and employment system, including social legislation can affect people functioning even though most patients reported during the interviews they were willing and capable to work.

Another concept of the Capability Approach is ‘culture and society’ and this influences employment. The reason behind the very low number of employed female patients was directly attributable to the culture of Saudi Arabian people. Even when there was an availability of resources and the freedom of choice (concepts important to the capability approach) women encountered barriers. For example, female participants in urban areas who wished to work and break cultural constraints found the lack of transportation services impacted on their actual functioning even though they were capable to work. Moreover, the freedom of choice to work for women was hampered by the availability of jobs being for men only; women who want to work will accept any job even if it’s unsuitable as they often do not have a choice of different job opportunities. Again accepting any job could directly affect job sustainability and work productivity ‘functioning’.

These concepts could also have an opposite effect on people’s employment status. The need for money ‘resources’ forced many people including female patients to look for jobs and sustain employment regardless of their health condition. Moreover, the responsibility of men to provide for the family in Saudi Arabia was the key reason why most employed patients were men.

Health condition and work environment were important elements of the capability approach that affected peoples’ functioning and capability. Based on the study findings and the themes which emerged from the literature review, the Capability Approach theory is most definitely applicable to health. It provides an effective framework that enables health and social professionals to effectively evaluate the capability of HD patients to work. It is hoped that the social security department, social affairs, and office of labour will consider such a framework to evaluate patients’ disabilities. This person-centred theory allows them to develop a more holistic view and evaluate each person as an individual which will enhance decision-making with regard to social benefits, and benefits received by employed patients, such as the official sick-leaves during HD treatment.

The capability approach when compared to other disability models (social and medical models of disability and the ICF) offers a joined up integrated perspective of health, society, the environment and the individual, which is important when trying to understand how the disability of HD affects an individual in terms of sustaining employment. Other models see either health or society as the main cause of disability, whereas the Capability Approach takes into consideration environmental and cultural issues certainly important to the context of this study. The Capability Approach enables the researcher to develop two models to evaluate functioning and capability of employed and unemployed HD patients (Figure 24 & 25).

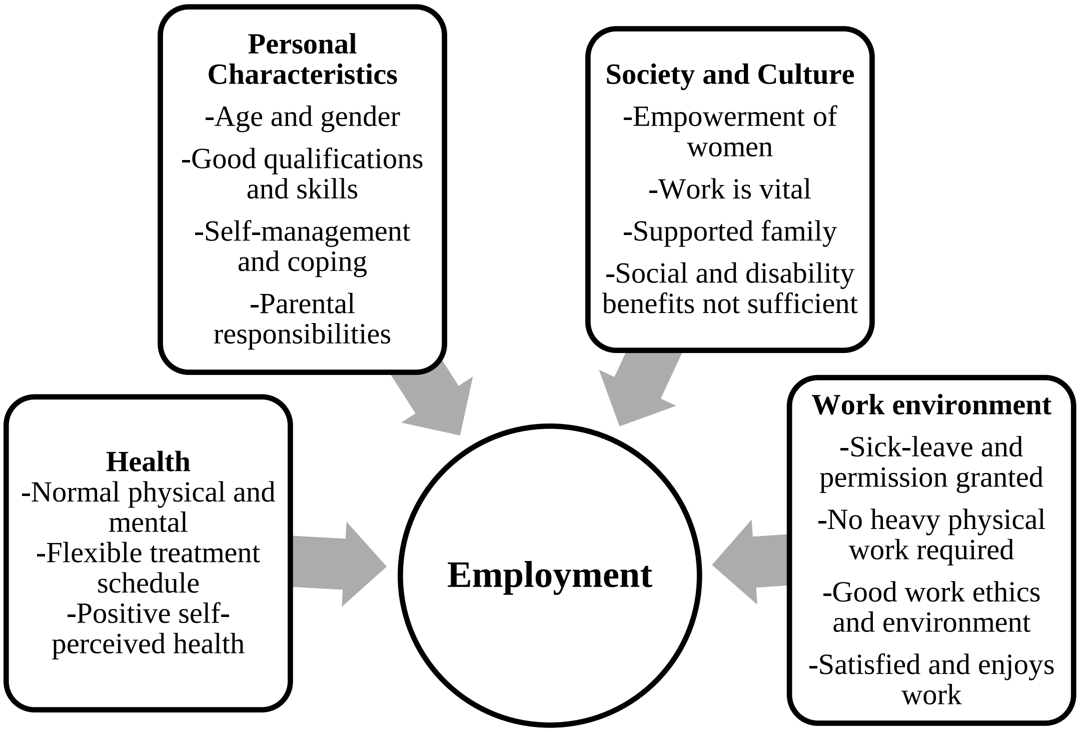

Figure 24: Model of Employment of HD Patients in Saudi Arabia

The two models incorporate all the different influencing factors and cause of disability that may have an impact on patients' employment. The models will help health practitioners and social workers to assess each HD patients as a single case to identify possible barriers to employment. Based on the outcome of the assessment several plans could develop such as coaching and training, education, financial support and more.

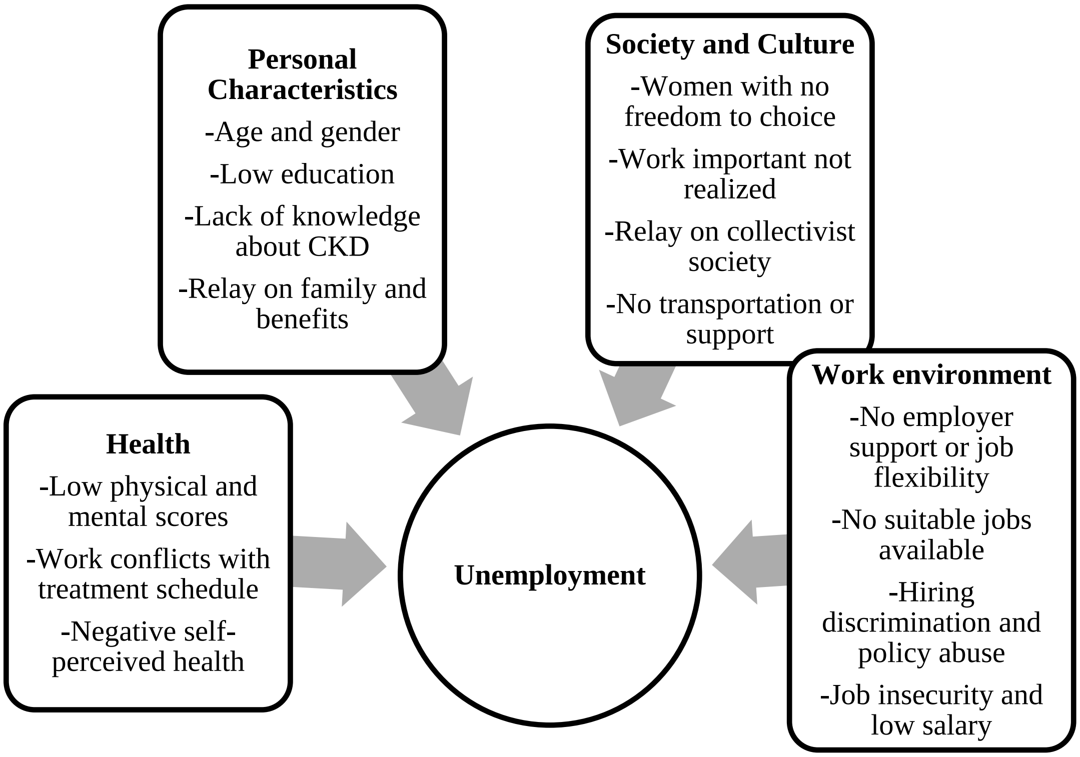

Figure 25: Model of unemployment of HD Patients

Unfortunately, there is no uniform way on how these factors affect each other, or which factor is superior to the others as this will vary from one individual to another. Moreover, working to remove barriers caused by one factor could lead to further barriers occurring from different factors. For example, unemployed female patients may perceive the only barrier to employment was her husband or family due to cultural reasons. When she is allowed to work she then faces issues where the only jobs available are for male employees only or transportation to work is impossible or too expensive. Therefore, these models need to be used to explore all aspects first to ensure that all barriers to employment and sustainability of jobs are identified and overcome.

Limitation and strength of the study

Methods

The study used a mixed methods sequential explanatory design which commenced with a quantitative phase followed by a qualitative phase to explain the results of the first phase or/and add depth to the understanding and meaning of the results. This was a powerful approach to examine employment and ability to work among CKD patients. The study findings highlighted that if the study had adopted a single quantitative design, the results of employment would have not been a reliable reflection of reality in the study context. Such skewed results can easily mislead the policy and decision makers when developing or reforming the employment strategy and initiatives.

The qualitative phase was critical to understand the barriers and facilitators that influenced a patient's ability to work and achieve employment sustainability. In a collectivist society like Saudi Arabia as well as the culture and traditions within the Saudi context, such barriers and facilitators would not be identified without interviewing the participants, both male and female patients. There are some limitations to adopting such an approach which were raised in detail in the methodology chapter, such as the difficulty to adopt implement this approach in a short period of time due to the need to analyse the first phase before starting the second phase. It was therefore, a great achievement to successfully conduct an explanatory sequential mixed method design by one researcher and within such a short period of time, requiring focus and considerable organisation skills.

Sample

The effective sample size of the study was calculated and determined using several scientific techniques, explained in the methodology chapter. Whilst the study aimed to examine employment among HD patients, it did so by including unemployed and employed patients to gain a wider overarching view of issues faced. It may have been pragmatic to have recruited as many employed patients in the sample as possible, particularly using different strategies to increase the sample size among female patients. Only three female patients participated in this study. The findings showed that gender played a significant key factor on employment status and sustainability. The factors influencing employment and work productivity among women were only identified by the data gathered from those three female patients and therefore there could be many more factors, not yet identified, affecting employment if the sample had recruited more employed female patients.

However, half of the participants in this study were women (the majority were unemployed). This is considered a great accomplish due to the difficulty facing many researchers to recruit women in their research in Saudi Arabia. The difficulties were mentioned in the ethical consideration in the methodology chapter such as the issue of interviewing women by a male researcher within the Saudi culture and religion. This certainly had an impact on the number of women who came forward to be involved in the second phase of the study.

Data gathering

The tools used in the quantitative phase are the SF-12 and the WPAI questionnaires. The SF-12 is widely used to examine the physical and mental condition of patients. This tool was helpful to examine how the physical and mental conditions of the patients influenced their employment and ability to work. However, the WPAI questionnaire was ineffective and should not be used among HD patients within the Saudi culture in future research. One reason is that the distribution of data gathered with this tool is not normal which limits the use of inferential statistical tests. Also, the questionnaire uses the absenteeism rate to calculate the productivity lost which will not be effective in public sectors in Saudi Arabia simply because of the official sick-leaves granted to HD patients. Therefore, it is unclear exactly how CKD effects the productivity of employees using this tool.

Chapter Nine

Conclusion and Recommendations

Introduction

The study within this thesis generates unique findings and a deeper understanding of who, what, why and how HD patients continue to work, or not, alongside managing a LTC. The study identified the employment status as well as the work productivity and activity impairments of HD patient in Saudi Arabia. This is the first study examining employment and sustainability of work among HD patients in Saudi Araba and in the Arab world which shares many similar social and cultural norms. The study shows that the unemployment rate was very high (75% of the participants) especially among female patients which reflects the male dominated working environment of Saudi Arabia.

Social, personal, cultural, environmental as well as the context within Saudi Arabia are all key factors that influence employment and ability to work among HD patients, besides their health condition. The application of the Capability Approach was beneficial to identify and comprehend all possible factors that had a positive or a negative impact on employment status and sustainability of work, among this group of patients. It would not have been possible to identify these factors using popular disability theories such as the social or health model, or the ICF model. Viewing disability within the confines of the health condition or as a result of society is not sufficient to fully operationalize the concept. Indeed whilst the ICF incorporates both medical and social models, it fails to consider personal characteristics of individuals and assesses people in an ideal environment, not real life. The Capability Approach facilitated the generation of two theoretical models with which to evaluate the level of disability experienced by employed and unemployed HD patients within Saudi Arabia context.

These models integrated the most influential factors that either enabled employed patients to sustain employment, or hindered many other patients to find and sustain work. Social and healthcare professional’s should not limit or standardize the outcome of the evaluation when using these models because there may be multi-layered factors that are intertwined and have a positive impact on one patient’s employment and a negative impact on another patient’s employment. Take gender for example, many female patients were not able to work due to cultural and social reasons such as taking care of the children and the house, while men were responsible for providing for the family. It was obvious in this case that being a female was a barrier to employment. However, another females who broke through the cultural constraints and continued their education, were able to find good jobs and due to the low number of Saudi female workers in some sectors, they often were able to choose and transfer from one role to another which helped them sustain employment. This example shows the opposite impact of the same factor when evaluating from the perspective of a different patient.

