Influence of Spirituality on Health Outcomes and General Well-Being in Patients with End-Stage Renal Disease

Ali Ahmed Alshraifeen

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University of Stirling

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Declaration

I declare that this thesis is entirely my own work and has been submitted only for the degree of PhD in the University of Stirling.

Signature _____ Date _____

Dedication

Dedicated to my parents, family and friends in Jordan……..

Acknowledgment

First and foremost, I would like to use this unique opportunity to acknowledge the divine support of the almighty God for seeing me through this PhD journey.

My thesis has taken me on a very long journey and there have been many who have helped me along the way. I am deeply indebted to the Schools of Nursing, Midwifery and Health at the University of Stirling in the United Kingdom and the Hashemite University in Jordan for funding this PhD study.

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Abstract

End-stage renal disease (ESRD) introduces physical, psychological, social, emotional and spiritual challenges into patients' lives. Spirituality has been found to contribute to improved health outcomes, mainly in the areas of quality of life (QOL) and well-being. No studies exist to explore the influences of spirituality on the health outcomes and general well-being in patients with end-stage renal disease receiving haemodialysis (HD) treatment in Scotland. This study was therefore carried out to examine and explore spirituality in the day-to-day lives of patients with ESRD receiving HD treatment and how it may influence their health outcomes and, in particular, QOL and general well-being.

The study described in this thesis employed a sequential mixed method approach over two stages: quantitative and qualitative. Following ethical approval, a cross-sectional survey was conducted with 72 patients from 11 dialysis units recruited from four Health Boards in Scotland. The participants in the study were regular patients attending the dialysis units three times per week. Data on patients' quality of life, general well-being, and spirituality were collected using self-administered questionnaires including demographic information: the Short Form Medical Outcome Study Questionnaire (SF-36v2), the General Health Questionnaire, and the Spiritual Well-Being Questionnaire. The data were analysed using the Predictive Analytics Software for Windows. The findings highlighted that patients' quality of life was markedly lower than the United Kingdom general population average norms of 50. Increasing age was associated with

better mental health but worse physical health. The survey also found that there were no significant associations between spirituality and patients' quality of life and general well-being. However, it was considered important to complement and enrich the survey findings by gaining a deeper understanding of the influences of spirituality on patients' health outcomes and general well-being by carrying out the qualitative component of the study. Qualitative data were collected using semi-structured interviews with a subsample of 21 patients from those who participated in the survey. A thematic approach using Framework Analysis informed the qualitative data analysis.

Four main themes emerged from the qualitative interviews: 'E*motional and Psychological Turmoil*', 'L*ife is Restricted*', 'S*pirituality*' and 'O*ther Coping Strategies'*. The findings from the interviews confirmed that patients' quality of life might be affected because of the physical challenges such as unremitting fatigue, disease unpredictability, or being tied down to a dialysis machine, or the emotional and psychological challenges imposed by the disease into their lives such as wholesale changes, dialysis as a forced choice and having a sense of indebtedness. The findings also revealed that spirituality was an important coping strategy for the majority of participants who took part in the qualitative component (n=16). Different meanings of spirituality were identified including connection with God or Supernatural Being, connection with the self, others and nature/environment. Spirituality encouraged participants to accept their disease and offered them a sense of protection, instilled hope in them and helped them to maintain a positive attitude to carry on with their daily lives, which may have had a positive influence on their health outcomes and general

well-being. The findings also revealed that humour was another coping strategy that helped to diffuse stress and anxiety for some participants and encouraged them to carry on with their lives.

The findings from this study contribute knowledge to increase our understanding of the influence of spirituality on the health outcomes and general well-being of patients with end-stage renal disease currently receiving haemodialysis treatment. Based on the findings from this thesis, recommendations are made for clinical practice, patient and nurse education and for future research.

Publications

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Abbreviations

AIDS	Acquired Immune Deficiency Syndrome
AMED	Allied and Complementary Medicine Database
ANOVA	Analysis of Variance
ATLA	American Theological Library Association
BP	Bodily Pain
CAPD	Continuous Ambulatory Peritoneal Dialysis
CASP	Critical Appraisal Skills Programme
CINAHL	Cumulative Index to Nursing and Allied Health Literature
CKD	Chronic Kidney Disease
EMBASE	Excerpta Medica Database
ESRD	End-Stage Renal Disease
EWB	Existential Well-Being
F	Female
GFR	Glomerular Filtration Rate
GH	General Health Perceptions
GHQ	General Health Questionnaire
GRI	Glasgow Royal Infirmary
HD	Haemodialysis
HHD	Home Haemodialysis
HIV	Human Immunodeficiency Virus
HRQOL	Health Related Quality Of Life
IH	Inverclyde Hospital
KDQOL	Kidney Disease Quality of Life Questionnaire
KTX	Kidney Transplantation
M	Male
MCS	Mental Component Scores
MEDLINE	Medical Literature Analysis and Retrieval System Online
MeSH	Medical Subject Heading
MH	Mental Health
MOS SF-36	Medical Outcomes Study 36-Item Short Form Health Survey
MSPSS	Multidimensional Scale of Perceived Social Support
NBS	Norm-Based Scoring
NHS	National Health Service
NHS R&D	NHS Research and Development
NHSGGC	National Health Services Greater Glasgow and Clyde
NHS-WORES	National Health Services, West of Scotland Research Ethics Service
NICA	The National Interfaith Coalition on Aging
NKF	National Kidney Foundation
PASW	Predictive Analytics Software for Windows
PCS	Physical Component Scores
PD	Peritoneal Dialysis
PF	Physical Functioning

PPM	Populations Per Million
QOL	Quality of Life
RE	Role Emotional
RP	Role Physical
RRT	Renal Replacement Therapy
SF	Social Functioning
SH	Stobhill Hospital
SREC	School of Nursing, Midwifery and Health Research Ethics Committee
SRR	Scottish Renal Registry Report
SWBQ	Spiritual Well-Being Questionnaire
SWBS	Spirituality Well-Being Scale
UK	United Kingdom
USA	United States of America
VI	New Victoria Infirmary
VoLH	Vale of Leven Hospital
VT	Vitality
WHO	World Health Organization
WHOQOL	World Health Organization Quality of Life
WI	Western Infirmary

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Chapter 1- Introduction

This chapter offers a personal context and the rationale for why I decided to study the influences of spirituality on the health outcomes and general well-being in patients with end-stage renal disease (ESRD) receiving haemodialysis treatment (HD) and states the overall aim of the thesis and research questions (Section 1.1). A plan of the thesis is presented in Section 1.2, with a brief description of what is included in each chapter to aid navigation through the thesis and its argument.

1.1 Personal Context and Rationale for the Thesis

My interest in studying patients with ESRD and in particular those receiving HD treatment evolved from my role as a registered nurse together with my previous academic studies. Qualifying as a nurse in 1998, I worked in an intensive care unit in Jordan and in the Emergency Department in Dubai for four years. In 2003, I moved to the United Kingdom (UK) where I worked initially as a staff nurse in the Outpatient Department for one and a half years. During this time I came in contact with patients who were diagnosed with chronic illnesses such as rheumatoid arthritis, diabetes and ESRD. In early 2004, I moved to work in the Surgical Intensive Care Unit and I had my first contact with patients who were suffering with problems associated with kidney failure and which required renal support. Although I have not worked in a Dialysis Unit and with patients receiving HD treatment, this experience of working with seriously ill individuals who require renal support raised questions about the possible impact of this problem on their lives, especially if the kidney damage was irreversible and they would

have to be on HD for the rest of their lives. In addition, discussions with academic colleagues in Jordan highlighted that there was a lack of academic staff who possess the knowledge and experience of working with patients with ESRD and of conducting research to examine and explore the impact of this chronic illness on their health outcomes and general well-being. My lack of experience in working with such patients encouraged me to undertake a Diploma in Nephrology Nursing to expand my knowledge of kidney disease and to become aware of the treatment methods available at the time for these patients. I have selected patients receiving HD treatment as it is the most common method of treatment used in patients with ESRD.

Over time, I became more interested in understanding the process of transition into ESRD that this group of patients experience throughout their journey with the disease and, in particular, I was aware that, in the medically dominated world of healthcare, which focuses on offering traditional medical care, patients might receive little advice on how to manage and deal with their illness and how to satisfy their spiritual and psychological needs. Hence, I read widely around the potential impact of ESRD on patients' lives and the factors that may improve their health outcomes and reduce their struggle.

Many researchers have examined and explored the quality of life (QOL) and psychological problems in patients with ESD and some of them have emphasized that spirituality may be an important coping strategy that may facilitate adjustment. My focus was then turned to explore spirituality in the lives of patients with ESRD and how it may influence their health outcomes and, in particular, their QOL and general well-

being. Therefore, I started to search the literature to find existing research to acquire the basic knowledge and evidence that might answer such questions as: "What does spirituality mean to people with ESRD? Is there an association between spirituality and the QOL and well-being of patients with ESRD receiving HD treatment?" in order to use these studies as evidence to justify my thesis. Few studies were identified that could answer these questions (see Chapter 2).

Indeed, a diagnosis of terminal or chronic illness creates a crisis in a person's life and therefore individuals turn to their own values and beliefs to guide them through such crisis (Kendall, 1999). Patients struggling with chronic illnesses may experience feelings of guilt, loss, sadness, anxiety, diminished self-esteem, loss of role-function, communication problems with family and friends, questions about meaning in life, and religious struggles (Bussing and Koenjg, 2010). Chronic illnesses often threaten life and can cause considerable physical, emotional and psychological distress (Charon, 2006). Patients often undergo complex treatment regimens, are exposed to medications that have numerous side effects and uncertainty is constant. Thus, people struggling with chronic illnesses often engage in a process of reflection on the meaning of life and on the major spiritual and existential questions of life (Charon, 2006; Remen, 2006).

Spirituality has considerable potential to bring comfort to people who are chronically ill and can have a vital role in helping patients cope with and adjust to chronic illnesses (Albaugh, 2001; Walton, 2002). Spirituality has been described as an essential human component that can assist in finding meaning in illness, comfort, and optimism and provide a solid coping mechanism for adjustment to chronic disease (Albaugh, 2003;

Tanyi and Werner, 2003). Many researchers have examined the meaning of spirituality and its influence on the health outcomes of patients with chronic illnesses, including substance abuse (Wright, 2005; Leigh et al., 2005), disability (Do-Rozario, 1997), breast cancer (Henderson et al., 2003, Meraviglia, 2006), rheumatoid arthritis (Bartlett et al., 2003; Iaquinta and Larrabee, 2004), and Human Immunodeficiency Virus (HIV) (Cotton et al., 2006; Vance et al., 2011). In the majority of these studies, spirituality was found to be associated with more positive illness adjustment, is an important source of comfort in people living with life-threatening illness, and has been reported as a moderating factor for stress and disease outcomes (Koenig et al., 2001; Tanyi and Werner, 2003). Spirituality has also been found to play an important role in psychosocial adjustment to chronic illnesses (Albaugh, 2003; Tatsumara, 2003), as well as helping to transcend suffering in patients with Acquired Immune Deficiency Syndrome (AIDS) (Mellors et al., 2001) and offers comfort, strength, and trust in a higher power for patients struggling with a variety of life-threatening diseases (Albaugh, 2003). It has also been suggested that patients with greater spiritual well-being experience a better health-related quality of life (HRQOL) (Koenig et al., 1999; Tanyi and Werner, 2003). Overall, these studies suggest that spirituality is an important aspect of the health and well-being in patients' lives, especially to individuals with different types of chronic illnesses and, in particular, to those with a life-threatening disease. These studies also suggest that spirituality is a core human component that can decrease suffering in illness, facilitate recovery, and may be an important coping resource that enables people with chronic conditions to manage their condition.

Introduction

Compared to most chronic illnesses, ESRD challenges patients' abilities to adjust in the physical, emotional, psychosocial and spiritual areas of life. Patients with ESRD undergoing HD treatment may experience many physiological problems such as uremia, joint pain and cardiovascular complications (Gilbar et al., 2005), and may also experience a wide range of multiple and radical lifestyle changes that affect their QOL (Covic et al., 2004; Molsted et al., 2004; Kring and Crane, 2009; Cengic and Resic, 2010) and their social and psychological well-being (White and Grenyer, 1999; Weisbord et al., 2003; Tsay and Hung, 2004; Cukor et al., 2007; Yong et al., 2009). Patients with ESRD may also experience numerous, complex comorbidities such as heart disease, diabetes and dementia, and may experience substantial emotional and spiritual suffering (Saini et al., 2006; Davison and Jhangri, 2010). Patients may struggle to maintain their roles as workers, mothers, and wives (Tanyi, 2002) and may experience strained relationships as a result of the daily demands of the illness and treatment (White and Grenyer, 1999).

As these patients continue to live with the medical problems and associated stressors and lifestyle changes, questioning the meaning of illness and life, finding hope and support can occur and often becomes crucial in adjustment (Gregory et al., 1998, Tanyi and Werner, 2003; Koenig et al., 2004). Questioning the meaning in illness and life may therefore involve the search for spiritual answers. For patients with ESRD, spirituality may be an important resource that facilitates finding meaning in illness, supports adjustment and influences their health outcomes and well-being.

In the past decade, many studies have examined the influence of spirituality and

religiosity in ESRD (Patel et al., 2002; Berman et al., 2004; Ko et al., 2007; Thomas and Washington, 2012). However, despite the increasing interest in studying spirituality in the lives of patients with ESRD, the evidence remains inconclusive as some researchers found that spirituality was conducive to better HRQOL and satisfaction with life and medical care (Patel et al., 2002; Berman et al., 2012) while others found that there was no positive association between spirituality/religiosity and HRQOL in patients receiving HD treatment (Ko et al., 2007; Thomas and Washington, 2012). In addition, the majority of these studies used a quantitative approach and few studies explored spirituality among patients with ESRD using a qualitative or mixed method approach (see Chapter 2). Moreover, studies exploring whether spirituality influences the QOL and well-being of patients receiving HD treatment in Scotland do not exist. Therefore, this thesis was borne out of interest to contribute knowledge that might make positive contributions to improve patients' health outcomes and general well-being, as well as discovering whether patients receiving HD treatment in Scotland share the same views with other patients suffering with chronic illness regarding the meaning of spirituality and its influence on their health outcomes and well-being. Consequently, an in-depth review and critique of the literature examining spirituality among patients with ESRD was carried out (see Chapter 3) to identify research gaps and provide evidence for this study.

Informed by the literature review, the overall aim of the thesis was '*to examine and explore spirituality in the day-to-day lives of patients with ESRD receiving HD treatment and how it may influence their health outcomes and, in particular, QOL and*

general well-being'. This aim was addressed by examining the following research questions:

1. Is there an association between spirituality and the QOL and general well-being in patients with ESRD receiving HD treatment?
2. What does spirituality mean to people receiving HD treatment?
3. How does spirituality influence the QOL and general well-being in patients with ESRD receiving HD treatment?

1.2 Structure of the Thesis

A sequential mixed method approach was adopted to explore the influence of spirituality on the health outcomes and general well-being in patients with ESRD. This thesis consists of seven chapters following this Introduction:

Chapter 2 and Chapter 3 present the literature review in two parts. Chapter 2 (Part I) of the literature review offers a background to chronic kidney disease and ESRD. Chapter 3 (Part II) of the literature review starts by presenting the differences between the concepts of spirituality and religion, challenges defining spirituality and includes a comparison of different definitions of spirituality, followed by an outline of the search strategy for the main literature review. Critique of the literature highlights the need for further research on spirituality and its influence on the health outcomes and general well-being in patients with ESRD within the context of routine nursing care in dialysis units. The chapter concludes with the aim and research questions as informed by the literature review.

Introduction

Chapter 4 offers an overview of the research methodologies and the rationale for the methodology and design chosen for this study which has adopted a sequential mixed method approach. Data were collected using a cross-sectional survey followed by individual semi-structured interviews. A detailed description of the quantitative (survey) and qualitative (interviews) components is presented. This chapter also provides a description of the research process and ethical considerations of the study.

In Chapters 5 and 6, the study findings are presented. In particular, Chapter 5 provides an account of the responses to the exploratory surveys. Chapter 6 presents the findings from the analysis of the semi-structured interviews and the recurring themes in relation to the impact of ESRD and HD treatment on patients' lives, their views on spirituality and its influence on their health outcomes and general well-being.

Chapter 7 offers a critical discussion of the findings from the study in the context of the wider literature which illustrates new knowledge. The overarching argument is that ESRD and HD treatment are demanding and introduce many challenges into patients' lives and that spirituality might have a positive influence on patients' health outcomes and general well-being. Also in Chapter 7, the strengths and limitations of the study are discussed, and recommendations are made for clinical practice, patient and nurse education and for future research. The chapter concludes by presenting my personal reflection on being a researcher.

Chapter 2- Literature Review Part I

2.1 Introduction

Part I of the literature review addresses chronic kidney disease (CKD), its causes, symptoms and management (Section 2.2). A brief account is offered to highlight the impact of end-stage renal disease (ESRD) on patients' lives (Section 2.2.3).

2.2 Chronic Kidney Disease (CKD)

CKD is increasing amongst all population groups globally and the incidence of ESRD continues to rise, which is reflected in the increasing number of people with ESRD treated by renal replacement therapy (RRT) (Lysaght, 2002). The National Kidney Foundation (NKF) (2002) defines CKD as the presence of kidney damage for a period of three or more months caused by structural or functional abnormalities with or without a decreased glomerular filtration rate (GFR) which is defined as the flow rate of filtered fluid through the kidney, manifested by pathological markers, abnormalities in the blood or urine, or imaging tests. CKD can also be defined as the presence of low GFR of <60 mL/min/1.73m2 for three or more months with or without identifiable kidney damage (NKF, 2002).

CKD involves five stages depending on the severity of kidney damage and the level of decrease in kidney function. Stage five of CKD is referred to as ESRD which indicates the end of kidney function where the kidneys are working at less than 15% of their normal functioning. At this stage, RRT is essential to sustain life. However, not

everyone progresses from stage one to stage five. For the purpose of this study, I have chosen to study patients who are at stage five of their disease; namely ESRD.

2.2.1 Causes of Chronic Kidney Disease

The most commonly reported causes of CKD are vascular disease (i.e. hypertension), cardiac disease, peripheral vascular disease, diabetes mellitus, and chronic inflammation of the kidney (i.e. glomerulonephritis) (NKF, 2002). Other causes include familial disease (i.e. polycystic kidney disease), malignancy where bilateral nephrectomy (removal of the kidneys) is required, and infections such as HIV and hepatitis (B and C) (NKF, 2002).

2.2.2 Symptoms of Chronic Kidney Disease

Patients with CKD may develop the following symptoms: tiredness and less energy, trouble in concentrating, poor appetite, trouble in sleeping, muscle cramps, swollen feet and ankles, puffiness around the eyes (especially in the morning), dry, itchy skin and the need to urinate more often (especially at night) (NKF, 2002).

2.2.3 End-Stage Renal Disease

ESRD is the 5^{th} stage of CKD. The diagnosis of ESRD is a challenge due to its life-threatening nature and highly technical treatment. At this stage the damage to the kidneys is irreversible. The kidneys do not function properly or sufficiently which may lead to ill health as a result of the accumulation of wastes and fluids in the body causing potentially permanent and irreversible damage to body cells, tissues and organs.

2.2.3.1 Management of End-Stage Renal Disease

Developing ESRD means that the kidneys are unable to keep up with waste and fluid removal on their own and, therefore, RRT including HD, peritoneal dialysis (PD), and kidney transplantation (KTX) becomes the only option to support life (White and Grenyer, 1999). Although kidney transplantation may be the "gold standard" for treating ESRD, it is not available to everyone because there is a lack of donors nationally and many patients have to wait several years for a transplant (Bowman et al., 2011).

HD treatment is indicated when 85% to 90% of the kidney functions are lost (NKF, 2002). During HD the blood is pumped out of the patient's body by a machine and passed through an artificial kidney, called a dialyzer, through a vascular access, called fistulae, that is surgically created using the patient's arm or leg. This treatment is often required at least three times per week and each session can last between three to five hours (NKF, 2002). HD is typically carried out in a hospital or satellite unit where medical personnel are available. PD is very similar to HD; however in PD the blood is cleansed while still inside the body. Using a catheter surgically inserted into the abdomen, the peritoneal cavity is filled with dialysis fluid and the peritoneum functions like an artificial membrane in a dialyzer where excess water and wastes pass from the blood through the peritoneum into the dialysis fluid. The dialysis fluid is then drained from the body and discarded. This process is repeated 4-6 times every 24 hour period (Kidney Foundation of Canada, 2009).

Dialysis treatment, either HD or PD, keeps the body in balance by performing the following functions: (1) removes waste, salt and extra water to prevent them from building up in the body, (2) keeps a safe level of certain chemicals in the blood (e.g. potassium, sodium, and bicarbonate), and (3) helps to control blood pressure. For the purpose of this study, the focus will be on patients receiving HD treatment as it is the most commonly used form of treatment for patients with ESRD.

HD treatment often facilitates longer survival of patients with ESRD, thus increasing the incidence of patients on dialysis throughout the world (Miles and Friedman, 2001). At the end of 2012, there were 4,651 patients receiving RRT in Scotland. Of these, 52% had a functioning kidney transplant, 42% were being treated with HD and 6% with PD (Scottish Renal Association (SRA), 2012). 228 patients received a kidney transplant in Scotland in 2012; 27% of kidney transplants performed from 2008-2012 were from live kidney donors. The incidence of new patients starting RRT ranges from 51 patients per million (ppm) aged 20-44 years, up to 321 ppm in those aged ≥75 years. The rate for new patients was 108 ppm in the years 1998-2000 and 101 in 2012, as shown in Table 1.1 (SRA, 2012). These numbers indicate that there is increasing pressure on patients, staff, and the National Health Service (NHS).

Even though HD prolongs patients' survival and transforms the prognosis of patients with ESRD by improving their life expectancy, HD treatment brings with it a number of complications including dialysis site infection which often requires surgical or radiological intervention and can be very unpleasant for the patient (Miles and Friedman, 2001). Cardiovascular complications are also common amongst this group of patients

and increase the risk of precipitating myocardial infarction (Nolan, 2005). Other complications include bone disease and the development of renal osteodystrophy (Weisbord et al., 2003).

Although HD treatment can only treat the physiological problems, the resultant experience of being on dialysis places the patient and closer relatives under significant burden. Patients who receive HD treatment experience a wide range of multiple and radical lifestyle changes that affect the individual's social and psychological well-being, as discussed next.

2.2.3.2 Impact of End-Stage Renal Disease

As with other chronic illnesses, ESRD and its treatment predispose individuals to various physiological, psychological and social challenges, which may have a negative impact on the QOL and well-being of these patients. ESRD, however, has certain unique aspects relating to the technology involved in the treatment and the restrictions imposed by diet, fluid intake and an intense medical regime (Hagren et al., 2001). The fact that patients commit to a thrice weekly HD treatment plan for three to five hours per session and the need to travel back and forth to the dialysis unit are also factors that compromise patients' lives further (Welch and Austin, 1999).

The physical challenges have been reported by many studies and include fatigue, pruritus, sleeplessness, pain and general decrease in physical activities (Weisbord et al., 2003; Murtagh et al., 2007; Yong et al., 2009). Psychological challenges amongst patients with ESRD have been also reported by many researchers, including body

image distortion, lower self-esteem, helplessness and dependency on medical staff and technology (Patel et al., 2005; Morsch, 2006; Tanyi and Werner, 2008a). Psychological problems also include stress, anxiety, uncertainty and depression (Kimmel, 2005; Finkelstein et al., 2008). Evidence also suggests that the rate of patients diagnosed with a classified psychiatric disorder, such as depression, dementia and schizophrenia, in the ESRD population is substantially higher than that observed in other chronic medical conditions (Kimmel et al., 2002; Cukor et al., 2007). Depression is a common psychological challenge among the dialysis population and is generally linked to increased hospitalization and other complications including higher mortality (Kimmel et al., 2002; Gencoz and Astan, 2006; Finkelstein et al., 2008; Cengic and Resic, 2010).

The social challenges in the dialysis population include strained relationships with others, loss of roles and activities within the family and the wider community and the financial concerns arising from loss of employment (Leung, 2003; Tsay and Hung, 2004; Clarkson and Robinson, 2010). It has been also reported that the world of a dialysis patient can be isolated and social activities are greatly reduced (Faber et al., 2003). Furthermore, several studies have shown that, in comparison to the general population, patients with ESRD commonly report reduced physical functioning and overall physical activities (Covic et al., 2004; Molsted et al., 2004; Kaba et al., 2007; Seica et al., 2009; Kring and Crane, 2009; Santos et al., 2009). The World Health Organization (WHO, 1997) identifies QOL as the individual's perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards, and concerns.

2.3 Summary

It has been shown that ESRD is a chronic, debilitating, progressive and restricting disease that is likely to have a major impact on patients' health and, in particular, QOL and general well-being. The diagnosis of ESRD and the commencement of HD treatment introduce various challenges into patients' lives including physiological, psychological, emotional, spiritual and social challenges. Advancement in technology, addressing patients' physiological, psychological, social, emotional and spiritual needs and following treatment plans means that patients can survive longer while on HD treatment. However, the medical management of ESRD mainly focuses on prescribing a strict treatment regime, taking prescribed medications to avoid complications, and change in lifestyle to decrease signs and symptoms to improve QOL. Exploring QOL and well-being and other factors that may influence it, such as spirituality, social support and hope, has become an important area of health research in different populations with or without illnesses. Recently, there has been a major effort in assessing spirituality and its role in the lives of patients with ESRD (Kimmel et al., 2000; Patel et al., 2002; Walton, 2002; Tanyi and Werner, 2003) showing that spirituality can be an important coping strategy that may improve patients' QOL and well-being. Offering a better understanding of such an important concept might be valuable in identifying the future targets of the multidisciplinary management of ESRD and can be used to improve clinical practice and to develop appropriate policies or interventions to improve patients' health outcomes and general well-being. In Chapter 3, Part II of the literature review presents a critique of previous studies that have examined or explored spirituality among patients with ESRD.

Chapter 3- Literature Review Part II

3.1 Introduction

This chapter commences by presenting the differences between spirituality and religion (Section 3.2). The challenges associated with determining a universal definition of spirituality are outlined in Section 3.3. An overview of different definitions of spirituality follows, along with a discussion of the relative merits of each in Section 3.4. Review aims and questions and the search strategy for the main review are outlined in Sections 3.5 and 3.6, respectively. Next, Sections 3.7 and 3.8 present, discuss and critique the findings from the literature review on the meaning of spirituality and its role in the lives of patients with end-stage renal disease (ESRD). The chapter concludes by presenting a summary of the literature, knowledge gap and the aims and research questions of this thesis in Section 3.9.

3.2 Spirituality and Religion

The concept of spirituality is gaining more attention in the nursing arena. However, in spite of this increasing momentum, the term "spirituality" remains somewhat difficult to conceptualize (McBrien, 2006). Many people equate religion with spirituality, or use the words inter-changeably (Gorsuch and Walker, 2006), while others believe that equating spirituality and religion or using them inter-changeably is not valid (Scott, 2006). Hill et al. (2000) argue that spirituality is subsumed by religion, but some see religion as only one dimension of spirituality (Estanek, 2006). Tanyi (2002) agrees that

spirituality is the search for meaning, adhering to religion and balancing energy or basic trust.

While former definitions identified from the literature purport religion and spirituality to be synonymous terms, Murray and Zenter (1989) conversely assert that spirituality does not equate with formalized religion. Indeed, spirituality goes beyond religion in that it gives meaning and purpose to life in times of physical or emotional distress, regardless of the religious affiliation. According to Murray and Zenter (1989, p.259) spirituality is "*a quality that goes beyond religious affiliation, that strives for inspiration, reverence, awe, meaning and purpose, even in those who do not believe in any God. The spiritual dimension tries to be in harmony with the universe, strives for answers about the infinite and comes into focus when a person faces emotional stress, physical illness or death*". Therefore, spirituality is considered to be an individual's search for meaning and purpose in life. In contrast, religion is described as a formalized set of beliefs, customs and practices. Religion reflects an individual's ostensible identification with a particular religious denomination (Baker, 2003; McBrien, 2006). However, these very rigid beliefs, customs and values of any formal religion operate against the principles of individuality (Henery, 2003). Nevertheless, Smith (2000) and Wright (2000) are among many Christian writers who raise arguments against removing religion and God from discussions of spirituality. The differences between religion and spirituality mean that it is challenging to identify one definition of spirituality and some of these meanings are discussed next.

3.3 Challenges Defining Spirituality

Spirituality is a universal phenomenon (Berry, 2005) and it is not unexpected that it is increasingly receiving more interest than religion in the academic literature (Dy-Liacco et al., 2005). Research has focused on defining and conceptualizing the concept of spirituality (Pargament, 1999b), the measurement of spirituality (Miller, 2004; Levenson et al., 2005) and has explored the role of spirituality within a range of contexts such as the relationship between spirituality and health outcomes (Rippentrop et al., 2005; Tsuang et al., 2007; Schlundt et al., 2008; Park et al., 2009). However, the robustness of research addressing spirituality might be affected by the lack of a uniform definition of the concept. Researchers who are looking for a common and universal definition of spirituality in which to activate the concept will probably find it difficult and challenging with construct confounds, cross-cultural nuances and conceptual inadequacies (Thoresen and Harris, 2002; Berry, 2005). Several issues muddle the coherence of the construct including: the use of spirituality and religion inter-changeably in recent research, the blurring of boundaries between spirituality and other related constructs, the cultural challenges related to the conceptualization of spirituality and lastly, the deficiency of clarity relating to spiritual experiences and those practices that look to address a spiritual experience (Harmer, 2009).

How spirituality relates to religion is one of the challenges associated with determining a uniform definition. Pargament (1999b) suggests that spirituality sits within the broader domain of religion. On the other hand, Stifoss-Hansen (1999) describes religion as one element of an individual's more holistic pursuit of the spiritual. Spirituality and

religion have also been considered as two distinct and unrelated constructs (Verno et al., 2007; Helminiak, 2008). Spirituality and religion have also been used inter-changeably, or synonymously, in health and psychological research (Zinnbauer et al., 1997; Mattis, 2002). Unfortunately, using spirituality and religion synonymously is an increasing trend in published research in the field of health research (Berry, 2005).

The blurring boundaries in literature between spirituality and other related constructs is another challenge in determining a uniform definition such as psychological well-being, social and subjective well-being (Keyes et al., 2002), to name just a few. Existing research into spirituality has not sufficiently examined the associations between spirituality (however it is activated) and other existing constructs concurrently examined in health research. This is an area that needs further exploration.

Moreover, a universal definition also remains difficult because of the different perspectives relating to the right path or practice for exploring spirituality, including: Dharmic (e.g. Buddhism), Monotheistic (e.g. Christianity or Islam), Indigenous (e.g. Celtic or Shamanism), agnostic and atheist. Considering the many paths available, it is possible that people's definition of spirituality might be influenced by their own experience or practice of the spiritual (Stifoss-Hansen, 1999; Nasel et al., 2005). Researchers also debate whether all spiritual experiences can be considered equal. This is another challenge in finding a universal definition of spirituality. It is arguable whether the spiritual experiences of historical figures such as Mohammed, Jesus, Buddha can be considered the same as those the "every-day" person experiences on his or her spiritual journey. Research proposes that all spiritual experiences cannot be

considered equal with this premise based on varying depths of "consciousness" (Rosado, 2000). With researchers stating that spirituality develops across the individual's lifespan (Hill et al., 2000), it remains to be seen whether an individual's deeper stages of conceptual complexity translates into an experience of spirituality that is also more complex in nature (Reich, 2000).

Lastly, for spirituality to be considered a universal phenomenon, an important question needs to be answered. That is, does spirituality need to be culture, socio-economic, gender, age, or value neutral? Considerable research suggests that it is none of these things (Shahabi et al., 2002; Mansfield et al., 2008). The methodological and measurements confounds associated with exploring spirituality in existing research probably led them to fail in finding out whether it was culture, socio-economic, gender, age, or value neutral (Moberg, 2002). Hence, a definition for operationalizing spirituality must account for the subjective, individual and personal explanation of one's spiritual experiences. Given the previous challenges, it remains no surprise that the identification of a uniform and operational definition of spirituality has proven difficult and challenging (Pargament, 1999b; Miller, 2004). In their review of the literature looking into the different definitions of spirituality, McSherry and Cash (2004) conclude that it would appear that there is no such thing as a universal definition of spirituality and the theoretical probability of creating one is virtually impossible. In the next section, different definitions of spirituality are discussed to highlight the inconsistencies from current research in defining spirituality and in order to develop or adopt a definition of spirituality that will be used in my thesis. This definition will be

used to find out whether or not spirituality definitions identified by the study participants are in line with existing literature.

3.4 Different Definitions of Spirituality

As highlighted in Section 3.3, finding a universal definition of spirituality is challenging and problematic. Maher and Hunt (1993, p.22) propose that "*what makes the process of defining spirituality so elusive is the nature of the term itself. It is value laden and seemingly so cultural, religiously and ethnically bound, that any meaningful definition appears to be an exercise in futility*". However, the challenges associated with defining spirituality have not prevented an explosion in the development of spirituality measures. Hill and Hood (1999) carried out an extensive review of the literature and identified more than 120 definitions of spirituality. Yet, how spirituality is defined in the studies identified by Hill and Hood is a question that still needs to be answered. Unruh et al. (2002) also carried out another review of the literature to look into different meanings of spirituality and religiosity and identified seven themes highlighting how spirituality is defined in health literature, including: (1) transcendence or connectedness to a belief or higher being; (2) existential, not of the material world; (3) relationship to God, a spiritual being, a higher power, or a reality greater than oneself; (4) not of the self; (5) a life force of the person, integrating aspect of the person; (6) meaning and purpose in life; and (7) summative, including definitions that included many of the above-mentioned themes, as well as values and motivations.

The National Interfaith Coalition on Aging in the United States of America (USA)

(NICA, 1975) identified four sets of relationships/principles as the components of a person's spiritual well-being. These principles allow for an individual, multidimensional and subjective operationalization of spirituality and are summarized as follows: (1) spirituality as grounded in a belief in a higher being (i.e. God), which considers spirituality to be relevant to the thoughts and practices that underpin theologies either broadly or narrowly defined; (2) spirituality as grounded in self-fulfilment, a conceptualization of spirituality that focuses on human achievement or potential; (3) spirituality as grounded in the relationship with oneself, and (4) spirituality as grounded in the connecting of oneself to a larger "system", which focuses on one's relationships with the broader reference group, nature or ecology. While these are not definitions of spirituality *per se*, they offer a contemporary understanding of spirituality. For the purpose of identifying an operational definition of spirituality in my thesis, a number of definitions of spirituality were identified and evaluated against the NICA principles.

The first principle states that spirituality is grounded in a belief in a higher being and thus considers spirituality to be relevant to the thoughts and practices that underpin theologies either broadly or narrowly defined. Pargament (1999a) describes spirituality as "*a search for the sacred*" (p.12), whereas religion is described as "*a search for significance in ways related to the sacred*" (p.12). The "sacred" is an entity (e.g. God or Ultimate Being), object, principle or concept that transcends the self, that is, set apart from the ordinary and is worthy of worship (Hill et al., 2000). Pargament suggests that the self transcends through searching for the sacred, which may not include an

intermediate, “sacred” acts, such as the pursuit of academic excellence, or the like as worthy of worship, or self-fulfilment and personal satisfaction (Pargament, 1999b). As can be seen from Pargament’s definition, spirituality is placed within the broader domain of religion, suggesting that it can be influenced by the beliefs, values and principles of a specific religion. However, this is challenging and asserts the difficulty in determining a universal definition of spirituality considering that there is no one universal religion practiced throughout the world. The fact that different religious doctrines have adopted diverse and often competing religiosities may therefore make it impossible to identify a universal definition of spirituality. Moreover, placing spirituality within the domain of religion restricts research to a narrower and more traditional conceptualization of “God” (Stifoss-Hansen, 1999).

Given that there are various types of religions and that, although the majority of the UK population follow more traditional religious beliefs and practices (59% of the UK population is reported as being Christian) (UK Census, 2011), there are many who follow other religious beliefs and practices. Therefore, the first principle/definition of spirituality as highlighted above might not be applicable to people following Islam, or people of Dharmic (e.g. Buddhism) origins, for instance (McSherry and Cash, 2004). Hence, the ongoing use of Pargament’s definition of spirituality could be argued as limited.

The second principle defines spirituality as grounded in self-fulfilment which suggests that spirituality focuses on human achievement or potential and relationship with oneself. To reflect this principle, Stifoss-Hansen (1999) proposed that “*spirituality is*

people's search for meaning, in relation to the big existential questions" (p.28). Therefore, spirituality includes different characteristics that are not in line with Pargament's definition of spirituality. These characteristics include connectedness, authenticity, existentialism, meaning of life, holism and self and community, which are considered as aspects of an individual's spirituality, indicating that spirituality must be considered a broader, not a narrower, concept of religion. As can be seen from Stifoss-Hansen's definition of spirituality, it seems broader than that provided by Pargament and goes beyond the possibly narrow limitations of traditional religion. However, there remains a question as to whether searching for existentialism can result in one living a spiritual life. Pargament (1999a) debates whether it may or may not and asserts that finding meaning in life, which might be considered as part of existentialism, is not spiritual in nature or complexity. Further consideration of Stifoss-Hansen's definition of existentialist spirituality suggests that one seeks to know the self, free from beliefs, feelings and identities or labels created upon fear of losing one's physical and psychological identities (Ho and Ho, 2007). Seeking the self has a higher degree of complexity and may therefore require a lifetime dedication and self-discipline to master (if mastering the pursuit is, truly, possible) (Hamel et al., 2003).

Hill et al. (2000) offered another definition of spirituality, highlighting that it is the "*thoughts, feelings and behaviours that arise from a search for the sacred*" (p.66). They even developed a criterion for considering Pargament's definition of spirituality. According to Hill et al., "*the term 'search' refers to the attempts to identify, articulate, maintain, or transform while the term 'sacred' refers to the divine being, divine object,*

Ultimate Reality, or Ultimate Truth as perceived by the individual" (p.66). In opposing Pargament's definition, Hill et al. suggest that even though an individual's spirituality can be expressed through religion, it does not essentially need the institution of religion. Hill et al. (2000) consider the role of a Being or Purpose that is superior to the individual; namely the Transcendent, which might or might not involve God as the Higher Being. One's Higher Being or Purpose may be placed within or beyond the individual. The transcendent may be external to the individual, a recognition of something superior to the individual (Mahoney and Pargament, 2004).

The third and fourth principles identified by the NICA in the USA (1975) highlight that spirituality is grounded in the connecting of oneself to a larger system or with oneself. To reflect this principle, Reed (1992) offered a definition of spirituality that focuses more on the individual relationships with self, others, nature and a power greater than the self. According to Reed: ''*spirituality refers to the propensity to make meaning through a sense of relatedness to dimensions that transcend the self in such a way that empowers and does not devalue the individual. This relatedness may be experienced through connectedness with the self, connectedness with others, the natural environment and through relatedness to the unseen, God, or power greater than the self and ordinary source*" (p.350). As can be seen from Reed's definition, it appears that spirituality is firmly centred on interpersonal relationships and the community; where nature or the environment has a central role in one's experience of spirituality. Contrary to some other definitions of spirituality offered, the one offered by Reed suggests that one can only know who they are after they have achieved connectedness with self,

others, and the environment, and God or higher power. Considering Reed's definition further, by its very nature, it appears to be holistic. It demonstrates that spirituality means an awareness of oneself and our relationships with everything that is not the self (Meehan, 2002). It highlights that individuals seeking spirituality must identify, understand and value the essential socio-spiritual fabric connecting them with all others and nature (Fraser and Grootenboer, 2004).