This chapter draws together a list of recommendations for policy, practice, and future research work that aims to solve the issue of employment among HD patients in Saudi Arabia. Moreover, a dissemination plan is presented that aims to communicate the unique findings to scientists and professional in health and social care to better understand the phenomena and identify the need for areas of further research to enrich the understanding of the topic of interest. Finally, the chapter will close with a concluding remark.

Contribution and Originality of the Thesis

The study generated original results which added to the existing body of knowledge, confirming existing research but at the same time uncovering unique findings pertinent to the context of Saudi Arabia and Arab nations:

- This study was the first known study to examine employment, work-ability and productivity among Arab patients receiving HD, and therefore, most of the study findings were new and first in the field although some findings are consistent with the experiences of non-CKD patients managing different LTCs..
- The accuracy of asking someone if they are employed or not is not a sufficient measure of work in Saudi Arabia and potentially similar contexts. The Ministry of Health, for example, could administer a survey and find that most patients are working in Saudi Arabia, but this simplistic result would be both misleading and harmful to disabled people still able to actively take part in the labour market. Also, the current government initiatives are being used to pay people to stay at home which in turn is not improving their quality of life. This finding will help reform or establish strategies and policies that aim to prevent or reduce such corruption, taking advantage of the health status of CKD patients, particularly by private sector companies.
- The private sector in Saudi Arabia has as a part of their social responsibility a need to encourage disabled people to work. The Saudi government is trying to enable the private sector to discharge their social responsibility by encouraging them to offer disabled people work. This is linked to allowing the import of a specific number of foreign workers for every disabled Saudi citizen being employed in the company.

However, this policy is being abused and many companies are pretending to employ people in order to receive the benefits from employing disabled people and receive extra working visas to employ foreign workers.

- This PhD thesis is not only relevant to Saudi Arabia but also extends the existing knowledge base on employment and health. The study methodology tests a measure that has appeal to the wider renal community to generate an evidence base that demonstrates the impact of CKD on the labour market. It will help identify those people whose productivity is reduced, their activity impaired, with deteriorating health and allow early interventions to facilitate sustained employment among HD patients.
- The significant unemployment rate of women with CKD in Saudi Arabia, could reflect a similar context in other Arab countries, not always as a result of their health condition. The political and socio-cultural factors contribute considerably to the issue of unemployment among women. Many women patients in this study chose to stay unemployed, look after their children, and rely on their husbands and families for financial stability, even when employment opportunities were available.
- The application of the Capability Approach in health was extremely useful to examine different and wider concepts (including personal, environmental, social, health and cultural) that influence employment for people with a chronic health condition and disability. It combines different disability models, including the medical and the social models of disability, and brings together different perspectives to encompass a more holistic approach. Many women in Saudi Arabia are capable of

working but cannot, disadvantaged by their gender and believing that their society will not permit it.

- Under the umbrella of the Capability Approach theory and the systematic review of the literature, this research produced evaluation models for both employed and unemployed HD patients to enable healthcare professionals, social workers and labour organizations to identify and manage factors that could affect individual HD patients' employment status and work sustainability.

Recommendations

- ***Recommendations for Policy***
    - The Ministry of Labour should revise the employment strategy and the hiring process in the private sector, and reduce the abuse of the employment policy. However, this should be amended with caution as any change to the current employment strategy or policy could force many disabled people to leave their jobs.
    - The Ministry of Social Affairs and the Social Security Office should evaluate HD patients separately from other disabled patients, and consider each patient as a special case that need to be assessed individually in terms of employment and ability to work. This can be achieved using the produced models in this research, and develop a plan, for each case, that aims to overcome barriers to employment among HD patients. Social benefits and unemployment allowance should be based on the outcome of the assessment, which could also be repeated annually, to enable those who are able to work to find and

    sustain jobs, and to help those who are not able to work to receive appropriate financial support.
  - The government of Saudi Arabia should re-consider the official sick-leave granted to HD patients during the HD treatments days, and potentially limit the use of such privilege to those who are in need. Again this should be evaluated individually and at a regular interval by either social workers or healthcare practitioners.

- ***Recommendations for Practice***
  - Healthcare professionals including nurses, doctors, and occupational therapists are required to assess HD patients' physical and mental health and provide advice and a treatment plan that help them to live healthily and be productive in the workplace and in their social life.
  - Social workers who help HD patients to live a productive work life and sustain employment need to understand the implications of the study findings. This is because of the key influence that social, cultural, personal, and environmental factors have on unemployment among HD patients, in addition to health related factors and their treatments. The models to assess employment among HD patients in Saudi Arabia will help social workers focus on important factors for individuals to achieve such a goal and deliver best practice.

- ***Recommendations for Future Work***
    - Future research within the context of Saudi Arabia is required, particular using the qualitative approach to understand HD patients working experience for those people managing to sustain high level jobs in Saudi Arabia.
    - The application of the two models in practice with concurrent research evaluation will help to develop the Capability Approach theory further; in particular enhance the models to make it easier to highlight issues faced by individuals and develop person centred employment plans.
    - Future studies need to also examine productivity of work to develop or use effective tools that are applicable to the Saudi context as many tools and health economic research consider absenteeism as a productivity loss among employed patients which will not be effective in Saudi Arabian public sector simply because of the official sick-leaves granted to HD patients on the days of HD treatment.
    - Future survey research needs to adopt a mixed method approach to ensure that quantitative results are explained, valid and reliable, and overcome the issue of fake employment evidenced in Saudi Arabia, by private sector companies taking advantage of the disability status of HD patients.

Presentations to Date

- Alquwez, N. (2015). Employment status and sustainability, and person’s work ability among Chronic Kidney Disease patients receiving Haemodialysis in the Kingdom of Saudi Arabia. [Conference Poster]. In SPARC 15 Conference Proceedings (UK). University of Salford.
- Alquwez, N. (2015). Employment status and sustainability of work among HD patients in Saudi Arabia. [Presentation]. Celebrating PGR Research Day. University of Salford.
- Alquwez, N. (2016). Employment status, work productivity and activity impairment of chronic kidney disease patients undergoing haemodialysis. [Conference Poster]. In BRS 17 Conference Proceedings (UK). Birmingham.

Dissemination of Research Findings

The current plan to disseminate the study findings is:

- Full text of this thesis will be available online in the repository website of the University of Salford.
- Publishing scientific papers in peer reviewed journals presenting the study findings and the systematic literature review with regard to employment and HD patients. This will have many implications especially for social workers and healthcare professionals to better understand the phenomena and have an evidence base to deal with such issue when caring for CKD patients.

- Presenting the study findings in conferences and events that are related to the subject of this research – nationally and internationally to raise awareness of the unexpected factors that could directly affect the employment status of HD patients, especially in Saudi Arabia.
- Findings of this study will be send to, and possible meetings will be organised with, policy and decision makers in the Ministry of Social Affairs, Ministry of Health, Ministry of Labour to raise their awareness about the issue of employment among HD patients which will, hopefully, improve the employment strategies to accommodate this group of patients and reduce any potential limitations that could affect HD patients employment sustainability.

Concluding Remarks

This is the first study in Saudi Arabia and the Arab world that examines the employment status and evaluates the work ability and productivity of HD patients both quantitatively and qualitatively. The study provides new, unique findings and evidence on how the employment status of HD patients is being affected by many factors related to health, society, personal characteristics, work ethics and environment, culture and traditions, employment policy and strategies. The impact of society and culture on employment among HD patients will inspire others, from different disciplines, to investigate, conduct further research, and work to increase employability and sustainability of jobs among this group of patients in Saudi Arabia and in other Arab countries which share similar social and cultural norms. I look forward to working with other parties, and will use the findings of this study as a platform for future work in this area of interest, to ensure that HD patients will get a healthy and suitable work life that enables them to fully participate and be active members of society.

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Appendices

Appendix 1: Search protocol and Inclusion and Exclusion Criteria

Search Strategy

Boolean Operators		**Keywords**
AND	**OR**	Employment*
		Occupation*
		Job*
	OR	Sustain*
		Perform*
		Capab*
		Limit*
		Satisfaction*
	OR	“Chronic Kidney”
		Dialysis
		Haemodialysis
		Hemodialysis

Added to search for other LTCs	**AND**	Employment
		Chronic disease OR Long-term condition

Inclusion and Exclusion Criteria for Retrieved Literature

Inclusion	Exclusion
For CKD and other LTCs articles	
Research study, and systematic review Employment and long-term condition Employment status and sustainability of patients with long-term conditions Work status and work-ability and health related quality of life of LTCs patients	Non-English Papers Prevention and health promotion issues Intervention program Patients receiving occupational/exercise therapy Epidemiology and Histopathology Participants under 18 years old Work status and -ability of cancer patients
For CKD articles only	
Employment status and sustainability of CKD and HD patients Functioning and well-being of CKD and HD patients studied work status and work-ability Explore occupations of CKD & HD patients Factors affecting physical and mental functioning of CKD and HD patients. Major working life stressors for CKD and HD patients Studies measuring the ability of work among CKD and HD patients	Non-CKD papers Hospitalized or in an acute care setting HD patients. Acute renal replacement therapy

Appendix 2: Critique of quantitative studies

<table>
<tr><td>Title/ Author/ Date/ Setting</td><td colspan="5"><i>Work limitations and employer adjustments for employees with chronic illness,</i> Munir F et al. (2005), UK</td></tr>
<tr><td>Study overview</td><td>Setting/ Sample/ Ethics</td><td>Outcome measurement</td><td>Groups and Comparability</td><td>Data collection &analysis</td><td>Policy and practice implications</td></tr>
<tr><td>This study measured work limitations and work adjustments among chronically ill employees with regard to 3 distinct job characteristics:
1. Physical work demands
2. Cognitive work demands
3. Social work demands

Key findings:
Depression had the largest impact in all three work demand categories, while musculoskeletal pain principally affected physical work demands and migraine and diabetes largely affected cognitive work demands. For other chronic illnesses, it was the generic symptoms of the illness (for example, fatigue) that resulted in a work limitation, rather than the specific nature of</td><td>The sample is based on cross-sectional data from the first wave (pilot) of the Supporting Employees with Chronic Illness (SECI) study, where all 5500 employees from a UK university were invited to complete a questionnaire. A 44% response rate was achieved for completed returned questionnaires and 734 (34%) of the respondents declared at least one chronic illness on the questionnaire. The</td><td>Outcomes in the study included work limitations and work adjustments in terms of physical work demands, cognitive work demands and social work demands.

The validity and reliability of the instruments used to measure the outcomes were</td><td>The sample is a representative of the university's employee in terms of occupational groups, age, sex and tenure. The respondents were further divided into 8 groups according to their experienced chronic disease namely:
1. Depression & anxiety
2. Asthma</td><td>Data collection was done via email, which caused a low response rate. Data were analyzed using descriptive and logistic regression. Analyses were carried at 0.05 level of significance.</td><td>Implication to practice and policy was not discussed in the paper. However, it can be understood that some factors predict the work limitation and work adjustments of employees experiencing chronic illness. These factors should be taken into consideration when making policies when it</td></tr>
</table>

the illness itself. Employer work adjustments were available to those people with illnesses that required a physical work adjustment (for example, musculoskeletal pain). For other chronic illnesses, with the exception of depression, disclosing an illness was the strongest predictor for work adjustments in cognitive tasks and the provision of social support. Those with depression were least likely to receive a cognitive work adjustment, indicating either a low disclosure rate in this group or those employers' perceptions of depression may be a barrier to providing suitable work adjustments.	sample size calculation was not discussed in the paper. Inclusion criteria were also not defined. Ethical approval was not mentioned in the paper. Likewise, consent was not also solicited from the respondents. Ethical issues were not adequately discussed.	established.	3. Musculoskeletal pain 4. Irritable Bowel Syndrome 5. Arthritis 6. Migraine 7. Heart Disease 8. Diabetes		comes to these employees. Further, employees should be encouraged to disclose their chronic illness to their managers in order to make necessary work adjustment for them.

Other comments	Although the study sample was a representative of the employees in the university, the response rate was low and it cannot be neglected. The study was only conducted in a single setting which may limit the use of the findings. Moreover, the study did not cover the majority of chronic diseases, hence the indications of the findings are only limited to the involved group.

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Title/ Author/ Date/ Setting	*Gender differences in managing chronic illness at work: Exploring predictors for disclosure*, Munir F et al. (2006), UK

Study overview	Setting/ Sample/ Ethics	Outcome measurement	Groups and Comparability	Data collection &analysis	Policy and practice implications
The aim was to explore possible gender differences in the self-management of chronic illness as	The study was conducted in a university in UK. All	The outcomes measured in the study were	The study compared male and female	Data collection was done using a questionnaire sent via email. This method	The main finding of the study was emotional support

predictors for self-disclosure to line managers. **Key findings:** Women were more likely to report their illness to be medically diagnosed and experience pain and fatigue as a symptom of their illness. Men were more likely to report experiencing symptoms of their illness at least several times a week, which their illness affected their work and reported higher spells of 1 day sickness absence compared with women. Women were more likely to disclose their illness to their line managers and more likely to perceive receiving emotional support from outside of work and receiving emotional support from their line managers as being important. Receiving emotional support from line managers is the strongest predictor for	the 5000 employees were invited to participate in the study. A 44% response rate was achieved, of which 34% (734) reported to have at least 1 chronic illness. The 734 employees were included in this study. The sample size was adequate for an organizational research. The study used the same data from a previous study (secondary data analysis), which the authors failed to present in the paper. Ethical issues were inadequately discussed in the paper. Ethical approval was not	the self-disclosure of chronic illness by the employees to the line managers, effects of chronic illness to work, and support. The tools used were validated.	employees in their self-management of chronic illness. The sample sizes for each group were uneven. There were more female respondents than male respondents. Confounding variables were addressed in the statistical analyses.	resulted to a low response rate. Measure to improve the response rate was inadequately discussed. t-test and $\chi 2$ test for comparison between genders on demographics, chronic illness and work characteristics. Univariate logistic regression analysis were performed to assess the relative impact of illness experience, demographics and work characteristics on disclosing a chronic illness to line managers for both men and women together. Multivariate regression analysis was performed for the significant univariate predictors against disclosure.	from the line managers is the strongest predictor of disclosure of illness for both gender. This implies that managers should consider providing strong emotional support to their employees in order for them to have courage to disclose their illness. The line manager should possess necessary information i.e. how the chronic illness affects the employee at work in order to provide adequate practical and emotional support to their employees.

disclosure of illness for both genders.	sought and consent was not obtained.				
Other comments	The study have low sample, thus the findings should be cautiously interpreted when generalizing. The study also included limited measure of illness management.				
//					
Title/ Author/ Date/ Setting	*Health-related quality of life among hemodialysis patients at El-Minia University Hospital, Egypt*, Kamal NN et al. (2012), Egypt				
Study overview	Setting/ Sample/ Ethics	Outcome measurement	Groups and Comparability	Data collection &analysis	Policy and practice implications
The study was conducted to: 1. assess HRQOL of hemodialysis patients attending El-Minia University Hospital dialysis unit, 2. determine the relation between HRQOL and some sociodemograghic factors and clinical disorders, 2. compare HRQOL between patients performing hemodialysis for less than and more than 5 years **Key findings:** Majority of the respondents had	The study included a universal sample of 170 hemodialysis patients who were attending El-Minia University Hospital dialysis unit during the period from 1st January to 30th June 2011. The response rate was 98%. The inclusion criteria for the respondents were not presented, however, exclusion	The outcome measured in the study was the health-related quality of life of the HD patients. The Kidney Disease Quality of Life-36 (KDQOL-36) survey was used to measure the	The study focused on a single group, which were the HD patients. However, in the analyses, the respondents were grouped according to their sociodemographic factors and duration of receiving HD treatment to compare their HRQOL.	Data collection was performed through questionnaire guided interviews. The data collection process was poorly discussed in the paper. The author did not specifically mentioned essential components such as the time of data collection, duration of the interviews, when was it conducted, etc. There was also a confusing data analyses as the authors	The implication to practice was inadequately presented. The findings can be used to plan for programs that can improve the HRQOL of these patients. Since some of the sociodemographic characteristics of the respondents were associated to poorer HRQOL, these characteristics should be taken into consideration when attending these patients. HD patients

poor physical and mental quality of life (QOL). Older, female, married, illiterate and non-worker hemodialysis Patients reported lower HRQOL. Patients with Hepatitis C infection (HCV), diabetes and anemia had decreased QOL scores. Longer duration of HD treatment is associated with poorer HRQOL.	criteria which included patients receiving HD for >3months and patients who were admitted in the hospitals, were mentioned. Ethical issues were properly discussed. Permission to use the tool was not sought.	outcome. The validity and reliability of the tool was not presented in the paper.		mentioned that the qualitative data were analyzed using frequency distribution, chi squared test, student t test, one-way ANOVA test. Multiple regression analysis was used to identify the influence of the independent factors to the HRQOL.	should likewise be monitored regularly of their coexisting illness such as anemia, HCV infection, sleep disturbances and diabetes, which are also associated to poorer HRQOL.

Other comments	The study sample is low which limits the generalizability of the result. The study was also conducted in a single HD unit which is not a representation of all the units in the area. There was no clear measure on how the confounding variables were controlled.

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Title/ Author/ Date/ Setting	*Multidimensional health-status assessment of chronic hemodialysis patients: the impact on quality of life*, Guerini Rocco et al. (2006), Italy

Study overview	Setting/ Sample/ Ethics	Outcome measurement	Groups and Comparability	Data collection &analysis	Policy/practice implications
The study aimed to assess the health-status of patients with ESRD on HD and to define impairment of body functions and structures, limitations in activity,	The study included 45 patients with ESRD receiving HD during the first 6 months of 2003, in the Dialysis Unit of Trescore Balneario Hospital (Bergamo,	The outcomes measured in the study were the quality of life, impairment of body functions and	The study compared the patients undergoing HD and the	Data were collected using questionnaires. The procedure of data collection	Supporting rehabilitation programs along with their medical

<table>
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<td>restrictions in participation, and health-related quality of life to bring better insight to their rehabilitative needs.

Key findings:
ESRD was mainly caused by glomerulonephritis (22%). Tinetti’s test showed that 11% of HD patients could not walk without help.
HD patients had significantly lower quality of life compared to the general population.</td>
<td>Italy).

Ethical issues were not discussed in the paper. There was neither ethical approval nor indication that the study was approved by authorities in the hospital. Informed consent was also not solicited from the respondents. The use of the questionnaire as well as the data for the general population was not permitted by the copy right holder (implied because there was no discussion about it in the paper).</td>
<td>structures, limitations in activity, and restrictions in participation. The tools used in the study were appropriate; however, their validity and reliability were not presented.</td>
<td>general population in terms of their quality of life.</td>
<td>was not presented. Pertinent information about the data collection was not presented also.</td>
<td>treatment was suggested to increase their quality of life and social participation.</td>
</tr>
<tr>
<td>Other comments</td>
<td colspan="5">The study is very poor in many aspects. First, the design of the study as well as its methodology was poorly presented. Second, the sample is very low for a quantitative study, which results to the doubtful results. Third, there were ethical issues with regards to the ethical approval of the study, the hospital approval, and informed consent not solicited. Fourth, the title indicated that the study would look into the impact of the various dimensions of health status to the quality of life of the respondents; however, it was not presented in the findings and discussion section. The study did not examine the impact of those variables to the quality of life of the respondents. Fifth, the statistical analysis employed is inadequate to meet the aim of the study.</td>
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<tr>
<td colspan="6">///</td>
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<tr>
<td>Title/ Author/ Date/ Setting</td>
<td colspan="5"><i>Long-Term Health and Work Outcomes of Renal Transplantation and Patterns of Work Status During the End-Stage Renal Disease Trajectory</i>, van der Mei SF et al. (2011), Netherlands</td>
</tr>
</table>

Study overview	Setting/ Sample/ Ethics	Outcome measurement	Groups and Comparability	Data collection &analysis	Policy/practice implications
The study aimed to explore the health- and work outcomes of renal transplant recipients long-term after transplantation. It also examined the pattern of work status, work ability and disability benefits during the end-stage renal disease (ESRD) trajectory that precedes transplantation. **Key findings:** Of the respondents, 29% were severely fatigued. The participants had worse general health and vitality compared to the general population. Non-working recipients experienced worse renal function and general health and more physical functioning limitation as compared with those who were working. There was moderate work ability among the 60% of the working recipients. 30% of those working still receive disability benefits. During dialysis, more	The study involved 34 transplant recipients at the University Medical Centre Groningen (UMCG). Inclusion and exclusion criteria were well presented. Ethical issues were properly considered in the study. The study was approved by the Medical Ethics Review Committee of the UMCG. Likewise, written	Health and work outcomes were measured in the study. For health outcomes, health status and fatigue were measured. Work status, disability benefits, work ability and pattern of work outcomes were measured for work outcomes.	The study was conducted in a single group, patients who received a renal transplant. However, the health outcomes were compared with those of the general population.	Data collection was performed in three waves between March 1, 2002 and March 31, 2003. The first and second data collections were performed at 3 months and 1 year post-transplantation. The third collection was >6 years after the transplantation (March and April 2009). Eligibility assessment of the T2 study group (n = 58) showed that four recipients (7%) had died, three recipients (5%) were back on dialysis, and two (3%) had expressed unwillingness to participate in future studies. Of the remaining 49	The study implied that having new kidney does not lead to normal work status, but it has significant advantages as compared with dialysis in this respect. Continuous supportive measures should be implemented to patients post transplantation. Assessment of work-related problems should be done accordingly and this aspect of the patients should be taken into consideration in a inter-professional collaboration. Interventions based on empowerment and self-management of ESRD patients may also be of help.

sickness absence and less work ability was indicated by the work status trajectory; however, both improved after the transplant.	informed consent was solicited from the participants prior to participation.			eligible recipients, 34 (69%) agreed to participate.	
Other comments	The study involved low number of sample; however, the design and method of the study augmented this limitation.				

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Title/ Author/ Date/ Setting	*A Study of Quality of Life and its Determinants among Hemodialysis Patients Using the KDQOL-SF Instrument in One Center in Saudi Arabia*, Al-Jumaih A et al. (2011), Saudi Arabia				
Study overview	Setting/ Sample/ Ethics	Outcome measurement	Groups and Comparability	Data collection &analysis	Policy/practice implications
The study was conducted to assess the quality of life (QOL) among Saudi patients undergoing hemodialysis (HD). It also examined the impact of certain demographic and clinical factors on the QOL. **Key findings:** The respondents manifested low cognitive function, emotional role, physical role, and work status. Male and married patients manifested higher scores in the kidney diseases related items.	100 randomly selected Saudi patients attending the HD outpatients at King Abdulaziz Medical City, Riyadh was included in the study. 33 patients were randomly selected per dialysis shifts. Data collection procedure was not presented adequately.	The outcome was the quality of life measured using the KDQOL-SF36 Instrument. The validity as well as the reliability was insufficiently presented in the paper.	There was a single group focused in the study. The QOL of the respondents were compared in terms of the demographic and clinical characteristics of the group.	Data collection used a questionnaire. The data collection procedure was not presented in the study.	The authors failed to present the implications of the findings to practice. The findings may have an implication to nursing and medical practice. Nephrologists and nurses should consider assessing the QOL of these patients. Factors associated with lower QOL should be taken in to consideration

Patients who were males, younger, and have higher income had higher scores in physical health. Mental health scores were higher among males and higher income groups. Scores on kidney disease component were positively correlated with mental health and physical health components of the QOL.	The study did not mention any ethical consideration. Neither IRB approval nor getting informed consent from the respondents was reported.				in planning for care for the patients in order to achieve optimum life's satisfaction.
Other comments	The study involved low sample size which limits the generalizability of the results. It was also conducted in a single HD unit in the country which might not represent the whole HD population in the country. There was also an insufficient analysis on the impact of the demographic and clinical factors on the QOL.				
//					
Title/ Author/ Date/ Setting	*Employment in the patient with chronic kidney disease related to renal replacement therapy,* Julián-Mauro JC et al. (2012), Spain				
Study overview	Setting/ Sample/ Ethics	Outcome measurement	Groups and Comparability	Data collection &analysis	Policy/practice implications
The study examined the employment situation of patients with chronic kidney disease based on the type of RRT provided. Secondarily, the study assessed the rehabilitative function of each type of RRT in the important context of occupational activity and means for employment.	The study surveyed 243 patients of working age (16-64 years old) at 8 Spanish hospitals. The calculation of the sample size was clearly presented in	The outcome measured in the study was the employment situation of patients with CKD. The instrument/s	The study divided the patients with CKD according to the modality of renal replacement therapy (Hemodialysis, peritoneal dialysis	The data collection was carried out in 2 parts. The first collection was done from August 2007 to April 2008, where 165 patients from 5 hospitals were	It is essential to conduct assess the employment situation of the patients with renal problems at the start of their treatment. This

Key findings: 33.3% of the patients in working age were employed. More men were employed than females. Unemployed patients were significantly older than employed patients. Unemployed patients have higher mean time of treatment than employed patients. The rate of employment was much higher in patients on automated peritoneal dialysis than in patients on HD. Sex, age, time of treatment and modality were significantly associated with the probability of employment.	the study. However, the sampling technique used was not discussed. The sampling from each hospital was not discussed also. Ethical approval was not sought for the study. There was also a very limited discussion about the use of informed consent.	used in measuring the outcome was not discussed in the paper.	manual, automated peritoneal dialysis and transplantation). Employment situation were compared in terms of the modality.	surveyed. The second collection took place between November 2008 and May 2009 in the last 3 hospitals. The data collection procedure was not presented clearly.	will facilitate analyses of all possibilities that would allow for maintaining employment or re-orienting patient activity
Other comments	Ethical considerations were not discussed in the study considering that they involved patients. The sample size was enough to generalize the findings to the population of patients with chronic kidney disease in Spain.				
//					
Title/ Author/ Date/ Setting	*An exploration of the relationship between fatigue and physical functioning in patients with end stage renal disease receiving haemodialysis*, O'Sullivan D & McCarthy G (2006), Ireland				
Study overview	Setting/ Sample/ Ethics	Outcome measurement	Groups and Comparability	Data collection &analysis	Policy/practice implications
The study aimed to investigate the fatigue and physical functioning of	A purposive sample of 46 patients with ESRD	Fatigue was measured using the	The study examined one	There was no information	It was discussed that nursing care should also