Given that not all humans are spiritual or might be considered spiritual, the ongoing use of the previous principles/definitions of spirituality linking it to connectedness to the self, others and nature could also be argued as limited. Reviewing each of the definitions presented so far, if spirituality is a universal phenomenon relevant to all persons (Helminiak, 2008), then it is critical that research arrives at a universal definition of spirituality. It could be argued that the continual failure to develop a universal definition of spirituality may therefore place research exploring this concept and evaluating its relationships with health outcomes of patients with chronic illness, and ESRD, within a potential methodological paradox (Helminiak, 2008; Kohls et al., 2009). Given the diversity of perspectives as to what spirituality "is", I have used a definition that reflects the four principles highlighted earlier. This definition was developed by Nolan et al. (2011) during the European Association for Palliative Care Congress in Vienna with the aim of identifying one definition of spirituality that could be applied in Europe. According to Nolan and his colleagues: "*Spirituality is the dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and*

the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred" (p.88). Nolan et al.'s definition of spirituality contains the four principles discussed above and is in line with some other definitions; however, it goes further to reflect the four sets of relationships originally presented by NICA (1975). Fisher (1998) built his Four Domains Model of Spiritual Health and Well-Being on the NICA framework definition, which states that spiritual well-being is not limited to only religious or spiritual behaviours (e.g. belief in God, reading the Bible, church attendance, or praying) and experiences, but extends to the affirmation of life in relationships with oneself (personal), others (communal), nature (environment), and God (transcendental others).

While no one definition of spirituality is possible, Nolan et al.'s (2011) definition of spirituality is used as a working definition in my study to find out whether the definitions of spirituality offered by my study participants agree with it, how participants in my study viewed spirituality and how it might link to their health outcomes and well-being.

3.5 Review Aims and Questions

The literature review has two aims. First, to identify and critique available literature that explores the meaning of spirituality for patients with ESRD. Second, to identify and critique available literature that examines the relationship between spirituality and the health outcomes and general well-being of patients with ESRD. The review aimed to answer the following questions:

- What does spirituality mean to patients with ERSD?

- Are there associations between spirituality and the health outcomes and general well-being in patients with ESRD?

3.6 Search Strategy

It is not feasible to identify all available research studies on a particular topic to be included in a review (Aveyard, 2010). However, in this review all efforts were made to locate all studies pertinent to the subject under investigation. Therefore, more than one database was accessed to achieve a comprehensive search as shown in Table 3.1. The Index to Theses of Great Britain and Ireland was used to access British and international PhD theses related to the search criteria where possible.

Table 3.1: Electronic Databases Searched

Database	
CINAHL*	Provides authoritative resource of nursing and allied health professionals, students, educators and researchers.
MEDLINE	Provides authoritative medical information on medicine, nursing, dentistry, the health care system and much more.
PSYCHINFO	A database that indexes the psychological literature.
ATLA	Provides information on topics such as biblical studies, world religion, church history and religion in social issues.
AMED**	Covers a selection of journals in three separate subject areas: professions allied to medicine, complementary medicine and palliative care.
The Cochrane Library	Contains high-quality, independent evidence to inform healthcare decision-making.
PubMed	Comprises more than 21 million citations for biomedical literature from MEDLINE, life science journals, and online books.
British Nursing Index	Comprehensive index covering all aspects of nursing, midwifery and community healthcare.
Web of Knowledge	A multidisciplinary content providing retrospective coverage in the sciences, social sciences, arts, and humanities.
Science Direct	Contains over 25% of the world's science, technology and medicine full text and bibliographic information.

***CINAHL (**Cumulative Index of Nursing and Allied Health Literature); ****AMED** (Allied and Complementary Medicine Database)

Different Medical subject heading (MeSH) terms were used and the appropriate Boolean operators (OR, AND) were used to connect the various search terms used, as shown in Table 3.2. Google Scholar was accessed as a public site for research to obtain useful resources related to the field of interest (e.g. conference proceedings and support group publications). I also accessed relevant literature by cross-referencing from journals already available via databases as well as manual scrutiny of more recent journals to ensure that potential sources not yet listed in the computerised databases had not been overlooked (e.g. Nephrology Dialysis Transplantation, Kidney International). E-mail alerts using ZETOC, Medscape, EBSCO (EPNET alerts) and NCBI-PubMed were set and received either weekly or monthly to ensure that I was abreast of new literature as it was published.

Table 3.2: Search Terms used in the Search Strategy

Topic	Key words
Spirituality	Spiritual$ OR Religion OR Religious$
End-stage renal disease	End-stage kidney disease OR disease, end-stage kidney OR end-stage kidney disease OR kidney disease, end-stage OR chronic kidney failure OR end-stage renal disease OR disease, end-stage renal OR end-stage renal disease OR renal disease, end-stage OR renal disease, end-stage OR renal failure, end-stage OR end-stage renal failure OR renal failure, end-stage OR renal failure, chronic OR chronic renal failure OR ESRD OR Haemodialysis OR haemodialysis OR haemodialysis patients OR dialysis OR dialysis patients OR renal dialysis
Health and quality of life	Quality of life OR health related quality of life OR well-being OR QOL OR HRQOL OR health outcomes

Studies were included if they focused on the following: spirituality in the lives of patients with CKD, ESRD, or in people receiving HD treatment; explored or examined the relationship between spirituality and the QOL, health outcomes and general well-being of patients with ESRD; were published in English to avoid the problems arising from the need for translation, which I had no access to, and if they were published between 1999 and 2014. Although spirituality was introduced as a MeSH term in 2002, I used this timeframe to include all studies that have been conducted exploring spirituality in the past 15 years and to ensure that no seminal studies were overlooked. Also, this time frame was used because evidence beyond this date could be out of date and to avoid generating too large a volume of studies which can make it harder to critique and appraise them. However, only a limited number of studies were retrieved and therefore all retrieved studies were included in the review.

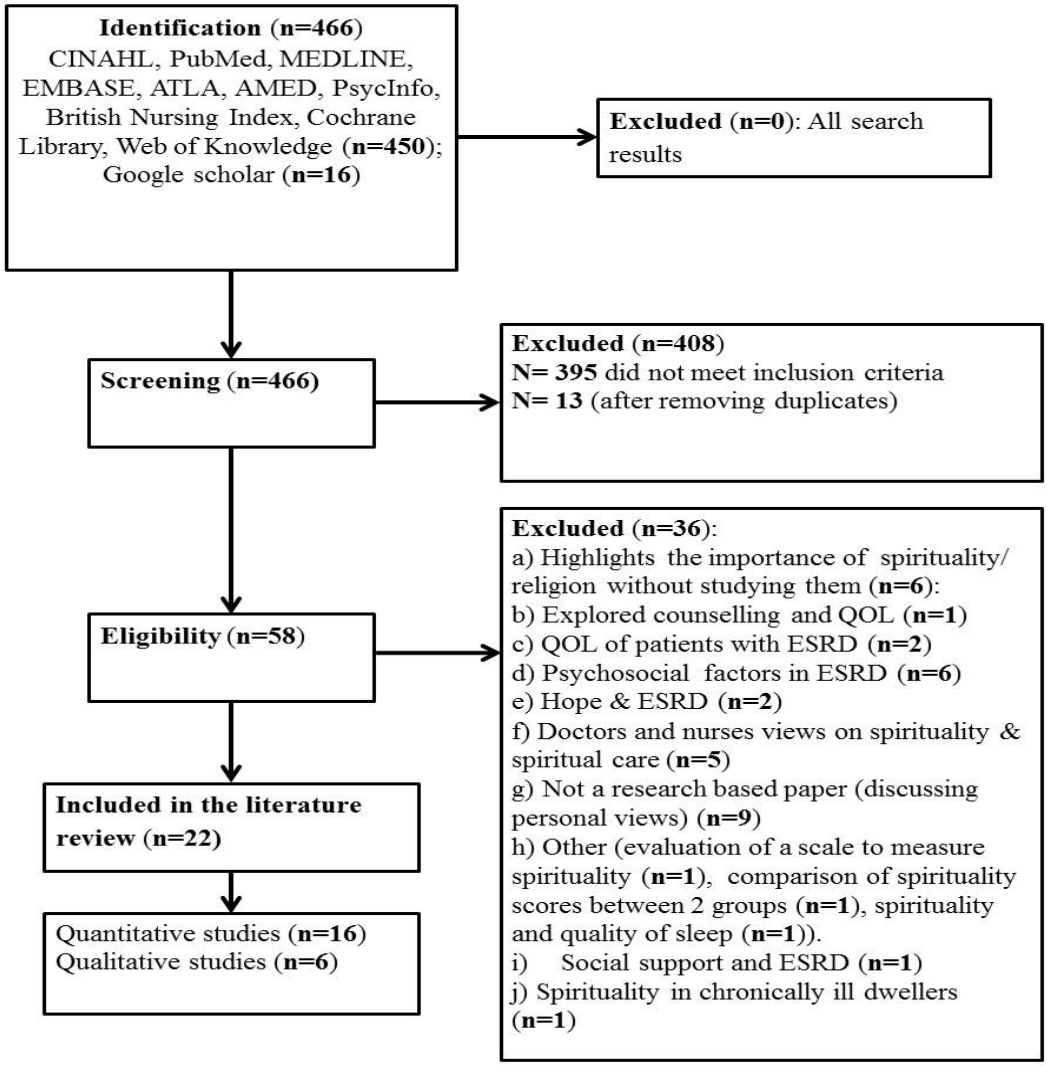
Studies were excluded if they were focusing on children with ESRD, caregivers of patients with ESRD, physiological outcomes, or interventions, as they were not relevant to the area of study (i.e. the role of spirituality in the lives of patients with ESRD). Studies were also excluded if they were commentary letters to editors or not reporting original research results.

3.6.1 Data Extraction

Abstracts of all retrieved studies were screened initially and all relevant studies were exported to RefWorks (version 2.0) to be read in full. Initial screening was carried out because the search strategy retrieved 466 papers. In total, 408 were excluded (n=395

did not meet the inclusion criteria and n=13 were duplicates). In total, 58 studies were exported to RefWorks. During further screening of a full text copy of each paper, 36 were excluded (as shown in Figure 3.1). After thorough reading, 22 studies were included in the final review (see Tables 3.4 and 3.5). Figure 3.1 highlights the process for study selection.

Figure 3.1: Studies Selection Process



3.6.2 Quality Appraisal

In total, 22 studies met the inclusion criteria and are included in this review. Six qualitative studies explored spirituality in patients with ESRD, and 16 quantitative studies examined the relationships between spirituality and religiosity and the psychosocial factors, mental health and the QOL or health-related quality of life (HRQOL) of patients with ESRD. The quality of the reviewed studies was assessed using the quality appraisal checklist (Appendix 1) that was developed based on the Critical Appraisal Skills Program (CASP, 2103) (as shown in Table 3.3). Also, a literature review matrix was developed for ease of referral and summation of retrieved studies (Appendix 1). Regular meetings with my supervisors were held to give an update on the search strategy progress and the process of data extraction. The matrix included the following headings: Author/s, year of publication, country, studies' research questions and aims, methodology and methods (i.e. design, sampling methods, participants' characteristics, inclusion and exclusion criteria, and data analysis methods), key findings and strengths and limitations. Due to the limited number of studies exploring spirituality in the lives of patients with ESRD, no study was excluded based on its quality.

Table 3.3: Checklist for Appraising the Included Studies

Qualitative Studies

No	Item	Yes	No	Can't tell
1	Was there a clear statement of the aims of the research?			
2	Is a qualitative methodology appropriate?			
3	Was the research design appropriate to address the aims of the research?			
4	Was the recruitment strategy appropriate to the aims of the research?			
5	Was the data collected in a way that addressed the research issue?			
6	Has the relationship between researcher and participants been adequately considered?			
7	Have ethical issues been taken into consideration?			
8	Was the data analysis sufficiently rigorous?			
9	Is there a clear statement of findings?			
10	How valuable is the research?			

Cohort Studies

No	Item	Yes	No	Can't tell
1	Did the study address a clearly focused issue?			
2	Was the cohort recruited in an acceptable way?			
3	Was the exposure accurately measured to minimise bias?			
4	Was the outcome accurately measured to minimise bias?			
5	Have the authors identified all important confounding factors?			
6	Was the follow up of subjects complete & long enough?			
7	What are the results of this study?			
8	How precise are the results?			
9	Do you believe the results?			
10	Can the results be applied to the local population?			
11	Do the results of this study fit with other available evidence?			
12	What are the implications of this study for practice?			

Adapted from CASP, 2013

3.6.3 Selected Studies

The literature review underlined a dearth of literature that explored and examined spirituality and its role in the lives of patients with ESRD receiving HD treatment. Three of the six qualitative studies retrieved explicitly explored spirituality in the HD population (Walton, 2002; Walton, 2007; Tanyi and Werner, 2008b). Although the main aim of the other three studies was not to explore spirituality, they highlighted that spirituality was important in the lives of their study participants as emerged from their findings. For instance, one study examined the lived experience of patients with ESRD

(Tanyi and Werenr, 2008a), one study explored the different coping strategies within this population (Yodchai et al., 2011) and the other study explored stories of spirituality in patients with chronic illnesses where a number of patients diagnosed with ESRD was recruited to participate (Molzahn et al., 2012). Only four quantitative studies examined the relationship between spirituality and QOL or HRQOL of patients receiving HD treatment. Noticeably, there were methodological limitations within the studies, which are discussed later. In general, these studies highlighted that spirituality is important in the lives of patients with ESRD and almost all studies emphasized the need for further research to explore this important concept amongst patients with ESRD.

3.6.4 Characteristics of Studies Included in the Review

3.6.4.1 Year and Place of Publication

The 22 studies retrieved were all published in English over a 12-year period between 2002 and 2014. Of these, 13 studies were conducted in the United States of America (USA) from 2002-2011; three studies were conducted in Canada from 2010-2012; three studies were conducted in three different Asian countries from 2009-2012, namely Taiwan, Thailand and Malaysia; and three studies were conducted in Brazil from 2012-2014. The increasing number of publications since 2002 suggests that there might be an increasing interest globally in exploring spirituality and its influence on the health outcomes and well-being in patients with ESRD. However, surprisingly, there were no studies identified that examined or explored spirituality among this specific population in the UK. One reason for this lack of research might be because of the cultural

differences in the perception of what is spiritual and what is religious, as "spiritual" in the USA is commonly equated with factors which in the UK are more likely to be termed as "religious" (Holloway et al., 2011). According to Holloway et al. (2011), more sophisticated empirical studies are required in the UK to show that a broader understanding of spirituality may improve health outcomes.

3.6.4.2 Methodological Limitations

Important methodological limitations exist within the retrieved studies in this review. For instance, there is often a lack of theoretical underpinning or linkage to a theoretical model in spirituality research among patients with ESRD, which could be important and help to build a bridge between theory and practice. Only two studies offered a theoretical justification of their study (Tanyi and Werner, 2003; Molzahn et al., 2012). Noticeably, there was a lack of consistency in defining spirituality. It was often used inter-changeably with religion, which may have resulted in reporting confusing or inconsistent findings. In addition, there was a lack of consistency in measuring spirituality and measuring other factors that might have a relationship with it (e.g. QOL). However, regardless of these limitations and because of the lack of research examining spirituality in patients with ESRD, no study was excluded based on its quality.

3.6.4.2.1 Design of the Studies Included in the Review

Of the 22 studies, six used a qualitative approach including grounded theory (Walton, 2002 and 2007; Yodchai et al., 2011), descriptive phenomenology (Tanyi and Werner,

2008a; Tanyi and Werner, 2008b) and one study used narrative inquiry (Molzahn et al., 2012). Ten studies employed a cross-sectional survey design. Six studies did not explicitly mention the study design; however, they seemed cross-sectional in nature. No studies reported using a longitudinal approach among patients with ESRD currently receiving HD treatment. Further research using such a design would be beneficial. As highlighted earlier, the majority of the studies (n=16) employed a survey design and, in particular, a cross-sectional design (n=10), indicating that it is the most commonly used method in studying spirituality/religion in patients with ESRD. This method may limit the ability of the studies to identify causal relationships between the studied variables and spirituality, thus limiting the generalizability of their findings.

3.6.4.2.2 Sample Size and Studied Population

Studies that are small in terms of the sample size might be limited sometimes in the generalizability and transferability of their findings, in particular, those with a small effect size, although they may have significance for similar populations (Patton, 2002). The sample size in the quantitative studies varied from as low as 51 participants (Song and Hanson, 2009) to as high as 633 participants (Kao et al., 2009). Four studies had ≤100 participants (51-74 participants), seven studies had a sample size ranging from 100 ≤ 200 and five studies had a sample size of ≥ 200 participants (200-633). Generalizing the findings from some of these studies to all dialysis populations might be difficult for several reasons; for instance, recruiting a small sample (e.g. Patel et al., 2002; Song and Hanson, 2009); recruiting participants from one dialysis unit (e.g. Ko et al., 2007; Martinez and Custodio, 2014) and studying a non-representative sample of

the dialysis population such as African Americans (Spinale et al., 2008; Thomas and Washington, 2011) or women only (Tanyi and Werner, 2008b). One qualitative study in this review (Yodchai et al., 2011) recruited a sample of only five participants and so, based on its findings, it might not be possible to conclude that all patients employ spirituality/religion as a way of coping with their disease.

In addition, using self-selection (e.g. Davison and Jhangri, 2010) and convenience sampling methods to recruit participants (e.g. Tanyi and Werner, 2003; Molzhan et al., 2012) limits the generalizability of some of the findings. Therefore, the findings from these studies should be treated with caution.

3.6.5 Structure of the Studies Reviewed and Critiqued

In this review, the findings from the retrieved studies are presented in a way that will answer the review questions set out in Section 3.5. Studies that explore the meaning of spirituality for patients with ESRD are presented first. Then, consideration is given to studies exploring the importance of spirituality and its influences on the health outcomes and well-being of patients with ESRD. The main themes that emerged from the literature review were: meaning of spirituality for patients with ESRD and spirituality in the lives of patients with ESRD. The latter theme comprises three sub-themes; spirituality and QOL, spirituality and psychological adjustment, and spirituality and satisfaction with care and treatment preferences. A summary of all retrieved studies is presented in Tables 3.4 and 3.5.

Table 3.4: Summary of the Qualitative Studies Retrieved in the Review

Author/s, year/ country	Aim/ Research question/ hypothesis	Methodology/ Methods					Key findings	Strengths (S), Limitations (L)
		Design/ sampling method	Sample & participants characteristics	Inclusion/ exclusion criteria	Tools	Data analysis		
Walton, J., 2002 USA	What does spirituality mean to HD patients? How does it influence the lives of HD patients? .	Grounded Theory All patients volunteered to participate	11 patients (4 men, 7 women), All receiving HD, aged 36-78 year, time on dialysis 6 months to 24 years (average 7 years), 3 married, 10 Caucasians and 1 American Indian, 3 had no religious affiliation.	Patients from rural areas, hospital based, out-patients HD units.	Interviews 60-90 minutes) and demographic data	Glaserian method of grounded theory Theoretical memos	Spirituality is a life-giving force from within, full of awe, wonder and solitude that inspires one to strive for balance in life. Spirituality is nurtured by connecting with people, God and the environment. Finding a balance is a central core category. Faith, presence, and receiving and giving back were subcategories. Spirituality is much broader and more encompassing than religion, involving relationships, decisions, problem solving, introspection, reflection, challenges of living, and so much more.	**S**: First study to use grounded theory design. Results validated by participants, 10 nurses and 1 social worker validated the results for clarity, understanding and clinical application. Clear approach to data analysis and theory generation. **L**: Lack of reporting on the demographics of participants. The study was conducted in one dialysis unit.
Walton, J., 2007 USA	To explore what spirituality means for individuals who are American Indians receiving HD treatment	Grounded Theory All patients volunteered to participate	21 participants (12 women, 9 men), All receiving HD treatment, aged 24-62 years. Period on dialysis from 1 month to 10 years.	English speaking, American Indians, 18 years and older receiving HD in two different dialysis units	16 In-depth interviews (45-2) hours Field notes and theoretical memos	Classic Glaser and Strauss method of grounded theory analysis	Spirituality is a way of "being in the world" and involved all aspects of living. Praying was the core category and was strongly infused throughout the other four categories: honouring spirit through reading the Bible, praying, and going to church weekly; resisting HD by refusing HD initially; healing old wounds which manifested in building esteem and respect, feeling loved, fighting addictions, setting limits, and caring for self. Connecting with family and community evolved through nurturing family, being with family and friends, belonging, and helping others. Praying was a powerful way to cope with the stress of HD. Prayer nourished inner strength and helped cope with hardships, offered hope and inner strength.	**S**: Grounded theory design, 5 interviews to verify saturation. Independent nephrology nurse (experienced in research) reviewed interview data to ensure rigour. Results reviewed by 6 participants, 2 American Indian nurses for understanding, clarity & application. **L**: Only American Indian in rural areas

Author/s, year/ country	Aim/ Research question/ hypothesis	Methodology/ Methods					Key findings	Strengths (S), Limitations (L)
		Design/ sampling method	Sample & participants characteristics	Inclusion/ exclusion criteria	Tools	Data analysis		
Tanyi & Werner, 2008a. USA	To explore and describe the experience and impact of spirituality in the day-to-day lives of women with ESRD.	Descriptive phenomenology Purposive and convenient sampling	16 women receiving HD 3 times/week aged 29-77 years. 11 Black American, 3 Caucasian, 1 Hispanic & 1 Asian. Time on HD from 7 months to 21 years, 2 Protestant, 3 Catholic, 3 Christian, 3 Baptist, and 1 Jewish, 1 Lutheran, 1 Seventh Day Adventist, 1 Pentecostal, and 1 Nondenominational, 3 married, 2 living with partners, 7 never been married, 3 widowed, and 1divorced	Older than 18yrs, English speaking On HD>6 months free of any acute medical conditions, not diagnosed with cognitive disability or mental illness	Interviews (45-90 minutes), interview guide. A second brief interview 10-15 minutes to clarify and corroborate findings	Colaizzi's (1978) methodology Field notes Line by line analysis	Spirituality is extremely important in living with illness and necessary treatment regime. Spirituality may be a significant consideration in nursing and interdisciplinary health care. Four themes emerged: Acceptance: spirituality enabled women to come to terms with their diagnosis and treatment, accept themselves and their lives, being able to face mortality. Understanding: spirituality is an inner force that engendered insights and allowed them to question, understand, and learn from their illness. Fortification: seeking God's help enabled them to endure and fight their illness. Women felt protected through the presence of God, angels, and Holy Spirit in their lives. Emotion modulation: spirituality is essential in buffering against & reducing anger, depression, anxiety, and bitterness, thereby fostering coping. Spirituality helped in reducing fear, giving peace & maintaining a positive outlook and encountering happiness.	**S**: First study to explore spirituality in depth with HD patients. Ethics addressed. Researcher's presuppositions about spirituality were noted to avoid bias. Trustworthiness of data highlighted. **L**: Women only, majority African American.
Tanyi & Werner, 2008b USA	To examine the lived experiences of community-dwelling women with ESRD undergoing HD treatment.	Descriptive phenomenology Purposive and convenient sampling	16 women from 2 HD centres. Aged 29–77 years, time on HD 7 months to 13 years, 11 Black American, 3 Caucasian, 1 Hispanic & 1 Asian, 2 Protestant, 3 Catholic, 3 Christian, 3 Baptist, and 1 Jewish, 1 Lutheran, 1 Seventh Day Adventist, 1 Pentecostal, and 1 Nondenominational, 3 married, 2 living with partners, 7 never married, 3 widowed, and 1 divorced	Older than 18yrs, English speaking On HD>6 months free of any acute medical conditions, not diagnosed with cognitive disability or mental illness	In-depth interviews (45-90 minutes), brief second interview (10-15 minutes) to clarify and corroborate data.	Colaizzi's (1978) methodology Field notes Line by line analysis	Three major themes emerged: A. Initiation: involved an initial phase of adjustment which was fraught with fear, confusion, hatred for the treatment, relying on loved ones and spiritual beliefs for support and finally accepting the diagnosis and the necessity of treatment. B. Appreciation: the middle phase of adjustment as women reached a point where they started appreciating HD treatment because it improved their health. C. Grappling: later phase of dealing with the negative effects of HD.	**L**: Women only, data collection may be limited due to lack of privacy in the dialysis units. Only two dialysis units.

Author/s, year/ country	Aim/ Research question/ hypothesis	Methodology/ Methods					Key findings	Strengths (S), Limitations (L)
		Design/ sampling method	Sample & participants characteristics	Inclusion/ exclusion criteria	Tools	Data analysis		
Yodchai et al, 2011, Thailand	To understand the process Thai patients with CKD use to adapt to requiring HD treatment	Grounded theory purposive sampling	5 patients, aged 24-66 years, (mean 45.40), 2 single, 2 married, 1 widow. Time on HD ranged from 3 months and 7 years (mean 50.80 months).	Diagnosed with CKD, received HD for at least one month, able to communicate and read in Thai, having vital signs within normal limits. Excluded if unfit (either physically or psychologically).	Data collected in Thai. In-depth individual interviews at participants' home using an interview guide (60-90 minutes). Field notes. Standard demographic Data collected. Data collected from January and May 2010	Strauss & Corbin 1998 Grounded theory approach including open, axial and selective coding. Verbatim transcribing Theoretical memos	Four main coping strategies (planning, adjustment and avoidance, belief in religion and superstition and living with hope) were used to adapt to HD and perform physiological functions, adapt or maintain self-concept and role function and interdependence. Planning, and adjustment and avoidance were used to cope with social and physical changes, while belief in religion and superstition and living with hope were used to cope with mental and spiritual changes. Patients reported a range of adverse effects including fluid restriction, fatigue, effects on sexual activity, altered body image, fear of dying, stress and depression and suicide.	**S**: Detailed analysis approach, follow up phone calls for clarification. Participants reviewed the transcripts for verification. **L**: Small sample of 5 from one religious group (Buddhist), sample from one dialysis unit.
Molzahn et al., 2012, Canada	To examine stories of spirituality in people living with serious illness	Narrative inquiry (qualitative design) Convenience sampling, word of mouth and snowball sampling	32 (18 men, 14 women), 10 with cancer, 14 with ESRD and 8 with HIV/AIDS, Aged 37–83 years (Mean = 61.2), time from diagnosis 1–50 years (Median = 8). All but 3 lived in urban settings, all but 3 were Caucasian (1 Indo–Canadian and 2 Aboriginal), 10 were Christian, 2 reported Aboriginal belief, 1 was Jewish, 19 reported either no religion or spiritual practices without a religious affiliation	English speaking, have at least 12 months experience living with the illness /treatment and agree to share their experience having serious illness and its impact on their perceptions about life	In-depth interviews (60-150 minutes) conducted between April 2008 and March 2009 Field notes	Thematic analysis according to Riessman (2008) N-Vivo Frequent meetings to verify findings	Four major themes emerged: reflecting on spiritual, religious and personal beliefs as most participants highlighted the importance of spirituality/religion in their lives. Crafting beliefs for their own lives as they described how their traditions changed over time. Finding meaning: participants realised that things happened for a reason and they came to terms with their illnesses over time, by comparing themselves with others and by turning to things that gave meaning to their lives. Transcending beyond words as it was difficult at times to talk about their beliefs	**S**: Based on a theoretical underpinning (social constructionist perspective, Gergen, 2004), rigour and validity checked following Lincoln and Guba (1985) criteria, ethics considered **L**: Self-selection may have motivated participants to take part in the study. One geographical area. Predominantly Caucasian

Table 3.5: Summary of the Quantitative Studies Retrieved in the Review

Author/s, year/ country	Aim/ Research question/ hypothesis	Methodology/ Methods					Key findings	Strengths (S), Limitations (L)
		Design/ sampling method	Sample & participants characteristics	Inclusion/ exclusion criteria	Tools	Data analysis		
Patel et al., 2002, USA	To investigate the interrelation-ships between religious beliefs and psychosocial and medical factors.	Quantitative design Random selection (all patients were considered eligible)	53 HD patients (30 women, 23 men). FROM September 2001 to November 2001, 86.8% African-American, 9.4% white, and 3.8% Asian. Age ranged from 31-90 years (mean 54.4). Time on treatment for ESRD ranged from 2-222 months (mean 46.6 months). 43.4% had diabetes.	Not specified in this study (highlighted in previous studies)	Face to face interviews using questionnaires (30 minutes), Karnofsky Performance Scale (Functional Status). The Illness Effects Questionnaire (IEQ): assesses how illness perception interferes with or affects personal, physical, and social behaviour. Beck Depression Inventory (BDI). The Multidimensional Scale of Perceived Social Support (MSPSS). The Satisfaction With Life Scale (SWLS). McGill QOL questionnaire. A question developed to assess spirituality	Data are reported as mean & SD. Unpaired *t*-tests and chi-square used to calculate differences between mean values and proportions of groups. Pearson's correlation.	Spirituality and religious involvement scores correlated significantly with greater SWLS (r= 0.26; p= .04 and r=0.38; p=.004, respectively) and higher perception of QOL (r=0.27; p=.05 and r=0.40; p=.002, respectively. Higher spirituality scores correlated with lower perception of burden of illness (r=0.33; p=.01). Higher spirituality and religious involvement scores correlated with lower BDI scores (r=-0.27; p=.05; and r=-0.42; p=.001, respectively). Religion as a coping mechanism correlated with higher FS score (r =0.37; p=.007), higher SWLS score (r=0.34; p= .01), lower IEQ score (r=-0.30; p=.03), and lower BDI (r=-0.34; p=.01) and CDI scores (r=-0.36; p=.007).Compared to women, men had higher BDI (mean 15.0±11.9 versus 9.1 ±7.4; p= .04), lower perceived levels of social support (66.0±14.8 versus 76.2± 11.1; p= .01), and higher religious involvement (p=.04). Age correlated with lower spirituality scores (r=-.28, p=.04). No correlations found between religious/spirituality involvement and Karnofsky scores.	**S**: Comparison made between participants and non-participants **L**: Small sample size, one dialysis unit, predominantly African Americans The use of face to face format may have introduced a risk of social desirability in giving the answers.

Author/s, year/ country	Aim/ Research question/ hypothesis	Methodology/ Methods					Key findings	Strengths (S), Limitations (L)
		Design/ sampling method	Sample & participants characteristics	Inclusion/ exclusion criteria	Tools	Data analysis		
Kimmel et al., 2003, USA	To determine relationships between symptoms and other factors that patients report are most important to them in determining their QOL, including measures of religious experience and social support	Quantitative with no specified methodology All patients on 3 dialysis units considered eligible Data collected from May 2001 and concluded December 2001	165 patients receiving HD treatment (response rate 86.8%), 33.3% African Americans, 63% White, 1.2% Asian, 4% were women,	Inclusion criteria not specified. Patients excluded if they lacked decision-making capacity, could not speak English, or were too sick to participate.	Questionnaires administered using an interview format Demographic data (e.g. age, gender, etc.). The Karnofsky Performance Status Scale, The Satisfaction With Life Scale (SWLS), McGill QOL (MQOL) questionnaire, A Support Network Scale composed of 8 items and A Spiritual Beliefs Scale (SBS) were developed for the study	A combination of bivariate and multivariate analyses (e.g. unpaired *t*-tests and chi-square), Independent sample *t*-tests, 1-way analysis of variance with a posteriori contrast tests, Linear regression analysis (sex, age, race, number of months treated for ESRD, Karnofsky score, haemoglobin and serum albumin levels, and Kt/V were used as predictors)	The SBS scores correlated positively with MQOL scale score (r= 0.24; p=0005), SIS score (r =0.18; P<.05), Support Network Scale (r= 0.21; p=.007), and SWLS (r=0.20; p=.01). Multiple linear regression analyses showed that higher scores on the SBS subscale associated significantly with female sex, older age, and African-American ethnicity. Spirituality, psychosocial factors, and symptoms are important determinants of QOL. Spirituality well-being associated negatively with reported symptoms.	**S**: 3 different dialysis units, mixed sample (white & African Americans), use of trained research assistant who followed the same approach with each participant, relatively large sample. **L**: Use of two questionnaires to measure spirituality that were not validated previously. McGill QOL asked about problems in the past 2 days (too short to assess difference). Differences in ethnic groups not considered
Tanyi & Werner, 2003, USA	To investigate the interrelationships between religious beliefs and psychosocial and medical factors.	Cross-sectional descriptive/correlation design, Convenience sampling Data collected from September 2001 to November 2001	65 women receiving HD treatment (31 African American and 27 Caucasian). Aged 24-82 years (mean=57.54years), average time on HD was 41.25 months, 61.5% Protestant, 16.9% Catholic	Participants included if they were diagnosed with ESRD and on HD for at least 6 months, receiving HD at least 3 times/week, speak English, and free from acute medical condition, cognitive disability, or mentally debilitating disease.	Psychosocial Adjustment to Illness Scale–Self-Report (PAIS-SR), Spiritual well-Being Scale (SWB), Self-perceived health measured by a tool designed by the researcher. Demographic data.	Pearson's Product Moment Correlation Coefficient (detailed analysis not specified).	Spiritual well-being variables were all positively and significantly related to overall psychosocial adjustment and psychological distress adjustment (p<.01).	**L**: Cross-sectional, women only, convenience sample limits generalizability

Author/s, year/ country	Aim/ Research question/ hypothesis	Methodology/ Methods					Key findings	Strengths (S), Limitations (L)
		Design/ sampling method	Sample & participants characteristics	Inclusion/ exclusion criteria	Tools	Data analysis		
Berman, et al., 2004, USA	To examine the relationship between religion and satisfaction with life, medical care and adherence in HD patients	Survey using an interview based questionnaire (45 minutes) Random sample Between June and August 2003	74 HD patients (31 men, 43 women), average age 54 years, 89% African Americans,	Not specified	Hoge Intrinsic Religiosity Scale, The Organizational & Non-organizational Religious Activity Scales, Karnofsky Performance Scale, BDI, MSPSS, SWLS, Coping Scale and The Schwartz Outcome Scale	STATA 7.0 Software Multiple regression analysis	Patient satisfaction with medical care was greater for those who had higher Organizational Religious Activity Scale scores (p=.021). Religious beliefs are related strongly to measures of satisfaction with life, whereas religious behaviours are related to satisfaction with medical care	**S**: Conduction of power analysis, high response rate (92%) **L**: Predominantly African Americans and Baptist affiliation, homogenous and small sample size
Finkelstein et al., 2007, USA	To examine spirituality in patients with ESRD	Not specified (Cross-sectional?)	200 patients receiving HD and peritoneal dialysis treatment No other details offered by researchers	Not mentioned	Spiritual Well-Being Questionnaire (SWBQ)	Not specified	A strong correlation was found between SWBQ scores and several QOL domains: (a) depressive symptoms assessed by BDI, (b) MCS scores of the SF-36 and (c) the global assessment of the patients' QOL. Existential score (ES) of the SWBQ correlated with BDI scores (p=.43), and the MCS scores (p=.45). Spirituality did not correlate with patients' compliance	**S**: Large sample **L**: Design and other measures not specified, no referral to analysis method, no inclusion/ exclusion criteria, no tables to show findings, ethical issues not addressed, no theoretical justification
Ko et al., 2007, USA	To determine if spirituality correlates with QOL scores. Is QOL as perceived by HD patient dependent on their religious or spiritual beliefs?	Cross-sectional From December 2004 to February 2005	112 patients (65 men, 47 women), 44% with working fistula, 41% used a graft, 15% used a catheter, 36% diabetics, 3% HIV, 17% previous transplant; 79.5% Christian, 15 Roman Catholics, 45 Protestants, 29 had other Christian faith, 9 atheist and 7 Muslims, 7 Hindu, Sikh, Buddhist, or other, 105 (94%) reported as religious, spiritual or both.	All had ESRD, receive HD 3 times/Week. Excluded if they were not mentally competent	The Royal Free Interview for Spiritual & Religious Beliefs Scale, The Kidney Disease QOL (KDQOL) questionnaire Demographic data	Pearson's correlations independent sample t-tests, one way ANOVA, and X^2 tests	There was a significant negative correlation with physical composite score and both the importance of practice of faith (r=-0.262, p=.01) and composite spirituality score (r=-0.212, p=.05). No correlation between mental health, emotional well-being or social function and spirituality scale.	**L:** One dialysis unit, predominantly African Americans (97%) and women

Author/s, year/ country	Aim/ Research question/ hypothesis	Methodology/ Methods					Key findings	Strengths (S), Limitations (L)
		Design/ sampling method	Sample & participants characteristics	Inclusion/ exclusion criteria	Tools	Data analysis		
Spinale et al., 2008, USA	To assess whether spirituality was an independent predictor of survival in dialysis patients with ESRD after controlling for age, diabetes, albumin, and social support.	Cross-sectional From October 2001 to November 2003 All patients considered eligible	166,black HD patients (102 men and 64), 89.2% African American, 7.8% white, and 3.0% of other ethnicity, 95 patients from one unit, mean age was 56.2±13.8 years, 45.2% had diabetes, 11.5% had HIV, mean duration on dialysis was 41.2± 43.5 months.	Not specified	MSPSS, 4 items to assess spiritual beliefs(not specified)	SAS (8.2), Kaplan-Meier curves, Spearman correlations, Proportional hazards regression	Social support scores correlated with spirituality scores (r=0.33, p=.0001), religion as coping mechanism scores (r=0.29, p=.0002), and religious involvement scores (r=0.22, p=.005). Patients with higher spirituality scores had significantly increased survival. Higher spirituality scores were associated with longer survival (hazard ratio [HR] 0.49; 95% confidence interval [CI] 0.27 to 0.88; p=.02	**L**: Predominantly African American, 18 participants lost to follow up, 14 patients had a transplant, Range of spirituality scale score (not previously validated) was very small limiting the significance of findings.
Kao et al., 2009, Taiwan	To evaluate the correlations between spiritual beliefs & HRQOL of HD patients.	Cross-sectional	633 patients (281 men, 352 women), mean age was 55.4±14.0 years, and the mean HD duration was 50.7±56.8 months. Seventy-two patients had no spiritual beliefs, while 379 and 182 patients had weak and strong beliefs, respectively	Patients included if they had been treated with maintenance HD for more than 2 months at 14 HD centres in northern Taiwan. Patients were excluded if they had dementia, consciousness disturbance, or communication problems.	SF-36, the Royal Free Interview for Spiritual & Religious Beliefs Demographic data	SPSS 12.0 One way ANOVA, analysis of covariance with post hoc Scheffe test.	Patients with no or with strong beliefs had higher role physical (p=.001) & social functioning (p=.001) scores than patients with weak belief. Adjusting for gender, time on dialysis, age, marital status, education, comorbidities, patients with no or with strong spiritual beliefs were found to have higher SF scores (p=.02) than patients with weak beliefs. HD patients with no or strong spiritual beliefs had higher SF-HRQOL than those with weak spiritual beliefs	**S**: 14 dialysis centres **L**: Cross-sectional design (unable to determine causality), no justification of methodology, recruitment strategy not highlighted.

Author/s, year/ country	Aim/ Research question/ hypothesis	Methodology/ Methods					Key findings	Strengths (S), Limitations (L)
		Design/ sampling method	Sample & participants characteristics	Inclusion/ exclusion criteria	Tools	Data analysis		
Song & Hanson, 2009, USA	To examine whether psychological and spiritual well-being is associated with African American dialysis patients end of life treatment preferences and acceptance of potential outcomes of life sustaining treatment	Cross-sectional using questionnaire based interviews Sampling strategy not specified From January 2007 to January 2008	51 ESRD patients (29 men and 22 women), 5 dialysis units, mean age was 58 years, 7 patients completed less than high school education, over 90% were retired or disabled, 17 (33.3%) were married or living with a significant other, (23.5%) were never married, and time on dialysis approached nearly 4 years.	Self-identified African American, 18 years or older, receiving dialysis for at least three months	Short Portable Mental Status Questionnaire (SPMSQ), Charlson Comorbidity Index (CCI), the Dialysis Symptom Index, The SF-12, the Self-Perception and Relationship Tool (measures psychosocial-spiritual well-being), the Goals of Care document (assess end of life treatment), and demographic data	Descriptive statistics, Chi square, Fisher's extract, Mann Whitney U test, permutation test with Monte Carlo estimation procedure	Religious involvement and importance of spirituality were not associated with end of life treatment preferences and acceptance of treatment outcomes. African American with ESRD expressed varied levels of psychological and spiritual well-being.	**L**: Small sample size, solely African American patients, no justification of cross-sectional design.
Davison & Jhangri, 2010, Canada	To describe the various dimensions of spirituality & spiritual well-being in patients with CKD To examine the relationship between the various constructs of spirituality & HRQOL	Prospective cohort study	253 patients, (81.5%), 9.1% were American Indian or Alaska Native, 2.4% were Asian, 1.2% were black	Inclusion: aged≥18 years; diagnosed with stage 4 or 5 CKD; receiving long-term dialysis, were enrolled in the pre-dialysis renal insufficiency clinic; and were cognitively able to complete the questionnaire in English	The Kidney Dialysis Quality of Life Short Form, the ESRD Spiritual Beliefs Scale, the Spiritual Perspective Scale, and the Spiritual Well-Being Scale	Descriptive analysis, Pearson correlation, Linear regression, multiple regression	The ESRD Spiritual Beliefs, SPS, and RWB scores were only weakly associated with social support and dialysis staff encouragement from the dialysis-specific items on the KDQOL (r=0.20 to 0.28, each P<001) and social support from the Support Network subscale of the ESRD Spiritual Beliefs Scale (r=0.28, P<.01). Negligible correlations existed between any of these religious scores and the SF-36 domains or single-item rating of HRQOL. EWB scores were moderately associated with several domains of HRQOL, including burden of kidney disease, effects of kidney disease, symptom burden, cognitive function, sleep, and quality of social interaction (r=0.20 to 0.43, each P<.01).	**S**: Diverse sample including patients on HD, HHD, peritoneal dialysis **L**: Self-selection may have introduced bias (only those interested may have chosen to participate), predominantly white patients, and limited to English speaking.

Author/s, year/ country	Aim/ Research question/ hypothesis	Methodology/ Methods					Key findings	Strengths (S), Limitations (L)
		Design/ sampling method	Sample & participants characteristics	Inclusion/ exclusion criteria	Tools	Data analysis		
Ibrahim et al., 2012, Malaysia	To measure the influence of illness perception and religious coping strategies on patients' HRQOL and to identify direct or indirect predictors of religious coping on illness perception and HRQOL of ESRD patients.	Not specified Cross-sectional? (interview based) Obtained ethical approval	274 patients, 51.5% males and 48.5% females, Malays (49.3%), married (75.9%), Muslims (52.2%), age ranged 51 to 60 years, 66.8% were on HD, 50.7% on HD for >36 months, 36.6% on HD 36-120 months and 12.8% on HD for <120 months	Patients with ESRD undergoing either HD or CAPD (Continuous Ambulatory Peritoneal Dialysis)	Revised Illness Perception Questionnaire (IPQ-R), Religious Coping Strategies questionnaire (RCS),and SF-36	SPSS 18.0 Descriptive statistics, Pearson correlation and multiple regressions	Patients who had positive religious coping perceived their illness to be less chronic, of a cyclical nature, had good personal control, experienced fewer consequences and better understanding of the illness. The components of illness perception explained 35% of the variance in PCS and 33% in MCS. These components influenced PCS and MCS indirectly through religious coping. Religious coping mediated the relationship between chronic timeline, illness coherence, personal control, consequences and cyclical with PCS and MCS. Greater use of positive religious coping positively affected PCS and MCS. Religious coping was a common mediator in all five components of illness perception (time line, illness coherence, personal control, consequences of disease and cycle) with the QOL for mental and physical components. Religious coping played a significant role in influencing the HRQOL of ESRD population.	**S**: 3 dialysis units, large sample size, **L**: Methodology not clearly specified/ justified. Could benefit from using a qualitative approach to explore spirituality/ religion in more depth.
Lucchetti,et al., 2012, Brazil	To identify religious aspects associated with mental health and quality of life in Brazilian dialysis patients. Hypothesis: different religious variables were associated (positively or negatively) with depressive/ anxiety symptoms and QOL in HD patients	Cross-sectional in 2 dialysis centres Voluntary participation	133 (patients receiving HD (response rate=64.8%), 52.6% males, 60.9% white, 58.9%, married, 53.4% with high income, 27.8% with hypertension, 24.8% diabetes, 17.2% glomerulonephritis, and mean of time on dialysis was 41.38 months.	Aged>18 years, at least 1 month on dialysis, not in use of acute or emergency treatments and mentally capable of answering the questions	Socio-demographic characteristics (sex, age, race, marital status, education), the Portuguese version of the Private and Social Religious Practice Scale, WHOQOL, BDI, the Beck Anxiety Inventory (BAI), visual analog scale for pain	SPSS (17.0), linear regression analysis, analysis of variance, R square, and Adjusted R square tests	49 (37.4%) patients attended religious services at least once a week, 102 (82.3%) prayed every day, 36 (28.1%) watched religious programs on TV at least once a week, and 34 (25.8%) read religious literature at least once a week. Under the adjusted model, reading religious literature was inversely associated with depressive symptoms ($P < 0.001$). The psychological domain of QOL positively associated with family income ($P = 0.037$), increase in religiosity ($P = 0.030$), and higher importance of religion for recovery ($P = 0.016$), but negatively associated with BDI score ($P < 0.001$). The social domain associated positively with greater importance of religion for recovery ($P = 0.032$)	**S**: Relatively large sample. **L**: Cross-sectional, inclusion of patients on HD for <6 months who may have not experienced major changes in their lives (may affect the results).

Author/s, year/ country	Aim/ Research question/ hypothesis	Methodology/ Methods					Key findings	Strengths (S), Limitations (L)
		Design/ sampling method	Sample & participants characteristics	Inclusion/ exclusion criteria	Tools	Data analysis		
Ramirez et al., 2012, Brazil	To investigate the associations of positive religious coping and religious struggle with psychological distress and HRQOL of HD patients. Hypotheses: (1) positive religious coping is associated with lower levels of psychological distress symptoms and better HRQOL independently of socio-demographic and clinical variables, and (2) religious struggle would be an independent correlate of anxiety and depressive symptoms and impaired HRQOL.	Cross-sectional Random selection From December, 2009 to June, 2010. Ethics obtained	170 patients receiving HD from 3 centres, mean age 48.4 years, 64.1% males, 57% married, 64.7% mulatto, 98.3% Christian, average of time with kidney disease was 99.6 months, and time on dialysis was 65.7±64.8 months.	Exclusion criteria: hearing impairment, inability to comprehend study instruments and unwillingness to participate.	Brief RCOPE, the Hospital Anxiety and Depression Scale (HADS) and the World Health Organization Quality of Life instrument-Abbreviated version (WHOQOL-Bref). Socio-demographic data (age, gender, marital status, ethnicity, religious affiliation, educational level	SPSS (15.0) Descriptive statistics, Kolmogorov-Smirnov test Multiple regression	positive religious coping did not correlate with depressive or anxiety symptoms, religious struggle correlated significantly with both depressive and anxiety symptoms; positive religious coping was associated with better overall HRQOL (p=.02), negative religious coping associated negatively with overall HRQOL (p<.001), positive religious coping associated with better mental health and social relations HRQOL (p<.001); religious struggle had an independent negative impact on all HRQOL dimensions, physical, mental and social (p<.001, p<.01, respectively).	**S**: Large sample , power analysis **L**: Cross-sectional design, no justification of selected methodology, predominantly Christians with Roman Catholic affiliation.
Thomas & Washington 2011, USA	To determine whether sociocultural differences have any effect on the HRQOL among African American HD patients. To examine relationships between religiosity, social support, and the HRQOL of African American HD patients. Hypothesis: HRQOL would be greater among African American HD patients with high religiosity and high social support.	Cross-sectional Nonprobability and voluntary sampling, Obtained ethical approval	176 African American HD patients (86 men, 90 women), age ranged from 20 to 85 (mean= 55.69), 52.8% Baptist, 55% were on HD for 1 to 5 years (mean=55 months),	Receiving HD for at least a month Excluded if they deemed mentally unstable, or if their physical condition would compromise participation	the Measure of Religious Involvement, the Medical Outcomes Study Social Support Survey, SF-36 demographic data (	Descriptive statistics, cross-tabulation, Hierarchical multiple regression	The results indicate that age, greater social support, less religiosity, and less chronicity related to other conditions contribute to greater physical quality of life among African American HD patients. Inconclusive findings whether spirituality/religion were associated with HRQOL of HD patients.	**L**: Cross-sectional, voluntary participation may have introduced selection bias (only those interested), only African Americans.

Author/s, year/ country	Aim/ Research question/ hypothesis	Methodology/ Methods					Key findings	Strengths (S), Limitations (L)
		Design/ sampling method	Sample & participants characteristics	Inclusion/ exclusion criteria	Tools	Data analysis		
Davison and Jhangri, 2013, Canada	To explore the relationship between psychosocial adjustment to illness, EWB, and HRQL in patients with advanced CKD To determine whether adjustment to illness mediates the relationship between EWB and HRQL	Cross-sectional Obtained ethical approval Sampling: not specified March 2007 and September 2008	253 patients with stage 4 & 5 CKD and HD patients, 81.5% white, 9.9% American Indian, 56.5% men,	Inclusion: 18 years old, receiving either chronic dialysis or diagnosed with Stage 4 or 5 CKD, and cognitively able to complete the questionnaire in English	SWBS, the Psychological Adjustment to Illness Scale (PAIS)-Self-Report, and KDQOL Short Form Demographic data	SPSS Descriptive statistics, Chi square and ANOVA, regression models	EWB associated with higher overall HRQL and mental (MHC) and physical (PHC) scores (p<.001). Only four of the seven domains of the PAIS (domestic environment, extended family relationships, social environment, and psychological distress) were associated significantly with EWB with p ranging from <.01 to <.001)	**S**: Large sample, different group of patients on different dialysis modality of treatment **L**: Cross-sectional design, predominantly white.
Martinez and Custodio, 2014, Brazil	To evaluate the relationship between mental health and spiritual well-being among HD patients.	Cross-sectional Observational study January to December 2011 Ethics obtained	150 patients receiving HD treatment	Excluded if they had hearing impairment, were younger than 18 years of age, had been on HD for <12 months, or declined to participate.	The General Health Questionnaire and the Spiritual Wellbeing Scale Demographic and clinical data	SPSS (18.0) Descriptive statistics, Pearson correlation, stepwise multiple Logistic Regression	Spirituality correlated significantly with mental health (p=.001). Spiritual wellbeing was the strongest predictor of mental health (P = .003), psychological stress (P =.006), sleep disturbance (P = .002) and psychosomatic complaints (P = .0003)	**S**: Relatively large sample. **L**: Cross-sectional design, one dialysis unit, methodology not justified, excluded patients with hearing impairment who may be able to read and who may have different views.

3.7 Meaning of Spirituality for Patients with End-Stage Renal Disease

Two studies explicitly explored the meaning of spirituality in patients receiving HD treatment (Walton, 2002; Walton, 2007). Table 3.4 presents the aims of these studies and identifies their main findings, strengths and limitations. Both studies were carried out in the USA, conducted by the same researcher and adopted a grounded theory approach. Walton (2002) was amongst the first to study spirituality in patients with ESRD and her findings initiated theory development and provided a theoretical underpinning for understanding spirituality in the dialysis population. A key issue is that both studies provide insight into the meaning of spirituality for people diagnosed with ESRD and receiving HD treatment; yet there was no agreement over one meaning of spirituality that can be applied to all dialysis populations. For instance, evidence from Walton's (2002) study, using semi-structured interviews with 11 patients receiving HD treatment, suggests that spirituality is a life-giving force that inspires one to strive for balance in life and is nurtured by connecting with people, God and the environment. On the other hand, Walton (2007) carried out another study with 21 patients in the USA and found that spirituality means "being in the world" and involves all aspects of living for those under investigation. Connection with the family, community, belonging and helping others emerged as other meanings of spirituality. In Walton's report (2007), praying was identified as a core category. However it was not clear whether or not participants identified connection with God as a meaning of spirituality. In both studies, the use of a grounded theory approach and the fact that the

researcher validated the findings by asking patients and nurses who had experience working with dialysis patients to confirm the findings to ensure clarity and application, increases our confidence in them. However, these findings must be treated with caution because the first study (Walton, 2002) was carried out in one dialysis unit and the second study (Walton, 2007) recruited American Indians only. Therefore patients' views and understandings of spirituality might not be generalizable to other dialysis populations, or to those with different ethnic backgrounds. Notwithstanding these limitations, these studies offer a way of increasing our understanding of the meaning of spirituality in the lives of patients with ESRD. Yet, more qualitative research is required with patients from different dialysis units and different religious and cultural backgrounds to gain an in-depth understanding of this important concept in general and, in particular, in Scotland as there were no studies identified that addressed spirituality in the lives of people receiving HD treatment.

3.8 Spirituality in the Lives of Patients with End-Stage Renal Disease

Out of the 22 studies highlighted in Tables 3.4 and 3.5, three studies used a qualitative approach and explicitly explored spirituality in patients receiving HD treatment. The other three studies also used a qualitative approach; however, their main focus was not to explore spirituality in patients receiving HD treatment. For instance, Tanyi and Werner (2008a) explored the lived experience of HD patients, Yodachi et al. (2011) explored coping strategies in HD patients and Molzhan et al. (2012) explored stories of

spirituality in groups of patients with chronic illnesses where patients with ESRD were a sub-group of them. These studies were included because they highlight that spirituality is an important coping strategy amongst their study participants. The findings from the qualitative studies are presented first before moving on to discuss the findings from the quantitative studies.

Evidence suggests that the way in which spirituality affects patients' lives is by encouraging them to search for meaning and purpose in life, which empowers and enables them to feel stronger in the face of a challenging disease. For example, Walton (2002) illustrated this in a grounded theory study with 11 patients receiving HD treatment in the USA. Similarly, in Canada, patients identified that spirituality is important in their lives and helps them to find meaning in illness, which empowers them to come to terms with their disease (Molzahn et al., 2012). Further evidence from three studies also suggests that the way in which spirituality affects patients' lives is by facilitating coping, which gives patients the ability to adapt and manage their daily lives. For instance, Walton (2007) carried out a grounded theory study in the USA which shows that spirituality and, in particular, praying is a powerful way of coping with the stress of HD treatment. Prayer nourishes inner strength and helps patients cope with hardships, offers hope and inner strength. Likewise, Tanyi and Werner (2008b) found similar findings from a phenomenological study with 16 dialysis patients in the USA. They found that spirituality is essential in buffering against and reducing anger, depression, anxiety, and bitterness, and thereby fosters coping. Correspondingly, in Thailand, patients also reported that spirituality helps them to adapt to HD treatment

and to maintain role function and interdependence as well as coping with the mental challenges of HD (Yodchai et al., 2011).

Findings from these studies offer an account that spirituality may be important in patients' lives as it encourages them to find meaning and purpose and offers them an important source of coping. However, these findings must be treated with caution for many reasons. First, samples included in these studies might not be representative of the whole dialysis population. For instance, Tanyi and Werner (2008a and 2008b) recruited women only, Walton (2007) recruited American Indians and Yudchai et al., (2011) recruited Buddhist patients only. In addition, three of the studies were carried out in one dialysis unit (Walton, 2002; Yodchai et al., 2011), or in one geographical area (Molzhan et al., 2012). Second, using self-selection as a sampling method may have introduced some bias as only those who are spiritual may choose to participate. This may also limit the generalizability of the findings.

However, despite these limitations, synthesizing the findings from the aforementioned studies it seems that there is growing evidence to support that spirituality may be important for the dialysis population. Yet, there remains a need for further research to expand on these findings considering their methodological limitations. The next section moves on to present the findings from the 16 quantitative studies that examined spirituality/religion in patients with ESRD. Their findings will be presented as follows: 'spirituality and quality of life', 'spirituality as a way of coping', and 'spirituality and treatment preferences and satisfaction with care'.

3.8.1 Spirituality and Quality of Life

Five studies explicitly examined the relationships between spirituality or spiritual beliefs and the QOL/HRQOL of patients receiving HD treatment (Kimmel et al., 2003; Finkelstein et al., 2007; Ko et al., 2007; Kao et al., 2009; Davison and Jhangri, 2010). In contrast, seven more studies (see Table 3.5) examined the relationship between religious factors or religious coping and the QOL/HRQOL of patients with ESRD (Patel et al., 2002; Finkelstein et al., 2007; Ibrahim et al., 2012; Lucchetti et al., 2012; Ramirez et al., 2012; Thomas and Washington, 2011; Davison and Jhangri, 2013). Of the 11 studies, five were carried out in the USA, two in Canada, two in Brazil, one from Malaysia and one from Taiwan. There were no studies identified from the UK to examine the relationship between spirituality and religion and the QOL/HRQOL of patients with ESRD. Sample sizes ranged from as low as 53 (Patel et al., 2002) to as high as 633 (Kao et al., 2009). Six of the studies specifically indicated the use of a cross-sectional design, whereas five studies did not specify a specific design although they seemed cross-sectional in nature. All used valid measures to assess spirituality and QOL such as the Free Interview for Spiritual and Religious Beliefs Scale (Kao et al., 2009), the Spiritual Perspective Scale and the Spiritual Well-Being Scale (Davison and Jhangri, 2010), McGill QOL questionnaire (Patel et al., 2002) and the Medical Outcomes Study Social Support Survey (SF-36) (Thomas and Washington, 2011).

ESRD introduces many physical and psychological challenges into patients' lives that may negatively affect their QOL. Patients receiving HD treatment must adjust on a daily basis to their treatment schedule, dietary limitations, and other potential

complications (Tanyi and Werner, 2003). Evidence from cross-sectional studies suggests that spirituality is important in the lives of patients with ESRD and may have a positive association with their QOL. For example, Kimmel et al. (2003) illustrated in a relatively large cross-sectional survey with 165 HD patients in the USA that spirituality is a determinant of QOL. Spiritual beliefs were positively associated with QOL ($p=.005$) and satisfaction with life ($p=.01$) and negatively associated with the number of reported symptoms ($p<.01$). Finkelstein et al. (2007) found in another study that scores on the Spiritual Well-Being Questionnaire (SWBQ) were associated with several QOL domains of the SF-36 questionnaire, with a caveat that none of these values were reported to highlight the strength or direction of the association. Likewise, Kao et al., (2009) carried out a large cross-sectional study ($n=633$) in Taiwan and found that patients with no or with strong beliefs had higher role physical ($p=.001$) and social functioning ($p=.001$) scores than patients with weak beliefs. Even after adjusting for gender, time on dialysis, age, marital status, education, and comorbidities, patients with no or with strong spiritual beliefs still had a higher social functioning scores ($p=.02$) than patients with weak beliefs.

Given the quality of these studies (i.e. recruiting a large sample, being carried out in different dialysis units) (Kimmel et al., 2003; Kao et al., 2009), it seems likely that spirituality can influence patients' QOL. However, these findings must be treated with caution for several reasons. Firstly, Kimmel et al. (2003) used two questionnaires to measure spirituality that were not validated previously and, therefore, more studies using these questionnaires are required to validate the questionnaires and the study

findings. Secondly, using the McGill QOL questionnaire, they asked patients about changes in the past two days which might be too short a time to assess any differences. Thirdly, they did not consider ethnic and cultural differences in their study, which may limit the generalizability of the findings. Lastly, the use of a cross-sectional design means that it was not possible to reveal the true relationship between spirituality and QOL. Thus, these studies might need to be replicated in order to confirm their findings.

In contrast, however, evidence from two studies suggests that spirituality has negligible associations with QOL in patients with ESRD. For instance, Davison and Jhangri (2010) carried out a relatively large cross-sectional study with 253 dialysis patients in Canada and reported insignificant associations between spirituality/religion and the QOL domains measured by the SF-36; with a limitation that the Spirituality Well-Being Scale (SWBS) used to assess spirituality mainly focuses on assessing religion rather than spirituality and that there were difficulties to distinguish between religion and spirituality in the ESRD Spiritual Beliefs Scale, which may have affected the findings. Similarly, Ko et al. (2007) found in another cross-sectional study (n=112) in the USA that spirituality has no correlations with mental health, emotional well-being, or social functioning; with a limitation that the study was carried out in one dialysis unit and recruited predominantly African American participants. Therefore, these findings need to be replicated to confirm whether spirituality influences QOL or not.

Given the findings from the previous studies, it seems that the relationship, whether positive or negative, between spirituality and the QOL of patients receiving HD treatment is not well understood as highlighted by the inconclusive findings from these

studies. Hence, more research is needed to examine these relationships and find out whether they support current research findings or contradict them, which would be undertaken in my thesis.

Spirituality and religiosity have been used inter-changeably in health and psychological research (Mattis, 2002), which indicates a lack of understanding of the possible discriminate nature between the two concepts (Harmer, 2009). However, in light of the scarcity of the research addressing spirituality in patients with ESRD, I included studies that examined the relationships between religion and QOL/HRQOL of patients receiving HD treatment. These studies are presented next.

Evidence from six studies suggests that religion or religious coping strategies can have an impact on the QOL of patients receiving HD treatment. This was illustrated in a cross-sectional study in Brazil by Lucchetti et al. (2012). According to Lucchetti and his colleagues, reading religious literature was inversely associated with depressive symptoms ($p<.001$). The psychological domain of QOL was positively associated with increasing religiosity ($p=.030$) and negative depression scores ($p<.001$). In addition, increasing importance of religion was positively associated with the social domain of QOL ($p= .032$); with a caveat that the sample recruited was on HD for < 6 months and, therefore, patients may have not experienced the full impact of ESRD and HD treatment on their lives. It has been reported in the literature that patients experience an improved QOL during the first six months after commencing HD treatment (Kring and Crane, 2009; de Abreu et al., 2011). Therefore, findings from Lucchetti et al.'s study should be treated with caution because it was not clear whether their study participants reported

better QOL as a result of religion or as a result of receiving HD treatment.

Ramirez et al. (2012) carried out another cross-sectional study in Brazil with patients receiving HD treatment (n=170) and found that positive religious coping was associated with better overall HRQOL (p=.02), better mental health and social relations (p<.001), while religious struggle had a negative impact on all dimensions of HRQOL; physical, mental and social (p<.001, p<.001, p<.01, respectively). Yet, the findings may be limited by the inclusion of predominantly Christian participants who have a Roman Catholic affiliation. Likewise, Davison and Jhangri (2013) found that in Canadian patients receiving HD treatment, Existential Well-Being (EWB) was associated with higher overall HRQL; mental and physical domains (p<.001); with a caveat that the sample was predominantly white. Even in a small sample of 53 dialysis patients in the USA, similar findings emerged (Patel et al., 2002). Patel and his colleagues found that religion as a coping mechanism correlated with higher functional status (p=.007), higher satisfaction with life (p=.01), and lower depression (p=.01). However, Patel et al.'s study was limited by the small sample, was carried out in one dialysis unit and recruited predominantly African Americans. In contrast, Thomas and Washington (2011) carried out a cross-sectional study (n=176) in the USA to show that there were inconclusive findings as to whether religion was associated with better or worse HRQOL of patients receiving HD treatment; with a limitation that the study included only African Americans which may limit the generalizability of the findings.

Synthesizing the findings from the previous studies, it seems that there is evidence to suggest that religion can have an impact on the QOL of patients with ESRD. The use of

cross-sectional design makes it difficult to infer causality to reveal the true relationship between religion and QOL. In addition, given the inconclusive findings from these studies about the relationship between religion and QOL, the limited number of studies available and the fact that all used a quantitative approach suggests that further research is needed using different methodologies to increase our understanding of the role of religion in the dialysis population and increase our confidence in the results already available.

3.8.2 Spirituality and Psychosocial Adjustment and Coping

Patients with ESRD experience many psychological problems such as depression, anxiety, uncertainty and dependency on the dialysis machine and the nursing staff (White and Grenyer 1999; Kimmel et al., 2003; Patel et al., 2005; Cukor et al. 2007; Cengic and Resic, 2010). Evidence from four studies (see Table 3.5) suggests that the way in which spirituality/religion positively impacts on patients' lives is by helping them to cope and adjust to their psychological problems and by empowering them to accept their treatment and feel stronger in the face of illness. Spirituality may affect patients' lives by acting as a buffer against depression and a wide variety of stressful events encountered by patients with ESRD. For example, Patel et al. (2002) illustrated this in a study conducted in the USA (n=53). In their study, spirituality and religious involvement were associated with lower depression scores ($p=.05$ and $p=.001$, respectively). Correspondingly, Tanyi and Werner (2003) demonstrated in another cross-sectional study in the USA (n=65) that spiritual well-being was positively associated with overall psychosocial and psychological adjustment in women receiving

HD treatment (p=.01); with a caveat that the study included women only and that the convenience sampling approach means that only those who met the inclusion criteria or those who could address the area of interest were recruited, which can introduce researcher bias. In another study from Brazil (n=150), Martinez and Custodio (2014) found that spirituality was significantly associated with better mental health (p=.001) and that spiritual well-being was the strongest predictor of mental health (p=.003), psychological stress (p=.006), sleep disturbance (p=.002) and psychosomatic complaints (p=.0003); with a limitation that the study was carried out in one dialysis unit. In contrast, Ramirez et al. (2012) carried out another cross-sectional study in Brazil (n=170) which showed that using religion did not correlate with depressive or anxiety symptoms, whereas religious struggle (i.e. tension, question, and conflict about spiritual issues within oneself, with other people, and with the Divine) correlated positively and significantly with both depressive (p<.0001) and anxiety (p<.0001) symptoms.

Notwithstanding the limitations of the studies discussed in this section, it seems likely that spirituality may play a role in affecting patients' lives by facilitating the process of coping; however, considering the differences in the findings about the relationship between spirituality and religion and the psychosocial adjustment among patients with ESRD, further research is needed to increase confidence in these results.

3.8.3 Spirituality and Survival, Satisfaction with Care and Treatment Preferences

Only three studies were identified in the review that explore the relationship between spirituality and survival (Spinale et al., 2008), spirituality and satisfaction with care (Berman et al., 2004) and spirituality and treatment preferences (Song and Hansen, 2009) in patients with ESRD. All were conducted in the USA and used cross-sectional design and valid measures to assess spirituality and religion (as shown in Table 3.5). Sample sizes ranged from as low as 51 participants (Song and Hanson, 2009) to as high as 166 (Spinale et al., 2008). Perhaps the difficulty assessing spirituality led to these studies only having small sample sizes on which to draw conclusions, which can affect their ability to identify significant findings.

Evidence from one paper suggests that spirituality may have a relationship with survival among patients with ESRD. Spinale et al. (2008) demonstrated in a cross-sectional study with 166 dialysis patients in the USA that spirituality and religion were important coping mechanisms (p=.0002). Evaluated by mean split in their entire sample, higher spirituality scores were associated with longer survival (hazard ratio [HR] 0.49; 95% confidence interval [CI] 0.27 to 0.88; p= .02). However, for the entire study population there were no associations between spirituality and survival. In addition, there was no association between religion as a coping mechanism and survival. These findings seem to be confusing. The reasons for that might be because: firstly, the study included a predominantly African American male population, 18 participants died during the follow-up and 19 participants received a kidney transplant which may have affected the

final analysis. Had the views of these participants been included in the analysis, the study may have yielded different findings. Secondly, the scale used to assess spirituality mainly focuses on assessing religion and faith rather than assessing spirituality as a multidimensional concept (i.e. there was a lack of variables to measure relationship with self, others, and nature) and the fact that the scale has not been subject to validity and test re-test reliability means that more studies are needed to establish if it was appropriate to assess spirituality.

Berman et al. (2004) carried out a survey to examine the relationship between religion and satisfaction with care and adherence to treatment in HD patients (n=74) which found that religiosity was associated with satisfaction with life and medical care (p=.021) but not with adherence to HD treatment. Furthermore, data from a small cross-sectional study that was carried out in the USA to examine the relationship between religion and end of life preferences in patients (n=51) receiving HD treatment, demonstrated that there were no associations between importance of spirituality and religion with treatment preferences and acceptance of treatment outcomes (Song and Hanson, 2009). Both studies recruited mainly African American participants and the small sample size may have limited the power of these studies to yield significant findings.

Despite their limitations, the three studies discussed in this section examined the relationship between spirituality and survival, satisfaction with care and treatment preferences: an area that had not previously been reported. The studies highlighted that, although the evidence remains inconclusive, the findings suggest that spirituality may

play a role in the lives of dialysis patients in terms of survival, satisfaction with care and treatment preferences. Consequently, there remains a need for more research to establish whether or not spirituality has a relationship with these issues.

3.9 Conclusion

This chapter has presented a literature review undertaken for this study. The critique of the literature highlights a dearth of studies specifically exploring and examining the role of spirituality in the lives of patients with ESRD and its influence on their health outcomes and well-being worldwide. Specifically, there were no studies identified from the UK (specifically from Scotland). However, the literature review shows that there is a growing body of evidence that suggests a positive relationship between spirituality and the health outcomes and well-being of patients with ESRD in that spirituality may play a role in the way that this group of patients adjust, cope, and manage their disease. However, the evidence is incomplete and there is a need for further research using various research methodologies to enhance our understanding of the role of spirituality in improving the well-being of patients with ESRD. Research relating to spirituality and its role in the dialysis population does not inform nursing practice. This might be due to the difficulty in defining and discriminating between spirituality and religion, which may affect the way that nursing interventions are implemented within dialysis units. Whether spirituality can be accurately measured is questionable and even though there is a plethora of validated instruments to assess spirituality, there remains a state of inconsistency measuring spirituality because most of these scales focus on measuring religion rather than spirituality (Koenig, 2004; Tanyi and Werner, 2007). Fisher (2009)

reported on nearly 200 spirituality measures which focus on four domains of spiritual well-being, with only about one third of them containing religious items.

The variations in the scope and focus of the retrieved studies also suggest that there is a need for future research to gain more insight into the role of spirituality in the lives of patients with ESRD. The heterogeneity of the participants and composition of the samples (e.g. recruiting women only, recruiting African Americans) in several studies is problematic and there are concerns regarding the generalizability of their findings to all dialysis populations. The reasons why the focus of spirituality research has been more on African Americans are not clear. However, research suggests that people from an African background view religion or spirituality to be more important in their lives and that they are more likely to pray privately, practise religious rituals, attend religious services, and believe that the Bible is the word of God (Jacobson et al., 1990; Levin et al., 1994). Ultimately, it is questionable whether these studies sufficiently reflect the range of individuals who are affected by ESRD, in terms of different cultures and different backgrounds, and whether it was these characteristics that influenced the findings of the studies. Indeed, this makes it less possible to generalise the findings of most of these studies to other groups of patients and those from other cultural, ethnic and religious backgrounds. Therefore, further research with the inclusion of more diverse samples is also needed.

Therefore, informed by the literature review, my study is the first (to my knowledge) to examine and explore spirituality in the day-to-day lives of patients with ESRD receiving HD treatment and how it may influence their health outcomes and, in

particular, QOL and general well-being in Scotland. This aim was addressed by examining the following research questions:

1. Is there an association between spirituality and the QOL and general well-being in patients with ESRD receiving HD treatment?
2. What does spirituality mean to people receiving HD treatment?
3. How does spirituality influence the QOL and general well-being in patients with ESRD receiving HD treatment?

Addressing spirituality among patients with ESRD may therefore help healthcare professionals and health policy makers in Scotland to recognize patients' different spiritual and psychosocial needs, in the hope that healthcare services in Scotland will shift to be more patient-centred to address the holistic care needs of patients receiving HD treatment. The next chapter discusses the methodology and methods used to conduct my study.

Chapter 4- Methodology and Methods

4.1 Introduction

This chapter presents an overview and justification of the methodology and methods adopted in this study. The chapter is presented in seven sections. Section 4.2 presents justification for choosing a mixed method approach. Section 4.3 offers a detailed description of the quantitative component of the study including the design (Section 4.3.1), population and the process for selecting the sample (Section 4.3.2), data collection process (Section 4.3.3) which describes the procedure for obtaining access and consent (Section 4.3.3.1), procedure for recruiting participants (Section 4.3.3.2) and the procedure for distributing the questionnaires (Section 4.3.3.3). Section 4.3.4 presents the data handling and statistical analysis process.

In Section 4.4, a detailed description of the qualitative components of the study is presented including the design (Section 4.4.1), procedure for recruiting participants (Section 4.4.2), procedure for obtaining consent (Section 4.4.3), procedure for obtaining access (Section 4.4.4), procedure for data collection (Section 4.4.5) and analysis (Section 4.4.6). Next, consideration is given to ethical issues for both components in Section 4.6. The chapter concludes by highlighting my role as a researcher in Section 4.7 and potential sources for bias in the study in Section 4.8.

4.2 Mixed Method Design

The choice of the research methodology should be guided by the nature of the question or problem to be investigated and by what is already known about the subject (Holloway and Wheeler, 2002; Burns and Grove, 2005). Based on the aim and research questions of my study, it was considered that using one single methodology would not be sufficient to address them. Therefore, a sequential mixed method design adopting quantitative (cross-sectional survey) and qualitative (semi-structured interviews) approaches was used to address the study aim and answer the research questions set out for each component. It was intended that the use of a mixed method design would offer a rich and in-depth understanding of how quantitative and qualitative methods can contribute to a better understanding of the relationships between spirituality and the health outcomes and general well-being in patients with ESRD. In particular, sequential quantitative-qualitative analysis (Onwuegbuzie and Teddlie, 2003) was used where data from the quantitative component were used to inform data collection and analysis in the qualitative component. The data collected from the interviews were used to further explore findings from the survey and help explain the quantitative findings where appropriate. Using a mixed method design was intended to capitalise upon the strengths of each method, offset their individual weaknesses and expand the scope of the study by providing a detailed picture about the subject under investigation (Brookes, 2007; Bryman, 2008).

Combining research methods in this way is not uncommon in health care research (Sale et al. 2002). The term "mixed methods" is generally defined as "*research in which the*

investigator collects and analyses data, integrates the findings, and draws inferences using both qualitative and quantitative approaches in a single study or program of inquiry" (Tashakkori and Creswell, 2007, p.3). The mixed method approach is also summarised as research design using qualitative and quantitative data collection and analysis techniques, either in parallel or in sequential phases (Tashakkori and Teddlie, 2003).

Research methodologies are usually based on specific paradigms which are a patterned set of assumptions concerning reality; knowledge of that reality; and particular ways of knowing that reality (Guba, 1990). For instance, the quantitative paradigm is connected to positivism and seeks to test existing theories (Ellis and Levy, 2009) and to measure and analyse causal relationships between variables in a value-free framework (Denzin and Lincoln 1994, Burns and Grove, 2005). Quantitative research employs different techniques, such as random sampling, blinding, highly structured protocols, and written or orally administered questionnaires with limited responses. In contrast, the qualitative paradigm is based on interpretivism and constructivism where there are multiple realities or truths based on one's construction of reality (Sale et al., 2002). The emphasis of qualitative research is on process and meaning with samples not meant to represent large populations (Reid, 1996; Sale et al., 2002). In my study, the structured questionnaire represents the positivist paradigm while semi-structured interviews represent the interpretivist paradigm.

Although research has moved beyond the debate around quantitative and qualitative research, combining both methods does not mean that it is always appropriate to do so,

and mixing research methods should not be used to support the weaknesses of one method with the strengths of another. Bryman (2007) identified favouritism towards a particular approach or set of findings as a barrier to the integration of qualitative and quantitative findings. Favouritism means that researchers emphasise one set of findings that they think is the predominant aspect of their study or those findings with which they are most familiar and confident (Bryman, 2007). Therefore, the findings are not combined in a way that is mutually illuminating and the fact that few good quality examples of integrated approaches exist within the literature means that there is uncertainty about the best approach to adopt when attempting to integrate qualitative and quantitative findings.

Greene et al. (1989) and Brannen (2005) identified five major purposes for conducting mixed methods research. These purposes include triangulation, where the quantitative findings are compared to the qualitative results, and complementarity, in which findings from one approach are intended to elaborate, enhance, illustrate, and clarify the results from the other approach. These purposes also include initiation, where both approaches are used to discover paradoxes and contradictions that lead to a re-framing of the research question; development, in which the findings from one approach help to inform the findings from the other approach; and expansion, where different approaches seek to expand the breadth and range of inquiry. Adopting multiple methods enhances rigour (Denzin and Lincloln, 2005; Bryman, 2005). Hence, both components (i.e. quantitative and qualitative) were carried out sequentially in my study for the purpose of triangulation and complementarity, which led to a more holistic analysis and wider

understanding of the influence of spirituality on the health outcomes and general well-being in patients with ESRD. The findings from each component are presented separately in Chapters 5 and 6 and synthesised and discussed in Chapter 7.

While each of these components is integral to this study, for ease of explanation, qualitative and quantitative components will be described separately in the following sections.

4.3 Study Settings (Quantitative and Qualitative Components)

People receiving HD treatment were recruited from 11 dialysis centres across four Health Boards representing 27.5% of the total number of dialysis centres in Scotland. The four Health Boards who gave ethical approval for the study were the National Health Services Greater Glasgow and Clyde (NHSGGC), NHS Fife, NHS Forth Valley and NHS Grampian. The dialysis centres were distributed over a large geographical area of Scotland. Geographically, the dialysis centres were located in four different local authority areas. All centres were responsible for the delivery of out-patient dialysis to patients and were nurse-led and supported by medical, allied health professionals, and secretarial staff.

4.4 Quantitative Component

4.4.1 Design

The aims of the quantitative component were to describe the health status, general well-

being and spirituality of patients with ESRD receiving HD treatment in Scotland and to identify possible relationships between spirituality and their health outcomes (i.e. QOL) and general well-being. These aims were addressed by examining the following research question:

1. Is there an association between spirituality and the QOL and general well-being in patients with ESRD receiving HD treatment?

Using a survey is a common research method in quantitative research, because it is a quick and economical method that allows the collection of significant amount of data from a sizable population (Polit and Beck, 2006; Jones and Rattray 2010) and enables comparisons between subgroups within a population (Coolican, 2004). A cross-sectional design obtains information from a single group of people at a single point in time; a 'snapshot' without any attempt to follow up over time (Polit and Beck, 2006; McKenna et al. 2010). However, in cross-sectional surveys it might be impossible to infer causality (Levin, 2006). That is, it will not be possible to determine whether or not higher or lower levels of spirituality lead to better or poorer health outcomes.

A cross-sectional design was considered to be the most feasible for the quantitative part of my study. It was hypothesised that using this design would help to: (1) determine the characteristics of people with ESRD receiving HD treatment in Scotland; (2) describe QOL and general well-being as well as spirituality of this group of patients, and (3) explore the relationships between them and other independent factors such as socio-demographic characteristics. Mckenna et al. (2010) suggest that a descriptive cross-

sectional design can be used to describe the characteristics and health status of a particular population as well as obtaining information regarding the prevalence, distribution and interrelationships of variables within a population (Polit et al., 2005).

A longitudinal study allows investigation of a causal link between independent and outcome factors (McKenna et al., 2010). However, very little baseline information is known about ESRD patients and spirituality and, therefore, using a cross-sectional design in my study was a necessary first step to investigate this population, generate inferences and hypotheses (Levin, 2006; McKenna et al., 2010) and recommendations for future research in the area of spirituality, QOL and general well-being among patients with ESRD in Scotland. Levin (2006, p.25) suggests that "*it is advisable to think carefully about what might be relevant because this is a good opportunity to gain a broad base of knowledge about subjects who have/do not have the outcome of interest*".

4.4.2 Population

4.4.2.1 Sample Selection

A target population is the entire set of individuals or elements who meet the sampling criteria (Burns and Grove, 2011) and to whom the study findings will be generalized or applied (Nieswiadomy, 2008). The target population in my study was all adults diagnosed with ESRD and currently receiving centre-based HD treatment across all Health Boards in Scotland. Initially, the study proposal was submitted to Greater Glasgow and Clyde Health Board as there were more than 500 patients who attend

dialysis centres within this Health Board weekly. This number was thought to be sufficient to recruit the required sample. After commencing the study and distributing study packs to participants, it was noticed that the response rate was low and therefore the study proposal was submitted to the NHS central Ethics Committee to obtain its approval to access other Health Boards across Scotland in order to reach a larger target population. The final number of Health Boards who gave permission to access their patients was four (further discussion about ethical issues is presented in Section 4.6). According to the nurse managers of the dialysis units an estimated number of 800 patients attend the dialysis units across the four Health Boards every week. These patients were considered eligible if they met the following inclusion and exclusion criteria.

Inclusion and Exclusion Criteria

Patients were included in the study if they were: (1) regular patients diagnosed with ESRD and currently receiving HD treatment; (2) been on HD for ≥ 6 months; (3) aged ≥ 18 years (the age of 18 or above was decided because the majority of patients with ESRD are above this age and capable of giving consent); and (4) English speaking (selecting English-speaking patients was because I had no access to independent translators and I had no access to interpreting services available to patients). If a person was experiencing distress or unwell on the day and if participating might aggravate their distress, then they were excluded. However, these patients were given an information leaflet about the study and given a period of time (2 weeks) to decide if they wanted to participate. If they changed their mind and agreed to participate they

were approached to obtain their consent. Patients receiving PD treatment or who had a kidney transplant were excluded as they might have a different experience than those on HD. Patients experiencing any psychological, neurological, or communication limitations that were likely to affect their ability to consent to participate were also excluded.