HD patients with ESRD. It was also conducted to examine the relationship between the two variables. **Key findings:** Fatigue was prevalent to these patients. There was also a substantial physical limitation manifested by this group of patients. It was also reported that as physical functioning levels increased, fatigue levels decreased. Significant relationships were found between overall physical functioning, older age and employment status.	receiving HD was included in this study. Inclusion and exclusion criteria were clearly defined. The study was conducted in a hospital in Ireland. Ethical approval was sought but other ethical considerations were not discussed. Informed consent was not solicited from the respondents before participation.	multi-dimensional fatigue inventory while physical functioning was measured using the Medical Outcomes Study Short-Form 36-item questionnaire. The validity and reliability of the tools were reported accordingly.	group of patients only. There was no other group involved.	about data collection. The statistical analyses were appropriately and clearly presented.	focus of fatigue and physical functioning of HD patients with ESRD. Fatigue and physical functioning should be monitored regularly. Standardized assessment of physical functioning ability is especially recommended to identify those at risk of reduced functioning which may have subsequent ramifications for fatigue and self-management abilities.
Other comments	The sample size is very low hence careful interpretation and use of the findings is needed.				
//					
Title/ Author/ Date/ Setting	*Factors associated with the quality of life of adults subjected to hemodialysis in a city in northeast Brazil*, Cavalcante MCV et al. (2013), Brazil				
Study overview	Setting/ Sample/ Ethics	Outcome measurement	Groups and Comparability	Data collection &analysis	Policy/practice implications
It was conducted to examine	291 patients	Quality of life	The study had	Data were collected	The renal patient care

socioeconomic, demographic, clinical, nutritional and laboratory factors associated with worse QOL in adults undergoing hemodialysis in Sao Luís, Maranhão, Brazil. **Key findings:** The respondents experienced worst QOL on work situation, burden of kidney disease, patient satisfaction, physical function and general health. Having less than 8 years of schooling, coming from the countryside and having cardiovascular disease were related to worst level of QOL.	undergoing HD treatment in a University hospital were included in the study. The sampling technique was not discussed in the paper. Ethical approval was sought from an ethical review board. No information about informed consent was mentioned in the study.	was the outcome measured in the study. The KDQOL-SFTM 1.3 was used as the measuring tool. The tool was appropriate to the sample group. The validity and reliability of the tool was properly presented as well.	one group only.	from January to July of 2009. Questionnaires were administered during the patient's HD session. Other data collection procedures for the other variables were adequately presented.	should consider the comorbidities, the level of education, and conditions of access to treatment site, especially patients coming from the countryside of State.

Other comments	

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Title/ Author/ Date/ Setting	*Psychosocial Issues and Quality of Life in Patients on Renal Replacement Therapy*, Panagopoulou A et al. (2009), Greece

Study overview	Setting/ Sample/ Ethics	Outcome measurement	Groups and Comparability	Data collection &analysis	Policy/practice implications
The study sought to examine the psychosocial variables associated to objective and subjective indicators of	The study involved 124 patients in a hospital in Greece. Among them, 40,	The outcomes measured in the study were	The study compared three groups of patients	The data collection was performed using a questionnaire. The	The findings of the study can assist in

quality of life in a single center cohort study of patients undergoing in-center hemodialysis (HD), Continuous Ambulatory Peritoneal Dialysis (CAPD) and renal transplant recipients (RTx). **Key findings:** RTx manifested better functional and employment status, more compliant and satisfied with their therapy and their relationship with the medical and nursing personnel. HD patients scored low in every aspect studied. Anxiety and depression were more prevalent in the HD patients and significantly linked with social issues such as unemployment and retirement Successful RTx is a better modality of therapy than HD or CAPD in terms of psychosocial and quality of life issues.	36 and 48 were HD patients, CAPD, RTx patients, respectively. Neither sampling technique nor sample size calculation was presented in the paper. Response rate was also not presented. The study was not approved by an ethical review committee. It was not also mentioned if approval from the hospital was sought. However, it was mentioned that an informed consent was solicited from the respondents prior to participation.	quality of life and psychosocial variables. The outcomes were measured using a special questionnaire formulated by the respondents. The validity and reliability of the tool was not presented.	namely HD patients, CAPD patients and RTx patients. Comparisons were presented in terms of demographic profile, functional and social status including employment status and sexual life.	data of data collection was not presented in the paper. However, the details regarding how data were collected in each group were presented. It was also not clearly stated who collected the data from the respondents.	identifying risk factors for poor health status and the degree to which they can be altered or modified. This can facilitate better planning and intervention to these patients.
Other comments	The sample size of the study is low, which have an implication on the ability of the findings to be used elsewhere. The authors only included patients who have good or excellent graft function after a successful transplantation. This might have affected the result of the study about higher satisfaction reported by Tx patients compared to dialysis patients. Furthermore, studied population was biased against HD as revealed by the authors. According to them, PD patients in their hospital received higher education, stronger family				

	support, and less comorbidity. This might affect the results' reliability.

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Title/ Author/ Date/ Setting	*The relationship between coping with stress and employment in patients receiving maintenance hemodialysis*, Yano E & Takaki J (2006), Japan

Study overview	Setting/ Sample/ Ethics	Outcome measurement	Groups and Comparability	Data collection &analysis	Policy/practice implications
The study assessed the relationship between emotion and task-oriented coping with stress with employment of patients receiving HD. **Key findings:** Emotional-oriented coping was negatively associated with employment among these patients (both male and female). For men, physical functioning and age were associated with employment while having gastrointestinal disease as comorbidity was related with employment in women. Unlike married women, married men were very	The study surveyed 317 patients who were receiving HD treatment in four medical facilities in Japan. Inclusion criteria were elaborately presented. Initially, there were 481 patients who agreed to participate in the study, but after being assessed against the inclusion criteria; only 317 patients were eligible for the study. The study was approved by an institutional review	The study focused on a single group of patients. However, comparisons of study variables were done by sex as previous studies have reported as being female was related with emotional-oriented coping. The authors thought that sex may be a confounder in	The study outcomes included coping with stress and employment in patients receiving HD. The outcomes were measured by tools such as the Japanese versions of coping inventory for stressful situation, health locus control scale and hospital anxiety and depression scale, the short form-36 health survey, an item on itchiness, self-efficacy on health-related behavior scale, and the social support scale. The scales were appropriate	The data collection was performed using questionnaires. The data collection process was not presented in the paper.	The study has an implication on policy makers. The findings could be used to develop new approaches in providing suitable employment to patients with physical disabilities including HD patients. Dialysis patients could also benefit from achieving economic independence. Likewise, nurses and other healthcare workers caring for such patients should considering assessing the use of emotional-related coping among these patients since it was found out that it is

likely to be employed. Patients who were employed (both sexes) were less depressed. Women who were employed were less anxious.	board and an informed consent was sought from each participant. Ethical issues were adequately attended.	the relationship of EOC and employment.	to the variables being measured Moreover, validity and reliability of each tool was properly presented.		associated with employment. It was suggested that vocational rehabilitation can be of use for EOC.

Other comments	The complex inclusion criteria limited that comparability of the findings from the eligible population of the study to the total eligible HD population in Japan. Further, the authors used a lot of measuring tool, which the patients might found very tiring to accomplish considering their current physical condition. This might contributed bias in the data collection process. The authors failed to discuss elaborately the data collection process, which lead the reader difficult to discern whether this data collection bias was considered.

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Title/ Author/ Date/ Setting	*In-depth study of the workers' perspectives to enhance sustainable working life: comparison between workers with and without a chronic health condition,* Koolhaas W et al. (2013), Netherlands

Study overview	Setting/ Sample/ Ethics	Outcome measurement	Groups and Comparability	Data collection &analysis	Policy/practice implications
The study sought to compare the frequency and type of problems, obstacles, retention factors and support needs experienced by workers with or without a chronic condition aged 45 years old and older. **Key findings:** Workers who were older and with chronic disease	8,417 workers from three large size companies, two medium size companies and four small sized companies were invited to participate in this study. Out of the total, 3,008 questionnaires were returned giving a response rate of 28%. 25 workers were excluded because of missing data giving a final sample of 2983 worker. The study specifically	The study compared to groups of samples, the workers with chronic health condition and workers without health condition. There was an	The study outcomes were experienced problems, obstacles, retention factors and support needs of the workers. A self-constructed dichotomous (yes or no) questions and open-ended questions were used to measure these outcomes. Further, the International	Data collection was performed from February to March 2008. Data collection procedure was not presented in details. Moreover, the data analyses used were	The findings of this study can be used to create interventions to facilitate sustainable working life for workers regardless if they have or do not have chronic illnesses. These interventions should include the

experienced more problems related to ageing, more obstacles and more needs as compared to workers without chronic health conditions. Problems and obstacles were manifested on physiological and psychological functions. In terms of work-related environmental factors, retention factors and need s to enhance sustainable working life were identified by the respondents.	included workers with a minimum age of 45 years. Sample size calculation and method used in the study were not identified in the paper. There was no discussion on how the number of sample was distributed among the companies involved in the study. Ethical approval was sought for the study. There was no information about the use of informed consent; however, ethical considerations were discussed.	even sample size between the two groups. The allocation of respondents for each group was not clearly presented.	Classification of Functioning, Disability and Health was used to classify and compare the workers' perspectives. These instruments were appropriate to measure the outcomes of the study. The validity and reliability of the instruments used was presented.	appropriate to answer the objectives of the study.	following: (1) an inventory of problems, obstacles and personal development opportunities, and (2) the possibility to discuss work-related environmental factors and adaptations based on the individual workers.
Other comments	The response rate of the study is low (36%). It may have led to selective participation. The study was not able to examine the perspectives and characteristics of the workers who failed to be included in the study. The findings might not be a representation of the workers in the production sector due to underrepresentation. Further, the study used open-ended questions as their way to conduct an in-depth understanding of the issues concerning this study. Since the design was quantitative, the information from those open-ended questions might not have been exhausted to benefit the study. The authors have mentioned that they had difficulty of defining and judging those open-ended data because the context for interpretation was missing.				

Appendix 3: Critique of qualitative studies

Title/ Author/ Setting/ Date	*The impact of endometriosis on work and social participation,* Gilmour JA et al. 2008, New Zealand			
Study Overview	**Context (setting/sample/ethics)**	**Groups and Comparability**	**Data Collection/ Analysis/ Bias**	**Policy and Practice Implications**
The study aimed to explore women's perception of living with endometriosis, its effect on their lives and the strategies used to manage their disease. It was a secondary analysis of the collected data in an earlier study, which aimed to explore the women's experience of severe and chronic pain. **Key Findings:** The study presented three themes focused on issues about disclosure of symptoms in the work place,	The study included 18 women aged 16 to 45, with endometriosis, and who were attending a local endometriosis support group in New Zealand. The selected sample was appropriate to the aims of the study. However, based from the method, the researchers did not specifically mention how the samples were selected and the time period of data collection. In terms of the setting, the researchers attended a meeting of one local endometriosis support group and discussed the study to the present participants. In addition, the information about the study was also published in the newsletter of the said support group. It was guided by feminist research principle approach. This approach was essential in deciding on a topic that of with great value to women, acknowledging the expertise of the participants in relation with their specific experience, and foregrounding the power of relations inherent in the research process.	The study involved in women (16-45 years old) who have endometriosis, attending a local endometriosis support group, college educated, and had been or currently working. The result of the study is specific to these women and might not be comparable with other women who do not possess those characteristics.	Data collection was done via face-to-face, tape and transcribed, unstructured interview. Thematic approach was used to analyse the data. Validity or trustworthiness of the data in representing the participants' stories was performed.	Nurses and other health professionals can play an important role in mitigating the negative impacts of endometriosis to patients' life. It was further recommended that primary health providers need to fully elucidate women's history of symptoms and to promptly refer for diagnostic procedures. Moreover, awareness about the disease and

the impact of symptoms on work, education and social participation, and the various strategies employed by these women to manage their disease.	Ethical approval for the study was granted by the local Health Ethics Committee and a university Human Ethics committee. How the consent was solicited from the respondents (either verbal or written) was not specified in the paper.			significant information related to it should be facilitated.
Other Comments	The limitation of the study included the limited variation of respondents, where the respondents were belonging to a specific group of women. Women with other characteristics such as low educational achievement, unemployed or women who do not attend support groups may have different stories to share.			
//				
Title/ Author/ Setting/ Date	*Patients' experiences of the impact of chronic back pain on family life and work*, De Souza L and Frank AO, 2011, Setting was not mentioned			
Study Overview	**Context (setting/sample/ethics)**	**Groups and Comparability**	**Data Collection/ Analysis/ Bias**	**Policy and Practice Implications**
The study investigated how individuals experience pain and its consequences for family life and work. **Key Findings:** The findings suggested themes relating to relationships with spouse	Eleven patients were purposively included in this study. They were experiencing spinal pain and were referred to a rheumatology outpatient clinic. The specific setting of the study was not revealed. The study was guided by the Frame Work Approach.	Information about the group of patients was vaguely discussed in the methodology section. It was only mentioned there that patients who have spinal pain and with referral to a rheumatology outpatient clinic was invited for the study. It cannot be clearly understood which group of patients were interviewed.	Data collection was done through a topic guided interviews. Tape recorders were utilized. The interviews took place in the patients' home, lasting for approximately 45 to 90 minutes. Data analyses were done	It was underscored the significant role of family in the management of complex spinal pain. Healthcare workers should consider the impact of the patients' pain to their relationships with their families and work. Since the experienced pain of the patients negatively

and partners, relationships with children and parents, relationships with other family and friends, and work-related problems.	The study was approved by the Local Research Ethics Committee. There was no detail about getting informed consent from the respondents was reported in the study.		following the process for the analysis of contextual qualitative data. Control of bias and establishment of validity and trustworthiness of the interpretation of the participants' stories were not mentioned in the study.	impact their relationships, supportive measures should be initiated for the patients, their family and working environment.

Other Comments	The study focused only on patients experiencing spinal pain. Experiences of other patients experiencing back pain were not explored in this study.

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Title/ Author/ Setting/ Date	*Chronic pain and occupation: an exploration of lived experience*, Fisher GS et al. 2007, USA

Study Overview	**Context (setting/sample/ethics)**	**Groups and Comparability**	**Data Collection/ Analysis/ Bias**	**Policy and Practice Implications**
The study was conducted to explore the experience of chronic pain from the perspective of those who were living with it. The relationship between chronic pain and occupation and the effects of chronic pain on daily routines, activities and relationship were also addressed.	The study was approved by the Institutional Review Board of the College Misericordia in Dallas Pennsylvania. Informed consent was obtained from the participants prior to participation.	The study involved individuals who self-reported having chronic pain for at least 2 years that had	Interviews were conducted by 4 graduate occupational therapy students during summer 2004. The interviews were conducted privately in locations chosen by the participants, such as their homes, workplace, etc. To reduce the likelihood of bias, the participants were	Practitioners were encouraged to recognize the holistic and multifaceted approach that can be used with people who have chronic pain.

Key Findings: Findings of the study revealed that chronic pain has life-changing influences on the patients. Chronic pain has negative effects on various aspects of a person's life, such as limited involvement in social activities and negative impact on their level of confidence. It can also affect the occupational performance of the patients. However, they resourcefully modified their routines and tasks and found enhanced meaning in favored occupations.	13 participants (4 men, 9 women), from eastern United States, with age ranged from 35 to 87 years old, and were experiencing chronic in for at least 2 years were included in the study. Participants were select through purposive sampling. Most of the participants live with their family and employed in various occupations. The pain experienced by the patients was diverse.	limited their function. This indicates that the findings of this study can be compared and applied to persons with the same experience.	interviewed by an interviewer who is not related to them. Additionally, demographic questionnaire and reflective questionnaire were also used to collect additional data. Data analyses were performed using thematic analysis. Trustworthiness of the study was established using triangulation, confirmability and transferability.	Occupational therapist may address physical and psychological needs of people who have chronic pain. Additionally, strategies for adaptation to improve occupational performance of these individuals should be provided by occupational therapists
Other Comments	The implication of this study was more on for the occupational therapists. The participants of the study had variety of different pain syndrome and medical conditions, which made the scope broad. However, the implications of the findings can be used to wider variations of patients experiencing chronic pain. There is also a question in the trustworthiness of the study as each participant was only interviewed once. Participant verification of the themes derived from the responses was also not conducted.			
//				
Title/ Author/ Setting/ Date	*Women's experiences of developing musculoskeletal diseases: employment challenges and policy recommendation*, Crooks VA, 2007, Canada			
Study Overview	**Context (setting/sample/ethics)**	**Groups and Comparability**	**Data Collection/ Analysis/ Bias**	**Policy and Practice**

				Implications
The study was conducted to answer the following questions: 1. How do women experience the workplace after the onset of a musculoskeletal disease? 2. What employment policy and programme suggestion can the offer for ways to better support chronically ill women in their abilities to maintain workforce participation? 3. How are these women's employment policy and programme recommendations informed by their own lived experiences and desires? **Key Findings:** Becoming ill with a musculoskeletal disease meant losing access to, and/or having diminished status within, places of paid work. Barriers to maintaining employment were identified by the participants, which included: (1) co-workers and employers' attitudes, disbelief and lack of understanding, (2) lack of accurate knowledge about musculoskeletal diseases, and (3) built environment and physical workspace. The women discussed seeking three main types of accommodations after the onset of the musculoskeletal disease: (1) modified duties, (2) modified hours of employment (3) physical accommodations.	The study involved 18 women living in the City of Hamilton, Ontario, Canada, who had developed one or more musculoskeletal diseases that were arthritic in nature. Ethical approval for the study was sought from McMaster University's Research Ethics committee. Obtaining informed consent was not discussed in the study.	The study included women who have one or more musculoskeletal diseases that were arthritic in nature. The findings can be compared with the same group of women.	Data were collected using semi-structured interviews. Each interview lasted for approximately 35 – 90 minutes in a location selected by the interviewees. Data collection was performed from September 2000 to January 2001. A thematic approach to the analysis was undertaken. Feedback approach was used to enhance credibility and interpretation of data.	The findings of the study have implications to policy. Policy makers should consider including flexible work hours, job-sharing and work-from-home initiatives, part-time work by people receiving disability income assistance, and wage support programmes that are awarded to the employee.

Other Comments	The study was only focused to women who had musculoskeletal disease. The findings of the study are limited to this group of patients and could not be generalized to other groups experiencing similar problems.

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Title/ Author/ Setting/ Date	*Supporting People with Multiple Sclerosis in Employment: a UK Survey of Current Practice and Experience*, Townsend G, 2008, UK			
Study Overview	**Context (setting/sample/ethics)**	**Groups and Comparability**	**Data Collection/ Analysis/ Bias**	**Policy and Practice Implications**
The aims of the study were: 1. To explore the knowledge and experience of professionals supporting people with MS in work 2. To identify the current practice of professionals supporting people with MS in work 3. To identify the training needs of professionals supporting people with MS in work **Key Findings:** The results showed that the impact of MS on employment was well understood, but that there was less awareness of the wider social influences on the ability to retain employment. There was evidence of a range of support being offered by some participants, but there appeared to be a gap between the problems reported and interventions offered overall.	The study included 70 respondents who were health professionals taking care of patients with MS. These health professionals included occupational therapists currently working with people with MS, MS specialists and disability employment advisers. The recruitment of participants was achieved through advertisements in print publications and through electronic advertisements on websites and emails. Ethical approval was not discussed in the paper.	The sample included occupational therapists currently working with people with MS, MS specialists and disability employment advisers. The results can be compared with similar groups of health professionals.	A postal questionnaire was sent to each respondent. It contained open questions in order to gain as wide an understanding as possible of a respondent's experience and practice. Data collection time was not mentioned. Quantitative data were analyzed using the SPSS version 13.0. The qualitative data were subjected to content analysis and coding. A Coding reliability exercise was carried out to check the completeness of the coding categories and to eliminate ambiguity or duplication.	Health professionals need to have relevant knowledge and skills in order to support people with MS in employment appropriately. Development of strategies, such as practice-based toolkit for health professionals, is recommended to support people with MS to retain employment.
Other Comments	This study is particularly true of the UK health and social services, which have been undergoing a continual process of change that has affected			

	the organisation and delivery of services. Careful use of the findings in other settings should be considered.

Appendix 4: Critique of mixed methods studies

Phase One (Quantitative)

Author/ Date/ Setting	(Murray et al., 2014) UK					
Study overview		**Setting/ Sample/ Ethics**	**Outcome measurement**	**Groups and Comparability**	**Data collection and analysis**	**Policy and practice implications**
Aim: to assess the impact of ESKD on education and employment outcomes in young adults key findings: "Themes impacting on education and employment included low energy levels, time missed, loss of self-esteem, and feelings of loneliness and isolation, which may progress to depression and recreational drug use. Lack of understanding from educators and employers resulting in lost work, and career ambitions changed or limited because of dialysis".		- young CKD adults (aged 18-30 years) - Ethical approval was obtained from UK national clinical research ethics system and a nominated ethics committee written consent had been obtained	Questionnaire survey developed by authors	(5 pre-dialysis)(8 dialysis)(45 kidney transplant recipients)	Face-to-face + Interviews conducted during clinic or home visits - no use of any software or program for data analysis	employer & care providers need to understand the negative impact of CKD (Low energy levels, lack of self-esteem, & depression) on Pt employment status &education achievement to invest in supporting those group of patients
Other comments	- a mixed methods cross-sectional study - small sample size - single Centre - 57% response rate - 71% male - ONLY 8 pts on dialysis					

Phase Two (Qualitative)

Author/ Setting	Semi-structured Interviews, (Murray et al., 2014)			
Study overview	**Context**	**Groups/ Comparability**	**Data collection/ Analysis/ Bias**	**Policy & practice implications**
impact of ESKD on education and employment outcomes in young adults	NA (see above table)	NA - conducted during clinic or home visits	Stratified sampling from a result of quantitative (mixed method) according to age, gender, ethnicity, & treatment modality to provide a representative sample	Partially applicable (see above table)
Other comments	Only investigate the impact of ESKD on education and employment outcomes in young adults			

Appendix 5: SF-12v2 Health Survey (English)

Your Health and Well-Being

This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. ***Thank you for completing this survey!***
For each of the following questions, please tick the one box that best describes your answer.

1. **In general, would you say your health is:**

Excellent	Very good	Good	Fair	Poor
▼	▼	▼	▼	▼
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

2. **The following questions are about activities you might do during a typical day. Does <u>your health now limit you</u> in these activities? If so, how much?**

		Yes, limited a lot	Yes, limited a little	No, not limited at all
		▼	▼	▼
a	Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	☐ 1	☐ 2	
b	Climbing several flights of stairs	☐ 1	☐ 2	

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
	▼	▼	▼	▼	▼
a Accomplished less than you would like	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
b Were limited in the kind of work or other activities	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

3. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

4. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
	▼	▼	▼	▼	▼
a Accomplished less than you would like	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
b Did work or other activities less carefully than usual	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

5. During the <u>past 4 weeks</u>, how much did pain interfere with your normal work (including both work outside the home and housework)?

Not at all	A little bit	Moderately	Quite a bit	Extremely
▼	▼	▼	▼	▼
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

6. These questions are about how you feel and how things have been with you <u>during the past 4 weeks</u>. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the <u>past 4 weeks</u>…

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
	▼	▼	▼	▼	▼
a Have you felt calm and peaceful?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
b Did you have a lot of energy?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
c Have you felt downhearted and low?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

7. **During the <u>past 4 weeks</u>, how much of the time has your <u>physical health or emotional problems</u> interfered with your social activities (like visiting with friends, relatives, etc.)?**

All of the time	Most of the time	Some of the time	A little of the time	None of the time
▼	▼	▼	▼	▼
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Thank you for completing these questions!

حالتك الصحية العامة

يستفسر هذا الاستبيان عن وجهة نظرك في صحتك. هذه المعلومات سوف تساعد على تتبع ما تشعر به ومدى قدرتك على أداء نشاطاتك المعتادة. *نشكرك على الإجابة عن هذه الأسئلة!*

لكل سؤال من الأسئلة التالية يرجى وضع علامة ☒ في المربع الخاص بالإجابة التي تصف بشكل أفضل ما تشعر به.

8. بشكل عام، هل تعتبر أن صحتك:

ضعيفة	لا بأس بها	جيدة	جيدة جدًا	ممتازة
▼	▼	▼	▼	▼
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

9. الأسئلة التالية تدور حول النشاطات التي قد تقوم بها أثناء يوم عادي. هل صحتك الآن تحدّ من قدرتك على القيام بالنشاطات التالية؟ إن كانت كذلك، فإلى أي حد؟

نعم تحدّها كثيرًا	نعم تحدّها قليلا	لا، لا تحدّها أبدًا

▼ ▼ ▼

أ النشاطات المعتدلة مثل تحريك طاولة أو دفع مكنسة كهربائية، أو لعب البولينغ أو البلياردو .... ☐ 1 .... ☐ 2 ....

ب صعود الدرج لعدة طوابق... ☐ 1 .... ☐ 2 ....