4.4.2.2 Sample Size

How large should the sample be to infer research findings back to a population? It is a question that is often asked at the start of a study (Bartlett et al., 2001). Indeed, identifying an appropriate sample size and dealing with non-response bias is essential while developing a survey research (Bartlett et al., 2001). Various factors should be considered when calculating the sample size (Tabachnick and Fidell, 2007). These include the number of independent variables, alpha level (alpha/ α=0.05), expected effect size (i.e. how strong the relationship between independent variable/s and dependent variable that it is going to measure), and the power (size of power to detect this effect, beta/β=0.20) (Tabachnick and Fidell, 2007). In order to determine appropriate sample size in an effort to produce meaningful outcomes in my study, G* Power was used. Using a small effect size of 0.20, alpha set at 0.05, and power of 0.80, the desired sample size for this study was calculated as 150 participants. Given that there was an estimated number of 800 patients who attend the dialysis units every week, it seemed that it would be possible to recruit 150 patients or more to the study which would allow for some attrition, given the nature of the patient group being studied.

4.4.3 Data Collection Process

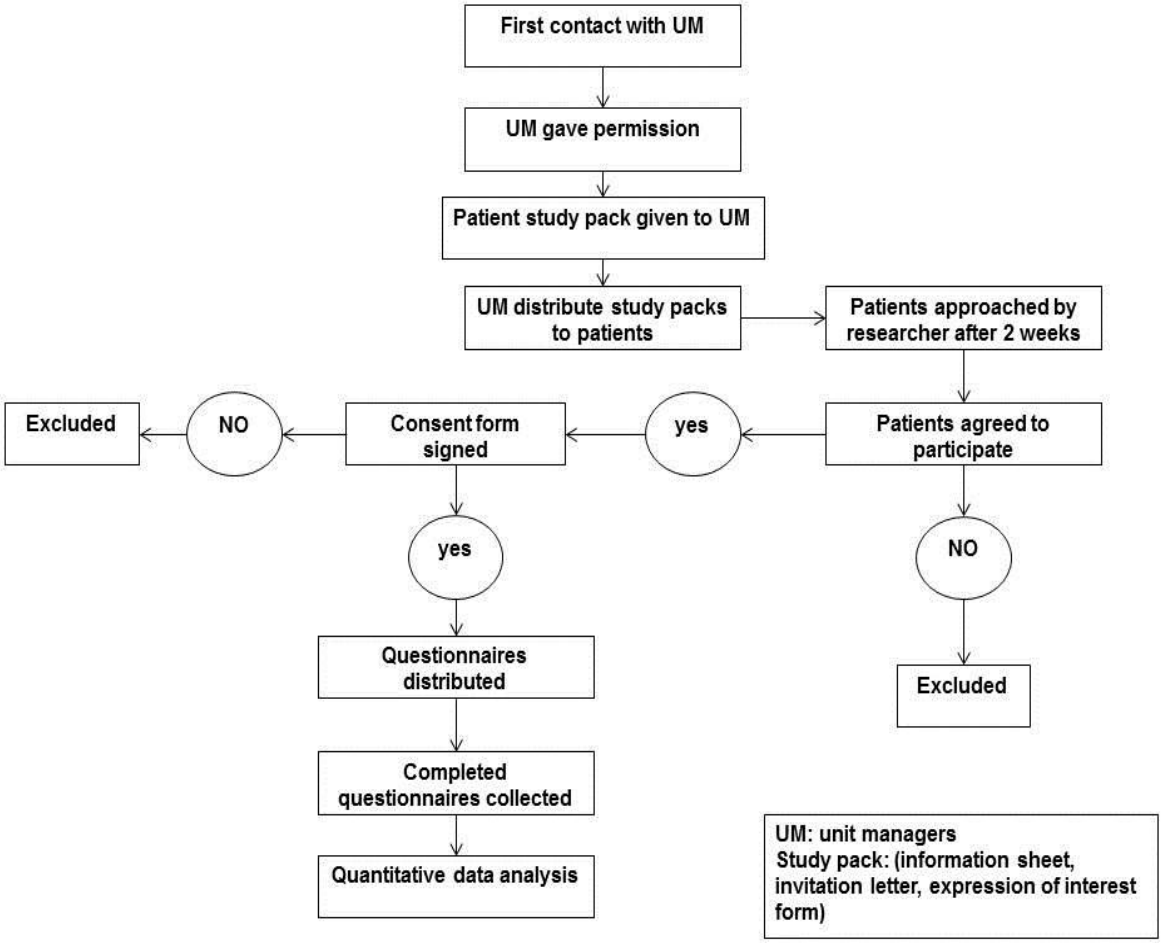
4.4.3.1 Procedure for Obtaining Access

It is important for researchers to establish a relationship with 'gatekeepers' to gain access to multiple informants (Feldman et al., 2003). Therefore, discussions and negotiations with 'gatekeepers' and, in particular, the nursing staff in the dialysis units, took place during the early stages of this research to obtain access to the study participants. This was important and provided the opportunity to review my proposal, negotiate requirements such as private rooms for interviews, and assistance in the recruitment process.

After obtaining ethical approval (see Section 4.6.1), I visited the dialysis units across the four Health Boards and met with the Unit Managers and the nursing staff. They were informed about the study as a necessary courtesy, regardless of their participation, which ensured familiarity with the study and with my presence as a researcher. They were assured that there would be minimal disturbance to the ward routine. I explained to them what was required to assist me in identifying potential participants. Unit Managers and the nursing staff were helpful and agreed to assist in distributing the study information packs and collecting patients' Expression of Interest Forms which were to be collected by myself at a later stage. Patient study packs included a letter of invitation (Appendix 2), information leaflet (Appendix 3), questionnaire booklet (Appendix 4), and an Expression of Interest Form (Appendix 5) with an envelope addressed to myself. Nurses were provided with an invitation letter (Appendix 6), study

leaflet and patients' inclusion and exclusion criteria. Figure 4.1 shows the data collection and analysis process.

Figure 4.1: Data Collection and Analysis Process



4.4.3.2 Procedure for Recruitment and Obtaining Consent (Quantitative)

The nursing staff distributed the study information pack to potential participants when they attended the dialysis units. Potential participants were asked to read it and if they

agreed to participate in the survey, they were asked to complete the Expression of Interest Form and return it in the envelope provided to the nursing staff. All participants were given a two-week period to think about the study. After the two-week period, I visited the dialysis units to collect patients' Expression of Interest Forms and to check with nurses the best time for me to come and see patients to start data collection. I then attended the dialysis units to see patients individually while they were connected to the dialysis machine. Permission was sought from the nursing staff on the day to see patients. I was introduced to patients by the nursing staff and patients were asked if it was suitable for them to speak to me.

The nature of the study was explained to the patients and they were asked to give a written informed consent if they were happy to proceed (Appendix 7). Informed consent ensures that research participation reflects the free choice and self-determination of individuals who enrol in research. I drew attention to confidentiality and anonymity in the consent process and participants were assured that their participation was respected, and that identifiable data would be kept confidential (Data Protection Act, the National Archive, 1998). They were also informed that they could withdraw from the study at any time without having to give a reason. In addition, participants were reassured that data collected would only be used for research purposes and for fulfilling the requirements of a PhD degree, future conference papers, and professional journal publications.

4.4.3.3 Distribution of Questionnaires

After obtaining participants' written consent, they were then given the questionnaire booklet and were asked to complete it and return it to myself. I was available outside the dialysis units and nursing staff were made aware of my presence to answer any questions that patients might have. Participants were given time to complete the questionnaire at their own pace, to the best of their ability and in the question order that it was presented. Participants were reassured that I was available to help them if required; for example, by reading the questions to them, especially if they were unable to use their dominant hand, or if they had any problems to prevent them reading. Participants were also encouraged to take questionnaires home if they felt it was easier for them to complete them at home and return them to myself in the self-addressed envelope provided. However, the three questionnaires taken home were not returned. Data collection commenced across the four Health Boards over a nine- month period from May 2009 to January 2010. Participants were recruited from different dialysis units within these Health Boards. These included: Glasgow Royal Infirmary (GRI), Stobhill Hospital (SH), New Victoria Infirmary (VI), Western Infirmary (WI), Inverclyde Hospital (IH), Vale of Leven Hospital (VoLH), Aberdeen Royal Infirmary (ARI), Queen Margaret Hospital, Doctor Gray's Hospital, Forth Valley Royal and St Andrews Hospital. Within the first few weeks it was noticed that the number of patients showing interest in undertaking the survey was insufficient. Therefore, I adjusted patient age in the inclusion criteria from 18-65 years of age to all patients who were above the age of 18 years as there was a large proportion of patients who were 65 years

of age and older. This proved to be successful as more patients were given the study information packs.

4.4.3.4 Selecting the Survey Measures

The data collection process should be objective, systematic and replicable (Meadows, 2003) and therefore the key questions for designing the data collection procedure were as suggested by Nieswiadomy (2008): What? How? When? According to Taillefer et al. (2003, p.310), "*a failure to provide a priori definition of the main concept is serious and unacceptable as not providing research questions or hypothesis can lead readers to make inaccurate interpretations about the results of a study, or the use and misuse of a model*". Therefore, it is essential to define the research concepts theoretically and operationally. The next sections outline the theoretical definitions of the investigated variables and clarify how they were measured.

4.4.3.4.1 Theoretical Definition of Variables (What?)

The theoretical definition is a conceptual definition which aims to clarify the theoretical meaning of a variable that may be derived from the theoretical framework or developed through concept analysis (Fawcett, 1999). For this study the investigated concepts are defined theoretically as follows.

End-stage renal disease

A patient with ESRD was defined as an individual who had been diagnosed by a physician as having a stage five chronic kidney disease requiring life-long HD

treatment. Patients who were on HD treatment and currently waiting for a kidney transplant were considered eligible for this study.

Quality of life

The World Health Organisation (WHO, 1997) defines QOL as "*an individual's perception of his/her position in life in the context of culture and value system in which they live and in relation to their goals, expectations, standards, and concerns*" (p.1). This definition incorporates a broad range of concepts that include an individual's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to relevant features of their environment.

General well-being

Well-being is the state of being comfortable, healthy, or happy (Oxford English Dictionary), which is a definition that is used in the academic literature; frequently in a way that echoes the WHO definition of well-being as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity". Well-being exists in two dimensions, subjective and objective. It comprises an individual's experience of their life as well as a comparison of life circumstances with social norms and values. The WHO definition says that well-being and health are interactive concepts with common determinants, such as health and social systems (WHO, 2013).

4.4.3.4.2 Operational Definition of Variables (How?)

The operational definition clarifies how the variables are measured. For measuring

concepts that were defined theoretically, it was essential to define them operationally. An operational definition means the availability of valid and reliable tools that can be used to measure these concepts (Burns and Grove, 2011). A measurement should be valid and reliable. Validity refers to whether an instrument truly measures what it is supposed to measure, given the context in which it is applied (Polit et al., 2005). There are a number of ways to assess the validity of an instrument, each of which must be considered when deciding to choose an appropriate measure. At the very minimum, an instrument must have face validity and content validity, which are assessed using non-empirical methods (Streiner and Norman, 2003). Reliability is concerned with the measurement consistency in measuring or observing the same phenomena (Parahoo, 1997). Reliability is a fundamental way to reflect the amount of error, random and systematic, inherent in any measurement (Streiner and Norman, 2003). In addition, valid measurement should be clear, comprehensible, and use unambiguous wording (Ruane, 2005).

Self-administered questionnaires were considered the most appropriate method for data collection in the survey. They were used to collect detailed socio-demographic data and to obtain the required data to describe the health status (i.e. QOL), well-being and spirituality of participants and examine the relationships between spirituality and patients' QOL and general well-being.

Self-administered questionnaires are the most common method of data collection in social and health research. Self-administered questionnaires have many advantages. For instance, questionnaires are potentially the cheapest, quickest methods of data

collection and can reach large numbers of people over wide geographical areas (Polit and Hungler, 1996). They require less time to administer and are time-efficient and convenient for the respondents who can complete the questionnaire at a time convenient to them (McColl et al., 2001). Moreover, the fact that questionnaires are structured and predetermined and cannot be varied in their wording and in the order in which they are answered, ensures that they have a fair degree of reliability (Parahoo, 2006).

Self-administered questionnaires, however, can be limited by the inability to probe deeper and to allow the respondents to express in detail what matters to them (Mathers et al., 2007). To overcome this issue in my study, an open question was added at the end of the questionnaire booklet asking participants about their perception of spirituality and to write any additional comments about this study or their experience in general. The conduct of the qualitative component also allowed further elaboration on participants' responses from the questionnaires. Having to complete questionnaires may place literacy demands on participants and this may have a potential influence on the quality of data obtained (Parahoo, 2006). Low response rates are another issue with questionnaires. Many reasons have been identified as to why people may not respond to questionnaires, including 'respondent burden', which is the discomfort placed on participants by making use of their time and effort to complete a questionnaire (Parahoo, 2006). To overcome this issue in my study, participants were asked to complete the questionnaires on their own to the best of their ability and while they were connected to the dialysis machine to save them time. Once the choice was made to use self-administered questionnaires, the next step was to consider the most appropriate

measures to employ to collect data from participants.

Socio-Demographic Characteristics

Socio-demographic characteristics were collected using a background sheet that was developed after reviewing previous studies that were conducted among patients with ESRD to collect data on patients' gender, age, period of time on dialysis, working status and living status. Patients' ages were divided into six categories (18-25; 26-35; 36-45; 46-55; 56-65; +66 years). The period of time on dialysis was divided into four categories (6 months-5 years; 6-10 years; 11-15 years; >15 years). Working status was classified as working: yes, no; part-time; full-time; and retired. Patients were also asked if they were living alone or not. One more question was added asking participants if they were interested in taking part in an interview. This question was added to facilitate the recruitment process for the qualitative component of the study.

Quality of Life Measure (The Medical Outcome Study, SF-36v2)

Many generic and specific instruments have been developed to measure QOL. Generic QOL measures are designed to be applicable across a wide range of populations and interventions and to facilitate the comparisons of health and functioning across populations, interventions and health conditions (Ware et al., 1994). Specific QOL measures are designed to measure health in a particular disease such as ESRD, or specific populations such as adult groups of patients (Haywood et al., 2002).

The rationale for using the Medical Outcomes Study 36-item (SF-36v2) in my study was because it was considered the most appropriate measure to assess patients' QOL.

The SF-36v2 was developed by Ware et al. (1993) and is considered the most widely used patient-based generic measure of health (Hawthorne et al., 2007). Version 2.0 of the SF-36 was developed in 1996 to overcome deficiencies identified in the original version (version 1.0) (Ware et al., 2000). The SF-36v2 is a generic QOL tool used globally to assess health status among general and specific populations with different health conditions. The SF-36v2 is useful in assessing disease burden, screening individual patients and also in evaluating the effects of different types of treatments on health benefits (Ware, 2000).

Evidence suggests that the SF-36v2 is a more sensitive instrument to assess changes in patients' health status over time than other generic health status measures like the Nottingham Health Profile, and the Sickness Impact Profile (Beaton et al. 1997; Coons, 2000; Vetter, 2007). It has been administered successfully in general population surveys in the USA, the UK and many other countries (Ware et al., 1995, Ware, 2000). It has also been used with elderly and young adult patients with specific diseases (Tan et al., 2010; Klooster et al., 2013). The SF-36v2 has been subjected to extensive validation studies, particularly in elderly adults (Jenkinson et al., 1996; Stephens et al., 2010; Kaupuzs, 2012). Permission to use the SF-36v2 in my study was obtained from Quality Metric Incorporated (Appendix 8, licence number QM003831).

The SF-36v2 can be self-administered, can be administered by a trained interviewer or through computerized administration, to persons aged 14 and older (Ware et al., 1995). It measures overall health status, provides scores on eight of the most important health dimensions widely used in health surveys and provides physical and mental health

summary scores (Ware et al., 2002). These dimensions are: Physical Functioning (PF), Role Physical (RP), Bodily Pain (BP), General Health Perceptions (GH), Vitality (VT), Social Functioning (SF), Role Emotional (RE), and Mental Health (MH). The PF, RP, and BP dimensions contribute to the scoring of the Physical Component Summary (PCS). The MH and RE dimensions contribute to the scoring of the Mental Component Summary (MCS), while the VT, SF and GH dimensions associate with the scoring of the overall MCS and PCS scores (Ware et al., 1994).

For each dimension, item scores are coded, summed, and transformed to a scale from 0 to 100, where 0 refers to the worst possible health status and 100 refers to the best possible health status (Table 3.1). Ware et al. (2000) introduced Norm-Based Score (NBS) which uses a cut-off point of mean (=50) and a standard deviation (SD) of 10. The introduction of NBS made the interpretation of the SF-36v2 results possible without the need of a previous study to be used as a norm. A mean score below 50 indicates below average health status, while a mean score above 50 indicates a better health status than the population average. For general health perception (item number two in the SF-36v2) 'Compared to one year ago, how would you rate your health in general now?' raw and transformed scores are not calculated. Responses to this item are treated as ordinal level data and are analysed using the percentage of subjects who select each response choice (Ware et al., 2002).

UK norms have been published by Jenkinson et al. (1996) in addition to the normative data published for the USA population (Ware et al., 1993). It is these UK norms that have been used to compare the scores obtained from patients with ESRD in my study.

Using these norms determined whether scores from my study participants were above or below those for the UK population norms. Full details of how the SF-36v2 questionnaire was scored in my study can be found in Appendix 9.

Table 4.1: A guide to the interpretation of the highest and lowest scores of the SF-36v2 (adapted with permission from Quality Metric Incorporated)

Dimension (number of items)	Lowest possible Score	Highest possible Score
Physical Functioning (10)	Very limited in performing all physical activities including bathing and dressing	Performs all types of physical activities without limitations due to health
Role Limitations due to physical problems (4)	Problems with work or other daily activities as a result of physical health	No problems with work or other daily activities due to physical health
Bodily Pain (2)	Very severe and extremely limiting pain	No pain or limitations due to pain
General Health (5)	Evaluates personal health as poor and believes it is likely to get worse	Evaluates personal health as excellent
Vitality(4)	Feels tired and worn out all of the time	Feels full of energy all of the time
Social Functioning (2)	Extreme and frequent interference with normal social activities due to physical or emotional problems	Performs normal social activities without interference due to physical or emotional problems
Role Limitations due to emotional problems (3)	Problems with work or other daily activities as a result of emotional problems	No problems with work or other daily activities as a result of emotional health
Mental Health (5)	Feelings of nervousness and depression all of the time	Feels peaceful, happy and calm all of the time

Reliability and Validity of the SF-36v2

The reliability and validity (content, criterion and construct) of the SF-36v2 have been confirmed in a large number of studies of general population samples in a variety of patient groups in the USA (McHorney et al., 1992; McHorney et al., 1993) and in the UK (Jenkinson et al., 1996; Walters et al., 2001). Ware (2000) used internal consistency

and test-retest methods to test the reliability of the eight scales and two summary measures (i.e. MCS and PCS). The SF-36v2 reliability statistics have exceeded the 0.70 standard which is recommended for measures used in group comparisons in more than 25 studies (Tsai et al., 1997). The same reliability trends were also reported across 24 patient groups with different diagnoses and socio-demographic characteristics (Ware et al., 1994; McHorney et al., 1994). More than 200 studies also reported reliability estimates which are consistent with these trends (Shiely et al., 1996).

Ware (2000) used two strategies to evaluate the validity of the SF-36 measures and to accumulate information for interpreting scale scores. First, content validity was comparable to other widely used generic health surveys (Ware et al., 1995). Systematic comparisons indicated that the SF-36v2 includes eight of the most frequently measured health concepts. Second, empirical approaches, including criterion-based approaches, factor analytic tests of construct validity and numerous correlation studies, were also used (McHorney et al., 1994; Ware et al., 1996).

General Well-Being Questionnaire

The rationale for using the General Health Questionnaire (GHQ-28) in my study was because it was considered as the most appropriate measure to assess patients' psychological well-being compared to other measures. The GHQ was originally developed by Goldberg (1979) as a 60-item instrument, but there are a range of shortened versions of the questionnaire, including the GHQ-30, GHQ-28, GHQ-20 and GHQ-12. The 28-item version of the questionnaire has been developed using factor

analysis and its main application has been for research purposes. The GHQ-28 is frequently used as an indicator of psychological well-being, which is considered to be a dimension of perceived QOL, (Krol et al., 1994; Dale et al., 2009). The GHQ-28 incorporates four subscales: somatic symptoms, anxiety and insomnia, social dysfunction and severe depression. The existence of these subscales permits analysis between them, which is an additional advantage of the GHQ-28 scale over the other versions (Bowling, 1992). The GHQ-28 has 28 items and each item is rated on a four-point scale (0= less than usual, 1= no more than usual, 2= rather more than usual, and 3= much more than usual). The total possible score on the GHQ-28 ranges from 0 to 84, with higher scores indicating psychological distress, and allows for means and distribution to be calculated, both for the global total and for the four subscales (Jackson, 2007). The GHQ-28 has been translated into 38 languages and over 50 validity studies have been published (Goldberg and Williams, 1988; Jackson, 2007). It has also been reported that reliability coefficients range from 0.78 to 0.95 in various studies (Jackson, 2007).

Spirituality Measures

The rationale for using SWBQ developed by Gomez and Fisher (2003) in my study was because it was considered the most appropriate measure to assess patients' spirituality and examine its association with patients' QOL and well-being. Other measures were considered, but were excluded as they fail to measure interpersonal relationships (i.e. The Index of Spiritual Orientation), fail to measure persons' relationship with the environment (i.e. The Mental-Physical and Spiritual Well-Being Scale), were limited to

personal aspects of spirituality (i.e. The Perceived Wellness Inventory), or totally exclude religion (i.e. The Spiritual Orientation Inventory).

The SWBQ measures four domains of spiritual well-being as identified by Fisher (1998) (Table 4.2). The SWBQ comprises 20 items; 5 items per each domain. Each item is scored on a 5-point Likert-type response (1= very low, 2= low, 3= moderate, 4= high, 5= very high). The SWBQ was developed with secondary school students to ensure that the language would be suitable for use with a range of adults as well. However, the validation of the instrument was based on a wide sample of the population aged 12 to 80 plus year-olds (Fisher, 2010). Other researchers used the SWBQ with adult patients diagnosed with cancer (Caldeira et al., 2014) and showed that it was a valid instrument to be used with patients with chronic conditions. Moreover, Meezenbroek et al. (2012) determined that the SWBQ was the most promising spiritual well-being measure currently available to measure spirituality. In another review of measures of spirituality, Kapuscinski and Masters (2010) offered no criticism of the SWBQ. Currently, different projects are using the SWBQ in palliative care, in patients with different types of chronic illnesses; however, results of these projects are yet to be finalised and published (personal contact with the SWBQ developer).

Gomez and Fisher (2003) examined the factor structure of the SWBQ using exploratory factor analysis in 537 secondary school students and reported that the Cronbach's alpha values for personal, transcendental, environmental and communal domains were 0.89, 0.86, 0.76 and 0.79 respectively, and that this was 0.92 for all items together. Gomez

and Fisher (2003) also examined the factor structure of the SWBQ using confirmatory factor analysis in 832 individuals and reported that the Cronbach's alpha values for the personal, transcendental, environmental and communal domains were 0.82, 0.95, 0.83 and 0.82 respectively. Cronbach's alpha is a summary measure which generates a value between 0 and 1 for each dimension (Cronbach, 1951): values greater than 0.8 are usually regarded as acceptable (Streiner and Norman, 1989).

Gomez and Fisher (2003) report that some people equate religiosity with spirituality and, therefore, they added five questions in addition to the 20 items included in the SWBQ to differentiate between these two constructs: religious and spiritual. These questions are: Do you have a religious group with which you identify? This is a standard question on religiosity and affiliation with a religious group. The second and third questions are 'How often do you go to church?' and 'How often do you pray or meditate?' These are measures of personal and intrinsic religiosity. The final two questions are: 'How important is religion in your life?' and 'How important is spirituality in your life?' These two questions are used to differentiate between those who are highly religious and those who are highly spiritual as some people might see religion as highly important in their lives but not spirituality and vice versa. These questions were used in my study as recommended by Gomez and Fisher (2003) to differentiate between highly religious and highly spiritual people and to determine whether being highly religious or highly spiritual had any associations with the QOL and general well-being in patients with ESRD.

Table 4.2: The Four Domains of the Spiritual Well-Being Questionnaire

Personal Domain	Communal Domain
Sense of identity Self-awareness Joy in life Inner peace Meaning in life	Love of other people Forgiveness toward others Trust between individuals Respect for others Kindness toward other people
Environmental Domain	**Transcendental Domain**
Connection with nature Awe at a breath-taking view Oneness with the environment Harmony with the environment Sense of 'magic' in the environment	Personal relationship with the Divine/God Worship of the creator Oneness with God Peace with God Prayer life

4.4.4 Data Handling and Statistical Analysis

4.4.4.1 Checking Data Set Accuracy

Following the return of the completed questionnaires, it was vital to check the data accuracy. Each questionnaire booklet was given a number for referral purposes. Lownthal's (20010) guidance was adopted to check the data set for errors and to ensure the accuracy of the data set. Lowenthal suggests a three-stage process to check the data set involving: eyeballing the data, where the data are scanned for errors; conducting frequencies for each variable, to check for unusual entries, which may have not stood

out visually in the first stage, and finally, to check the data entries manually and compare them with those from the original data collection instruments.

The nominal and categorical data in this study were inspected by running frequency tables, while the continuous data were inspected by running descriptive statistics, as appropriate. In conducting the frequencies of the variables, no major errors were noticed as there were no missing data, probably because I double-checked all questionnaires before leaving the dialysis units to ensure that all questions were answered. If there were any questions not answered, I went back to participants and clarified with them whether they chose to leave it blank or whether omitting the response was unintentional. This was the case on a very few occasions where unanswered questions were completed. In relation to the third stage of the process, where all entries were manually checked against the patients' responses in their original data collection instruments, I double-checked all entries within the questionnaire data sets (n=72).

4.4.4.2 Checking Data Normality and Outliers

Continuous data were also investigated for normality distribution by observing the Q-Q plots and the histogram. It was noted that the Q-Q plots were straight and that the histogram was normally distributed, suggesting normality of the data. The Skewness value for each continuous variable was also examined. Variables were considered normally distributed if the Skewness value falls between -1 and +1 (Pallant, 2007). In my study, the Skewness value of all continuous variables fell between -0.14 to 0.53,

suggesting normal distribution. In addition, the continuous variables were tested for linearity by checking the scatter-plots between each of the independent variables with the dependent variable (e.g. MCS and PCS). The identified outliers and the one extreme score for the age group (+66 years) in the overall physical health were included in the analysis as the study was exploratory, therefore all scores were considered legitimate.

4.4.4.3 Statistical Analysis

To address the first research question ‘is there an association between spirituality and the QOL and general well-being of patients with ESRD receiving HD treatment?’ the analysis was divided into two parts. Firstly, descriptive statistics, including frequencies and percentages for categorical variables and mean ± standard deviation for continuous variables, were computed to show the overall response rate and the number of participants recruited from each dialysis unit and to describe the socio-demographic data of participants. In addition, they were computed to describe patients’ QOL and general well-being. QOL mean scores were stratified by age to examine the differences among different age groups. Using Boxplots, the overall PCS and MCS scores and general well-being scores were stratified by age to illustrate any decline in physical health. Furthermore, to describe participants’ spirituality, the total score of the SWBQ, stratified by gender, was calculated and categorised into quartiles. Descriptive statistics were also used to describe religiosity questions, stratified by gender.

Secondly, to explore whether socio-demographic data and spirituality were associated with QOL and general well-being of patients with ESRD, mean comparisons were

conducted to explore significant differences. For example, mean comparisons were conducted to examine the differences in groups' mean scores in terms of socio-demographic data (e.g. age, gender, living status, working status, and period on dialysis) and QOL and general well-being. The same was performed to examine the differences among groups with different mean scores in terms of spirituality and religiosity questions and QOL and general well-being. Furthermore, parametric statistical techniques such as the independent sample t-test and the One Way Analysis of Variance (ANOVA) test were used to assess the differences between group mean scores. Independent sample t-tests were used to compare and to find the differences between the mean scores of two groups, while ANOVA was used for multiple group comparisons. If the ANOVA output was statistically significant, the post-hoc technique was used to find which of the three groups were statistically different. When there are multiple statistical comparisons to be made, this increases the risk of type 1 error. However, corrections were made for this by reporting the Bonferroni correction value for the ANOVA tests, if appropriate. All statistical tests were two tailed with $p < .05$ as the significance level.

4.5 Qualitative Component

4.5.1 Design

The overall aim of the qualitative component was to explore spirituality in the day-to-day lives of patients with ESRD receiving HD treatment and how it may influence their

health outcomes and, in particular, QOL and general well-being. This aim was addressed by examining the following research questions:

1. What does spirituality mean to people receiving HD treatment?

2. How does spirituality influence the health outcomes and general well-being in patients with ESRD receiving HD treatment?

The qualitative component followed an interpretive design using semi-structured interviews. An interpretive approach provides a deep insight into "*the complex world of patient experiences from the point of view of those who live it*" (Schwandt, 1994, p. 118). The interpretive approach has its roots in philosophy and the human sciences and centres on the interpretation and creation of meaning by human beings; it is concerned with how the social world is interpreted, understood, and experienced. Interpretive research also assumes that reality is socially constructed and that the researcher becomes the vehicle by which this reality is revealed (Walsham, 1995; Cavana et al., 2001). Hence, the researchers are not divorced from the phenomenon under study, but they must take into account their own position in the setting and situation as they are the main research tool (Mantzoukas, 2004). Being considered as a research tool is consistent with the construction of the social world characterised by interaction between the researcher and the participants (Mingers, 2001).

It was considered that the qualitative approach would complement and elaborate on the findings from the cross-sectional survey. It was hypothesised that if the survey finds a significant (positive or negative) association between spirituality and QOL and well-

being that the use of semi-structured interviews would offer an explanation for these associations. Conversely, if spirituality had no association with QOL and general well-being, then using a qualitative approach might help explain the reasons why participants in my study viewed spirituality to be irrelevant or not important in their lives.

4.5.2 Population and Recruitment Process

The population of interest in my study consisted of all adult patients currently receiving centre-based HD treatment. The recruitment process for the qualitative part of the study commenced during the survey. In particular, an additional question was added to the questionnaire booklet to ask participants if they were willing to take part in an interview at a later stage. A convenience sub-sample of patients (n=36) indicated, on the questionnaire, their willingness to be interviewed. Convenience sampling involves the researcher choosing the most conveniently available people as participants (Polit and Beck, 2006) and is a common form of qualitative sampling (Ritchie and Lewis, 2003). In order to explore the different range of views to further answer the research questions, it was deemed appropriate to include all participants who had expressed their willingness to take part in the interviews (n=36). However, some participants died during the course of the study, others received a kidney transplant, I was not given permission to approach some participants who were transferred onto home HD (HHD) and some participants chose to withdraw from the study when I contacted them before conducting the interviews, leaving a final number of 21 participants.

4.5.3 Procedure for Obtaining Consent

The 21 participants who agreed to take part in the interviews were contacted directly to arrange a convenient date and time to conduct the interview. All participants (n=21) requested to be interviewed while receiving their treatment which was more convenient for them. One day before the interview, participants were contacted by telephone to confirm the arrangements. On the day of the interview, I met the nursing staff and was introduced to participants. At the outset of each interview participants were re-briefed about the main purpose of the interview as well as the risks and benefits of participating. If participants were still happy to participate, written informed consent was sought before commencing the interview (Appendix 10). I drew attention to confidentiality and anonymity in the consent process and participants were assured that their participation was respected and that identifiable data would be kept confidential (Data Protection Act, the National Archives, 1998). They were also informed that they could withdraw from the study at any time without giving a reason. In addition, participants were reassured that data collected would only be used for research purposes and for fulfilling the requirements of a PhD degree, future conference papers and professional journal publications.

4.5.4 Procedure for Obtaining Access

Before commencing the interviews, I visited the study sites. This visit was intended to re-introduce myself to participants and the nursing staff as the interviews took place more than eight months after completing recruitment for the quantitative component.

Nursing staff were re-briefed verbally about the aim of my study to gain support and cooperation in organising the interviews. Liaising with the Unit Managers and nursing staff of each dialysis unit was beneficial in avoiding times when participants were tired or having any physical or psychological distress, which might have a negative impact on their well-being and participation.

4.5.5 Data Collection Process

Qualitative data collection took place from December 2011 to February 2013.

4.5.5.1 Demographic Data

Demographic data, such as participants' age, gender, education level, marital status, and period of time on dialysis, were collected at the end of each interview. Although some of these demographic data were collected during the survey, they were collected again to describe the characteristics of the sample who took part in the interviews (see Section 6.2).

4.5.5.2 Semi-Structured Interviews

Individual interviews are probably the most widely used method in qualitative research (Ritchie and Lewis, 2003; Creswell, 2008). Interviews are the method used most frequently for generating in-depth personal accounts, understanding the personal context and exploring issues in depth and detail (Ritchie and Lewis, 2003). Interviews are mostly useful for encouraging participants to talk freely about the topics of interest in a study (Polit and Beck, 2006). Furthermore, interviews allow the researcher to

observe the participants' body language, level of understanding and degree of cooperation, all of which are useful features in facilitating interpretation of the data (Polit and Beck, 2006; Robson, 2002). Hence, semi-structured interviews were appropriate for my study as the main aim was to examine and explore spirituality in the day-to-day lives of patients with ESRD receiving HD treatment and how it may influence their health outcomes and, in particular, QOL and general well-being. Therefore, the use of semi-structured interviews allowed for gaining detailed understandings of patients' perspectives and perceptions on spirituality and its influence on their health outcomes and general well-being.

In summary, I used semi-structured interviews in my study for the following reasons. Firstly, to help answer the second and third research questions, namely 'What does spirituality mean to people on dialysis?' and 'How does spirituality influence the QOL and general well-being of patients with ESRD receiving HD treatment?' Secondly, for complementarity and triangulation purposes (i.e. to complement, clarify and explore in more depth the results from the survey) as discussed in Section 4.2.

The quality of an interview depends on the quality of the interaction between the interviewee and the interviewer (Kumar, 2011; Creswell, 2013). The quality of data collected also depends on the quality of the interviewer and the role and proficiency of the researcher (Polit and Hungler, 1998; Kumar, 2011). Initially, I had no experience in conducting interviews and my interviewing skills needed improvement. However, before commencing any interviews, I undertook some interviews with my colleagues within the University of Stirling to improve my skills on how to conduct them. In

addition, with the progress of my study and data collection, my listening skills developed and I started using more prompts and probes to elicit participants' perceptions and understandings as well as to facilitate discussions (Knight, 2002; Walliman, 2005). The reflective notes written after each interview were helpful and served as prompts in the subsequent interviews.

All interviews were conducted in the dialysis units as per participants' requests. The interviews were carried out during the first couple of hours of their dialysis sessions to avoid any risk of developing adverse side effects as a result of their treatment, as patients can become tired or may develop medical complications (e.g. low blood pressure). With regard to offering participants a venue of their choice, there were no other options available apart from conducting the interviews within the dialysis units because my ethical approval did not give me permission to conduct the interviews at participants' homes. However, curtains were pulled around patients to maintain a minimum level of privacy. All interviews were digitally recorded with participants' consent and later transcribed verbatim.

At the start of the interviews, participants were reassured that there were no right or wrong answers. Termination and closure of the interviews occurred when the interview ceased to produce new information or when the participant appeared tired. Body language, such as nodding in acknowledgment, was used to confirm understanding and to encourage more explanation. Not posing several questions at once without giving the participant an opportunity to fully respond allowed the participants to provide more clarity in their answers. Signalling the end of the interview using phrases such as "the

final topic …" or "in the last few minutes …" allowed participants to gradually return to the level of everyday social interaction (Ritchie and Lewis, 2003). Throughout and at the end of each interview, I asked participants whether there was anything else they would like to add. This approach provided participants with an opportunity to make any further points which the questions had perhaps not managed to elicit, but which they considered to be important. For example, one participant talked about the sacrifice of kidney donors and their families which he finds mentally challenging because of his increasing sense of indebtedness towards his family and the families of kidney donors.

At the end of the interviews, participants were thanked for their participation and they were reassured that their contribution was valued and useful. Participants were also advised that if they had any questions they could contact me at any time. My contact details were given to participants and were also available on the information sheet and invitation letter.

As well as the interviews being fully recorded, reflective accounts about each interview were written about the environment of the interview, any difficulties or limitations encountered and what were the main points arising from the interview. Reflective accounts helped me in the subsequent interviews as I was able to identify if some areas needed further exploration. Newly emerging ideas were noted and further explored in subsequent interviews. The reflective accounts were processed on a Word document and helped me in gaining a deeper understanding of the data and during the process of data analysis, as I was able to link the emerging themes from the transcripts with those developed when I was writing the reflective accounts, which formed the basis of the

initial analysis. For instance, I wrote a general memo after analysing five interviews which helped to identify the main stressors patients were facing, the main coping mechanisms they used, and highlighted their definition of spirituality (Appendix 11).

The unpredictable nature of the dialysis units presented a challenge while conducting the interviews. Frequently, there were different alarms and noises from the dialysis machines as well as having other staff moving in and out of the dialysis units (e.g. domestic staff, ambulance staff), which made the environment for conducting the interviews more challenging. However, whenever there was any disturbance, the interviews were stopped and re-commenced as soon as the unit became quiet. Nurses were informed that I was there to conduct the interview and that I was using a digital recorder to facilitate the interviewing process and reduce the risk of recording any of their interactions.

4.5.5.2.1 The Topic Guide

Semi-structured interviews are based on an interview guide that focuses on the topics that need to be discussed, but also to allow flexibility so that researchers can develop questions and pursue areas of interest during the data collection process (Holloway and Wheeler, 2010). Topic guides offer a tool to enhance the consistency of data collection and help to ensure that all relevant issues are covered systematically and with some uniformity (Ritchie and Lewis, 2003). Hence, participants were not always asked questions in the same order or way across interviews and the topics were followed as they emerged from participants' responses. Using a topic guide in my study (Appendix

12) helped to ensure that all participants were given similar opportunities to express their views on predetermined questions considered to be most appropriate to address the research questions.

Different questions were included in the topic guide to address the study aim and research questions. For example, four questions were included in the topic guide to explore the impact of ESRD and HD treatment on patients' lives. These were; 'Can you tell me a bit about yourself?', 'How did you start on dialysis?', 'How do you feel since you started on dialysis?', and 'Can you tell me about the effects dialysis has on your life (i.e. physically, psychologically, and socially)? In addition, to address the second and third research questions, 'What does spirituality means to you?', and 'How does spirituality influence patients' health outcomes and general well-being?' the topic guide included a broad question: 'Can you tell me what you know about spirituality?' This led to two subsequent questions: 'What does spirituality mean to you?' and 'How does spirituality help you cope with your illness?' with the aim of exploring participants' views on spirituality and the significance of its role in their lives. Finally, other questions were also added to the topic guide such as, 'How do you cope with your disease demands?' to explore the different coping strategies these patients use to deal with their disease.

The survey findings also complemented and informed the topic guide with further questions being added as other areas emerged from initial qualitative analysis (e.g. during the familiarisation stage, as discussed in Section 4.5.4.3.1). By the time the decision was taken to add these questions, 14 interviews had already been conducted.

Nevertheless, adding these questions was considered important to examine whether they would produce different findings or enhance the depth of findings already obtained. The questions added were:

1. How does going to church and praying help you to cope/adapt with dialysis?
2. In what way has religion affected your way of coping with your disease and being on dialysis?
3. How did being on dialysis for a long time affect your way of coping?

The topic guide was designed to explore the impact of dialysis treatment on participants' lives and elicit their views on spirituality and how spirituality might influence their health outcomes and general well-being. In most interviews, the issue of spirituality was discussed towards the end of the interviews when participants were asked about the meaning of spirituality and its role in their lives. Nevertheless, some participants brought forward the issue of spirituality/faith at the outset of their interview and when this issue was highlighted it was probed in more depth to obtain more details about this concept as this was central to address the overall aim of this thesis. Once the interviews were conducted it was necessary to proceed with data analysis, which is described next.