كل الوقت   معظم الوقت   بعض الوقت   قليل من الوقت   أبدًا

▼   ▼   ▼   ▼   ▼

أ   أنجزت أقل مما كنت تريد .... ☐1 .... ☐2 .... ☐3 .... ☐4 .... ☐5

ب   كنت محدوداً في نوع العمل أو النشاطات الأخرى .... ☐1 .... ☐2 .... ☐3 .... ☐4 .... ☐5

10. **خلال الأسابيع الأربعة الماضية، كم من الوقت حصلت معك أي من المشاكل التالية خلال تأدية عملك أو نشاطاتك اليومية العادية الأخرى كنتيجة لصحتك الجسدية؟**

11. **خلال الأسابيع الأربعة الماضية، كم من الوقت حصلت معك أي من المشاكل التالية خلال تأدية عملك أو نشاطاتك اليومية المعتادة الأخرى كنتيجة لمشاكل عاطفية (مثل شعورك بالكآبة أو القلق)؟**

كل الوقت   معظم الوقت   بعض الوقت   قليل من الوقت   أبدًا

▼   ▼   ▼   ▼   ▼

أ   أنجزت أقل مما كنت تريد .... ☐1 .... ☐2 .... ☐3 .... ☐4 .... ☐5

ب   أديت العمل أو النشاطات الأخرى باهتمام أقل من المعتاد .... ☐1 .... ☐2 .... ☐3 .... ☐4 .... ☐5

12. **خلال الأسابيع الأربعة الماضية، إلى أي مدى تعارض الألم مع عملك العادي (بما في ذلك عملك خارج المنزل والعمل المنزلي)؟**

لم يتعارض أبدًا	تعارض بشكل قليل	تعارض بشكل متوسط	تعارض بشكل كبير	تعارض بشكل كبير جدًا
▼	▼	▼	▼	▼
1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

13. **هذه الأسئلة تدور حول ما تشعر به وكيف سارت الأمور معك خلال الأسابيع الأربعة الماضية. الرجاء إعطاء إجابة واحدة عن كل سؤال بحيث تكون الأقرب لما كنت تشعر به. كم من الوقت خلال الأسابيع الأربعة الماضية...**

كل الوقت	معظم الوقت	بعض الوقت	قليل من الوقت	أبدًا
▼	▼	▼	▼	▼

أ هل أحسست بالهدوء والطمأنينة؟.............. ☐ 1 .... ☐ 2 .... ☐ 3 .... ☐ 4 .... ☐ 5

ب هل كانت لديك طاقة كبيرة؟.................... ☐ 1 .... ☐ 2 .... ☐ 3 .... ☐ 4 .... ☐ 5

ج هل أحسست بالحزن والاكتئاب؟ .... ☐ 1 .... ☐ 2 .... ☐ 3 .... ☐ 4 .... ☐ 5

كل الوقت	معظم الوقت	بعض الوقت	قليل من الوقت	أبدًا
▼	▼	▼	▼	▼

7. **خلال الأسابيع الأربعة الماضية، كم من الوقت تعارضت صحتك الجسدية أو مشاكلك العاطفية مع نشاطاتك الاجتماعية (مثل زيارة الأصدقاء والأقارب، إلخ...)؟**

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

شكرًا على الإجابة عن هذه الأسئلة!

Appendix 6: WPAI V2.0 (English)

WORK PRODUCTIVITY AND ACTIVITY IMPAIRMENT QUESTIONNAIRE: GENERAL HEALTH V2.0 (WPAI:GH)

The following questions ask about the effect of your health problems on your ability to work and perform regular activities. By health problems, we mean any physical or emotional problem or symptom. *Please fill in the blanks or circle a number, as indicated.*

1) Are you currently employed (working for pay)? ____NO ___YES
   If NO, tick "NO" and go to question 6.

The next questions are about the **past seven days**, not including today.

2) During the past seven days, how many hours did you miss from work because of your health problems? *Include hours you missed due to sick days, times when you went in late, left early, etc., because of your health problems. Do not include time off to participate in this study.*
   ______HOURS

3) During the past seven days, how many hours did you miss from work for any other reason, such as holidays or time off to participate in this study?
   ______HOURS

4) During the past seven days, how many hours did you actually work?
   ______HOURS *(If "0", go to question 6.)*

5) During the past seven days, how much did your health problems affect your productivity while you were working?

   Think about days when you were limited in the amount or kind of work you could do, days when you accomplished less than you would like, or days when you could not do your work as carefully as usual. If health problems affected your work only a little, choose a low number. Choose a high number if health problems affected your work a great deal.

Consider only how much health problems affected
productivity while you were working.

Health problems had no effect on my work	0 1 2 3 4 5 6 7 8 9 10	Health problems completely prevented me from working

CIRCLE A NUMBER

6) During the past seven days, how much did your health problems affect your ability to do your regular daily activities, other than work at a job?

By regular activities, we mean the usual activities you do, such as work around the house, shopping, childcare, exercising, and studying, etc. Think about times when you were limited in the amount or kind of activities you could do and times when you accomplished less than you would like. If health problems affected your activities only a little, choose a low number. Choose a high number if health problems affected your activities a great deal.

Consider only how much health problems affected your ability
to do your regular daily activities, other than work at a job.

Health problems had no effect on my daily activities	0 1 2 3 4 5 6 7 8 9 10	Health problems completely prevented me from doing my daily activities

CIRCLE A NUMBER

WPAI V2.0 (Arabic)

استبيان حول الإنتاجية في العمل وإعاقة النشاط:

الصحة العامة، الإصدار 2.0 (WPAI-GH)

تدور الأسئلة التالية حول تأثير مشاكلك الصحية على قدرتك على العمل والقيام بأنشطتك المعتادة. والمقصود بالمشاكل الصحية أي مشاكل أو أعراض بدنية أو نفسية. *يرجى ملء الفراغات أو وضع دائرة حول الرقم المناسب، بحسب ما هو موضح.*

1. هل تشغل وظيفة ما في الوقت الحالي (تتلقى أجرًا لقاء عملك)؟_____ لا ____نعم

*إذا كانت الإجابة **لا**، فضع علامة قبل كلمة ”**لا**“، وانتقل إلى السؤال رقم 6.*

تدور الأسئلة التالية حول **الأيام السبعة الماضية**، دون اليوم.

2. في خلال الأيام السبعة الأخيرة، كم بلغ عدد الساعات التي تغيبت فيها عن العمل بسبب مشاكلك الصحية؟

قم بإضافة إجمالي الساعات التي تغيبت فيها بسبب الأجازات المرضية والأوقات التي وصلت فيها متأخرًا أو غادرت فيها مبكرًا، وما إلى ذلك، بسبب مشاكلك الصحية. لا تقم بتضمين الفترة الزمنية التي تغيبت فيها للمشاركة في هذه الدراسة.

_____ساعة (ساعات)

3. في خلال الأيام السبعة الأخيرة، كم بلغ عدد الساعات التي تغيبت فيها عن العمل لأي سبب آخر، مثل عطلة أو إجازة أو التغيب للمشاركة في هذه الدراسة؟

_____ساعة (ساعات)

4. في خلال الأيام السبعة الماضية، كم بلغ عدد ساعات عملك الفعلية؟

_____ساعة (ساعات) *(إذا كانت الإجابة ”صفر“، فانتقل إلى السؤال رقم 6).*

5. في خلال الأيام السبعة الماضية، ما مدى تأثير مشاكلك الصحية على معدل إنتاجيتك أثناء عملك؟

فكر في الأيام التي كنت فيها مضطرا للتقصير من حيث كمية أو نوع العمل الذي يمكنك القيام به أو نوعه والأيام التي أنجزت فيها قدرًا أقل مما كنت ترغب فيه أو الأيام التي لم تستطع فيها القيام بعملك بعناية كالمعتاد. إذا كانت المشاكل الصحية قد أثرت على عملك بشكل بسيط، فاختر رقمًا منخفضًا. واختر رقمًا مرتفعًا إذا كانت المشاكل الصحية قد أثرت على عملك بشكل كبير.

فكر فقط في مدى تأثير المشاكل الصحية
على الإنتاجية أثناء عملك.

لم تؤثر المشاكل الصحية على عملي 0 1 2 3 4 5 6 7 8 9 10 منعتني المشاكل الصحية تمامًا عن العمل

ضع دائرة حول الرقم المناسب

6. في خلال الأيام السبعة الماضية، ما مدى تأثير مشاكلك الصحية على قدرتك على القيام بأنشطتك اليومية المعتادة، بخلاف أداء وظيفتك؟

المقصود بالأنشطة المعتادة الأنشطة الاعتيادية التي تقوم بها كالعمل حول المنزل أو التسوق أو رعاية الأطفال أو ممارسة التمرينات الرياضية أو الدراسة، وإلى ما هنالك. فكر في الأوقات التي كنت فيها مقيدًا بنوع وحجم معين من الأنشطة التي يمكنك القيام بها والأوقات التي أنجزت فيها أقل مما كنت ترغب. إذا كانت المشاكل الصحية قد أثرت على أنشطتك بشكل بسيط، فاختر رقمًا منخفضًا. واختر رقمًا مرتفعًا إذا كانت المشاكل الصحية قد أثرت على أنشطتك بشكل كبير.

فكر فقط في مدى تأثير المشاكل الصحية على قدرتك على القيام
بأنشطتك اليومية المعتادة، بخلاف أداء وظيفتك.

لم تؤثر المشاكل الصحية على أنشطتي اليومية	0	1	2	3	4	5	6	7	8	9	10	منعتني المشاكل الصحية تمامًا من القيام بأنشطتي اليومية

ضع دائرة حول الرقم المناسب

Reilly MC, Zbrozek AS, Dukes EM. The validity and reproducibility of a work productivity and activity impairment instrument. Pharmacoeconomics. 1993 Nov;4(5):353-65.

Appendix 7: Patient Characteristics Questionnaire

استبيان معلومات عن المشارك

SEX: الجنس	☐ Male ذكر	☐ Female انثى			
Age group: العمر	☐18-25	☐26-35	☐36-50	☐51-65	
Marital status: **الحالة الزوجية**	☐Single اعزب	☐Married متزوج			
Education: التعليم	☐High-school or less ثانوي او اقل	☐Undergraduate level جامعي	☐Postgraduate level دراسات عليا		
Employment status: **الحالة الوظيفية**	☐ Employed موظف	☐ Unemployed غير موظف	☐ Self-employed صاحب عمل	☐ Retired متقاعد	☐ Looking for work ابحث عن عمل
When did you start HD? **تاريخ بدء الغسيل الدموي**	☐Less than a year اقل من سنة	☐1 to 2 years سنة الى سنتين	☐3 to 4 years ثلاث الى اربع سنين	☐5 years or more اكثر من خمس سنوات	
If employed, does your job require heavy physical activities? **ان كنت موظفا، هل عملك يتطلب جهد بدني**	☐ Yes نعم	☐ No لا			
In your main job were you working... **هل وظيفتك بـ**	☐ Full time دوام كامل	☐ Part time دوام جزئي			
If applicable, why you took a part-time rather than a full-time job. Was it					

because...

ماسبب اختيارك للدوام بشكل جزئي

☐ You were a student/you were at school لاتمكن من الدراسة وانا اعمل	☐ You were ill or disabled مريض او عاجز	☐ You could not find a full-time job لم اجد عمل بدوام كامل	☐ You did not want a full-time job لا اريد ان اعمل بدوام كامل

Frequency of HD:عدد مرات الغسيل	☐Once a week or lessمره بالاسبوع	☐Two times a weekمرتين بالاسبوع	☐Three times a week ثلاث مرات اسبوعيا

Duration of HD: مدة الغسيل	☐One hour ساعه واحده	☐Two hours ساعتين	☐Three hours ثلاث ساعات	☐Four hours اربع ساعات

How long in total does it usually take you to travel from home to HD centre?

كم تستغرق من الوقت للوصول لقسم الغسيل الكلوي

☐ Less than 15 minutes اقل من ربع ساعه	☐ 15 minutes to 30 minutes من ربع الى نصف ساعه	☐ 30 minutes to 1 hour من نصف ساعه الى ساعه واحده	☐ More than 1 hour اكثر من ساعه

How do you usually arrive to HD centre? **كيف تصل لقسم الغسيل**	☐Ambulance/bed بالاسعاف او بسرير متحرك	☐Walk ماشيا	☐Wheel chair كرسي متحرك

Did you have just had to make any change at all to your occupation?
هل قمت بأي تغيير بحالتك الوظيفية مؤخرا

☐ No changed at	☐ Changed due to health condition and after starting	☐ Changed due to other reasons

allلم اقم بأي تغيير	HD نعم وذلك بسبب المرض والغسيل الكلوي	than health condition and CKD نعم لاسباب اخرى غير مرضية	
Do you retired or thinking to retire due to health reasons?هل تقاعدت او تفكر بذلك لاسباب مرضية		☐ Yes نعم	☐ No لا

Thank you…

Appendix 8: Interview guide

(v1.2 30.3.2015)

The in-depth interview will be guided by the theory of the Capabilities Approach to explore and offer new insight as to how facilitators and barriers may affect work ability and employment sustainability among HD patients.

Opening

After welcoming and thanking the participants for their involvement in this phase, the participants will be asked to talk about their experience in work before and after starting HD.

Then, the researcher will start the interview by introducing the participants with the results of the questionnaires they filled in the first phase of the study. After that the researcher asks open-ended questions based on the concepts and domains of the theory of the Capabilities Approach below:

CA Concepts & domains	Discussion
Personal characteristics, resources, and social environment	Items of the demographic questionnaire will be discussed such as education level and gender, and how this affects their employment status and work-ability.
Clinical environment and health condition (functioning)	Results of the SF-12v2 questionnaire will be discussed in this domain to explore how the health condition of the participants and the treatment modality affect their work.
Work environment and choices (capabilities)	Results of the WPAIv2 questionnaire will be discussed to gain deeper understanding of how their ability to work affects their employment or their choices such as applying for early retirement or looking for another job. And is such choices and opportunity available for them.

	Also, how the (first domain) affect the availability of these choices and opportunities
Agency	How the participants feel toward future, what are their expectations and desires? What are their goals and plans to maintain their employment status and/or sustain and improve their ability to work

Appendix 9: Ethical Approval Letter from UoS

University of Salford
MANCHESTER

Research, Innovation and Academic Engagement Ethical Approval Panel

College of Health & Social Care
AD 101 Allerton Building
University of Salford
M6 6PU

T +44(0)161 295 2280
HSresearch@salford.ac.uk

www.salford.ac.uk/

7 April 2015

Dear Nahed,

RE: ETHICS APPLICATION HSCR15-07 – Employment status, sustainability, and person's work ability among Chronic Kidney Disease (CKD) patients receiving Haemodialysis (HD) in the Kingdom of Saudi Arabia (KSA)

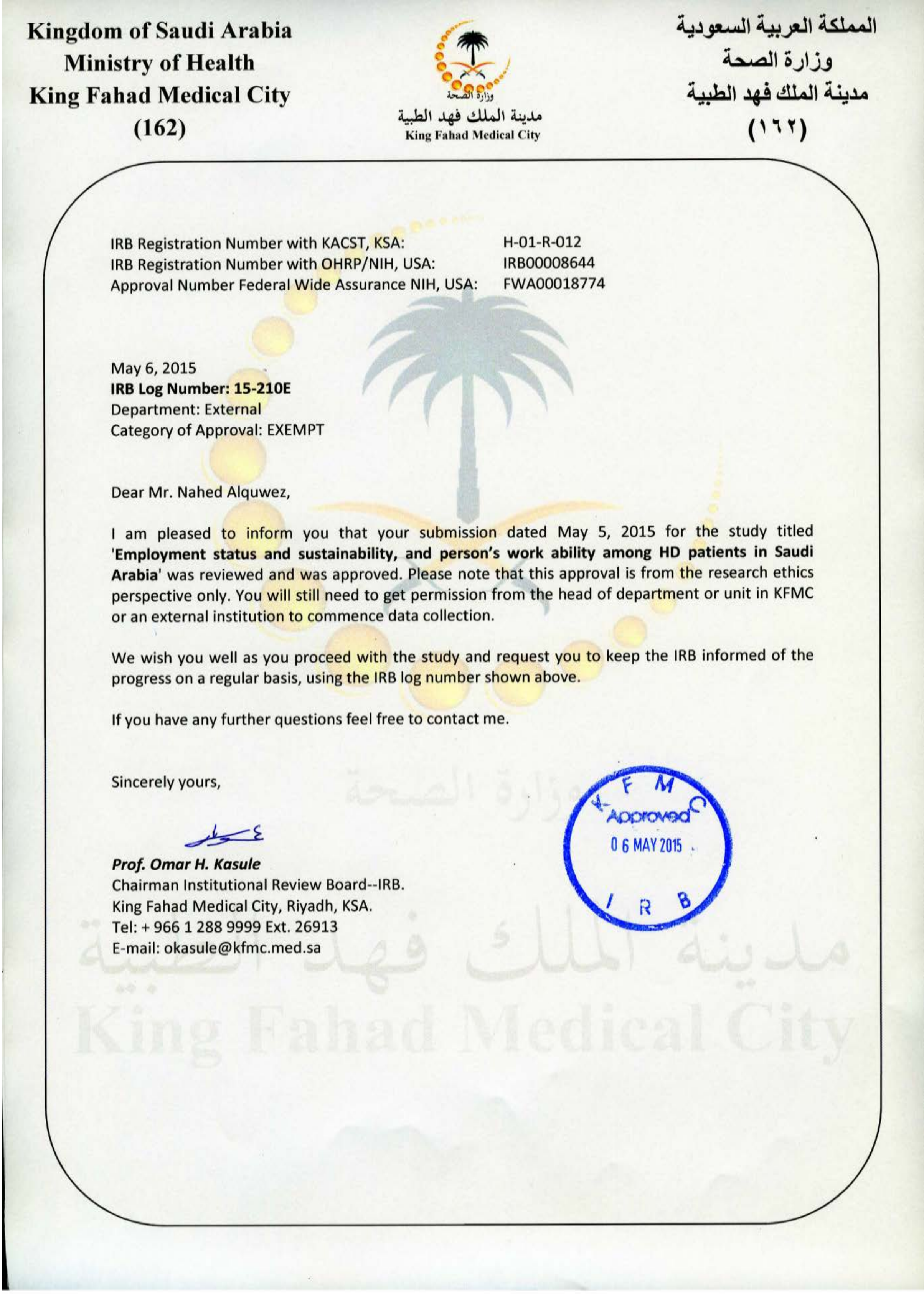
Based on the information you provided, I am pleased to inform you that application HSCR15-07 has been approved.

If there are any changes to the project and/ or its methodology, please inform the Panel as soon as possible by contacting HSresearch@salford.ac.uk

Yours sincerely,

Sue McAndrew
Chair of the Research Ethics Panel

Appendix 10: Ethical Approval Letter from Ministry of Health in Saudi Arabia



Kingdom of Saudi Arabia
Ministry of Health
King Fahad Medical City
(162)

المملكة العربية السعودية
وزارة الصحة
مدينة الملك فهد الطبية
(١٦٢)

IRB Registration Number with KACST, KSA:	H-01-R-012
IRB Registration Number with OHRP/NIH, USA:	IRB00008644
Approval Number Federal Wide Assurance NIH, USA:	FWA00018774

May 6, 2015
IRB Log Number: 15-210E
Department: External
Category of Approval: EXEMPT

Dear Mr. Nahed Alquwez,

I am pleased to inform you that your submission dated May 5, 2015 for the study titled '**Employment status and sustainability, and person's work ability among HD patients in Saudi Arabia**' was reviewed and was approved. Please note that this approval is from the research ethics perspective only. You will still need to get permission from the head of department or unit in KFMC or an external institution to commence data collection.

We wish you well as you proceed with the study and request you to keep the IRB informed of the progress on a regular basis, using the IRB log number shown above.

If you have any further questions feel free to contact me.

Sincerely yours,

KFMC
Approved
06 MAY 2015
IRB

Prof. Omar H. Kasule
Chairman Institutional Review Board--IRB.
King Fahad Medical City, Riyadh, KSA.
Tel: + 966 1 288 9999 Ext. 26913
E-mail: okasule@kfmc.med.sa

Appendix 11: Organizational agreement from MOH, Saudi Arabia

الادارة العامة للبحوث والدراسات
القيد: 1991676
التاريخ: 22-07-1436هـ 11-05-2015م
مرفقات:

1991676

المملكة العربية السعودية
وزارة الصحة
الإدارة العامة للبحوث والدراسات

الرقم:......
التاريخ:
المشفوعات

الموضوع: بحث الطالب/ناهض القويز.

سعادة/ مدير مركز البحوث بمدينة الملك سعود الطبية المحترم

ص. لسعادة / رئيس لجنة الأخلاقيات مدينة الملك سعود الطبية المحترم

السلام عليكم ورحمة الله وبركاته، ، ،

إشارة إلى موضوع الطالب / **ناهض عبدالله القويز**، مبتعث من وزارة التعليم ، لدراسة درجة الدكتوراة في تخصص "التمريض"، كلية التمريض جامعة سالفورد بالمملكة المتحدة، رقم الهوية الوطنية (١٠٢٣٢٣٢٥٨٨) والرقم الأكاديمي (٠٠٤٠٣١٦) وعنوان الرسالة:

" الحالة والوضع الوظيفي لمرضى الغسيل الكلوي الدموي بالمملكة العربية السعودية"

نحيطكم علماً بأن الطالب قد إستوفى كافة المستندات المطلوبة وتمت مراجعتها من قبل اللجان المعنية بالإدارة العامة للبحوث والدراسات بوزارة الصحة ولجنة الأخلاقيات بمدينة الملك فهد الطبية (مرفق صورة)، وتمت الموافقة على تسهيل مهمة إجراء هذا البحث، وحيث أن المذكور عاليه سينفذ دراسته في مستشفى مدينة الملك سعود الطبية بالرياض (قسم الغسيل الكلوي الدموي).

وعليه، نأمل من سعادتكم التفضل بالإطلاع والإيعاز لمن يلزم بتسهيل مهمته لجمع البيانات اللازمة بما يضمن أن لا يكون هناك أي تأثير على خدمة المراجعين خلال قيامه بمهام بحثه، مع العلم بأن وزارة الصحة تضمن حقوقها في نتائج هذا البحث من خلال إتفاقية المشاركة في البيانات والتي تم توقيعها بين الباحث والإدارة العامة للبحوث والدراسات.

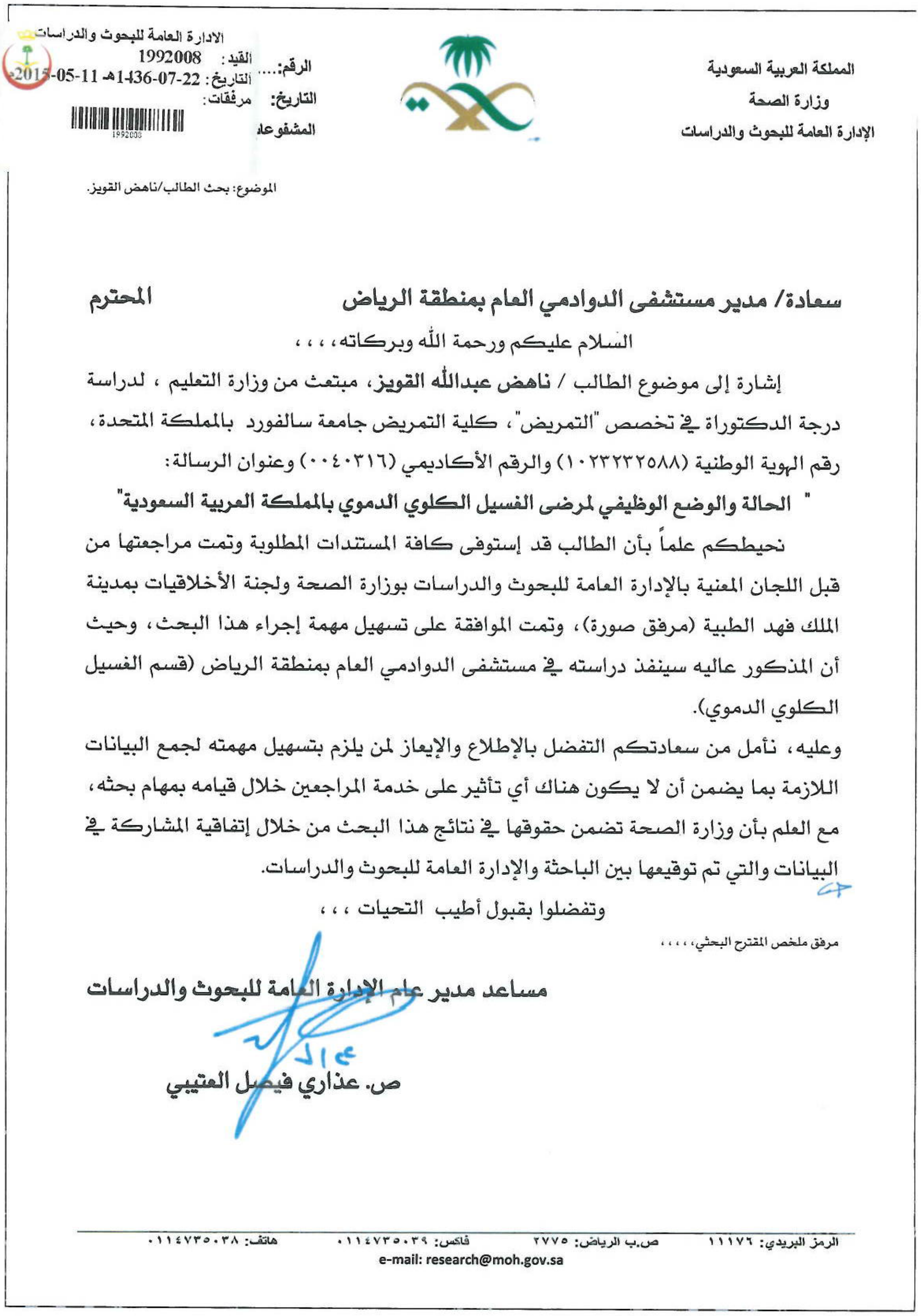
وتفضلوا بقبول أطيب التحيات ، ، ،

مرفق ملخص المقترح البحثي، ، ، ،

مساعد مدير عام الإدارة العامة للبحوث والدراسات

ص. عذاري فيصل العتيبي

الرمز البريدي: ١١١٧٦ ص.ب الرياض: ٢٧٧٥ فاكس: ٠١١٤٧٣٥٠٣٩ هاتف: ٠١١٤٧٣٥٠٣٨
e-mail: research@moh.gov.sa



المملكة العربية السعودية
وزارة الصحة
الإدارة العامة للبحوث والدراسات

الرقم:....
التاريخ:
المشفوعا

الادارة العامة للبحوث والدراسات
القيد : 1992008
التاريخ : 22-07-1436هـ 11-05-2015م
مرفقات :

الموضوع: بحث الطالب/ناهض القويز.