4.5.6 Data Analysis

The goals of data analysis were to examine the meanings/themes therein to provide a broad, rich and deep understanding of patients' views, experiences and perceptions on

spirituality and its influence on their health outcomes and general well-being. Creswell and Plano Clark (2007) noted that "*data analysis in mixed methods research consists of analysing the quantitative data using quantitative methods and the qualitative data using qualitative methods*" (p.128). Hence, data collection and analysis of the quantitative and qualitative elements were carried out separately in a sequential order. It was at the stage of interpretation that the findings were integrated in such a way that the findings were mutually illuminating (Chapter 7). In total, 21 semi-structured interviews were conducted totalling more than 19 hours' interviewing time. Interviews lasted between 26 minutes and 123 minutes.

The Framework Analysis developed by Ritchie and Spencer (1994) was the method chosen for analysing the qualitative data in my study. Framework Analysis is not a theoretical framework and does not inform the design and selection of the research and interview questions. It is a methodological procedure for labelling, coding, mapping and interpretation of large bodies of qualitative data and comprises five stages which provide systematic data analysis when carefully followed. Table 4.3 summarizes these stages and their features.

Table 4.3: Summary of Framework Analysis

Stage of Analysis	Feature of this Phase
1. Familiarisation	Gaining an overview with the transcripts of the data, listening to audio-tapes, reading and re-reading the field notes and transcripts.
2. Identifying a thematic framework	Key themes placed within a thematic framework sorted hierarchically into main and sub themes, which is developed based on the research question/aims.
3. Indexing/Coding	Thematic framework is systematically applied to the interview transcripts. Portions or sections that correspond to a particular theme are identified.
4. Charting	Headings and subheadings drawn from the thematic framework and research questions represent themes for each respondent.
5. Mapping and interpretation	Data are sifted and charted according to core themes and analysed in order to define concepts, find associations and provide explanations for the data.

4.5.6.1 Stage One- Familiarisation

The analytical process in qualitative research is iterative and begins during data collection (Miles and Huberman, 1994), as it did in my study. Hence, familiarisation with the data commenced during the interview process through listening and re-listening to each interview many times before commencing transcribing. Taking this approach allowed me to become familiar with participants' language and completely familiar with the data. All interviews were transcribed by me. I read and re-read the transcripts several times which facilitated familiarisation with the data. This process also helped me to identify if anything was missed during the transcribing process. If something was missing, corrections were made. Each interview was analysed in detail. At this stage, a summary of each interview was prepared detailing the demographics of the participants, together with reflective notes written about the content and conduct of each interview. These notes helped inform my conduct of subsequent interviews and

enhanced the emergent themes. The coding process of the interviews started immediately after the first interview with initial themes being highlighted or recorded in the margin of the transcript. At this stage, several hundred pages of transcripts and hours of recording seemed difficult to manage but they appeared to be rich in detail.

4.5.6.2 Stage Two- Identifying a Thematic Framework

According to Ritchie and Spencer (1994), in most analytical approaches, data management initially involves deciding upon the themes or concepts under which the data will be labelled, sorted and compared. Therefore, at this stage I used open coding to identify initial themes emerging from the data. These initial themes were arranged chronologically according to the sequence of events happening with patients since the time of their diagnosis and throughout their journey with the disease. For example, text passages emphasizing events that happened with patients after their diagnosis were compiled under "after diagnosis". Text passages addressing problems and challenges that developed after commencing dialysis (e.g. physical or psychological problems) were compiled under "impact of the disease". In addition, text passages highlighting the meaning of spirituality and its role in patients' lives were compiled under "spirituality", and text passages addressing other means of coping (e.g. humour) were compiled under "other coping strategies". This approach yielded a long list of what appeared to be important themes within the data (see Tables 4.4 and 4.5). A Word document was used to log these concepts as they emerged during reading or listening to the interviews.

The development of the thematic coding scheme was an iterative process in which I

moved back and forth between the coding scheme and the transcripts, continuously revising the coding scheme and re-coding the transcripts. Although the use of qualitative computer software packages, such as NVivo, can be useful in helping to manage the organisation of data, manual coding was used since this is "*sufficient and speedier for small scale research projects*" (Arksey and Knight, 1999, p.163). This allowed me to easily compare the data and themes between the interviews at a glance. In addition, in light of the time constraints during this stage of the thesis, the use of NVivo was not feasible due to the time and effort it requires to learn the software (Robson, 2011).

Table 4.4: Initial Themes for 'After Diagnosis' and 'Impact of the Disease'

1. After diagnosis	2. Impact of the disease
1.1 Fear of the unknown	2.1 Many restrictions in life (sexual activity, relationships)
1.1.1 Unclear future/worries	2.2 Lack of energy/tiredness
1.2 Unclear impact of dialysis machine on life /impact of dialysis	2.3 Physically draining
1.3 Ability to support the family	2.4 Sleepy
1.4 Diagnosis was a shock	2.5 Some days better than others
1.4.1 I was never ill	2.6 No point planning/ can't plan ahead
1.4.2 It was a blow/ hard to take	2.7 Loss of muscle power/mass/tone
1.5 Life is taken away/ life marked out	2.8 Frequent hospitalisation
1.5.1 Dull/mundane life	2.9 Side effects (pain, depression, heart & joint problems, cramps, etc)
1.5.2 On HD for the rest of my life	2.10 Diet and fluid restrictions
1.5.3 HD dominates life/ never a day off	2.11 Unable to work
1.5.4 Not what I chose for my life	2.11.1 Medically retired
1.5.5 Terminal illness	2.11.2 No enough working hours
1.6 Can't cope without husband/wife	2.12 Hard socialising
1.6.1 Do dialysis for my wife	2.12.1 Secluded
1.6.2 Husband/wife deals with challenges	2.13 Loss of freedom/ dependent on others
1.6.3 Indebted/grateful to donors	2.14 Tied to a machine
1.7 Affected by fellow patient's death	2.14.1 Dialysis 3 times/week
1.7.1 Could be me	2.14.2 Half your life on dialysis/ dialysis consumes time
1.7.2 Connection to fellow patients	2.15 Lack of counselling/ benefit advice/Lack of information/Lack of services/ facilities/Lack of communication

Table 4.5: Initial Themes for 'Spirituality' and 'Other Coping Strategies'

3. Spirituality	**3. Spirituality (continues)**
3.1 Spirituality means believing in Christian values/ faith	3.4 Spirituality means connection with nature
3.1.1 Belief in God, religion/ Roman Catholic	3.4.1 Nice neighbours, comfortable environment /Appreciate surroundings
3.1.2 Praying, reading the Bible and going to church	3.5 Spirituality helps me to get through day-to-day
3.2 Spirituality means connection with others	3.5.1 Spirituality gives me strength/encouragement and positive outlook/Faith gives me strength
3.2.1 Be a good friend	3.5.2 Spirituality/religion helps me to cope
3.2.2 Good human being (helpful, not harming, sharing, kind & considerate, ease 'others' burden) / Do best for your family	3.5.3 God always helps me/saviour always look after me/I'm not alone
3.2.3 Support from family and friends	3.5.4 Meditation gives me energy/ prayers and reading the Bible give me inner peace and contentment
3.2.3.1 'Friends' cheer you up, offer distraction, friends prayers	. 3.5.5 Contribute to charities
3.2.4 Support from significant others (nurses, doctors, church, employers)	3.5.6 Sense of belonging going to church
3.3 Spirituality means connection with self	3.5.7 Why me?
3.3.1 Feeling positive and in harmony	3.5.7.1 Tested by God
3.3.2 Inner calmness, contentment, law abiding, inner strength	3.5.8 Maintain a positive attitude
3.3.3 Accept the illness and HD treatment	3.5.8.1 Strive to be positive / See the bigger picture
3.3.3.1 Get on with it/ Learn to live with it/ adapt it into your life/live day to day/accept restrictions (work with limitations/ follow guidelines/not complaining)	3.5.8..2 Positivity is part of spirituality
3.3.3.2 Dialysis is part of my life/keeps me alive	3.5.8.3 Others worse off
3.3.3.3 More time to come to terms with it/adapt over the years (growing older)	3.5.8.4 Positivity is an obligation
3.3.3.4 Engage in life (write novels/compose music/fund raising/join clubs/gym)	3.6 Spirituality gives me Hope
	3.6.1 Hope for a kidney
	3.6.2 Hope for a normal life
	4. Other Coping Strategies
	4.1 Sense of Humour
	4.1.1 Humour diffuses stress
	4.1.2 Humour helps coping/offers distraction

4.5.6.3 Stage Three- Indexing

As described earlier, indexing means that the researcher identifies portions or sections of the data that correspond to a particular theme. Once the recurring themes were compiled, the next step was to develop a conceptual framework or 'index', drawing on both the recurrent themes and the issues introduced into the interviews through the topic

guide. At this stage, I reviewed the themes carefully and those that were similar were compiled together and highlighted in different colours (see Table 4.6). The use of colour coding helped me to visualise the data in that initial themes that could be linked to a certain key theme were compiled together. For example, all initial themes related to '*emotional/psychological turmoil'* were typed in red font. Initial themes related to '*life is restricted*' were typed in blue, and this process was adapted for all remaining themes. Themes with the same colour were then grouped together. At this stage the major themes began to emerge. Initial themes were grouped under a smaller number of broader, higher order main themes and placed within an overall framework. The four main themes that emerged and which are discussed later, in Chapter 6, were:

1. Emotional/psychological turmoil
2. Life is restricted
3. Spirituality
4. Other coping strategies

Table 4.6: Constructing the Index and Themes Grouping

1. Emotional and psychological
1.1 Fear of the unknown/unclear future/worries
1.2. It was a shock (hard to take)
1.3 Terminal illness/on HD for the rest of my life
1.4 Life marked out/ Life taken away/ dialysis dominates life
1.5 Not what I chose for my life
1.6 Indebted to carers
1.7 Grateful/indebted to donors
1.8 Affected by fellow 'patient's death'

2. Life is restricted
2.1 Many restrictions in life (sexual activity, relationships)
2.2 Lack of energy/tiredness/ Sleepy/ Muscle wastage
2.3 Side effects/ Frequent hospitalisation
2.4 Diet and fluid restrictions
2.5 Unable to work/ medically retired
2.6 Some days better than others/ No point planning
2.7 Tied to a machine/ dialysis consumes time
2.8 Loss of freedom/ dependent on others
2.9 Hard socialising/ limited recreational pursuits (gym, gardening, exercise)
2.10 Lack of counselling/ Lack of information/ Lack of communication

3. Spirituality
3.1 Spirituality meaning
3.1.1 Believing in Christian values/ faith
3.1.2 Belief in God, religion/ God is the saviour
3.1.3 Spirituality means connection with others/ Be a good friend/ Good human being/ social relationships
3.1.4 Spirituality means connection with self (own values)/ come to terms gradually/creative outlets
3.1.5 Spirituality means connection with nature
3.2 Fear of the unknown/uncertainty/shock
3.3 Fellow 'patient's death'
3.4 Spirituality helps me to get through day to day
3.4.1 Spirituality helps me to accept my illness
3.4.2 Spirituality gives me strength/ encouragement/ positive outlook
3.4.3 Spirituality helps me to cope/ God always helps me
3.4.4 Faith gives me strength
3.4.5 I'm not alone
3.4.6 Contribute to charities
3.5 Why me?
3.6 Maintain a positive attitude
3.6.1 See the bigger picture
3.6.2 Positivity is part of spirituality
3.6.3 Others worse off
3.6.4 Positivity is an obligation
3.7 Hope
3.7.1 Hope for a kidney transplant/ Hope for a normal life

4. Other means of coping
4.1 Sense of humour

Once the initial list was created, it was important to construct a more manageable index. Constructing and indexing were accomplished through identifying links between the themes, grouping them thematically then sorting them according to the levels of generality so that the index became a hierarchy of main themes, sub-themes and sub-sub-themes. Here, it was helpful to type the themes on a Microsoft Word file and re-sort them until they had been developed into a manageable structure. This structure ensured

conceptual clarity within the framework and to check there were no overlapping areas or omissions. The emerging themes were presented in terms that stayed close to the language and terms used in the data set. Table 3.7 presents the final coding framework that was applied and used in presenting the findings of the qualitative component in Chapter 6. The final coding framework includes themes, some of which comprise sub-themes and sub-sub-themes, and some which include sub-themes with no sub-sub-themes.

Table 4.7: The Final Coding Framework

Themes	Sub-themes	Sub-sub-themes
1.Emotional/psychological turmoil	1.1 Wholesale changes	
	1.2 Forced choice	
	1.3 Indebtedness	
2. Life is restricted	2.1 Limitations	2.1.1 Unremitting fatigue 2.1.2 Limited income 2.1.3 Diet and fluid restrictions 2.1.4 Side effects
	2.2 Unpredictability	
	2.3 Tied down	
3. Spirituality	3.1 Spirituality meaning	3.1.1 Connection with God/super being (angels) 3.1.2 Connection with others 3.1.3 Connection with self 3.1.4 Connection with nature
	3.2 Spiritual Struggle	3.2.1 Uncertainty 3.2.2 Death of fellow patients 3.2.3 Why me?
	3.3 Benefits of Spirituality	3.3.1 Acceptance 3.3.2 Fortification 3.3.3 Maintain a positive attitude
	3.4 Hope	3.4.1 Hope for a kidney transplant/ Normal life
4. Other coping strategies	4.1 Sense of humour	

4.5.6.4 Stage Four- Charting

At this stage, it was important to group and sort the data to locate similar content together under themes. The purpose of grouping and sorting data allowed me to focus on each subject in turn so that the details and distinctions that lie within could be unpacked. Although the ordering was subject to change at this stage, this initial physical clustering of material allowed an intense review of the content to take place which was required for subsequent stages of analysis that focused on the research questions. At this stage, the final coding framework was applied to the whole data set and a summary for each theme was developed, including its sub-themes and initial codes to facilitate comparison across interviews and within each interview. This process helped any overlaps to be identified between themes and to highlight similar themes across interviews.

4.5.6.5 Stage Five- Mapping and Interpretation

The final stage of data analysis involved summarising and synthesizing the original data. Following this approach served not only to reduce the amount of data to a more manageable level, but also to begin the process of refining the essence of the evidence for later representation. In addition, this approach ensured that every word of the original material was inspected to consider its meaning and relevance to the area under investigation. Therefore, the tables created in the previous stages were used to explore relationships between the themes, for example, between patients' perceptions of spirituality and their use of this concept in coping with dialysis, and to provide

explanations for the findings from the interviews. Different strategies were used to enhance the quality and credibility of the findings and the reliability and validity of the analysis (see Section 7.4.3), including the use of appropriate quotes to illustrate key themes and examples (as shown in Chapter 6), and comparing the results identified from the interviews with those of other studies (as shown in Chapter 7).

4.6 Ethical Considerations

The study was conducted in accordance with the approval received from the School of Nursing, Midwifery and Health Research Ethics Committee at the University of Stirling (16th July 2009, Appendix 13), and the local research ethics committee at the clinical site, the West of Scotland Research Ethics Committee (22nd April 2010, Appendix 14). A summary of the ethical considerations in this study are considered next.

4.6.1 Obtaining Ethical Approval

Prior to commencing any fieldwork and obtaining access to the clinical sites, it was important to obtain ethical approval for the study from key institutions. Therefore, the research proposal and patients' study pack were submitted to the School of Nursing, Midwifery and Health Research Ethics Committee (SREC) at the University of Stirling. After obtaining this ethical approval, approval was also sought from National Health Services, West of Scotland Research Ethics Service (NHS-WORES). This was considered satisfactory at the start of the study as this Health Board had a total number of more than 500 patients who were currently receiving HD in different dialysis centres within different hospitals. However, due to challenges in recruitment and the poor

response rate from the NHSGGC, further ethical approvals and applications to access other Health Boards were obtained. Duplication of paperwork and repeated answering of similar questions was time-consuming but unavoidable because of the decision to include other Health Boards. In addition, NHS Research and Development (NHS R&D) officers from all Health Boards issued a letter confirming that I had approvals from relevant institutions and provided evidence to nursing staff that I had permissions to conduct my study.

4.6.2 Ethical Issues (Quantitative and Qualitative Components)

Involvement in research requires general awareness and acknowledgment of appropriate and inappropriate conduct (Strydom, 2002). In accordance with the School of Nursing, Midwifery and Health guidelines, the ethical principles that guided this study after obtaining formal ethical approval included: sensitive topic/potential risk to participants, voluntary participation, non-maleficence, and confidentiality and anonymity.

4.6.2.1 Sensitive Topic/Potential Risk to Participants

Research in health care commonly involves sensitive topics and is often associated with potential social and psychological harm (Boulton, 2009). It is important to acknowledge that, for some participants, discussing issues around spirituality might be sensitive. However, in this study I was interested in speaking to patients about their views and perceptions on spirituality and its role in their lives rather than discussing issues around their beliefs or providing them with potential fear-causing information (e.g.

complications of the disease). Hence, all patients were approached in a sensitive manner, were given a full description of what the study was about and were assured that they would not be pressured to participate. In order to safeguard against any potential physical or psychological risks to participants or to me as a researcher, all questionnaires and interviews were completed in the dialysis unit. Participants were assured that if they became emotionally distressed that I was available at the dialysis unit should they wish to discuss any issues relevant to the study. In addition, contact details for an independent person within the University of Stirling were also given to participants should they wish to discuss any issues of concern.

4.6.2.2 Voluntary Participation and Non-Maleficence

Participants were offered the opportunity to base their decision to participate or withdraw on a full explanation of the study and its content. Due to the nature of the research and to ensure that patients did not feel obliged to participate, patients were reminded that their participation was entirely voluntary and that they could decline participation or withdraw at any stage of the study, without it adversely affecting the treatment or standard of care that they received. The responsibility of the researcher is to protect participants from any form of harm. Therefore, participants were advised that if they felt uncomfortable or distressed by any of the issues arising from the questionnaires or during the interviews they could take a rest period to compose themselves and carry on with the study at a time which was more convenient, or that they could withdraw from the study if they wished to do so. Although there were no noted instances of distress caused to patients by their participation, it was also important

for me to be aware of the potential for distress that patients might experience because of their participation and to give thought to how this could have been appropriately managed. Therefore, participants were assured that if they became distressed or tired and decided to withdraw from the study, any information already obtained would be removed and destroyed. Fortunately, there was no need for this to happen.

4.6.2.3 Confidentiality and Anonymity

Researchers have a responsibility to maintain confidentiality and anonymity. Hence, participants were assured that pseudonyms would be used when presenting the data from the interviews and that access to data would be restricted to me and to my study supervisors. Also, in accordance with the regulations set out in the Data Protection Act (1998), digital recordings were uploaded to my computer and all computer-generated data were password-protected. In addition, all questionnaires and interview transcripts were kept in a locked cabinet and no third party had access to the data. It was essential to ensure that all documentation, reports and publications relating to the study did not contain any identifiable data about patients who took part in the study. All patients who consented to participate were given a unique study number from which patients could not be identified by anyone other than myself. Patients were also assured that their responses were confidential and that their anonymity would be protected. It is intended that data collected during the study will be securely archived for five years in accordance with the University of Stirling regulations. All participants were informed that they could receive feedback on the research results upon my receipt of such a request. Therefore my contact details were provided on the invitation letter and the

study information leaflet.

4.7 Researcher's Role

I am a male, early middle-aged and from an Arab-British background. I am a Muslim and spirituality, for me, focuses mainly on practicing religion and maintaining a close connection with God. However, I do value other aspects of spirituality such as having meaningful relationships with others, nature and with myself. Participants, however, were not made aware of my religious background unless they asked me directly, which was the case for one participant. I made notes of my own perceptions of spirituality to avoid being judgemental. I accepted patients' views on spirituality and presented them as they emerged from the interviews. Throughout this study, I was recognized as a student researcher who was at the dialysis unit for a specific reason. It was not until the qualitative stage of the study that in-depth discussions with patients about their views, perceptions and understandings on spirituality took place. During this study a respectful and mutual relationship developed between me and the study participants. None of them made any direct comments about me or my religious or cultural background. I recognise that I was an integral part of the research process and that my personal characteristics may have been influential in the conduct of this study.

I had an important role in the process of data collection, particularly in the interviews. I followed a coherent approach in conducting the interviews. The richness of the data I obtained suggests that participants did feel comfortable about disclosing information

and expanding on it on their own terms. The combined meanings and understandings that participants chose to share are central to the achievement of the aim of my study.

4.8 Potential for Bias

In this section, I consider the sources of potential bias in my study in terms of study design and my role as a researcher. Murphy et al. (1998) suggest that the validity and confidence of study findings are increased where there is evidence of researcher sensitivity to the way in which the data may have been shaped by the researcher and their presence. First, during the survey, participants' and the nursing staff were informed that I was available to help them when required. Although it might be important to develop a good relationship with patients to clarify unclear questions or read the questions to participants who could not do so, it may have influenced patients' responses and motivation to complete the questionnaire. Polit and Beck (2006) propose that the absence of an interviewer ensures that there are no biases reflecting respondents' reaction to the interviewer rather than to the questions themselves (Polit and Beck, 2006). Hence, to minimize this risk, I sat outside the dialysis units and did not have any direct contact with participants while completing the questionnaires unless I was called to help some of them who were unable to use their dominant hand and for those who were blind.

In following ethical and management approval, recruitment had to be carried out by the nursing staff at the dialysis units. Although this was important to ensure fewer patients were missed, it raised the possibility of 'gatekeeping' as patients may have been subject

to biased selection from the nursing staff; for instance, those patients who they thought to be tired or unfit to participate may have been excluded by the nursing staff from being identified as eligible participants. It has been noted that 'gatekeeping' by clinical staff has the potential to slow or skew recruitment and, therefore, it may affect the response rate and representativeness of the sample. Although I acknowledge this as a potential source for bias, it was outwith my control as my ethical approval did not grant me permission to approach participants to distribute the study packs. Therefore, it was important to keep an ongoing dialogue with the nursing staff to minimise the risk of 'gatekeeping'.

Interviews can be subjective so the analysis and interpretation of the data may be subject to researcher bias. However, discussions with my supervisors, colleagues and an expert in mixed method research were helpful to ensure trustworthiness of the thematic analysis. It is also recognized that interviews allow the researcher to probe participants' responses for further clarification, yet the very nature of this can contribute a degree of bias within the study (Robson, 2002) as the researcher might lead participants towards responses that they may not have previously considered. To minimize this, I followed the topic guide as closely as possible in each interview. In addition, I used neutral probing to minimise the possibility of leading patients towards a specific response, such as "Can you tell me what you mean?" and "Can you tell me more?", which are less likely to influence the content of participants' responses (Polit et al., 2005). Finally, using reflective notes about my role as a researcher and the impact of this on the process of data collection and analysis was another strategy used to minimize researcher

bias.

4.9 Summary

This chapter has presented a detailed discussion of the methodology and the methods chosen in this study. The study followed a sequential mixed method approach (Section 4.2). It has been shown that quantitative and qualitative methods (Sections 4.4 and 4.5) have been used for the purpose of triangulation and in a complementary fashion; firstly, to provide insight into and evaluate the impact of ESRD and HD treatment on patients' health and general well-being; secondly, to explore spirituality in the day-to-day lives of patients and how it may have influenced their health outcomes and general well-being. This chapter has also presented a detailed discussion of each component of the study, including the design, aims and research questions, the sample, methods and the analysis strategies used to ensure that the study aim was met. The chapter has also presented the ethical issues concerning both components of the study (Section 4.6) as well as reflection on my role as a researcher and potential sources of bias. The next chapter presents the main findings from the survey.

Chapter 5- Quantitative Component Findings

5.1 Introduction

This chapter presents the findings from the cross-sectional survey analysis. The chapter is presented in three main sections. Section I describes (a) the response rate and (b) the socio-demographic characteristics of study participants. Section II presents (a) the quality of life (QOL), (b) general well-being of patients with ESRD and (c) factors associated with patients' QOL and general well-being. Section III presents spirituality and its association with patients' QOL and general well-being, followed by a summary of the chapter.

5.2 Response Rate

Recruitment was carried out in 11 dialysis units distributed over four Health Boards in Scotland over nine months from May 2009 to January 2010. The overall estimated number of patients in all dialysis sites, according to the Unit Managers, was 800 potential participants, as shown in Table 5.1. However, the number of subjects who were given out the study pack or who refused the invitation to participate in the survey was unknown because I only had access to those who had agreed to participate, as indicated by the returned Expression of Interest Forms. As can be seen from Table 5.1, the hospitals with the highest numbers of returned questionnaires were the Victoria Infirmary and Queen Margaret Hospital. Although Forth Valley Royal Hospital had a total of 98 patients, only one patient agreed to take part in the survey. I was dependent

on the nursing staff to recruit participants as specified by my ethical approval and, therefore, I was unable to perform any statistical analysis to compare participants with non-participants.

Table 5.1 shows that an estimated number of 364 questionnaires were distributed and only 72 questionnaires were completed and returned, giving a final response rate of 19.7%. All questionnaires were given out at the start of the dialysis sessions to avoid patients becoming tired or exhausted and to ensure that patients' treatment routine was not affected. On average, the questionnaire booklet was completed by the majority of participants (n=64) within 30-40 minutes. However, it took more than one hour to be completed by four participants because they were weak and tired. I had to read out the questionnaire to four participants, of whom two were blind and the other two had their fistula in their dominant right hand and were unable to use it to complete the questionnaire. All participants (n=72) completed the questionnaire while they were connected to the dialysis machine. Three additional participants preferred to complete the questionnaire at home and then post it back to me in the self-addressed envelope provided. However, these participants did not return the questionnaire.

Table 5.1: Number of Participants per Hospital, Estimated Numbers of Study Packs Given Out, and Number of Participants Who Completed the Questionnaire

Hospital Name	Number of patients per dialysis unit	Estimated number of packs given out	Number of participants who completed the questionnaire	Estimated response rate per each site
Glasgow Royal Infirmary	110	40 (36.4%)	10	10 (25%)
Western Infirmary	50	15 (30%)	2	2 (13.3%)
Victoria Infirmary	110	40 (25%)	12	12 (30%)
Queen Margaret Hospital	82	50 (60.9%)	12	12 (24%)
Stobhill Hospital	110	40 (25%)	8	8 (20%)
Vale of Leven Hospital	30	20 (66.6%)	7	7 (35%)
Inverclyde Hospital	50	15 (30%)	5	5 (33.3%)
Doctor Gray's Hospital	24	24 (100%)	8	8 (33.3%)
Forth Valley Royal	98	40 (40.8%)	1	1 (2.5%)
St Andrews Hospital	16	10 (62.5%)	2	2 (20%)
Aberdeen Royal Infirmary	120	70 (58.3%)	5	5 (7.1%)
Total number	800	364 (45.5%)	72	72 (19.7%)

% (of the total number of study packs distributed per each site)

5.3 Socio-demographic Characteristics

Demographic data with frequencies and percentages for the sample are presented in Table 5.2. Date of birth was recorded for each patient. Participants' age was categorized into 10-year groups for ease of reporting. Table 5.2 shows that there were more men (56.9%) than women (43.1%). The majority of participants were aged 46 years and older. Forty-six participants (63.9%) were living with their family, the majority were unemployed (68%), and 61.1% had been on dialysis between six months to five years (n=44). A total of 37 (51.4%) participants reported that they had no religion.

Table 5.2: Socio-Demographic Characteristics of the Sample

Demographic Data	Number	Percentage (%)
Gender		
Male	41	56.9
Female	31	43.1
Age		
18-25	3	4.2
25-35	5	6.9
36-45	9	12.5
46-55	19	26.4
56-65	20	27.8
66+	16	22.2
Do you live alone?		
Yes	26	36.1
No	46	63.9
Do you have a religious group?		
Yes	35	48.6
No	37	51.4
Do you work?		
Yes	9	12.5
No	49	68.0
Retired	13	18.1
Part time	1	1.4
Period on dialysis		
6 months-5 years	44	61.1
6 years-10 years	17	23.6
11 years-15 years	4	5.6
>15 years	7	7.9
Total	**72**	**100**

5.4 Quality of Life and General Well-Being of Patients with End-Stage Renal Disease

5.4.1 Quality of Life

In this section, the results highlighting patients' QOL and general well-being are presented before the results examining if there were any associations between socio-demographic characteristics and spirituality and the QOL and general well-being of

patients with ESRD.

To investigate the health status of patients with ESRD, the SF-36v2 was used to provide a generic population-based measure of broader health status and to compare the current data results with the health of the UK population (Jenkinson et al., 1996) (see Section 4.3.3.4). Ware et al. (2000) suggest using a norm-based or cut-off score of a mean of 50 and a standard deviation of 10 to interpret the results of SF-36v2. A mean score below 50 indicates below average health status, while a mean score above 50 indicates a better health status than the population average.

The Mean scores (± SD) of the eight subscales of SF-36v2 and the two component summary scores (i.e. MCS, PCS) are provided for the entire sample (n =72) in Table 5.3, then broken down by demographic characteristics and spiritual well-being and religiosity questions in order to identify factors associated with QOL and general well-being. Table 5.3 shows that patients with ESRD scored considerably lower than the UK general population. The mean scores of the eight domains of the SF-36v2 for the total sample ranged from 25.75 to 47.84, indicating that these patients had poor perceived health status. Limitations due to Physical Functioning (PF) and Role Physical (RP) problems were the lowest rated domains (Mean=25.75 and 26.24 respectively), while Vitality (VT) was the highest rated domain (Mean=47.62). Noticeably, the physical component summary score (PCS) was markedly lower than the mental component summary score (Mean= 26.53 and 47.84 respectively).

Table 5.3: Mean Scores of the SF-36v2 Domains of patients on Haemodialysis in Scotland

SF-36v2 Domains		N= 72	
		Mean	**SD**
Physical Health	PF	25.75	12.61
	RP	26.24	11.48
	BP	33.19	11.52
	GH	43.22	6.04
Mental Health	VT	47.62	6.78
	SF	36.27	5.28
	RE	35.66	15.59
	MH	43.66	6.07
PCS		26.53	7.26
MCS		47.84	7.52

PCS (Physical Component Summary Scores), **MCS** (Mental Component Summary Scores), **SD** (Standard Deviation)

5.4.1.1 General Health Perception among Dialysis Patients in Scotland

General health perception was assessed using item number one in the SF-36v2 questionnaire which asks patients to rate their health in general. The question is scored using a 5-point ordinal scale ranging from one "Excellent" to five "Poor". Table 5.4 presents a description of patients' general health perception. The results show that 28 (38.9 %) patients rated their general health as fair, followed by 25 patients (34.7%) who rated their general health as good. Only nine patients (12.5%) rated their general health as poor, whereas three patients rated their general health as excellent (4.2%).

Table 5.4: Perceived General Health among Dialysis Patients

Total N= 72	
Perceived General Health	**N (%)**
Excellent	3 (4.2)
Very good	7 (9.7)
Good	25 (34.7)
Fair	28 (38.9)
Poor	9 (12.5)

% (of the total number of participants)

Patients were also asked to rate their health compared to one year ago to assess how they perceived their health at the time of data collection. Item number two of the SF-36v2 questionnaire was used to measure health transition. Results show that the majority of patients (n=37; 51.4%), in general, perceived that their health was about the same as one year ago (Table 5.5).

Table 5.5: Perceived General Health Compared to One Year Ago as Rated by Dialysis Patients

Total n=72	
Rating Scale of Health Transition	**N (%)**
Much better now than one year ago	11 (15.3)
Somewhat better now than one year ago	11 (15.3)
About the same as one year ago	37 (51.4)
Somewhat worse now than one year ago	10 (13.9)
Much worse now than one year ago	3 (4.2)

N (number), **%** (of the total number of participants)

5.4.2 General Well-Being of Patients with End-Stage Renal Disease

It was discussed earlier (see Section 4.3.3.4) that the GHQ-28 can be scored using the

values of 0 to 3 for each response with a total possible score ranging from 0 to 84. Using this method, a total score of 23/24 is the threshold for the presence of stress and anxiety. In my study, scores ranged from 2 to 69 with a mean score of 25.58 (SD=13.9). According to the developers of the GHQ-28 there is no cut-off point to be used to interpret results. However, higher scores denote higher stress and anxiety and therefore reduced general well-being (Sterling et al., 2003). Hence, scores on the GHQ-28 in my study were divided into quartiles for ease of interpretation (Figure 5.1). Figure 5.1 shows that 34 (47%) participants scored 23 and higher, indicating the presence of stress and anxiety in their lives. Of these 34 participants, the majority (n=14) scored 23-28, eight participants scored 30-39, seven participants scored 40-49 and three participants scored 50-59. Only two participants scored very highly on the GHQ-28 (67 and 69, respectively), indicating that they were highly stressed about their current situation.

Figure 5.1: Total General Health Questionnaire Scores by Quartiles

5.4.3 Physical, Mental Component and General Well-Being Scores Stratified by Age Groups

Boxplots were constructed (Figure 5.2 and Figure 5.3) to illustrate the declining physical health and improving mental well-being of patients with ESRD in relation to their age. The boxplot provides a vertical view of the data and plots the 25th percentile, the median (the 50th percentile), the 75th percentile, and outlying or extreme values. The weak trend of improving overall MCS scores with increasing age is evident in Figure 5.3. Figure 5.4 illustrates the trend of reduced stress and anxiety with increasing age.

Figure 5.2: Boxplot for Overall Physical Health and Age Comparisons

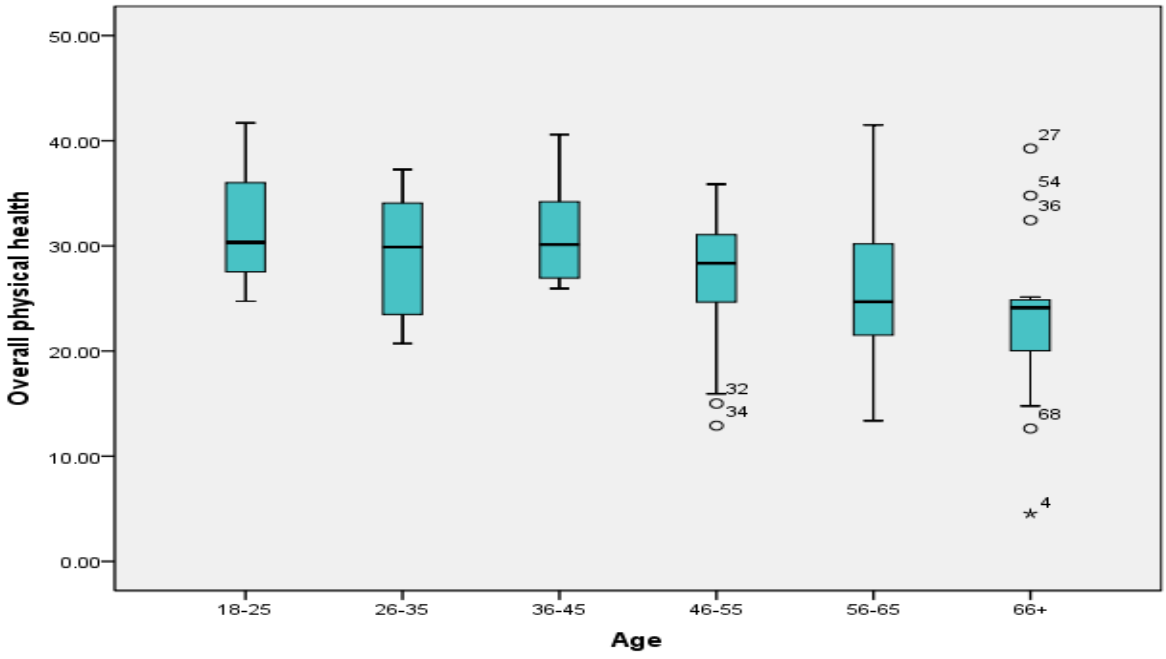


Figure 5.3: Boxplot for Overall Mental Health Scores and Age Comparisons

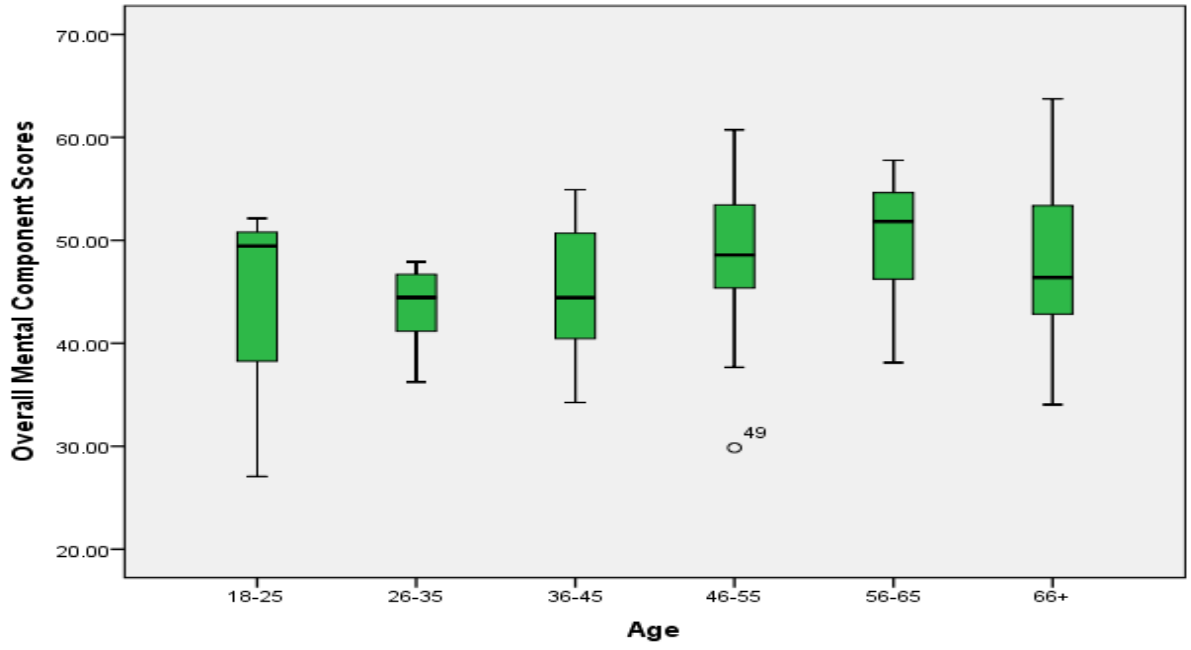
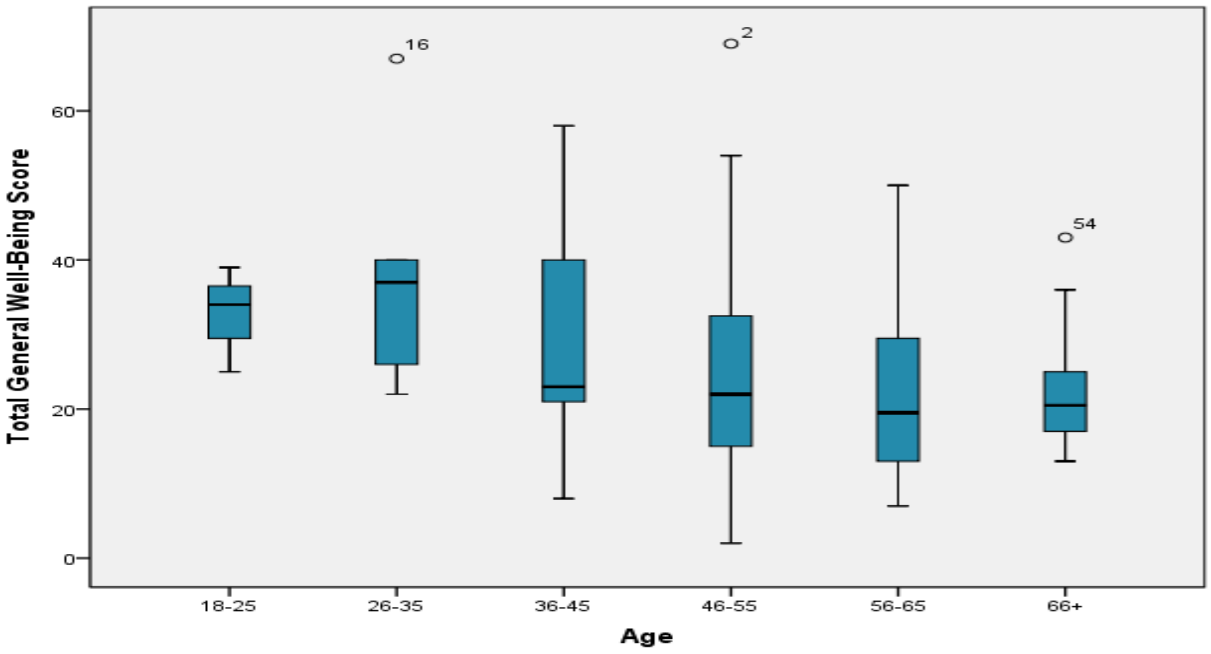


Figure 5.4: Boxplot for Total General Well-Being Scores and Age Comparisons



5.4.4 Quality of Life for Patients with End-stage Renal Disease Stratified by Age Groups

Given the results for MCS and PCS by age, I explored them further by evaluating specific domain of the SF-36v2 by age (Table 5.6). As can be seen from Table 5.6, patients who were 66 years and older achieved the lowest mean scores for the Physical Functioning and Role Physical domains of QOL (Mean=21.12, 23.70 respectively), suggesting that they were struggling physically as a result of their disease. Noticeably, young patients aged 18-25 years scored substantially higher on the Physical Functioning domain than the other age groups (Mean=36.60). An important finding was that the mean scores for Vitality and Mental Health domains were very close to the UK general population norms in all age groups. Patients aged 26-35 years scored higher than the average norms in the Vitality domain (Mean=51.0).