سعادة/ مدير مستشفى الدوادمي العام بمنطقة الرياض المحترم

السلام عليكم ورحمة الله وبركاته، ، ،

إشارة إلى موضوع الطالب / **ناهض عبدالله القويز**، مبتعث من وزارة التعليم ، لدراسة درجة الدكتوراة في تخصص "التمريض"، كلية التمريض جامعة سالفورد بالمملكة المتحدة، رقم الهوية الوطنية (١٠٢٣٢٣٢٥٨٨) والرقم الأكاديمي (٠٠٤٠٣١٦) وعنوان الرسالة:

" الحالة والوضع الوظيفي لمرضى الفسيل الكلوي الدموي بالمملكة العربية السعودية"

نحيطكم علماً بأن الطالب قد إستوفى كافة المستندات المطلوبة وتمت مراجعتها من قبل اللجان المعنية بالإدارة العامة للبحوث والدراسات بوزارة الصحة ولجنة الأخلاقيات بمدينة الملك فهد الطبية (مرفق صورة)، وتمت الموافقة على تسهيل مهمة إجراء هذا البحث، وحيث أن المذكور عاليه سينفذ دراسته في مستشفى الدوادمي العام بمنطقة الرياض (قسم الفسيل الكلوي الدموي).

وعليه، نأمل من سعادتكم التفضل بالإطلاع والإيعاز لمن يلزم بتسهيل مهمته لجمع البيانات اللازمة بما يضمن أن لا يكون هناك أي تأثير على خدمة المراجعين خلال قيامه بمهام بحثه، مع العلم بأن وزارة الصحة تضمن حقوقها في نتائج هذا البحث من خلال إتفاقية المشاركة في البيانات والتي تم توقيعها بين الباحثة والإدارة العامة للبحوث والدراسات.

وتفضلوا بقبول أطيب التحيات ، ، ،

مرفق ملخص المقترح البحثي، ، ، ،

مساعد مدير عام الإدارة العامة للبحوث والدراسات

ص. عذاري فيصل العتيبي

الرمز البريدي: ١١١٧٦ ص.ب الرياض: ٢٧٧٥ فاكس: ٠١١٤٧٣٥٠٣٩ هاتف: ٠١١٤٧٣٥٠٣٨
e-mail: research@moh.gov.sa

Appendix 12: Participant Study Information Sheet

Code:

Research Study: Participant Information Sheet

Employment status and sustainability, and person's work ability among Chronic Kidney Disease (CKD) patients receiving Haemodialysis (HD) in the Kingdom of Saudi Arabia (KSA)

What is the purpose of the research project?

There is little information on employment status and sustainability of work among HD patients in Saudi Arabia. This study seeks to explore employment status, individual's work ability and employment sustainability among CKD patients undergoing HD. The research will generate a deeper understanding of who, what, why and how HD patients continue to work, or not, alongside managing a long-term condition.

What would I have to do if I agree to participate?

You can participate in this research in two ways:

a) You will be requested to complete three questionnaires enclosed with this information pack. It should take you approximately 10 to 15 minutes to complete each questionnaire. By doing this, your involvement for the first phase of the research will be completed.

b) If you wish to participate in the second phase of the research, you will be involved in an interview in order provide a deeper understanding of how employees with CKD are able to maintain their employment status against factors such as age, gender, number of diagnosed diseases, compared to unemployed participants and to explore and offer new insight as to how things that help you to stay in work, and difficulties that make it difficult to remain as a working person may affect your work ability and employment sustainability. The interview should last no longer than 1-2 hours and will be scheduled at a date that is convenient to you, in a preferred location whether at your home or a dedicated quiet room within the HD centre. If you are interested in being involved in an interview then please complete the reply slip provided and return it in the envelope to the researcher with your completed questionnaire.

What benefit or risk is there to me if I participate in the research?

There will be no direct potential benefits to you if you take part in the study. However, you will assist the researcher to search for ways to improve HD patients' work ability and employment sustainability and to fulfil the requirement of his PhD programme. Being involved in this research will cause no harm to you and your family.

What if I agree to participate then want to withdraw?

You can withdraw from the research at any time during the study by contacting the researcher directly and providing your personal code available at the upper right of your information sheet, without giving a reason why. By doing this, all information you have provided and your contact details will be removed from the study database and you will not be contacted further. Also, all possible comments made by you will be removed from discussion transcripts and will not be used in the study findings.

How will you use the information I provide and keep it confidential so no-one can recognise it was from me?

Information you will provide will be kept confidential in a database that is password protected, accessed only by the researcher. Your responses to the questionnaires, personal and clinical information and if applicable your contribution within the interview will be downloaded within a matter of hours and stored safely and confidentially on a password protected computer, then removed from the audio-tape recorder. Five years after the study is completed, to allow any challenges once peer reviewed papers are published, digital recordings will be erased along with your contact details and if applicable to you interview information will be stored anonymously.

How will the study findings be published?

The outcomes of the study will be used for the researcher PhD thesis and will be written in a way that protects the identity of the people who participate. The same procedures will be applied when publishing any study reports or articles. Participants have the right to ask for a copy of the thesis when published.

What if I want to complain about how the research is being conducted?

If you have any complaints regarding any aspect of how this research is being conducted then please contact your nurse educator in the HD unit who speak Arabic (add details later) or email the supervisor of the researcher (in English) whose contact details are provided below. If you have any questions about the study that require clarification then please contact the researcher who can speak both English and Arabic and his contact details are also provided below.

Researcher:

Add HD nurse details when confirmed

Thank you for taking the time to read this information

(v1.2 30.3.2015)

Participant Study Information Sheet (Arabic)

Code:

منشورة معلومات الدراسه للمشاركين

عنوان الدراسة: الحالة والوضع الوظيفي لمرضى الغسيل الكلوي الدموي بالمملكة العربية السعودية

ماهو هدف الدراسة؟

لايوجد حاليا ابحاث كافية عن الحالة والوضع الوظيفي لمرضى الغسيل الدموي الكلوي في العالم عموما وفي المملكة العربية السعوديه خصوصا. الهدف من هذه الدراسه هو معرفة ماسبق ذكره بالاضافه للبحث عن الاسباب التي قد تؤثر سلبا او ايجابا على الوضع الوظيفي للمرضى حتى يصبح هنالك تصور مبني على بحث علمي قد يساهم في رفع توصيات و تشريع سياسات لمساعدة هؤلاء المرضى من الناحية المعيشية.

ارغب بالمشاركة بهذه الدراسه، ماذا يجب علي فعله؟

الدراسة ستكون على مرحلتين. تستطيع المشاركة في كلتا المرحلتين او المرحلة الاولى فقط وذلك بالتوقيع على الاقرار الخاص بالدراسة والمرفق مع هذه المنشوره.

المرحلة الاولى: سيكون هنالك عدد 3 استبيانات قد تستغرق المدة لتعبئتها حوالي 10 دقائق للاستبيان الواحد (سيتواجد الباحث للمساعده في تعبئة الاستبيانات، اذا رغبت).

المرحلة الثانية: سيكون هنالك مقابلة شخصية مسجله صوتيا لمدة ساعه تقريبا مع الباحث للسؤال عن الاسباب والعوامل التي قد تضر او تحسن الوضع الوظيفي للمرضى.

ماهي الفوائد او الاضرار التي قد تترتب على مشاركتي بهذه الدراسة؟

لن يكون هنالك فوائد مباشرة لمشاركتك بهذه الدراسه. ولكن مشاركتك ستساعد الباحث على انهاء مرحلة الدكتوراه والخروج ببحث علمي قد يفيد مرضى الغسيل الكلوي مستقبلا. علما بأن مشاركتك لن ينتج عنه اي ضرر بإذن الله.

هل استطيع الانسحاب من الدراسة بعد موافقتي بالمشاركة؟

نعم تستطيع ذلك بدون ذكر الاسباب حيث ان مشاركتك تعتبرتطوعية وليست اجبارية. عند الانسحاب سيتم حذف كل المعلومات والبيانات الخاصه بك ولن يتم الاستفادة منها.

كيف سيتم التعامل مع بياناتي الشخصية والمعلومات التي سأشارك بها؟

سيتم حفظ جميع البيانات والمعلومات الخاصه بك في جهاز الحاسب الخاص بالباحث والمحمي بكلمة سرية وبرنامج مكافحة الفيروسات والتجسس. ايضا، سيتم تبديل استخدام اسم مستعار او كود خاص لكل مشارك حرصا على الخصوصية.

كيف سيتم نشر نتائج الدراسة؟

سيتم استخدام نتائج الدراسة لغرض كتابة رسالة الدكتوراه للباحث. هذا قد يتطلب نشر الرساله و تقارير ومقالات علمية مرتبطه بنتائج الدراسه مستقبلا مع مراعاة الخصوصية لجميع المشاركين. علما بأنه يحق لكل مشارك المطالبة بنسخه من رسالة الدكتوراه بعد نشرها.

ماذا افعل عند وجود اي ملاحظه على البحث او الباحث؟

تستطيع رفع ملاحظاتك لرئيس/ة التمريض بالقسم او مخاطبة الباحث مباشرة عن وجود ملاحظة على الحث نفسه. اما اذا كان هنالك ملاحظه على الباحث، فتستطيع مخاطبة مشرف الدكتوراه الخاص للباحث عن طريق قنوات الاتصال الموجوده بالاسفل.

معلومات الباحث	**معلومات مشرف الدكتوراه للباحث**
ناهض بن عبدالله القويز	**بروفيسور باولا اورمندي**
00966504293295	+44 (0) 161 295 0453
00447476241089	P.Ormandy@salford.ac.uk
n.a.n.alquwez@edu.salford.ac.uk	University of Salford, UK

Appendix 13: Study Participant Consent Form

University of Salford MANCHESTER

RESEARCH STUDY

Participant - CONSENT FORM

Title of Project: Employment status, sustainability, and person’s work ability among Chronic Kidney Disease (CKD) patients receiving Haemodialysis (HD) in the Kingdom of Saudi Arabia (KSA)

Name of Researcher(s): ***YES*** ***NO***

- I confirm that I have read and understand the information sheet (*Dated: v 1.2 30.3.2015)* for the above study and have had the opportunity to ask questions. ☐ ☐
- I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected. ☐ ☐
- I understand that my name and involvement in the study will remain confidential. ☐ ☐

☐ ☐

- I understand that any personal information about me such as my email contact address will not be shared outside of the study team and will only be used for this research. ☐ ☐
- I understand that the information I provide could be used as part of the final study report or journal publications but any comments used will not be identifiable to me. ☐ ☐

- I agree to take part in an audio-taped interview. ☐ ☐
- I agree to take part in the above study.

____________________	______________	______________________
Name of Participant	Date	Signature
____________________	______________	______________________
Name of Researcher	Date	Signature

(v1.2 30.3.2015)

Study Participant Consent Form (Arabic)

RESEARCH STUDY

اقرار المشاركة بالدراسة

عنوان الدراسة: الحالة والوضع الوظيفي لمرضى الغسيل الدموي الكلوي بالمملكة العربية السعودية

اسم الباحث: ناهض عبدالله القويز

م	*العنصر*	*نعم*	*لا*
1	**لدي معلومات كافية عن ماهية الدراسة وتمت الاجابة على تساؤلاتي**	☐	☐
2	**مشاركتي بالدراسة تطوعية بحيث استطيع الانسحاب بأي وقت وبدون ذكر الاسباب**	☐	☐
3	**اعلم بأن مشاركتي و معلوماتي الشخصية ستعامل بسرية تامه**	☐	☐
4	**معلوماتي الشخصية ومشاركتي بالبحث ستكون مخصصة فقط لهذه الدراسة**	☐	☐
5	**ارغب بالمشاركة بالمقابلة الشخصية والتي سيتم تسجيلها صوتيا**	☐	☐
6	**ارغب بالمشاركة بهذه الدراسة**	☐	☐

______________________ ______________ ____________________

اسم المشارك **التاريخ** **التوقيع**

__ناهض عبدالله القويز ______________ ______________________

اسم الباحث **التاريخ** **التوقيع**

(v1.2 30.3.2015)