Table 5.6: Mean Scores on the Eight Domains of the SF-36v2 Stratified by Age

Age group	PF Mean (SD)	RP Mean (SD)	BP Mean (SD)	GH Mean (SD)	VT Mean (SD)	SF Mean (SD)	RE Mean (SD)	MH Mean (SD)	MCS Mean (SD)	PCS Mean (SD)
18-25 years (n=3)	36.60 (7.7)	28.37 (7.1)	31.68 (6.6)	40.50 (3.7)	45.89 (3.1)	35.89 (5.3)	35.66 (19.4)	39.75 (8.8)	42.88 (13.7)	32.25 (8.6)
26-35 years (n=5)	25.06 (14.3)	24.59 (10.9)	36.61 (14.8)	44.58 (5.7)	51.00 (10.2)	36.97 (4.5)	22.02 (12.8)	41.22 (4.1)	43.29 (4.7)	29.08 (6.9)
36-45 years (n=9)	31.79 (12.6)	30.20 (16.9)	32.17 (12.6)	44.31 (4.9)	45.54 (5.8)	34.10 (6.01)	39.16 (17.8)	40.67 (6.4)	44.84 (6.4)	31.13 (4.7)
46-55 years (n=19)	25.04 (13.6)	25.78 (11.9)	34.96 (13.1)	44.71 (7.3)	47.07 (5.7)	35.33 (4.7)	36.76 (17.5)	45.31 (5.9)	48.58 (7.7)	26.49 (6.6)
56-65 years (n=20)	25.95 (11.9)	27.03 (10.4)	31.83 (11.0)	42.87 (5.5)	48.60 (7.5)	38.85 (5.3)	37.95 (13.9)	44.94 (5.1)	50.20 (6.1)	25.62 (6.7)
+66 years (n=16)	21.12 (11.4)	23.70 (10.1)	32.59 (10.3)	41.37 (6.1)	47.49 (7.4)	35.22 (5.1)	33.77 (13.7)	43.26 (6.7)	48.03 (8.2)	23.25 (8.3)
Total (n=72)	25.75 (12.6)	26.24 (11.5)	33.19 (11.5)	43.22 (6.04)	47.62 (6.8)	36.27 (5.3)	35.66 (15.6)	43.66 (6.1)	47.84 (7.5)	26.53 (7.3)

PF (Physical Functioning), **RF** (Role Physical), **BP** (Bodily Pain), **GH** (General Health), **VT** (Vitality), **SF** (Social Functioning), **RE** (Role Emotion), **MH** (Mental Health), **MCS** (Mental Component Summary), **PCS** (Physical Component Summary)

5.4.5 Factors Associated with Quality of Life and General Well-Being

5.4.5.1 Socio-Demographic Characteristics

To explore the association between socio-demographic factors and the QOL (measured by the SF-36v2) and general well-being (measured by the GHQ-28), the study sample was divided into two groups according to gender and living and working status; into six groups according to their age; and into four groups according to their period on dialysis. Table 5.7 shows that, as age increased, the mean scores for the overall MCS approached the average norms, but the overall PCS scores were markedly lower than the average norms, particularly for patients who were aged 66 years and older (mean=23.25). This result indicates that increasing age might be associated with better mental health but

worse physical health. The lowest mean score for the MCS (mean=42.88) was among patients who were 18-25 years old, suggesting that they were the main group affected by the disease. There were no significant differences in the overall MCS between men and women, those who were living alone or with their families, and for those who were working or not. Interestingly, patients who were on HD for 11 to 15 years achieved higher mean scores than the UK average (Mean=52.12), possibly indicating that the longer patients are on dialysis the better they are coping with it. Even though the overall PCS mean scores were all significantly lower than the UK average norms, there were no significant differences between men and women, those who lived alone or with their families, and period of time on dialysis.

The independent sample t-test showed that there was a significant difference in the overall PCS mean scores between workers (Mean=30.73, SD=6.2) and non-workers (Mean=25.86, SD=7.2; t (70) =2.010, p=.048, two tailed). The magnitude of the differences in the means (Mean difference = 4.9, 95% CI: 0.37 to 9.7) was moderate (eta squared = 0.06). This result suggests that those who are working report better physical health or maybe they are able to work because they have better physical health.

With regards to general well-being, patients who were aged 56-65 and +66 years achieved the lowest mean scores (Mean= 22.90, 22.14 respectively), suggesting that increasing age might be associated with reduced levels of stress and anxiety and therefore better well-being. The independent sample t-test showed that there was a significant difference in the general well-being mean scores between men (Mean= 22.0, SD= 11.4) and women (Mean=30.32, SD= 15.8; t (52) = 4.77, p= .016, two-tailed). The

magnitude of the differences in the means (mean different= -8.32, 95% CI: -15.04 to -1.60) was moderate (eta squared= 0.08). This result suggests that women might be more stressed and anxious about their disease and thus report worse general well-being. Participants who were on dialysis for 11 to 15 years achieved the lowest mean score of 16.75 for general well-being, suggesting that they were the least stressed group of participants. There were no other differences in mean scores for those who were living alone or with their families, or for those who were working or not.

Table 5.7: Mean scores for MCS, PCS, and General Well-Being by Socio-Demographic Characteristics

	MCS Mean ±SD	f (p)	**PCS Mean ±SD**	f (p)	**General Well-Being Mean ±SD**	f (p)
Age						
18-25	42.88 ±13.7		32.25 ±8.6		32.67 ±7.0	
26-35	43.29 ±4.7	1.38	29.08 ±6.9	2.07	38.40 ±17.6	1.56
36-45	44.84 ±6.4	(0.242)	31.13 ±4.7	(0.080)	29.11 ±15.5	(0.183)
46-55	48.58 ±7.7		26.49 ±6.6		25.63 ±17.0	
56-65	50.20 ±6.1		25.62 ±6.7		22.40 ±12.6	
+66	48.03 ±8.2		23.25 ±8.3		22.19 ±7.9	
Period on HD						
6months-5 years	47.43 ±7.9		25.91 ±7.5		27.59 ±16.0	
6 yrs-10yrs	47.49 ±6.9	0.51	28.18 ±6.5	0.39	23.88 ±11.0	1.06
11yrs-15yrs	52.12 ±6.4	(0.675)	26.07 ±9.0	(0.757)	16.75 ±7.6	(0.372)
>15yrs	48.73 ±7.4		26.69 ±7.5		22.14 ±3.8	
	MCS Mean ±SD	**t (p)**	**PCS Mean ±SD**	**t (p)**	**General Well-Being Mean ±SD**	**t (p)**
Gender						
Male	47.30 ±6.5	5.01	27.38 ±6.4	1.76	22.00 ±11.4	4.77
Female	48.55 ±8.8	(0.507)	25.41 ±8.3	(0.258)	30.32 ±15.8	(0.016)
Living Alone						
Yes	48.95 ±8.1	0.51	25.26 ±8.6	2.13	22.04 ±10.5	4.57
No	47.21 ±7.2	(0.348)	27.25 ±6.4	(0.267)	27.59 ±15.4	(0.075)
Working status						
Yes	47.52 ±5.1	3.14	30.73 ±6.1	2.10	22.50 ±14.6	0.19
No	47.25 ±7.7	(0.906)	25.86 ±7.2	(0.048)	26.08 ±13.9	(0.457)

MCS (Mental Component Summary), **PCS** (Physical Component Summary)

Having discussed the health status (i.e. QOL) and general well-being, the focus now turns to discussing spirituality in order to answer the main research question for the survey: 'Is there an association between spirituality and the QOL and general well-being in patients with ESRD receiving HD treatment?'

5.5 Spirituality and Quality of Life and General Well-Being

The SWBQ was used to assess patients' spirituality and examine if there were any relationships between spirituality and the QOL and the general well-being of patients with ESRD (as discussed in Section 4.3.34).

5.5.1 Total Spiritual Well-Being

According to the authors of the SWBQ, there is no cut-off point for which the researcher can say if a patient scores above this number that means they have scored high on spiritual well-being. However, higher scores on SWBQ denote higher spirituality (Fisher, 2010). Researchers can use the raw scores for the subscales of the SWBQ or the total score for the questionnaire in order to describe a patient's spirituality. Therefore, in my study the total scores of the SWBQ were used to categorise participants. The total score of the SWBQ was divided into approximate quartiles: very low=20-55, low=55-68, high=69-76, and very high=77-100. Thirty-nine participants scored lower than 68, indicating lower spiritual well-being. Alternatively, 33 participants scored more than 69, indicating higher spiritual well-being. Only one participant scored 20, which was the lowest possible score on the SWBQ; however, two participants achieved the highest possible score on the SWBQ: 100. Table 5.8 shows

the SWBQ scores in relation to gender in quartiles. The numbers in these approximate quartiles were not equal because more than one patient could have the same total score. For example, four patients scored 55 in the SWBQ. 21 participants of the total sample (29.1%) scored very low on the SWBQ, indicating low spiritual well-being. Of them, the proportion of men (29.8%) was higher than women (8.3%). Only 18 participants of the total sample (25%) scored very high on the SWBQ, indicating high spiritual well-being.

Table 5.8: Total Spiritual Well-Being Scores by Gender in Quartiles

SWBQ score	Number of participants		Total (%)
	Male (%)	Female (%)	
Very low (20-55)	15 (20.8)	6 (8.3)	21 (29.1)
Low (56-68)	11 (15.3)	7 (9.7)	18 (25)
High (69-76)	9 (12.5)	6 (8.3)	15 (20.8)
Very high (77-100)	6 (8.3)	12 (16.7)	18 (25)
Total	41 (56.9)	31 (43.1)	72 (100%)

% (of the total number of participants)

Results for the importance of religion, importance of spirituality and other questions measuring religiosity were stratified by gender only, not by age groups, because of the small sample size (Table 5.9). Table 5.9 shows the results on the importance of religion and spirituality in the lives of patients with ESRD by gender. As can be seen, 38.9% of the total sample reported that spirituality was important in their lives. The proportion of women (9.7%) who reported that spirituality was very important in their lives was higher than the proportion of men (4.1%). Furthermore, 44.4% of the total sample reported that religion was not important in their lives. The proportion of men (29%)

who reported that religion was not important in their lives was higher than the proportion of women (15.3%).

Table 5.9: Importance of Religion and Spirituality in Patients' Life by Gender

	Importance of religion in your life			**Important of spirituality in your life**		
	M (%)	**F (%)**	**Total (%)**	**M (%)**	**F (%)**	**Total (%)**
Very low	18 (25)	7 (9.7)	25 (34.7)	11 (15.3)	3 (4.2)	14 (19.4)
Low	3 (4.2)	4 (5.6)	7 (9.7)	4 (5.6)	3 (4.2)	7 (9.7)
Moderate	12 (16.7)	7 (9.7)	19 (26.4)	13 (18.1)	10 (13.9)	23 (32)
High	6 (8.3)	5 (6.9)	11 (15.3)	10 (13.9)	8 (11.1)	18 (25)
Very high	2 (2.8)	8 (11.1)	10 (13.9)	3 (4.2)	7 (9.7)	10 (13.9)
Total	**41**	**31**	**72 (100)**	**41**	**31**	**72 (100)**

M: Male, **F**: Female, **%** (of the total number of participants)

With regard to how often participants attended church or religious groups, Table 5.10 shows that most participants (44.4%) reported that they never go to church. Of these, the proportion of men (29.2%) was higher than that of women (15.3%). More women (n=5, 6.9%) attended church at least once a week.

Table 5.10: Frequency of Church/Religious Group Attendance (apart from weddings or funerals)

Response	**Number= 72**		**Total (%)**
	M (%)	**F (%)**	
Never	21 (29.2)	11 (15.3)	32 (44.4)
Once a year	5 (6.9)	3 (4.2)	8 (11.1)
2-3 times a year	6 (8.3)	5 (6.9)	11 (15.3)
Once a month	1 (1.4)	4 (5.6)	5 (6.9)
Most weeks	6 (8.3)	3 (4.2)	9 (12.5)
At least once a week	2 (2.8)	5 (6.9)	7 (9.7)
Total	**41**	**31**	**72 (100%)**

M=Male (n=41), **F**=Female (n=31), **%** (of the total number of participants)

Table 5.11 below shows the results on how often participants pray. As can be seen, 37.5% of the total sample reported that they never prayed, while 27.8% prayed on a daily basis. The proportion of men who reported that they never prayed (26.4%) was higher than women (11.1%). Conversely, the proportion of women who prayed on a daily basis (18.1%) was higher than that of men (9.7%).

Table 5.11: Frequency of Prayer

Response	N=72		Total (%)
	M (%)	F (%)	
Never	19 (26.4)	8 (11.1)	27 (37.5)
Only in times of real need	4 (5.6)	6 (8.3)	10 (13.8)
1-2 times a year	1 (1.4)	2 (2.8)	3 (4.2)
Once a month	1 (1.4)	0	1 (1.4)
Weekly	9 (12.5)	2 (2.8)	11 (15.3)
Daily	7 (9.7)	13 (18.1)	20 (27.8)
Total	**41**	**31**	**72 (100)**

M= male, **F**= female, **%** (of the total number of participants)

5.5.2 Socio-Demographic Characteristics and Spirituality

Mean comparisons, the independent samples t-test and ANOVA were computed to explore if there were any significant differences between spirituality mean scores by patients' socio-demographic characteristics (Table 5.12). Table 5.12 shows that there was a significant difference between mean scores for men and women on total spiritual well-being. Therefore, an independent sample t-test was conducted to compare the total spiritual well-being scores for men and women. The test displayed a significant difference between men (mean= 60.76, SD= 17.8) and women (Mean=72.97, SD= 15.6, t (70) = -3.04, p=.003, two-tailed). The magnitude of the differences in the means (mean difference= -12.21, 95% CI: -20.22 to -4.20) was moderate (eta squared .02).

This result suggests that women might be more spiritual than their male counterparts.

Table 5.12: Spirituality Well-Being Stratified by Gender, Living and Working Status

Spirituality	Gender		t (p)	Living Alone		t (p)	Working Status		t (p)
	Men (n=41)	Women (n=31)		Yes (n=26)	No (n=46)		Yes (n=9)	No (n=63)	
	Mean ±SD	Mean ±SD		Mean ±SD	Mean ±SD		Mean ±SD	Mean ±SD	
SWBQ Total	60.67 ±17.8	72.97 ±15.6	-3.04 (0.003)	64.65 ±21.1	66.78 ±15.9	-0.48 (0.63)	62.56 ±10.4	64.61 ± 17.7	-0.334 (0.73)

5.5.3 Spiritual Well-Being and Religiosity and Quality of Life

Participants were categorised into four groups according to their scores on the SWBQ (group 1: very low=20-55; group 2: low= 55-68; group 3: high 3= 69-76; group 4: very high 4=77-100). As can be seen from Table 5.13, one-way ANOVA analysis showed that there was a statistically significant difference at the $p<.05$ level in the overall PCS scores for the four groups: $F (3, 68) =3.3$, $p=.024$. The effect size, calculated using eta squared, was large (0.13). Post-hoc comparisons using the Tukey HSD test determined that the mean score for Group 1 (Mean= 23.21, SD=6.6) was significantly different from Group 2 (Mean= 30.02, SD= 7.1). Group 3 (Mean= 27.75, SD= 5.9) and Group 4 (Mean= 25.90, SD= 7.8) did not differ significantly from either Group 1 or 2. This result suggests that higher spirituality could be associated with worse physical health.

Table 5.13: Mean Scores for MCS, PCS, and General Well-Being by Spiritual Well-Being and Religiosity Questions

Spiritual Well-Being Quartiles	**MCS Mean ±SD**	**f (p)**	**PCS Mean ±SD**	**f (p)**	**General Well-Being Mean ±SD**	**f (p)**
Very Low (20-55)	47.21 ±8.0	0.471	23.21 ±6.6	3.35	55.33 ± 15.6	1.40
Low (55-68)	49.31 ±7.4	(0.703)	30.02 ±7.1	(0.024)	50.50 ±9.76	(0.250)
High (69-76)	46.40 ±7.2		27.76 ±5.9		57.80 ±15.5	
Very High (77-100)	48.30 ±8.1		25.91 ±7.8		49.56 ±12.7	
Importance of Religion in Life	**MCS Mean ±SD**		**PCS Mean ±SD**		**General Well-Being Mean ±SD**	
Very Low	46.76 ±7.1	1.51	26.85 ±8.3	0.861	56.80 ±15.4	1.07
Low	46.09 ±9.6	(0.208)	27.75 ±3.8	(0.492)	52.43 ±13.5	(0.374)
Moderate	46.66 ±6.4		26.26 ±6.5		51.05 ±11.7	
High	48.95 ±6.9		28.65 ±4.9		54.73 ±15.6	
Very High	52.76 ±8.7		23.07 ±9.7		47.10 ±9.9	
Importance of Spirituality in Life	**MCS Mean ±SD**		**PCS Mean ±SD**		**General Well-Being Mean ±SD**	
Very Low	47.45 ±8.4	0.570	24.82 ±8.2	0.590	53.14 ±11.3	0.590
Low	44.83 ±8.3	(0.686)	28.89 ±6.3	(0.671)	60.43 ±19.3	(0.671)
Moderate	47.35 ±6.8		27.05 ±7.0		52.96 ±13.1	
High	48.73 ±6.8		27.27 ±6.1		52.22 ±15.3	
Very High	50.01 ±9.2		24.75 ±9.5		50.50 ±12.1	
Frequency of Church/ Religious Group Attendance	**MCS Mean ±SD**		**PCS Mean ±SD**		**General Well-Being Mean ±SD**	
Never	47.39 ±6.5	1.16	26.79 ±7.4	0.964	54.38 ±16.4	1.39
Once a Year	45.34 ±8.3	(0.334)	27.69 ±7.0	(0.447)	58.13 ±16.8	(0.240)
2-3 Times a Year	45.53 ±9.1		27.72 ±7.5		55.55 ±9.5	
Once a Month	52.71 ±7.3		20.02 ±3.6		53.80 ±10.4	
Most Weeks	50.92 ±6.4		25.80 ±8.6		50.22 ±7.7	
At Least Once a Week	48.89 ±9.5		27.75 ±6.6		41.86 ±3.2	
Frequency of Prayer	**MCS Mean ±SD**		**PCS Mean ±SD**		**General Well-Being Mean ±SD**	
Never	47.53 ±7.1	0.376	26.15 ±6.6	0.479	53.63 ±15.1	0.608
At Times of Real Need	46.80 ±6.1	(0.863)	25.32 ±8.0	(0.791)	59.20 ±13.1	(0.694)
1-2 Times a Year	43.36 ±6.8		26.26 ±14.6		48.33 ±4.6	
Once a Month	47.75		28.53		49.00	
Weekly	48.36 ±6.0		29.56 ±5.1		49.82 ±11.8	
Daily	49.16 ±8.4		25.91 ±8.0		52.40 ±14.4	
Identification with a Religious Group	**MCS Mean ±SD**	**t (p)**	**PCS Mean ±SD**	**t (p)**	**General Well-Being Mean ±SD**	**t (p)**
Yes	48.16 ±9.1	0.350	26.81 ±7.7	0.314	52.17 ±13.1	-0.611
No	47.53 ±5.7	(0.727)	26.27 ±6.9	(0.754)	54.16 ±14.5	(0.543)

Although there were no other significant differences in mean scores for the overall MCS and general well-being scores by spiritual well-being quartiles and religiosity questions, there seemed to be a trend of increasing mean scores for the overall MCS for those who scored high to very high on the importance of religion and importance of

spirituality. While these results were not statistically significant, they suggest that increasing importance of religion and spirituality may be associated with better mental health. These trends were not as evident for the PCS scores and general well-being. Figures 5.5 and 5.6 illustrate the comparisons between means of overall MCS, PCS, and general well-being scores by importance of religion and importance of spirituality.

Figure 5.5: MCS, PCS, and General Well-Being Scores by Importance of Religion

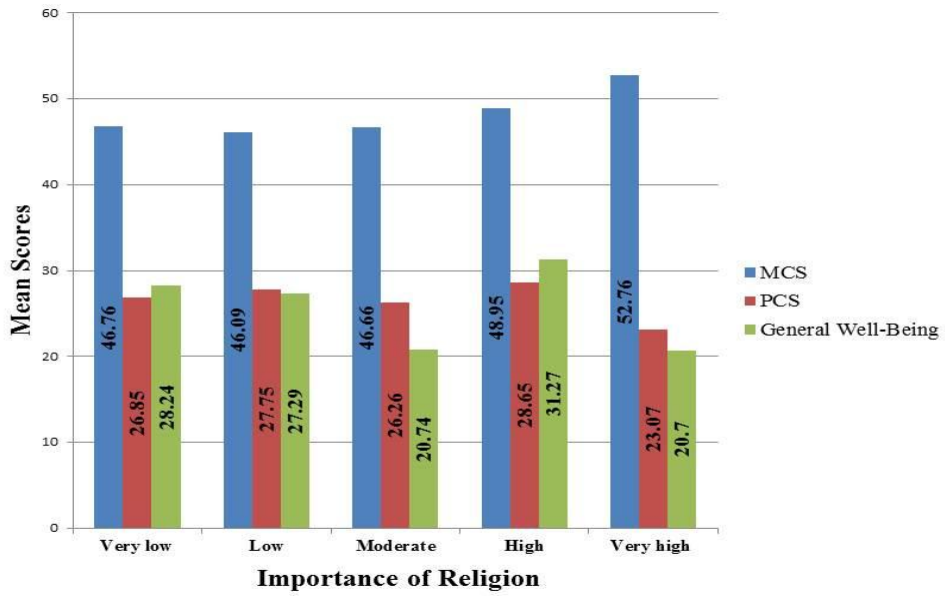
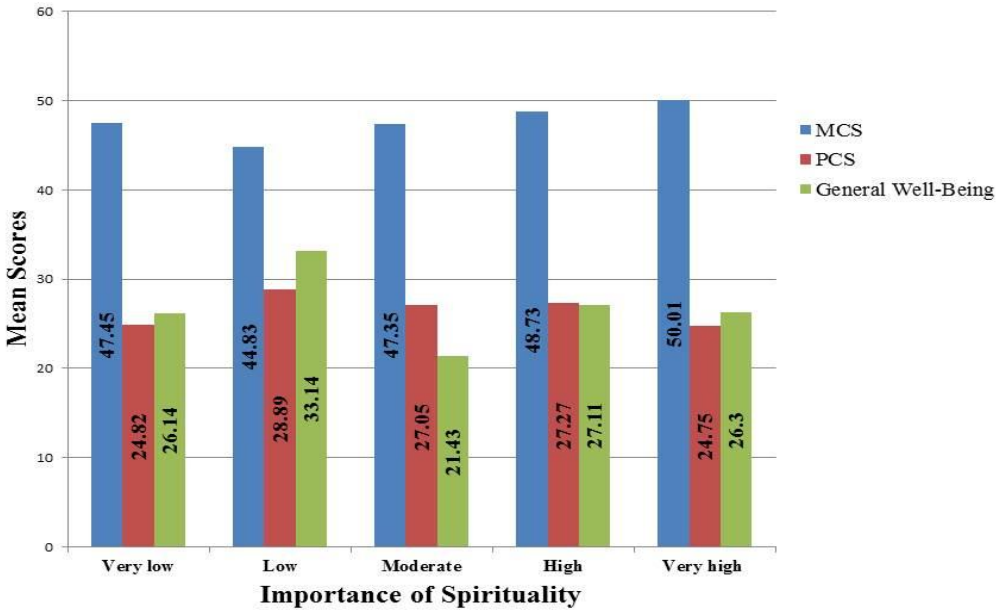


Figure 5.6: MCS, PCS, and General Well-Being Scores by Importance of Spirituality



Given the significant results for the overall PCS by spiritual well-being quartiles (Table 5.13), one-way ANOVA was carried out to determine if there were significant differences between spiritual well-being scores and the specific domains pertaining to overall PCS; namely, Physical Functioning (PF), Role Physical (RP), and Bodily Pain (BP), as these domains measure the physical health of individuals within the SF-36v2. Also, I looked at these results in relation to the Vitality (VT), Social Functioning (SF), and General Health (GH) domains as they also contribute to the overall PCS and MCS scores (Table 5.14). Table 5.14 shows that there were significant differences between spiritual well-being scores and the following: Physical Functioning ($F(3, 68) = 4.1$, $p = .010$) with a large effect size, calculated using eta squared (0.15) and Role Physical

(F (3, 68) = 2.92, p=.040) with a large effect size, calculated using eta squared (0.11).

For the Physical Functioning domain, Post-hoc Tukey HSD determined that significant differences were found between Group 1 (Mean= 22.55, SD=11.8) and Group 2 (Mean= 32.93, SD= 13.6, p=.040). Post-hoc Tukey HSD also determined that significant differences were found between Group 2 (Mean= 32.93, SD= 13.6) and Group 4 (Mean= 20.49, SD= 12.4, p=.013), suggesting that being more spiritual may have a negative effect on physical functioning. No significant differences were found between Group 3 and Groups 1, 2, and 4. For the Role Functioning domain, Post-hoc Tukey determined that significant differences were found between Group 1 (Mean= 21.48, SD= 9.9) and Group 2 (Mean= 31.85, SD= 11.1, p=.024), again suggesting that being more spiritual may have a negative impact on physical health. No significant differences were found between Group 1 and Groups 2, 3, and 4.

Table 5.14: Mean Scores for the Overall PCS Dimensions of Quality of Life by Spiritual Well-Being Quartiles

PCS	Spirituality Well-Being Quartiles				f (p)
	Very Low (20-55) Mean ±SD	Low (55-68) Mean ±SD	High (69-76) Mean±SD	Very High (77-100) Mean±SD	
PF	22.54 ±11.8	32.92 ±8.6	27.95 ±8.6	20.48 ±12.4	4.05 (0.010)
RP	21.48 ±9.9	31.85 ±11.1	27.24 ±10.0	25.38 ±13.0	2.92 (0.040)
BP	32.31 ±9.8	30.96 ±12.2	31.68 ±12.3	37.72 ±11.8	1.29 (0.283)
GH	41.55 ±7.1	44.31 ±3.9	43.11 ±6.5	44.17 ±6.1	0.87 (0.459)
VT	47.26 ±8.0	48.55 ±5.7	45.89 ±7.6	48.55 ±6.0	0.54 (0.653)
SF	36.66 ±6.4	35.60 ±3.9	25.54 ±5.6	37.09 ±5.1	0.36 (0.777)

PCS (Physical Component Scores), **PF** (Physical Functioning), **RP** (Role Physical), **BP** (Bodily Pain), **GH** (General Health), **VT** (Vitality) and **SF** (Social Functioning).

5.6 Reflection on Results

Having discussed the relationship between spirituality and the QOL and general well-being of patients with ESRD, it seems that spirituality and the QOL and well-being of these patients are not associated. However, this might be as a result of type 2 error within this study (i.e. failure to reject the null hypothesis when it is in fact false) as the small sample size might not be sufficient to capture the true relationship between these variables. In addition, this may have been influenced by gatekeeping and biased selection from the nursing staff as they might have given the study pack to patients who they thought were the most appropriate to be recruited, or it might be because those who were more spiritual chose to participate. Hence, further studies are required to validate my study findings and examine the relationship between spirituality and QOL and well-being of patients receiving HD treatment in Scotland.

However, even with a small sample size, Cronbach's alpha values of 0.89 for the Personal domain, 0.86 for the Communal domain, 0.88 for the Environmental domain, 0.88 for the Transcendental domain and 0.79 for the total SWBQ, suggest that it was reliable to measure spirituality and its associations with patients' QOL and general will-being among participants in my study.

5.7 Participants' Feedback about the Study

Participants were encouraged to add any comments about the survey or the questionnaires by adding text to a box at the end of the questionnaire booklet.

Interestingly, some participants added a few comments with regard to their interest in participating. For example, James said, "*I thought this is an interesting issue and one I have not heard or discussed in my unit or other units I have attended. I believe this is an area which does influence a number of patients, nurses, doctors. How much and who does it influence is an intriguing question. Good luck with your work"*.

5.8 Summary

This chapter has presented the results from the survey. The study shows that patients receiving HD treatment in Scotland have poor QOL and impaired general well-being. Increasing age was negatively associated with lower mean scores for the Physical Functioning and Role Physical domains of QOL and the overall PCS means suggesting that increasing age is associated with reduced physical activities. Gender was positively associated with general well-being, indicating that female participants reported more stress and anxiety; thus worse general well-being.

Additionally, there was a trend of increasing mean scores for the overall MCS with increasing importance of spirituality and increasing importance of religion in patients' lives, suggesting that using them to cope with ESRD and HD treatment could be associated with better mental health. There were no other statistically significant associations between spirituality, the other religiosity questions and the QOL and general well-being of patients with ESRD. The next chapter presents the findings from the qualitative component of the study.

Chapter 6- Qualitative Component Findings

6.1 Introduction

This chapter presents the findings from the in-depth analysis of 21 semi-structured interviews with 11 men and 10 women who shared their experiences as patients currently undergoing dialysis treatment. Throughout this chapter verbatim quotations from the interviews are used to present the similarities and differences in participants' views. Pseudonyms are used to identify participants. Hesitations such as 'mmm' and 'eee' have been removed if this did not alter the meaning of the quotes. The chapter starts by presenting the demographic characteristics of patients who participated in the interviews (Section 6.2). The approach to developing thematic analysis is presented in Section 6.3. The main findings are then organised into four major themes that emerged from the analysis of the interviews in Sections 6.5, 6.6, 6.7 and 6.8, respectively. A summary of the key findings is presented in Section 6.9, followed by a synthesis of the quantitative and qualitative data sets in Section 6.10.

6.2 Demographic Characteristics of Participants

Recruitment for the qualitative component was carried out during the survey by asking participants if they were interested in participating in an interview at a later stage (see Section 4.4.2). Of the 72 participants who completed the questionnaire, 36 participants indicated their willingness to participate in the interviews. Of these 36 potential participants, four participants died, three had a transplant, three had moved to home HD

and five participants withdrew without giving a reason, leaving a final sample of 21 participants who took part in the interviews. Table 6.1 shows the demographic characteristics of these participants. The sample comprised 11 men and 10 women, ranging in age from 21-73 years with an average age of 58 years. All participants were currently receiving centre-based HD treatment. The period of time on dialysis ranged from 4 years to 31 years with an average of 8.5 years. The majority of participants live alone (n=13), two were working part-time; six were unemployed and 13 were retired. All were White British, four were Roman Catholic, one was a Church of Scotland follower, one followed the Baptist Church and one followed the Scottish Episcopal Church.

Table 6.1: Demographic Characteristics of the Qualitative Component Participants

Pseudonym	Gender	Age	Past Medical History Relevant to ESRD	Years on dialysis	Living and Working status	Spirituality or religious affiliation
Kevin	Male	64	Diagnosed in 1984. Two kidney transplants: first in 1985, second in 1997 (failed in 2007). Liver transplant (1997)	On HD since 2007 (6 years)	Lives with family Retired	Buddhism (not practising now) Appreciates connection with self, others and nature
Andrew	Male	63	Diagnosed in 1981. Home HD (1981-1986), Kidney transplant (1986-2002), Centre HD 2002-2005, third Transplant 2005-2009	Since 2009 (3rd time) (4 years)	Lives with family Retired	Roman Catholic Connection with self, others and nature.
Isabel	Female	55	Diagnosed in 2008	On HD since 2008 (5 years)	Lives with family Retired	Roman Catholic Connection with self, others and nature
Katy	Female	57	Diagnosed in 2009	On HD since 2009 (4 years)	Lives alone Retired	Believes in God (not a church goer). Connection with

						nature and others
Helen	Female	47	Diagnosed in 2007, 3 previous liver transplants	On HD since 2007 (6 years)	Lives alone Retired	Believes in God (not a church goer)
Alexander	Male	57	Diagnosed in 1986, Kidney transplant (1988 (failed in 2004)	On HD since 2004 (9 years)	Lives alone Retired	Connection with nature and others
William	Male	21	ESRD at the age of 3 months Kidney transplant in 2003 (failed in 2007)	On HD since 2007 (6 years)	Lives alone Unemployed	Connection with nature
Carol	Female	36	Diagnosed at the age of 16 HD at the age of 18 (for 4 years). Kidney transplant in 1997 (failed in 2007)	On HD (2^{nd} time) since 2006 (7 years)	Lives with family Unemployed	Practising Buddhist rituals Connection with nature and others
George	Male	58	Diagnosed in 1995, First HD 1995-2003 Kidney transplant in 2003 (failed in 2008)	On HD (2^{nd} time) since 2008 (5 years)	Lives alone Retired	Connection with nature
Charles	Male	55	Diagnosed in 2009	On HD since 2009 (4 years)	Lives alone Unemployed	Not a great believer in spirituality
Joyce	Female	70	Diagnosed in 1999, Kidney transplant in 2002 (failed in 2009), ESRD in 2009	On HD since 2009 (4 years)	Lives alone Retired	Church of Scotland Connection with nature and others
Ruth	Female	46	Diagnosed in 2002, CAPD (2002-2006)	On HD since 2006 (7 years)	Lives alone Unemployed	Roman Catholic (not a church goer), Connection with self and nature
James	Male	66	Diagnosed in 2000	On HD since 2001 (12 years)	Lives with wife Retired	Roman Catholic. Connection with self, nature and others
Neil	Male	63	Diagnosed in 1997	On HD since 2009 (4 years)	Lives with wife Works part-time	Connection with self, others and nature
Donald	Male	66	Diagnosed in 1982, Kidney transplant in 1982 (failed in 2003)	10 years	Lives with wife Works part-time	Connection with nature and others
Jennifer	Female	66	Diagnosed in 1984, Kidney transplant in 1986 (failed in 1986)	On HD since 1986 (27 years)	Lives alone Retired	Connection with self, others and nature
Sarah	Female	65	Diagnosed in 2008	On HD	Lives alone	Scottish Episcopal

				since 2008 (5 years)	Retired	Church Connection with nature and others
Iain	Male	73	Diagnosed in 2003	On HD since 2003 (10 years)	Lives alone Retired	Not a great believer in spirituality
Ewan	Male	67	Diagnosed in 1976, Two kidney transplants: first one in 1978 (failed in 2001); second one in 2001 (failed in 2008)	On HD since 2008 (5 years)	Lives alone Retired	Connection with others and nature
Claire	Female	52	Diagnosed in 1995, Kidney transplant in 1995 (lasted 5 days)	On HD since 1995 (18 years)	Lives with family Unemployed	Connection with others, nature and self
Marty	Female	68	Diagnosed in 2006	On HD since 2006 (7 years)	Lives alone Retired	Baptist Church. Connection with others, self and nature

6.3 Developing Thematic Analysis

The interviews were analysed using Framework Analysis (as discussed in Section 4.4.6). The final coding framework that emerged from analysing the interview data allowed themes, sub-themes, and sub-sub-themes to be identified within and between interviews, mapping the importance of each of the themes and identifying possible connections between them (Spencer and Ritchie, 1994; Green and Thorogood, 2004). Four main themes emerged from the interviews including '*emotional/psychological turmoil*', '*life is restricted*', '*spirituality*', and '*other coping strategies*'. Each theme comprised several sub-themes, as shown in the final coding framework (Table 6.2).

Table 6.2: The Final Coding Framework

Themes	Sub-themes	Sub-sub-themes
1.Emotional/psychological turmoil	1.1 Wholesale changes	
	1.2 Forced choice	
	1.3 Indebtedness	
2. Life is restricted	2.1 Limitations	2.1.1 Unremitting fatigue 2.1.2 Limited income 2.1.3 Diet and fluid restrictions 2.1.4 Side effects
	2.2 Unpredictability	
	2.3 Tied down	
3. Spirituality	3.1 Spirituality meaning	3.1.1 Connection with God/super being (angels) 3.1.2 Connection with others 3.1.3 Connection with self 3.1.4 Connection with nature
	3.2 Spiritual Struggle	3.2.1 Uncertainty 3.2.2 Death of fellow patients 3.2.3 Why me?
	3.3 Benefits of Spirituality	3.3.1 Acceptance 3.3.2 Fortification 3.3.3 Maintain a positive attitude
	3.4 Hope	3.4.1 Hope for a kidney transplant/ Normal life
4. Other coping strategies	4.1 Sense of humour	

6.4 Presentation of the Analysis

Although I wanted to examine and explore the influences of spirituality on the health outcomes and general well-being of patients with ESRD, it was important to show that ESRD and HD treatment also have a considerable impact on almost all aspects of patients' lives. Hence, for the purpose of complementarity and triangulation (as

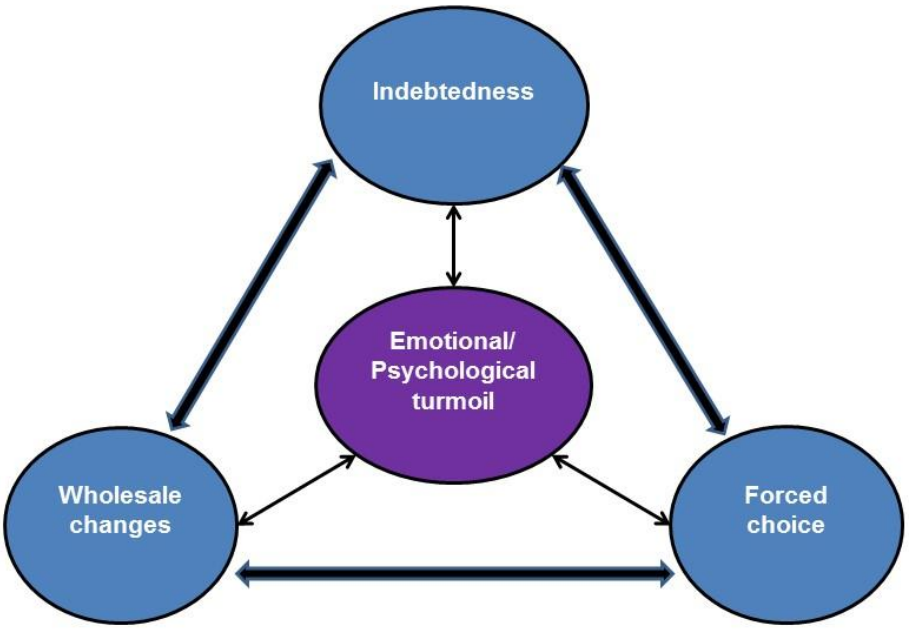
discussed in Section 4.2), I will start by presenting a brief account of the impact of the disease on patients' lives as it emerged from the interviews before presenting the findings addressing spirituality. Sections 6.5 and 6.6 present the first two themes '*Emotional and psychological turmoil*' and '*Life is restricted*' to highlight the main issues arising in participants' lives after their diagnosis and throughout their journey with the disease as well as while receiving HD treatment. Section 6.7 presents '*Spirituality*' as the third theme to highlight the important role of spirituality and its influence on their health outcomes and well-being, followed by Section 6.8 which briefly highlights the '*Other coping strategies*' used by patients to cope with illness and HD treatment. Throughout this chapter, figures representing main themes are presented in a purple circle in the centre surrounded by dark blue circles highlighting sub-themes.

6.5 Emotional and Psychological Turmoil

This theme emerged from participants' descriptions of the various types of emotional and psychological difficulties that structure their experiences in relation to their disease. Emotional and psychological difficulties were reported by some participants during the early months after their diagnosis with ESRD and throughout their journey on HD. Some participants realised that their lives seemed to have been reduced as a result of the major changes introduced into their lives. The introduction of these changes means that they are dependent on caregivers, which further contributes to their struggle to cope. These findings highlight that the introduction of ESRD and the need to commence HD can have a significant impact on patients' QOL and well-being. Figure 6.1 represents the first theme "E*motional/psychological turmoil*". Emotional and psychological

turmoil comprises three sub-themes: wholesale changes, forced choice and indebtedness.

Figure 6.1: Emotional and Psychological Turmoil



6.5.1 Wholesale Changes

The nature of the disease enforced wholesale changes into patients' lives. For some participants, who receive HD treatment three times a week, it is not possible to ever regain a semblance of the former self, free from reliance on a dialysis machine. They feel that they can never achieve a comparable level of wellness reflective of their old self. Participants report that the disease takes control and therefore their lives become

circumscribed:

> *It doesn't feel like life, I know what I'm like when I'm not ill, and it's quite different when I'm ill, because I'm normally quite an energetic person and the person I'm as somebody with kidney failure to me it doesn't bear a huge resemblance to the person I'm when I'm well, so that's really depressing.* (Kevin: Interview: 1)

For Kevin, his life now is totally different because of the changes introduced as a result of his disease. He has changed from a lively, vigorous person to one who is totally dependent on a machine. These changes may have been perceived to be transient at first; however, the growing realisation that these changes are long-term may give rise to poor mental well-being that might develop into clinical mental ill health such as depression.

The feeling that life has been taken away was also reported:

> *It (dialysis) basically just dominates my life, I suppose it takes over, everything is taken over by it, as I say, I probably don't cope with it well and you know there is no support mechanism for helping you cope.* (George: Interview: 9)

George points out that the institutional routine of coming to dialysis three times per week dictates one's life and the lack of available services, such as counselling, aggravates his ability to manage his daily live. Dialysis is perceived as an intrusion and patients have no choice but to dialyse.

6.5.2 Forced Choice

Some participants describe how they feel that the disease is imposed on them and that they have no choice but to be on dialysis. HD treatment enforced life-changing decisions on some participants, such as opting not to have any babies despite being at a reproductive young age:

> Y*ou can't have children because if you have children then it is not good for the baby, the baby would not survive because you still need to get dialysis, and I can't really plan and choose when to have a baby and that is sore a bit, just need to hope.* (Carol: Interview: 8)

For Carol, who was young at the time of diagnosis, the decisions she had to make were perceived as life-changing with the expectations of having a family imposing a major challenge on her life. Carol reports that her dream of having a baby was put on hold with the introduction of ESRD into her life. Her use of the word '*sore*' reflects the level of distress she was facing and the hurt she experienced when she took that decision. Nevertheless, she can always hope for a kidney. When this happens she might be able to live her life to the full again and have her own children.

Others were forced to take redundancy or early retirement because of HD treatment. Hence, changing future plans was obligatory. For instance, James was at a working age and was planning to move abroad where he could settle with his wife. However, the introduction of the disease into his life forced him to change his plans. His acknowledgement that his plans were '*ripped*' reflects the stress and disappointment he

was facing after his diagnosis:

> *I went onto dialysis when I was about 56, but our plan then was to move from Scotland to Spain to a warmer climate to retire in Spain, but when this happens the plans all ripped.* (James: Interview: 13)

James also acknowledges that taking early retirement as a result of the disease was another forced decision he had to make. As a well-paid and highly skilled worker he thinks that taking early retirement was a major financial loss that was caused by the disease. Early retirement was not an imaginable end for James, especially because he was a young man at the time of diagnosis with his future ahead of him:

> *I used to travel with heavy construction equipment, it was a very well-paid, very skilled job and I have learned all the skills through the years and to have to end it all at the end abruptly and go into retirement was a big blow, I never thought that would happen.* (James: Interview: 13)

It is evident that the introduction of ESRD into patients' lives forced them to make life-changing decisions. These decisions may have introduced more stress into their lives which may contribute to their spiritual, emotional, psychological, and financial struggles and therefore negatively affecting their QOL and well-being.

6.5.3 Indebtedness

Some participants state that the introduction of the disease into their lives created a sense of indebtedness towards their caregivers or kidney donors in appreciation of their

help and support while on dialysis. Commencing HD treatment changed their perspective from a completely independent person to someone who is dependent to some degree on a caregiver to carry on with everyday life. Despite their loss of freedom and independence, participants reported an increased sense of appreciation towards their caregivers:

> *Dialysis completely affects the whole family, mostly my husband because he brings me in every morning and he is the one who is there to deal first-hand with all the changes, that he has to help me get dressed, he has to help me with lots of things and he is wonderful, really wonderful, I just could not imagine coping with this condition without him.* (Isabel: Interview: 3)

> *I couldn't possibly have carried on without the help of my wife, she has been really supportive because it's a bit unfair on her because she has to be a nurse all the time, and she used to run after me all the time.* (Andrew: Interview: 2)

These two patients express their gratitude towards their caregivers and in particular their spouses. The continuous support from them is invaluable in terms of providing them with the right level of care even though this might be a burden on the caregivers themselves. Isabel appreciates her husband's constant support and assistance with transportation and household chores even though it may raise issues of concern over dependence and self-care. Interestingly, Andrew's use of the word '*unfair*' while talking about his wife's relentless support may create a sense of injustice as a result of the joint loss of plans imposed by the introduction of dialysis into their lives.

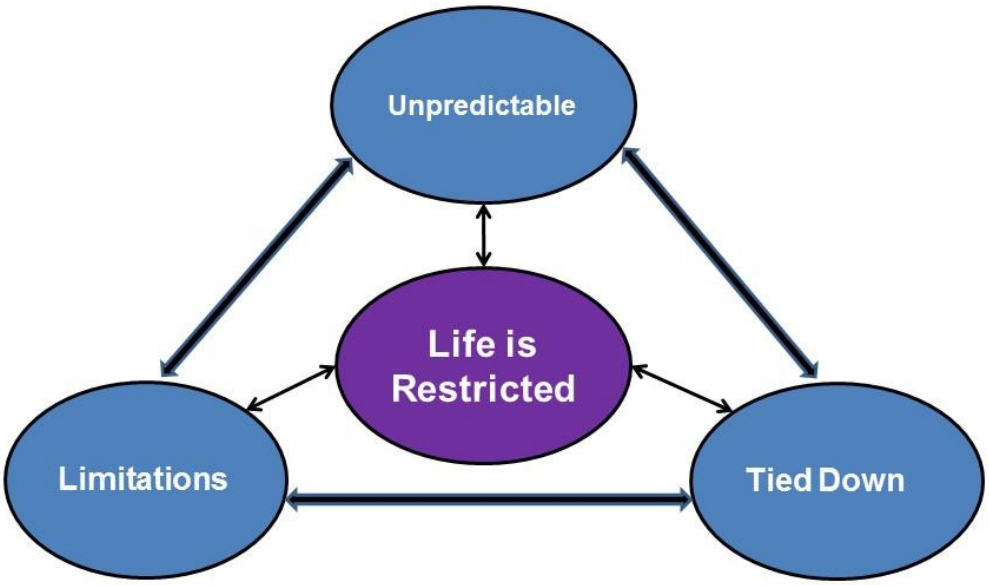
Clearly, the continuous and effortless support from patients' families and caregivers is valuable but mentally challenging. One of the positive aspects of such a mutual relationship is that some participants may strive to maintain a good QOL and look after their own health in appreciation of these sacrifices and this may therefore have a positive impact on patients' health outcomes and well-being.

The next section considers the different restrictions on life that patients identified in the interviews, presented under the second theme, '*Life is restricted*'.

6.6 Life is Restricted

Participants described the losses they experienced throughout the course of living with ESRD and being on HD treatment. These losses include physical and physiological abilities which all contribute to the demands and consequences of the disease. Most participants feel that their lives are controlled by the unremitting nature of the disease, which is perceived to be all-encompassing. The restrictions on life continue to be an on-going issue for this group of patients. Restrictions on life imposed by the disease and being on dialysis treatment further contribute to the negative impact of the disease on the QOL and well-being of patients with ESRD. Figure 6.2 next shows the key finding, '*Life is restricted'*, and its constituent sub-themes: limitations, unpredictability and tied down.

Figure 6.2: Life is Restricted



6.6.1 Disease Limitations

All participants reported at least one physiological limitation as a result of HD treatment. These limitations varied from being totally exhausted and unable to perform daily activities to having limited income, diet and fluid restrictions and developing adverse side effects as a result of dialysis. The sub-theme of limitations comprises four sub-sub-themes including '*Unremitting fatigue'*, '*Limited income*', '*Diet and fluid restrictions*' and '*Dialysis side effects*' that are presented next.

6.6.1.1 Unremitting Fatigue

Most participants reported unremitting physical fatigue as the most common restriction associated with HD treatment. Physical fatigue leads at times to lengthy periods of sleeping or resting after HD treatment because of physical tiredness and exhaustion. Unremitting fatigue may also lead to a degree of limited mobility and lack of exercise or the inability to continue with key recreational pursuits, such as playing golf, performing music, and gardening. The inability to exercise may lead to muscle wastage and exacerbates the patient's inability to engage in pleasurable activities.

ESRD as a progressive disease was brought up by James, who reports a continuous cycle of changes over the years in terms of lacking energy and strength. His use of the words '*completely tires you out*' underpins the all-encompassing nature of dialysis and its constant effect on all aspects of daily life:

> *Haemodialysis completely tires you out, you have no energy at all; when I went on dialysis first I was a lot better, but gradually over the years it has got worse, the energy levels have got really bad.* (James: Interview: 13)

Physical fatigue leading to prolonged periods of sleeping or resting after each dialysis session was also reported. Carol describes her tiredness and overall physical fatigue after HD. Her use of the words '*drains you*' highlights the broad-spectrum impact of dialysis treatment. Although dialysis is a process of removing toxic substances and extra fluid from the body, the removal of body fluid means that patients, in general, feel tired and exhausted, especially if the amount of fluid removed is in excess of what was

prescribed in their treatment plan:

> *Dialysis can make you more tired, it can drain you as well and you feel really tired, especially that night after dialysis all you want to do is sleep, it is tiring.* (Carol: Interview: 8)

The limitations imposed by unremitting physical fatigue may in turn have a negative impact on patients' QOL, leading to an increased level of weakness and decreased levels of physical energy, and may contribute to depression-related feelings which can affect their well-being.

6.6.1.2 Limited Income

The decision to give up work or reduce working hours introduces financial challenges and further restrictions into patients' lives and changes their role within the family. Although some participants report that going back to work would be a great achievement, this was not feasible due to the nature of their progressive illness. For example, Kevin, who had a successful band and who was earning enough money to maintain a good QOL, finds that being financially dependent on his wife is demoralising:

> *More money, I think more money would have helped, could have distracted myself and my wife. I really don't like the fact that my wife has to earn all that money, that's really demoralising.* (Kevin: Interview: 1)

Demoralising for Kevin means a change of role within the family from being the main

breadwinner, a husband and an artist, to someone who is dependent on others who he thought perceived him as becoming an invalid. The inability to carry out his normal duties and looking after himself to becoming dependent on others, regardless of whether it was his wife or someone else, may give rise to the sense that his life is restricted:

> *Demoralising is not right, I mean it's not right from my point of view, I don't like to be an invalid and being looked after by somebody, regardless whether it was my wife or anyone else. I don't like being in hospital, I don't like depending on other people.* (Kevin: Interview: 1)

Helen agrees that HD treatment introduces financial challenges into patients' lives. Coming for HD three times a week means fewer hours that she can commit to work. The physical tiredness because of her treatment further contributes to her inability to work:

> *I'm on the haemodialysis machine for 4.5 hours three times a week; I'm just too tired to work now*. (Helen: Interview: 5)

The inability to work and the need to reduce the number of hours participants could commit to work on a weekly basis means that they become less economically productive and are generating less income to maintain a good QOL.

6.6.1.3 Diet and Fluid Restrictions

Most participants acknowledge that diet and fluid restrictions are among the most

challenging problems enforced by HD treatment because of the strict treatment regimen that they have to put up with to avoid adverse side effects. Some participants had to give up things they love, such as drinking alcohol or eating certain types of food as a consequence of the diet and fluid restrictions.

Andrew reports that diet and fluid restrictions are the main problems facing him while on dialysis. The restrictions meant that he had to give up foods he loves to eat as they can be harmful to his health:

> *The main problems were the fluid intake, I found it very hard to work with the 2 litres between dialysis, and the diet was a restriction, certain foods that I could not take.* (Andrew: Interview: 2)

As a result of their diet and fluid restrictions, some participants feel that they are continuously instructed to follow a strict treatment regimen. Consequently, they had to give up eating food that is high in potassium, calcium and magnesium such as mushrooms, tomatoes, or dairy products. Also, giving up alcohol is reported as one of the issues they had to put up with as a result of their fluid restrictions.

Carol feels that she is always advised and feels compelled to follow guidelines. In fact, her feeling that her life is marked out by instructions underlines her struggle to adapt to these restrictions. James also reports that he had to give up drinking alcohol that he considers an important aspect of his social life because of his treatment regimen. Therefore, giving up social life as a result of the fluid restrictions may introduce further challenges into his life:

> *You are always told you cannot eat this, you cannot drink that, it is all this negative stuff because you need to watch your fluid which is like 2 litres a day and you always feel like your life is been marked out.* (Carol: Interview: 8)

> *I'm on a litre a day fluid, so you cannot drink beer or anything with potassium, you can only eat so many things, everything I like they told me I cannot eat, mushrooms, cheese, dairy products and things like that, I used to drink socially, at the weekend.* (James: Interview: 13)

Diet and fluid restrictions are one of the main challenges that this group of patients has to deal with on a daily basis. Patients feel that they are bound and always constrained to follow guidelines. Diet and fluid restrictions may in turn contribute to increasing levels of stress which can have an impact on their QOL and well-being. Not following the rules and guidelines may negatively impact on their lives and can introduce more adverse side effects.

6.6.1.4 Dialysis Side Effects

Some participants describe difficult dialysis experiences in terms of developing adverse side effects as a result of attending HD treatment three times per week. Pain is the most common problem, followed by developing heart problems, frequent hospitalization, struggling with dialysis access and oedema. These side effects may contribute to their inability to engage in pleasurable activities because of the risks involved and the need to drink more water at times and therefore developing adverse side effects.

HD treatment can affect the circulatory system that can then affect the dialysis access

(i.e. fistula). For example, Andrew reports that the impact of dialysis has affected his circulatory system as he is always experiencing problems having a functioning fistula, which is required for all dialysis patients. Fistulae are formulated by connecting an artery directly to a vein, frequently in the forearm. Fistulae are widely recognised as the gold standard in HD vascular access due to their lower rate of infective and thrombotic complications (Murphy et al., 2000). Andrew states that during his time on dialysis he had many fistulae that failed as a result of the negative impact of dialysis on his circulatory system. His use of the words '*running out of options*' underlines his continuous concerns about his dialysis access site:

> *I've had seven fistulas and at the present time I don't have a fistula that works, so that's a big worry, I'm running out of options because I have been on kidney dialysis for so long in my life.* (Andrew: Interview: 2)

Negative effects as a result of the excessive loss of blood components were also identified. For instance, James recognises that losing some of the blood components such as magnesium, zinc and potassium can lead to muscular pain and other problems. He suffers with these problems as a result of being on dialysis for a long time. Although he has been on dialysis for that length of time, the continuous effects associated with every dialysis session continue to be a major problem in his life:

> *After I get dialysis I cramp badly, so that's lack of magnesium, lack of zinc, lack of salt the machine is taking out of you, but these things over the years gradually were killing you, you've got joint pain, you've got bad leg pain.* (James:

Interview: 13)

In summary, participants identified constraints. They described their constant struggle because of the various problems associated with HD treatment. Non-functioning fistulae, muscular cramps and pain were reported as the most bothersome side effects associated with HD. Experiencing different side effects because of HD treatment may also limit their ability to engage in life as much as they want to, thus increasing their physical and psychological struggles which can negatively affect their QOL and well-being.

6.6.2 Unpredictability

One of the main issues reported by some participants is the unpredictable nature of HD treatment, which may add to the restrictions imposed on their lives. The inconsistent health status means that participants lose spontaneity in terms of planning ahead. Disease unpredictability is a major challenge and, as a result, some patients have had to give up something they love, such as going on holidays because of the amount of planning involved.

Kevin's description of the unpredictable nature of dialysis from feeling '*quite reasonable to suicidal'* underlines the broad-spectrum effect of the treatment. Although his fatigue is familiar, the inconsistent symptoms pattern generates uncertainty. By '*feeling good*' he is referring to his fatigue level and the amount of activity he can tolerate. Disease unpredictability may therefore increase his difficulties.

> *Physically the hard part is that I never know from one day to the next how I'm going to feel, so I can wake in the morning and feel quite good like I did this morning, I thought quite reasonable, but some days I wake up and I just feel suicidal and just amazingly worn out, just completely worn out, and I can barely do anything at all.* (Kevin: Interview: 1)

Spontaneity and ability to plan daily activities, even for the days when patients are not at the dialysis unit, are also circumscribed by the inconsistent nature of HD treatment. For Isabel, the constant effect of HD with frequent fatigue diminishes her ability to plan ahead as a result of uncertainty about her physical status:

> *You can't make spontaneous plans, you don't know in what physical state you will be in after you have had your treatment, and there is days that you could literally just sleep on the days you are not on the treatment.* (Isabel: Interview: 3)

Unpredictable and varying health means that participants are unable to engage in any form of planning. Unpredictability at times changes from physical to mental fatigue and continues to produce tension and anxiety in patients' lives which can affect their well-being.

6.6.3 Tied Down

Some participants report losing independence and recreational pursuits as a result of being tied down to a dialysis machine. HD treatment means that patients need to attend

the dialysis units three times per week for a treatment session that can last for 3.5 to 6 hours at a time, requiring patients to travel to dialysis units, which further adds to the time constraints imposed by dialysis. The combination of regular travel and lengthy treatment sessions impacts on personal freedom. These lengthy sessions introduce more restrictions into patients' lives as they become unable to engage in any form of social activities, such as going to the pub or going out with friends, or personal activities, such as going out shopping or doing housework, taking into consideration their varying physical health.

Ruth, who attends dialysis for six or seven hours at a time, reports that dialysis becomes mentally boring and physically tiring. The regularity of her treatment means that as soon as she is over one session she is already preparing for the next one. Thus, she is restricted probably because of her mode of thinking with regard to dialysis treatment. However, she acknowledges that she is resigned to the fact that it is a way of living and therefore she needs to do it:

> *Just get fed up coming in here sitting for 6, 7 hours at a time and doing it, and you get tired fairly easy, and there is not a lot you can do, you can go home to come back in here, so there is not a lot you can do during the day, so it's tiring, boring I suppose, but it's got to be a way of life now, so I've got to do it.* (Ruth: Interview: 12)

Carol agrees that the regularity of her treatment raises the sense that her life is marked out by being tied down to the dialysis machine, which affects her life. Although she

thinks about stopping HD treatment, she feels that she has to continue it because of the potential risks involved with ending the treatment:

> *You always feel like your life has been marked out, it's not about your choice to do, you know, like sit here three days a week and being tied up to a machine.* (Carol: Interview: 8)

Jennifer sums up the struggles of participants because of the time constraints imposed by HD. The fact that she has to commit half of her life to HD treatment and travelling time underpins the time-consuming nature of HD, which interferes with other aspects of her life:

> *I'm here 3 days a week for 4 hours and it takes the whole day, so that's half of your life in a way, there is other things I want to do.* (Jennifer: Interview: 17)

Clearly, lengthy HD sessions and being tied down to a machine introduce further restrictions into participants' lives. Participants feel that they have lost their freedom because of the time constraints of HD which might affect their ability to engage in any social or leisure activities and therefore they feel that HD treatment compromises their social network, which can further contribute to the negative impact of the disease and dialysis treatment on patients' QOL and well-being.

6.6.4 Summary of Sections 6.5 and 6.6

The findings I have presented in Sections 6.5 and 6.6 add to what is known about the negative psychological and physical impact of ESRD and HD treatment. The

continuous demands of ESRD and HD treatment introduce many challenges and restrictions into patients' lives and continue throughout their time on HD. However, my study is the first 'to my knowledge' to examine and explore the health status of patients receiving HD treatment in Scotland and, therefore, the findings make a valuable contribution to knowledge and strengthen the argument whether or not these are the only challenges that patients with ESRD are facing on a daily basis. Despite these challenges, patients continue to strive to find a way to help them cope with ESRD and HD treatment, as discussed next.

6.7 Spirituality

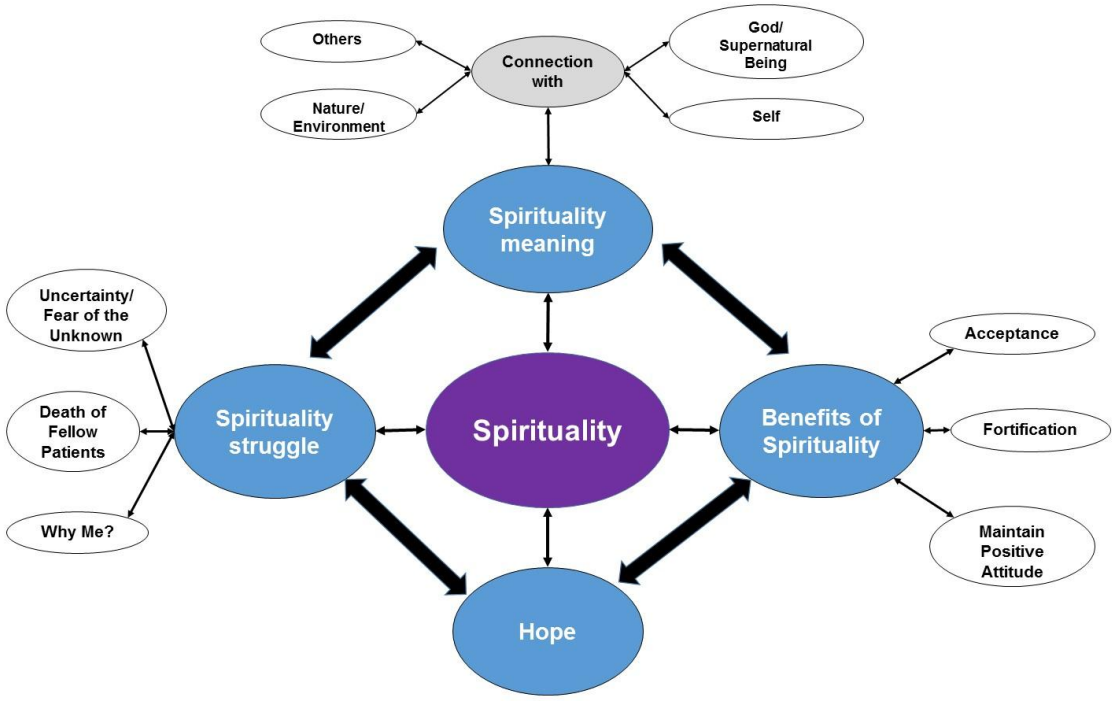
6.7.1 Overview

Some participants' understanding of spirituality shows that it is a multidimensional concept incorporating different levels of meanings and experiences. Most participants commonly share beliefs that spirituality means having a connection with God or higher being, connection with others, the self and nature/environment. With regard to coping and how spirituality affects their QOL and well-being, some participants report that spirituality helps them throughout the course of their disease by assisting them to accept HD and providing them with a sense of protection through their spiritual beliefs, which helps them to carry on with their daily lives. The differences between the concepts of spirituality and religion were discussed earlier (see Section 3.2).

Meanings of spirituality are presented first. The focus then moves to presenting the sub-theme 'spiritual struggle' to emphasize the level of stress that these patients experience

because of these struggles. Next, the benefits of spirituality are presented to show how it may influence participants' QOL and general well-being. Hope and its significant role in helping patients cope with HD treatment is highlighted next. Figure 6.3 below illustrates the theme of spirituality and its constituent sub-themes.

Figure 6.3: Spirituality Themes and Sub-Themes



6.7.2 Meaning of Spirituality

For some participants, spirituality means having a connection with God, or supernatural beings such as angels, or through practising Buddhist rituals. For others, spirituality means having a connection with the self by having personal values like inner strength and calmness or having the ability to manage their lives despite their challenging

disease. Spirituality also means having a connection with others by being a good human being, not harming others, being kind and considerate, supportive, and sharing. Connection with others is manifested through having the support required while on HD from family, friends and significant others. Moreover, spirituality means having a connection with the environment/nature such as going out to the countryside at times of stress, enjoying scenes of greenery, or visiting other places that have nice beaches, sun and fresh air. However, for some participants, spirituality incorporates all of the aforementioned meanings. These meanings are explored next.

6.7.2.1 Connection with God/Supernatural Being

Some participants identified that spirituality means having a belief in God or having faith and belief in a superior being that is beyond their understanding. Belief in God is manifested through attending church, reading the Bible and performing regular prayers. For some participants, connection with God did not mean that they needed to be a regular churchgoer, yet these participants recognise that they can talk to God at any time and place when required.

Jennifer reports better communication and relationship with God after her diagnosis. In fact, through prayer, she turns to God for assistance at times of hardship. She always receives the help she asks for which can be helpful in coping with dialysis.

> W*hen I feel at a dark place, I get myself sorted if I pray and ask God for help and I always get help, I think I always do, it is always good to look back and you can see that you have had help and that helps me.* (Jennifer: Interview: 17)

Carol and Joyce consider that spirituality means belief in God and being a Catholic. Carol's use of the words, '*faith means the world to me*', underlines the significance of practising religion in her life. Similarly, Joyce reports that spirituality mostly links to regular church attendance and practising religion through reading the Bible and performing regular prayers:

> *I consider myself a spiritual person and I'm a Roman Catholic and my faith means the world to me.* (Carol: Interview: 3)

> *I always went to church, I have a great faith and I pray and read the Bible.* (Joyce: Interview: 11)

Kevin, on the other hand, states that practising Buddhism is part of being spiritual. Engaging in lengthy meditation retreats underlines the significant role of such practices in his life:

> *I was quite deeply involved with a Buddhist group and I used to do meditation retreats, I did these (meditation retreats) quite a lot, a week or two weeks' long silent meditation retreats, meditate 8 or 9 hours a day.* (Kevin: Interview: 1)

According to these participants, spirituality means believing in and having a relationship with God or a supernatural being. Belief in God is expressed through practising religion, attending church and reading the Bible.

6.7.2.2 Connection with Others

Some participants report that spirituality means having moral values towards others,

such as being a ‘good’ human being by helping and not harming others, and by being kind and considerate. Those participants feel that they can see ‘good’ in people and help others despite their struggle with an uncontrollable disease. Some participants describe how the formal and informal support from families, friends and significant others (e.g. the medical team and employers) help them cope with HD treatment. Social support offers them distraction from their situation, reassurance that they are valued and that they can maintain their role within the family and encourages them to carry on with their lives. Those participants express their continuous appreciation towards their family and friends because of their continuous support, encouragement and assistance in providing help with the management of their daily lives. The willingness of family members to maintain relationships and provide continuous care may therefore enhance adjustment to the disease and its complex demands. Having these mutual relationships with others may in turn help them to develop a sense of personal satisfaction that may reduce their stress and anxiety and this can positively impact on their QOL and well-being.

Andrew raised the issue of self-satisfaction as a result of being spiritual. He emphasizes that loving life, family and friends are important aspects of his spirituality. In general, spirituality means to be a ‘*good human being*’ which means being helpful, living in peace and not introducing harm into other peoples’ lives:

> *Spiritually like you are doing your best for your family and you are a good friend, like to feel that you loved your life, that you’ve loved your family and friends, and basically that you are a good human being, that you wouldn’t do*

> *any harm to anybody and that you would help your fellow man.* (Andrew: Interview: 2)

Isabel agrees that her willingness to help others is part of her spirituality. She feels that introducing happiness into others' lives is a motivation to help others and reduce their burden:

> *If I can make someone feel better I will try and do that, if I can ease their burden, because I consider that every person you come across should have a smile in their face.* (Isabel: Interview: 3)

Joyce further acknowledges that being a loving, supportive and helpful person are parts of her spirituality. She perceives the love and support between her and others as a mutual relationship in that she gives as much as she receives. She even goes beyond helping family and friends to help others, even though they are strangers:

> *I'm a great believer in loving one another, if you ask any of my friends the majority of them will tell that I support them as much as they support me, I think I'm a very loving person, I mean my family is very important to me and if I can help them out, if I could help any of my friends out then I would do so, when you meet people in the street, and I have done it already.* (Joyce: Interview: 15)

Some participants report that the support received from family and friends is instrumental and helps them throughout their journey with HD. The continual support from families and friends offers participants a sense of security and distraction. For instance, Carol highlights that her ability to cope with dialysis is driven by the constant

support from her family and friends. She values the fact that family and friends do not raise issues about dialysis during their discussions, which she perceives as helpful as she is not constantly reminded of her current situation:

> *I don't know how I cope with it, I suppose if it wasn't from having good friends and family, you know, it just keeps me going and like my fiancé is supportive as well, they don't keep talking about it.* (Carol: Interview: 8)

The support from friends is also important and distracts participants from their stressful situation. Kevin recognises that the presence of friends during times of hardship is significant. Although he might be experiencing difficulties, he perceives his interaction with friends as normal because that's what friends do. For him, friends help in relieving stress by helping him to break away from his stressful situation:

> *Friends take you out of yourself, you can talk about something else, you don't have to sit there and going over in your mind over the crap things about your life, they (friends) can take you over in a different direction, into things that are interesting that doesn't have anything to do with being sick, so you become a slightly different person.* (Kevin: Interview: 1)

Isabel talks further about the significant role of socialising with friends and their continuous support in providing the required encouragement, which she describes as *'recharges my batteries'*. Socialising with friends and sharing different experiences is important and gives her the strength to carry on with her life:

> *I love having the friends in, I love being able to interact, everyone does a*

> *different job, everyone lives a different life and that recharges my batteries, so I would say out of the month we probably have two Saturdays or two Fridays in that month that we have a wee get together with different friends and that is very important to me.* (Isabel: Interview: 3)

Most participants commonly share a level of satisfaction with the help and support received from significant others, particularly the medical team and the nursing staff, which can play an important part in coping with HD treatment. Dialysis nurses spend 12-18 hours weekly with this group of patients and therefore the support from them is central to the patients' care. For example, Joyce appreciates the availability and expertise of the nursing staff in providing proper care, especially when patients develop complications as a result of their treatment. She also appreciates the presence of cheerful staff and fun environment while on dialysis as this can help them cope:

> *They (nurses) are all very good when we are in here, I mean they are excellent and very helpful, quite often you become unwell on the machine, they will come and put some more fluid back in you and lie you flat, and if you are sick they will get you a sick bowl, there is always a good banter between the nurses and the patients.* (Joyce: Interview: 11)

Andrew values the support from doctors throughout his journey with the illness. Andrew's use of the words, '*running out of options*', emphasizes his struggle with the adverse side effects of HD; nevertheless, he perceives the continuous support and assurance from the medical team with regard to the availability of solutions as

encouraging:

> *I mean the doctors you see, they tend to be very positive and encourage you and as I keep worrying I'm running out of options, when I speak to them they always say, "Well, there is always something that we can do," and that helps.* (Andrew: Interview: 2)

The help and support received from employers was also important. For example, Donald reports that his employer's support distracts him from his financial worries. His employer's support helped him to focus on other issues that are of more concern to him, such as the management of the various challenges of HD:

> W*hen I was working I always had the support and the company behind me. I have always had that support plus the financial support from them which let me concern myself with my health and they would take care of me, my wages were in the bank every month whether I was at my work or not and they gave me something less to worry about.* (Donald: Interview: 15)

These participants value the support from the clinical team which is encouraging and helps them to carry on with their lives. Participants express their trust in their caregivers to find other options when they face problems. Employers' support offered them distraction from their financial worries and helped them focus on their own health, which was helpful in coping with dialysis.

In summary, spirituality means having a connection with others. Connection with others through loving, helping, being supportive and '*being a good human being*' reflects the

importance of having such mutual relationships. The continuous help and support from families, friends and significant others (e.g. nursing staff) distracts patients from their stressful situation and encourages them to carry on with their lives despite their restrictions. Consequently, in appreciation of the endless and valuable support from their caregivers they look after their own health, which can lead to an improved QOL and better well-being.

6.7.2.3 Connection with Self

Some participants express their spirituality through having a connection with the self by having inner strength, contentment and inner calm. Having these values might help them to manage and adjust their lives from the initial shock of diagnosis to positively dealing with the uncertainty concerning QOL and effectively managing the decline in their health status. Consequently, participants start to adapt to the changes introduced into their lives and through time they come to terms with these limitations and losses. Furthermore, they start to engage in life by developing creative outlets such as writing novels, joining art clubs and engaging in some pleasurable social activities (e.g. walking and cycling).

As can be seen from the next two quotes, Isabel acknowledges that her calmness enables her to deal with dialysis treatment which she perceives as a test from God. Jennifer states that her ability to overcome her challenges was mostly as a result of having inner contentment.

My mum had an absolute strength of character and an inner calm, and she

> *instilled it in us, which I consider to be part of your spirituality.* (Isabel: Interview: 3)

> *Spiritually means I get contented, my spiritual side is my content side, it just gives me that inner peace and contentment and that's probably why I'm still here.* (Jennifer: Interview: 17)

Carol, however, thinks that spirituality offers her a better mental ability to deal with different challenges in life. She views her mental ability to deal with these challenges as an inner strength that helps her to adapt and maintain a positive attitude:

> *Spirituality would mean like mentally how you are feeling positive, like your emotions, just keeping your spirits up, like in harmony, like how you are mentally coping with things and live in peace*. (Carol: Interview: 8)

Some participants value their ability to manage and adjust through coming to terms with the challenges of their illness, which was helpful and may have helped them cope. According to these participants, working with their restrictions was a huge burden initially; nevertheless, the longer they are on HD the more comfortable they feel which they consider important and enables them to adjust to HD treatment.

Helen admits that her perception of the disease changed over time as she manages to incorporate disease challenges into her life routine. Helen perceives HD as going to work and this change of perception may reflect a positive version of the sick role:

> *I was kind of knew that I was going to go on dialysis at some stage, so I knew*

> *what I was expecting, I didn't expect what I thought it was going to be like, how much it will take up of your life, so that just took a while to get used to, now I look at it like going to work in the morning.* (Helen: Interview: 5)

Growing older while on HD enables other participants to come to terms and cope with it. For example, Donald recognises that his mentality towards HD changed over time. Being on HD treatment for a long time helped him to accept it and therefore he manages to cope better. He is hoping that he will receive a kidney transplant and be able to get back to normal life:

> *I felt I have got used to it over the years. Mentally I suppose I have accepted it better, I'm a lot older now and I have accepted that it has happened and I just hope that I get a transplant at the end.* (Donald: Interview: 15)

Ewan agrees that over the years he has learned from his experience and therefore he manages to deal with HD. Attending HD now is more pleasant and easier than it was during the early stages. Based on his many years of experience on HD, Ewan has developed a strategy to reflect on his own experience and appreciate what he has, which helps him to cope with it:

> *You learn different things as you grow older; you develop your methods of coping, before I was struggling with it, now it is fairly pleasant. Sitting here and reflecting on what's happening, helps you cope, appreciate what you have got, appreciate the beauties of life and try to stay with that positive component to your life, I can find my way through most problems in my life now.* (Ewan:

> Interview: 19)

Being on HD for a long time and growing older empowers participants to adapt and cope with it. Appreciating life and the positive outcomes of HD treatment assists them to deal with it and this might positively influence their health outcomes and well-being.

Some participants also describe how developing creative outlets such as writing novels, attending craft clubs, composing music and sharing in fundraising activities to help fellow patients, helps them cope. Creative outlets may provide distraction by engaging the mind and body in something participants like, may offer participants relaxation or a way to avoid becoming self-absorbed as a result of HD, or may help them recreate their experience in a way that makes it more manageable. For example, Kevin reports that writing and composing music offers him distraction from his stressful situations. Kevin's efforts were crowned by the successful publication of a novel and the writing of another. Nevertheless, it is not clear from the interview whether writing novels is helping him financially:

> *I'm not working at the moment, I'm sort of house husband you can say and although I still do music a bit, I don't perform anymore, but I write, compose music and I'm writing a novel. I wrote a novel during the time, I started in 1987 and it was published in 2000, I'm writing another novel now.* (Kevin: Interview: 1)

For Helen, attending craft and Gaelic clubs on a weekly basis may have not only served to enrich her solitary leisure time, but may also provide an opportunity for building up a

greater community and therefore coping better with HD:

> *Monday, I go to my craft club, we do lots of different things, I do cross-stitch, we do netting, crocheting, and card-making. Thursday I get up early and I go to my Gaelic class, which is in a centre in Paisley.* (Helen: Interview: 5)

James also reports that being involved in other social activities, such as fundraising, can be helpful in coping. James participates in fundraising activities to help and support fellow patients. James and his wife are both involved in fundraising activities which gives an example of the value of being together in an activity that is not caring-related:

> *We (Scottish Kidney Association) are giving back-up for the British Kidney Association and charities, what we do now try and raise money to take patients away every 2 years on a holiday, that keeps me going, me and my wife are involved in that quite heavily.* (James: Interview: 13)

For these participants, spirituality means having a connection with the self by having inner strength, contentment, calmness, and the mental ability to deal with their challenges. Connection with the self evolves through coming to terms with ESRD and HD treatment, developing and engaging in creative outlets. Connection with the self may therefore provide positive means to cope with the vicissitudes of living with chronic illness as it helps them to remain engaged in daily life routines and this may impact positively on their QOL and general well-being.

6.7.2.4 Connection with Nature/Environment

Some participants state that spirituality means having a connection with the environment/nature. Having a connection with the environment evolves through appreciating surroundings such as enjoying scenes of greenery, visiting places that have nice beaches, sunny, fresh air, and living in a good community. Having a connection with nature may help them by reducing the levels of stress and anxiety associated with HD treatment and therefore this might have a positive impact on their general well-being.

Carol and George report that they use visualisation as a relaxing technique. Carol considers that visualising an environment with nice scenes such as an island with blue sky is part of her spirituality. Visualisation helps her to find inner peace and offers her distraction from a stressful situation. George concurs that visualising a nice environment, having times of carefreeness and enjoying scenes of greenery offers distraction. Through visualisation, both of them can cope better with HD:

> *Spirituality means that you do something that relaxes you, it could be anything at all, just sit and do a bit of Buddhism, like humming or something, close your eyes, think of a nice sky, nice blue sky or something, or a nice island or lie and feel the sand and the water and the wind blowing on your face, stuff like that can help.* (Carol: Interview: 8)

> *Spirituality means to me going out into the countryside, being able to walk with trees, I like trees, always have done, fresh air, countryside, also means to me the*

> *Isle of Mull which is where I'm from.* (George: Interview: 9)

For Helen, having a comfortable and relaxing environment can be part of spirituality and helps her cope:

> *Spirituality means living in an area where you've got good neighbours, no hassle, no young ones going around doing naughty things and everything is quite comfortable, my neighbours are quite good and they help you if you need something done; basically live in a good community.* (Helen: Interview: 5)

These participants feel that having a sense of connection with the environment and enjoying nature are valuable in their lives and this helps them cope with HD treatment. Nevertheless, other participants feel that spirituality does not mean anything to them and therefore does not play any part in coping with HD.

As can be seen from the next quotes, although spirituality did not mean anything important to them, this group of participants linked spirituality to religion. For example, William links spirituality to religion and stresses that he is not a believer in God; however, he recognises that spirituality can be used by other patients in their daily lives:

> *I do not have any personal belief but I believe spirituality helps people through their life and through their day-to-day life.* (William: Interview: 7)

Likewise, Charles links spirituality with religion but he indicates that it is not a major aspect in his life. However, Charles perceives ESRD as a punishment because he is a person with a good character:

> *Spirituality means nothing to me really; I'm not a believer in God or anything like that, I was never made to go to church, I do not really have any beliefs. I have got the disease; I think I have not really done anything wrong in my life, so things like that make it harder to believe in something.* (Charles: Interview: 10)

In summary, some participants identified that spirituality means having a connection with God or supernatural being, others, their self and nature. Having these meaningful connections enables them to deal with the challenging demands of HD treatment and this might have a positive impact on their health outcomes and general well-being. Yet, these patients express a level of spiritual struggle that was introduced into their lives after their diagnosis and commencing HD treatment as discussed next.

6.7.3 Spirituality Struggle

Some participants describe how the challenging nature of their illness and HD treatment may develop into spiritual struggle. Spiritual struggle may develop as a result of their uncertainty about the future, losing freedom and control over their lives. The difficult experience of losing fellow patients raised the question that this could be me and thus reflecting on their own mortality which may further contribute to their spiritual struggle. Spiritual struggle may in turn develop into a sense of anger towards God by asking *'Why me?'* as patients feel that they are being punished or tested by God, which may introduce further spiritual struggle into their lives. Interestingly, the *'Why me?'* question was reported by participants who describe themselves as Catholics but not by others. The spirituality struggle sub-themes comprised three sub-sub-themes including

'*Uncertainty*', '*Death of fellow patients'* and '*Why me?*' which are discussed next.

6.7.3.1 Uncertainty

The early days and months after initial diagnosis and commencement of HD treatment were plagued with periods of emotional upheaval and doubts about the future and health status for the participants. The experience of being dependent on a dialysis machine and losing control over kidney functions challenged their sense of security about the physical self. Some participants recalled how they were shocked and unprepared at the time after receiving their diagnosis, as they were not aware of the possible effects that commencing HD treatment would have on their lives. Research about different disease states has consistently demonstrated that chronically ill individuals who experience increased levels of uncertainty report diminished levels of overall adjustment to their condition (e.g. Mullins et al., 2001; McNulty et al., 2004). In my study people who were at a working age and considered themselves to be fit, perceived the diagnosis as shocking and hard to deal with:

> *I would not say it has not affected me, it was a big blow at the time, you are going from a super fit guy who is running about all over the country, you are making big money, and bang: the next thing you are nothing.* (James: Interview: 13)

For James, uncertainty is manifested through the change in physical status. His description of the change in his physical status from being '*super fit*' to '*nothing*' underlines the level of impact the disease can introduce into patients' lives. He admits

that the diagnosis was overwhelming and that it changed his life from being a person who is fully independent to someone who is dependent on a machine to stay alive. The sense of becoming non-productive and giving up his job was a '*blow*' which underpins the shock he experienced following his diagnosis.

Katy agrees that, although she is trying to keep her spirits up, the shock of diagnosis and the need to commence HD aggravate her spiritual struggle and therefore she finds it difficult to maintain a positive attitude. For her, dialysis is a continuous cycle where patients need to attend the dialysis unit three times per week:

> *I have been on dialysis for 4 years, it's quite insidious, it is a shock when you go on it at first and you keep your spirits up because the rest of your general health is not too bad, but when you are on it for three days a week every week in life, it is very difficult to maintain a positive outlook.* (Katy: Interview: 3)

Some participants also identified lacking clarity about the future and the possible impact of the disease and HD treatment. For example, Andrew, who was at a young age when he was diagnosed, reported that the uncertainty about keeping his job and supporting his family were of major concern. Inability to carry on working created tension and stress in his life as he was the main breadwinner. Fear of the unknown underpins his lingering doubts about his future life; nevertheless, this fear was lifted once he knew that he could keep his job:

> *I hadn't a clue what was ahead of me, I was frightened of the unknown; I didn't know how going on a kidney machine would affect me, I was a young man at*

> *that time, I didn't know whether I would be able to carry on working and support my family.* (Andrew: Interview 2)

Jennifer agrees that the potential impact of the illness on her life was unexpected. She did not realise that she would be on HD for a long time as she thought that she would be on it for a few months and then go back to her normal life. Jennifer has now been on HD for 30 years; however, the initial days were marked with doubts about the possible effects of the disease on her life. Lack of knowledge about the potential impact of HD and the unexpected length of treatment underpins the significance of providing this group of patients with the required information concerning their treatment regimen to ease their doubts and future concerns:

> *You are told that you are going on dialysis, I did not realise that it was going to be for 30-odd years, I did not realise the impact it would have.* (Jennifer: Interview: 17)

In summary, James, Katy, and Jennifer talked about the doubts and uncertainties encountered during the early stages after their diagnosis and commencing HD treatment, which created many concerns about whether they could carry on with their lives and support their families.

6.7.3.2 Death of Fellow Patients

Some participants are deeply affected by tragic events that happen within the dialysis units. These events may therefore contribute further to their spiritual struggle. In particular, some participants view the death of fellow patients as stressful and raise the

question that this person *'could be me'*, or that it could be their family who are facing this sad situation. Although developing an affinity or connection with other patients is important for some participants as they are all *'in the same boat'*, as it is an intricate part of facing the challenge of HD day by day, observing other patients' death or deterioration is difficult for them as they might struggle emotionally to cope with despair and maintain a positive outlook. Consequently, some participants attempt to avoid being too friendly with others even though sharing experiences with fellow patients might help them cope:

> *While I've been on dialysis, three people I've got quite close to have died, and one in particular just died in January, and it really affected me going to her funeral, really rocked me because I was standing there and I was thinking my God this could be me, this could be my family standing here and it has really made me feel very mortal that day, she was of a similar age, similar kind of background and although I only actually physically have known her 10 months, I felt a connection to her.* (Isabel: Interview: 3)

Isabel reports that, although she knew one patient for a short period of time, she felt connected to her. Nevertheless, the death of that patient was a stressful event in her life. Isabel's use of the words '*rocked me*' and '*very mortal*' underlines her struggle trying to deal with this event. The death of fellow patients can be a reminder for these patients about their mortality which is reflected in her use of the words '*this could be me*'.

Neil also asserts that a relationship with fellow patients develops over time and

therefore they become like an extended family. However, knowledge of their death or deterioration becomes challenging and acts as a reminder of their own fate. Neil manages to deal with this stressful situation by avoiding thinking constantly about it as this may lead to depression:

> *You feel like a certain affinity to the people in this unit and especially when you build up sort of a friendly relationship over a period of time and then you suddenly find out that this person is going to die in 3 weeks, that's quite difficult at times, but if you dwell on it, and let yourself get depressed about it, it's quite difficult.* (Neil: Interview: 14)

James avoids being too friendly with fellow patients, which is his way of overcoming the negative impact of their deaths. During his time on HD he has developed friendly relationships with many patients, some of whom have died. The death of other patients is challenging and '*hard to take*'; however, by '*keeping himself to himself*' he manages to avoid this sad situation:

> *I've got friendly with a lot of them (other patients) and then they die, this has happened to me, since I started I knew 30 patients they've passed away, you go to more funerals than anything else, you just get to the stage you are not going to get too friendly with anybody because that's what happens here. Over the years since I went on it, you lose more friends than what you gain, I'm not going to do pal, too friendly with them, just keep yourself to yourself.* (James: Interview: 13)

The feelings that these patients experience, especially when someone they had a relationship with, or shared experience with dies, can be a constant reminder of their own mortality and risk of the same fate. These feelings may therefore introduce more stress into their lives and this can have a negative impact on their well-being. Nevertheless, avoiding being too friendly with fellow patients is one way to overcome such a sad experience.

6.7.3.3 Why me

Patients struggling with a chronic illness experience spiritual struggles and often ask the question '*Why me*?' When their question remains unanswered they ask other questions like '*Is God punishing me? Does God even care about me? Does God even have the power to make a difference?*' (Koenig, 2004; Sulmasy, 2009). While such existential concerns are normal and to be expected in the short term, some patients get "stuck" in these spiritual struggles and, without help, are unable to resolve them on their own. The result is that they cannot rely on spiritual beliefs that might otherwise give them comfort and hope. In my study some participants mourned the losses they experienced or might experience as a result of being on HD treatment. They grieve the loss of control over their lives and are often angry or in denial. Often they ask '*Why me*?' and experience fear and anxiety over the possibility of living a life on HD. For instance, Katy believes in God although she is not a regular churchgoer. She expresses spirituality through her belief, performing prayers and talking to God. For her, asking the '*Why me?*' question and why she has ended up on HD underpins her spiritual struggle. Katy recognises that other patients with a chronic illness may have the same

ideation:

> *Some days you are alright, other days it does very much bring you down, like I'm ok at the moment obviously, I don't have any problems, but sometimes you do think 'Why me?' and I suppose everybody with an illness has got that frame of mind sometimes.* (Katy: Interview: 4)

Ruth is Catholic and used to attend church regularly before dialysis. She perceives dialysis as a punishment from God because she was a young woman with a young family at the time when she was diagnosed with ESRD. Being the sole carer for her ill husband meant less time to commit to attend church and therefore she was unable to fulfil her duties towards God. As a result, she feels that God has punished her by introducing the disease into her life. Hence, she stopped going to church as a reaction to her sense of injustice imposed by developing ESRD:

> *At that time I was going to church, so it's kind of 'Why me?' Am I been selfish saying, 'Why me?' Why not somebody else, may be somebody that's a bit older, 11 years married before I found out that I had the kidney problems, so why couldn't it be somebody else? I've been married and got a young family, why couldn't it be years later or whatever before anything happened?* (Ruth: Interview: 12)

In contrast, Joyce is a Church of Scotland member, attends communion on a regular basis and always maintains a good connection with God through praying, reading the Bible and regular church attendance. Joyce acknowledges that she has never questioned

God in asking *'Why me?'*. Her belief in God empowers her to see HD differently as the presence of God in her life gives her the strength to overcome her challenges. The ability to cope and manage her daily life is mostly as a result of her strong faith in God as he is the saviour:

> *I mean I've never said, 'Why me?' I mean why not me? I mean why am I any different from anybody else? No, I have a great faith and I think if it wasn't for the faith I have, then I might have had problems coming through this, but no, I can't say that I've had, I think the Lord is always with me.* (Joyce: Interview: 11)

Evidently, some participants perceive HD as a punishment or test from God and this may create a sense of struggle trying to cope with it and therefore this might have a negative impact on their well-being. Others who are strong believers perceive the disease differently as they feel that they can cope because of their strong faith.

6.7.4 Benefits of Spirituality

Some participants describe how spirituality may have helped them cope with the day-by-day challenges imposed by their disease and throughout their time on HD treatment. Often they talk about the important role spirituality plays in helping them accept their treatment as part of life and offers them the strength to overcome their challenges. Spirituality gives them the strength to maintain a positive attitude in the face of a difficult and unpredictable disease and treatment regimen. The 'benefits of spirituality' sub-theme comprises three sub-sub-themes including '*Acceptance*', '*Fortification*', and

'*Maintaining a positive attitude*', which are discussed next.

6.7.4.1 Acceptance

Acceptance emerged from some participants' description of how spirituality gives them strength in the face of a challenging situation. Other participants report that spirituality helps them to accept their diagnosis and HD treatment as part of life and therefore accept their new situation. Accepting the new situation enables them to follow medical advice and helps them to re-establish control over their lives. Acceptance empowers them to live day by day and allows them to carry on with life to the best they can. Acceptance comes through belief and trust in God as he is *'the saviour'*. Accepting ESRD and HD treatment through spirituality may therefore help patients cope with their disease and this might have a positive influence on their health outcomes (i.e. QOL) and general well-being by reducing their stress and anxiety.

Helen acknowledges that spirituality gives her the strength to carry on with life. Spirituality means that she is mentally able to fight the negative impact of HD. Her ability to adapt enables her to overcome her physical limitations as a result of the power derived from being spiritual:

> *Spirituality gives me strength and helps me to get on with life, not to sit there and feel miserable and not to do anything because I can't do, I just have to get up and do it; spirituality gives me strength to get on with life.* (Helen: Interview: 5)

Isabel agrees that religion plays an important part in her life and empowers her to cope

on a daily basis despite the inconsistent nature of the illness. Her sense of security evolves through the presence of God and faith in her life:

> *I wouldn't say it (dialysis) made me more religious because it didn't, my religion is part of my life, at times it's not as big a part of my life as I feel it should be, but the day-to-day living that I do, I just try and cope with it and some days you cope with it better than others.* (Isabel: Interview: 3)

Jennifer further recognises that spirituality gives her the power to cope with HD. Reading the Bible, praying and talking to God offer her strength to deal with difficult situations and guide her through her day-to-day living. Interestingly, she states that survival is mostly linked to spirituality:

> *Spiritually I get contented, if I'm struggling with stuff bottom line I will pray and I will read my Bible, it just gives me that inner peace and contentment and that's probably why I'm still here because that makes me cope with things that are really tough and that will make me cope, I can cope with anything if I'm spiritually sound.* (Jennifer: Interview: 17)

Other participants reported that accepting HD treatment as part of life helps them to overcome their daily challenges. They acknowledge that HD keeps them alive and therefore they continue to attend their dialysis sessions, accept their limitations by working through them and by being a 'good' patient through following guidelines. Most participants report that accepting HD as part of life and as the only available treatment option at the time helps them cope with it.

Alexander, who has had a failed transplant before and cannot receive a kidney transplant because of his underlying co-morbid conditions, acknowledges that accepting HD as part of his life enables him to cope. He perceives the lack of available options and the inability to receive a kidney transplant as stressful and challenging. However, he manages to deal with it mentally by ignoring the fact that he is not a suitable candidate for a kidney transplant:

> *Unfortunately in my case I will be on dialysis the rest of my life, so you've got to put that in your mind for the rest of your life, like it's part of your life, be in 3 times a week for the rest of your life, and you've got to get that into your brain and deal with that, nothing I could do about it, nothing the doctors can do about it, it is just my particular situation.* (Alexander: Interview: 6)

Ruth agrees that accepting HD treatment as part of life helps her cope with it. Her use of the words '*pick yourself up*' underlines her mental ability to overcome the fact that she will be on HD for the rest of her life:

> *I suppose you just have to get on with it and pick yourself up and get on with it. At the end of the day it's one of these things, it is part of life, it is just part of life.* (Ruth: Interview: 12)

Some participants acknowledge that HD treatment keeps them alive and therefore they continue to attend their treatment because stopping it may lead to limited chances of survival. For Joyce, knowing that HD keeps her alive is her motivation to continue attending dialysis sessions. The decision to stop HD treatment means limited chances of

survival:

> *I've got to go there (dialysis centre), it is just part of life and if you want to live then you've got to come here; this is what keeps us alive.* (Joyce: Interview: 11)

Being a 'good' patient by following the prescribed rules and following medical team advice is another motivation to cope. Following guidelines means that they need to modify their lifestyle and find some way of compromise to adapt to their restrictions. This was the case for Andrew who states that adjustment means following guidelines and living within the prescribed rules to cope with HD. Andrew recognises that the negative experience of other patients encourages him to follow these guidelines:

> *You've got to try and live within the rules, the other patients I've known they just couldn't do without the drink, and they suffered because of that.* (Andrew: Interview: 2)

Clearly, for some participants, spirituality can play an important part in accepting the disease. Spirituality can help them to overcome the day-to-day challenges of living with HD. Spirituality helps some of them to accept HD treatment as part of life and realize that it is the only available option to keep them alive and by being a 'good' patient and following the prescribed guidelines. Consequently, they develop a sense of control over their challenging disease and treatment regimen and this may have a positive influence on their health outcomes and general well-being.

6.7.4.2 Fortification

For some participants, seeking strength through spirituality and the presence of God and faith in their lives to handle challenges and problems associated with HD becomes a daily undertaking. Knowing that their spirituality imparts strength and the feeling that they are protected empowers them to tolerate and 'fight' their illness and this can positively impact on their health outcomes and improve their well-being. Participants describe spirituality as protective and this protection comes through '*God*', '*Faith*', '*Prayer*', or '*Angels*', which helps them to adapt as they feel that they are not alone while on HD.

Some participants reported an overwhelming sense of the transcendent presence of God in their lives. The introduction of chronic illness creates a sense of increased connection with God, especially after the commencement of HD treatment. However, the feeling that they are not alone through the presence of God and faith in their lives gives them the strength to endure their illness. For example, Joyce points out that the presence of God in her life is instrumental as it gives her the strength to handle the physical challenges of HD:

> *I know the Lord is always there and I just dump everything on him, that's not a problem to me and I seem to get the strength to overcome and manage to do what I have to do.* (Joyce: Interview: 11)

Carol believes that she is protected by the presence of angels and this gives her the power to deal with her difficult situation. Her indication that she does not believe in

God but believes in angels indicates that, as part of their spiritual metaphor, people may choose elements of a religious framework that suit them at times of suffering. Practising Buddhist rituals also helps her during stressful times, thus she is able to cope better with HD:

> *I just don't believe there is a God, I believe there are angels. Anybody will listen to that they think I'm off my head, but angels and like your Buddhism all nice stuff, people that are there to give you the power, to just feel that kind of peace, when you are feeling kind of anxious.* (Carol: Interview: 8)

In summary, the presence of spirituality in the lives of some participants comes through connection with God and faith. They feel that spirituality offers them a sense of security and empowers them to cope with HD as they feel they are protected. This protection gives them the strength to become more self-reliant and confident about fighting their disease, carry on with their lives, and overcome their challenges and this may have a positive influence on their health outcomes and improves their well-being. For some participants, they could rely on spirituality or God to seek help at times of crisis.

6.7.4.3 Maintaining a Positive Attitude

Some participants describe how spirituality helps them to maintain a positive attitude about HD treatment and how this helps them cope with their daily challenges. Maintaining a positive attitude may therefore have a positive influence on their health outcomes and might be important in reducing their stress and anxiety which can lead to better general well-being. For some participants, a positive attitude evolves through

being spiritual/religious, while others feel that positive thinking develops over time as they learn how to live with HD and gives inner strength, which is a quality that empowers them to cope. Finding something positive from their experience encourages them to maintain a positive attitude. For example, one participant feels that her ability to raise her children while on HD is a positive personal achievement. Comparing oneself with others who are in a worse-off situation is another way of maintaining a positive attitude about dialysis. Some participants feel that maintaining a positive attitude is an obligation at times, which may introduce some stress into their lives as they feel they are bound to maintain this attitude despite their difficulties.

Some participants acknowledge that maintaining a positive attitude towards HD and others emerges through spirituality, religion, belief in self and helping others. For example, James states that religion means being positive. His drive to help others, although difficult at times, underpins his spiritual self. For him, religion always empowers him to sustain this attitude towards the self and others:

> *I think that your religion is a positive attitude, I say that I try and help people, you might not be able to, that's what I've always had this sort of positive attitude and I think your religion helps you.* (James: Interview: 13)

Maintaining a positive attitude means having an inner strength that helps participants cope with HD. This was the case for Isabel who believes that being positive means having inner strength which enables her to manage her illness. Being '*irritatingly upbeat*' is a value that prevents her from going into despair. Allowing herself to go into

despair or think negatively about her situation can introduce more stress into her life:

> *I consider myself to be very positive, when I was leaving the NHS, I had a manager who quote un-quote said I was irritatingly upbeat which I consider a quality, I never transcend into complete and utter despair ever, can honestly say I've never done that, I won't allow myself to.* (Isabel: Interview: 3)

Isabel believes that she can find positivity in life even though she is struggling with HD. Isabel recognises that dialysis introduces many challenges in her life; however, she acknowledges that her ability to work through these challenges and raise her children is a positive achievement, which she perceives as encouraging:

> *I worked through them (challenges) and I brought my children up and I consider that to have been a positive, when I look back, I was pretty under par for about 20 years but I managed it.* (Isabel: Interview: 3)

Some participants report that comparing themselves with other patients who have more severe illnesses and troubles, whether they are HD patients or patients suffering from a different disease, encourages them to be positive. Having this frame of mind helps them feel that their situation is not so bad after all as they might feel that they are spared something far worse such as being on HD and struggling with different types of complications, or having another disease with a limited life span, or worse health outcomes such as cancer.

For example, Katy considers that seeing other patients who are in a worse-off condition than her helps her to maintain a positive attitude. Seeing other patients who are

struggling or are medically more affected by their conditions helps her cope:

> *I try to keep positive thoughts rather than negative, some days you just feel that when you feel so down especially when I get out of bed and I don't feel very well, it does bring me down, but I say mostly I try to be positive because there are people worse-off than me and I think if you can look at it that way it is a help.* (Katy: Interview: 4)

Carol agrees that, although it is difficult to maintain a positive attitude constantly, seeing other people struggling with other illnesses, especially cancer patients who have limited survival chances, is her motive to maintain a positive attitude. Hence, maintaining a positive attitude helps her cope and carry on with life:

> *It's hard always to be positive and then you feel selfish if you are negative because there are other people worse-off than you, so you always think there is always people, wee kids sort of with leukaemia or cancer stuff like that, they've no chance of living and stuff like that and that's what kind of keeps you going.* (Carol: Interview: 8)

This group of patients feel that maintaining a positive attitude helps them cope with HD which can be important and can play a significant role in improving their health outcomes as they strive to look after themselves and therefore this can enhance their well-being by reducing their anxiety. Comparing the self with other patients who are on dialysis or suffering with a different illness and who are in a worse-off situation also encourages them to cope and carry on with their lives.

Some participants, in contrast, report that maintaining a positive attitude in the face of a challenging course of illness is an obligation which can be in itself difficult and unrealistic at times. They feel that they are bound to be always positive though they might not feel like it. The expectations of being positive, therefore, may become a burden that can negatively affect those patients and in turn may lead to further stress.

Isabel talks about her continuous striving to be positive in a way that can be interpreted as evidence of a fighting spirit, or coping mechanism. However, this interpretation overlooks the extent to which this woman feels that 'thinking positive' is not a natural reaction to having been on HD, but rather as a moral obligation towards her mum as she was her sole carer. The fact that being positive is not something that she thinks about, rather it is something that she has to do, give an example of how maintaining a positive attitude is an obligatory demand which she cannot or does not want to overlook:

> *If I wasn't a positive person and didn't have hope then that would grossly affect my mum's well-being and her quality of life, just something you have to do and it's not something I think about, I don't think my family would agree that I did it every day, but I'm not superhuman, am I? I've got human frailties like everybody else, but I certainly strive to be positive.* (Isabel: Interview: 3)

Ruth's awareness of the potentially negative impact of embracing negativity and the expectations of others to see her in that state drives her to maintain a positive attitude for the benefits of her family, although it might be challenging at times:

> *I've got to be positive, I've got to be positive to get on with life, rather than kind*

> *of being down all the time, so I've got to try and stay positive and try not to let it get me down, try and stay positive, be positive for my kids.* (Ruth: Interview: 12)

For Isabel and Ruth, maintaining a positive attitude towards the self and others is an obligation. Hence, they may struggle to express their concerns with regard to their own situation because of the fear of upsetting their caregivers. As a result, they might force themselves to maintain positivity and hide these worries which can be a burden on their own lives and may have an impact on their mental health and thus might negatively impact on their QOL.

In summary, some participants report that they manage to cope with their disease and demanding treatment through maintaining a positive attitude towards HD, which is considered as part of being spiritual. Thinking positively about HD helps them cope and overcome their challenges. Feeling that they are bound to be positive, however, may introduce further challenges which may give rise to more stress and tension. However, some participants admit that blaming God for what has happened to them by asking '*Why me?*' can be a barrier affecting their coping.

6.7.4.4 Hope

Some participants also talked about how spirituality helps them to maintain high levels of hope which may help them cope with the continuous demands of HD treatment. For some participants, hope encourages them to remain optimistic despite their situation, while for others hope means the opportunity to receive a kidney transplant that will lead to an improved health status and regain a normal life, free from complications.

Although spirituality fosters and maintains a sense of hope and purpose in the midst of the existential challenges of life (Carroll, 2001; Onken et al., 2002; Holloway et al., 2011), in my study those who reported that hope helps them to manage their illness mainly link it to receiving a kidney transplant. For instance, James recognises that hope is important, keeps him alive and encourages him to carry on with his life. For him, hope means being optimistic, that he will achieve what he is hoping for and that he will receive a kidney transplant. However, in his case it is not possible due to his underlying medical conditions and therefore he keeps positive and hopeful that his condition will not deteriorate:

> *Hope, well, that's what kept me alive 11 year on dialysis, it's hope, you will get there you know. For the first few years you are hoping, you will get a transplant and you get other things, you just hope things go on as they are, you will not get any worse, things keep alright, and your family keep alright.* (James: Interview: 13)

Most participants report that hope for a kidney transplant and having a complications-free life are their main drives to continuing with dialysis treatment until they receive the new kidney. For example, Ruth states that hope for a kidney transplant keeps her positive. A new kidney may transform her life into a new life without dialysis. This transformation in turn may impact on her personal circumstances from being a person who is totally dependent on a machine to stay alive to a person with more freedom and control. Also, the new kidney may transform her relationship with her family from being dependent on others to someone who can build a mutual relationship with her

loved ones:

> *I would like to hope one day that I would maybe get a transplant, then it would have a whole different look on, I suppose, in life or live in a way that I would think positive and think how it would affect the family, how things would turn out.* (Ruth: Interview: 12)

Isabel agrees that going into despair may affect her life physically and psychologically which can stop her from receiving a new kidney. Her use of the words *'absolute'* and *'utterly the holy grail'* highlights hope as a spiritual aspect and illustrates her continuous striving to maintain higher levels of hope and that one day she will receive a kidney transplant, which in turn might have a great impact on her life:

> *I have got to keep my spirits up, I have got to keep well because if I don't then I won't get a kidney and that is the holy grail for me, absolute and utterly the holy grail, so I'm not going to do anything that would stop me getting a kidney because I want my chance to live a pain-free, varied and wonderful life again and that will happen when I get a kidney.* (Isabel: Interview: 3)

In summary, hope empowers some participants to carry on with life despite their disease challenges. Hope means being positive and is considered important in helping them cope with HD. Maintaining high levels of hope and being optimistic that they will receive a kidney transplant and live a normal life again are their main drives to carry on with dialysis until they receive a new kidney. Receiving a new kidney may then positively impact on their health outcomes and well-being as having a kidney means a

complete transformation in life for some participants as they will be able to live their life again and have more time and control.

6.7.5 Summary

The examples from the data presented so far support the argument that spirituality might play an important part in coping with ESRD and HD treatment. It was shown that the meanings of spirituality offered by participants in my study add to those available from the literature. However, the emphasis on the connection with nature/environment, as identified in my study, is a meaning of spirituality that is often not referred to in the literature. It was also shown that, although participants experience spiritual struggles because of the uncertainty about the future, death of fellow patients, or asking the '*Why me?*' question, they often turn to spirituality. This gives them many benefits such as the ability to accept their illness and demanding treatment, maintaining a positive attitude in the face of a challenging disease and giving them the strength required to live with it. Spirituality instilled hope among these participants and therefore they remained optimistic that they will receive a kidney transplant which will transform their lives. Considering the limited amount of work exploring the influence of spirituality on the health outcomes and general well-being of the dialysis population, my findings add to knowledge by examining the role of spirituality, for the first time, amongst patients receiving HD treatment in Scotland. Thus, the argument – that in my study spirituality is important and may positively influence the health outcomes and well-being of patients with ESRD – is strengthened. Although it might not be the main focus of my thesis, some participants identified humour as another coping strategy that can help

them cope with ESRD and HD treatment and this is briefly discussed next.

6.8 Other Coping Strategies

6.8.1 Sense of Humour

Some participants describe how they manage to find a way of coping with the psychological, emotional and physical challenges associated with HD. Coping strategies or mechanisms are helpful actions undertaken by people whose survival and livelihood are compromised or threatened (WHO, 1997). The ability to use humour as a coping strategy in the face of illness may empower them to overcome their disease challenges and this may have a positive influence on their health outcomes and well-being.

Some participants report that humour helps them cope through maintaining positivity towards HD and by diffusing stress and this helps them recreate a sense of control over their situation which may contribute to them coping better. For example, Joyce reports that laughter distracts her from unpleasant and stressful situations. Laughing on a daily basis impacts on her psychological status by switching her focus to something other than her HD treatment:

> *Laughing is very important; I think everybody should laugh at least once a day because I think that is one of the most important things in life; if you laugh you forget what other things are going on.* (Joyce: Interview: 11)

Carol agrees that having a sense of humour and making fun of her current situation

plays an important part in diffusing stress and anger. She further continues to describe how her perception of HD changed as a result of having humour in her life by making something that is threatening, unthreatening. A sense of humour encourages her to be positive and therefore she acknowledges that laughter makes a difference in her life:

> *Because if you can laugh at yourself and laugh at situations it diffuses anger a lot. Humour diffuses an awkward situation and I think that's important because that keeps your spirits up, and that makes a difference, definitely makes a difference.* (Carol: Interview: 3)

For Alexander, the ward environment and the presence of cheerful nursing staff and fellow patients is important in diffusing stress and can assist in coping with HD. Coming to dialysis can be depressing because of the nature of the disease and the HD routine; however, cheerful staff and other patients help him to overcome this depressing situation. He appreciates the effort of cheerful nursing staff who strive to keep things enjoyable to the best they can. Their cheerful demeanour changes his self-perception and elevates his mood:

> *It is a good ward because it is quite a fun ward, it is not depressing, you come here and you feel a bit depressed, oh God, it is going to be doom and gloom, but it is not like that, it is a good atmosphere, a fun atmosphere, we have a good laugh with the staff and with patients, a good banter and things like that and that is a good thing.* (Alexander: Interview: 6)

> *Nurses make things as enjoyable as much as possible, any day you come in and they always seem to be cheerful and that is a good thing, if you see people happy about you; it makes you a bit happier I think.* (Alexander: Interview: 6)

In summary, some participants report that humour can help them cope by distracting them from their situation and by diffusing the stress associated with HD treatment. The availability of a good, fun environment and cheerful nursing staff is important and assists some patients to overcome their challenging treatment regimen.

6.9 Summary of the Key Findings

The interviews revealed that ESRD and HD treatment are demanding and all-encompassing. In particular, participants spoke about the different psychological, emotional, physical, and spiritual challenges introduced into their lives because of HD which may have had a negative impact on their QOL and general well-being. However, the analysis revealed that participants continually strive to find ways of coping with these challenges. In particular, participants spoke about spirituality and how it may influence their health outcomes and general well-being. Some participants gain several benefits of spirituality throughout their journey with ESRD and while receiving HD treatment. For instance, some participants identified that spirituality means having a connection with God or Supernatural Being which gives them a sense of strength and protection in the face of a challenging disease. In addition, connection with self, which evolves through having inner calm and strength, and connection with others, which evolves through having mutual relationships with others, were other meanings of

spirituality offered by some participants. Inner calm and strength equip them with the mental ability and self-satisfaction to manage and adjust to their new situation, whereas having mutual relationships with others distracts them from their stressful situation and encourages them to maintain their roles within the family and wider society, which in turn enables them to accept their disease and live with their challenges. Through spirituality, some participants manage to maintain a positive attitude towards their illness and remain hopeful that one day they will receive a kidney transplant which might positively transform their lives. In addition, having a sense of humour enables some participants to manage their day-to-day lives and overcome their disease challenges. Having a sense of humour offers them distraction and helps in diffusing stress, which may change their perception of HD treatment from something that is life-threatening to something that is unthreatening and manageable. These findings are valuable and contribute to knowledge, particularly because little previous work has been carried out to explore the health status and mainly the QOL and general well-being of patients with ESRD, and also to explore the influences of spirituality on their health outcomes and general well-being. These findings suggest that spirituality might be an important resource and an instrumental coping strategy that may help patients carry on with their lives effectively.

6.10 Synthesis of Quantitative and Qualitative Findings

As highlighted in Chapter 1, the overall aim of my study was *to examine and explore spirituality in the day-to-day lives of patients with ESRD receiving HD treatment and how it may influence their health outcomes and, in particular, QOL and general well-*

being.

Both sets of data revealed that ESRD and HD treatment had a significant impact on patients' health status and general well-being. Participants reported a progressive and unpredictable disease that introduces various challenges into their lives, starting at the time of diagnosis and continuing throughout their journey on HD. Firstly, data from the survey revealed that all domains of QOL of patients receiving HD treatment were markedly lower than the UK general population; in particular, the domains that link to patients' physical health (e.g. Role Physical, Physical Functioning and Vitality). Data from the interviews complemented these findings and explained why patients' QOL may have been compromised as a result of their disease and treatment regimen. For example, the interviews revealed that participants in my study reported many restrictions in their lives because of the demands and challenges of HD treatment and, in particular, unremitting fatigue, disease unpredictability and adverse side effects. The interviews explained that the decline in physical health might be because of the constant physical fatigue and lack of energy that these patients experience on a daily basis which may limit their abilities to engage or perform daily activities or plan ahead and this might have a negative impact on their QOL.

In addition, data from the survey demonstrated that the mental health domain of QOL was the least affected among participants in my study, indicating that patients were able to manage and adapt to their disease. The qualitative analysis explained that, although the stress levels were high among participants in my study, their ability to manage their daily lives and overcome their challenges suggest that it has little impact on their mental

health and the ability to cope with ESRD and HD treatment.

Furthermore, data from the survey revealed that, overall, 47% of participants reported that stress and anxiety were present in their lives, which may have had a negative impact on their well-being. Data from the interviews complemented these findings and explained why patients' well-being might have been compromised. In particular, the interviews revealed that participants developed psychological and emotional struggles as a result of their disease. In the interviews, it was shown that stress and anxiety might be present in patients' lives because of the uncertainty about their future, the inability to maintain their role within the family and wider society, and the wholesale changes and life-changing decisions that they had to make throughout their time on HD. The interviews also revealed that stress and anxiety may have increased as a result of being totally dependent on a dialysis machine and mostly relying on caregivers to maintain a reasonable life. These findings give a clear indication of the negative impact of ESRD and HD treatment on the QOL and well-being of this group of patients.

Secondly, with regard to spirituality in the lives of patients receiving HD treatment, data from the survey analysis revealed that 46% of the total sample rated spirituality to be high to very high in their lives. Data from the interviews complemented these findings and revealed that spirituality was important for most participants (n=15). The survey analysis demonstrated that religion was important for 68% of participants, a result that was confirmed in the interviews as the majority of participants reported that they do practise some form of religion (i.e. praying, reading the Bible and frequent church attendance).

Although it was not statistically significant, data from the survey analysis identified a trend of improving overall MCS mean scores with increasing importance of religion but no other significant association between spirituality and religiosity questions and other domains of QOL and general well-being. However, data from the interviews revealed that, although some participants reported spiritual struggles as a result of their fear of the unknown and uncertainty about the future, spirituality was an important coping strategy that helps some of them to accept their disease and manage the different challenges of their treatment through the presence of God or supernatural beings in their lives, which gave them a sense of protection. The interviews also revealed that spirituality helps some participants to maintain a positive attitude towards their illness and encourages them to maintain hope that one day they will receive a kidney transplant, which might have a positive influence on their health outcomes and general well-being.

The interviews also revealed that participants valued the continuous support from their families, friends and significant others; a meaning of spirituality that offers them distraction and diffuses their stress. The conscious choices made by some participants in my study to look after their own health in appreciation of the constant support from their family, friends, and significant others explained the positive impact of having mutual relationships with others on their health outcomes and general well-being

Finally, data from the survey analysis revealed that age was associated with reduced stress and anxiety and therefore better general well-being. Data from the interviews explained that for some participants growing older helps them cope better as they feel

they are mentally equipped to deal with the challenges of their disease and HD treatment and helps them adjust their lives accordingly by coming to terms with their disease and accepting their limitations.

This chapter has presented the findings from 21 semi-structured interviews conducted with a group of patients currently receiving HD treatment. The gaps identified in the literature review (see Chapter 3, Part II) were taken into consideration and this highlights that understanding spirituality and its role in the lives of patients with ESRD receiving HD treatment has not yet been fully achieved. This is largely owing to the limited number of studies exploring this important concept among this group of patients, or the use of designs that fail to capture the real picture of how spirituality may influence patients' health outcomes and general well-being. The findings presented in this chapter add to what is known in the literature about the impact of ESRD and HD treatment on patients' health outcomes and well-being, add to knowledge by presenting an account, for the first time, about the health status of patients with ESRD receiving HD treatment in Scotland and about spirituality and its influence on their health outcomes and general well-being. The findings from the analysis of the quantitative and qualitative data sets served the purpose of triangulation and complementarity and suggest that combining both data sets could help to expand upon the understanding provided by each set of findings, offer a more complete picture of patients' health status and well-being and provide insight into and deeper understanding of the meanings of spirituality and its influence on patients' health outcomes and general well-being. In Chapter 7, I discuss the key findings from Chapters 5 and 6 in greater detail.

Chapter 7- Discussion and Conclusion

7.1 Introduction

The study set out to examine and explore spirituality in the day-to-day lives of patients with end-stage renal disease (ESRD) receiving haemodialysis (HD) treatment and how it may influence their health outcomes and, in particular, quality of life (QOL) and general well-being. A mixed method design was used to achieve the study aim because it facilitated obtaining detailed insight into the impact of the disease and the role of spirituality in patients' lives.

This chapter presents and integrates the key findings arising from the synthesis of both data sets in order to address this aim and answer the following research questions:

1. Is there an association between spirituality and QOL and general well-being in patients with ESRD receiving HD treatment?

2. What does spirituality mean to people receiving HD treatment?

3. How does spirituality influence the QOL and general well-being in patients with ESRD receiving HD treatment?

The chapter begins with a summary of the key findings in Section 7.2. These findings are then discussed and integrated in detail with reference to the wider literature and existing research in Section 7.3. A critical consideration of the strengths and limitations associated with the methodology adopted in this study are discussed in Sections 7.4 and

7.5, respectively. Recommendations are then made for clinical practice in Section 7.6, patient and nurse education in Section 7.7 and future research in Section 7.8. The thesis is concluded in Section 7.9 and I offer a personal reflection on being a researcher in Section 7.10.

7.2 Summary of Key Findings

Synthesis of the findings demonstrated that ESRD and HD treatment are demanding and all-encompassing and introduce many challenges into patients' lives: psychological, physical, emotional, and spiritual. Another principal finding that emerged from this study is that, although there was no statistically significant association between spirituality and patients' QOL and general well-being in the survey, the qualitative analysis revealed that spirituality might be important in their lives to overcome the challenges and restrictions imposed by ESRD and HD treatment. In particular, the study demonstrated that participants held a range of meanings of spirituality and emphasized that it might be an essential coping strategy that helps them throughout their journey with the illness and while receiving HD treatment, which may have positively influenced their health outcomes and general well-being.

7.3 Discussion of the Findings

Understanding the relationship between spirituality and its influence on the health outcomes and well-being of patients with chronic illnesses and, in particular, in patients with ESRD is an under-explored area. My thesis demonstrates a contribution to

knowledge of the existing discourse on such influence. The next section presents a brief discussion of the findings about the impact of ESRD and HD treatment on patients' QOL and well-being.

7.3.1 Patient's Health Outcomes and Well-Being

The mean scores in all domains of QOL among the study participants and, in particular, those linked to patients' physical health (e.g. Role Physical, Physical Functioning and Vitality) were markedly lower than the United Kingdom (UK) general population norms, suggesting that ESRD and HD treatment can have a significant negative impact on patients' QOL. Participants reported diminished QOL as a result of being unable to perform any physical activities or losing the ability to engage in daily routines. The findings in my study contribute to knowledge by exploring why patients' QOL may have been affected and, in particular, the findings from the interviews suggest that QOL is often discussed in the context of having the physical abilities and energy to perform activities, visiting places, maintaining social relationships with family and friends, having a pleasing diet, having enough money, and not being sick or struggling with adverse side effects. These findings add to those identified in a quantitative study in Israel which found that the QOL of patients with ESRD was significantly lower than the general population (Frank et al., 2004) and that domains of QOL (e.g. PF, RF, PCS) linked to patients' physical ability were the most affected (De Oreo, 1997; Lamping et al., 2000). The findings also add to those identified in a previous qualitative study which found that patients living with ESRD were restricted because of the different types of losses they suffered as a result of their disease, such as losing freedom, choices,

physical ability, rituals, and decision-making opportunities which attributes to the demands and consequences of ESRD (Al-Arabi, 2006).

The findings from my study also show that participants were in a continuous battle to live with the demands of their illness and HD treatment. In particular, uncertainty about the future, losing freedom, losing identity by becoming dependent on others and the dialysis machine were factors that contribute to patients' psychological struggle. These findings add to previous research where patients with ESRD receiving HD treatment reported that the early months after diagnosis and the commencement of HD treatment were marked by periods of emotional upheaval and doubts about the future, diminished QOL as a result of losing control over kidney function and becoming dependent on the dialysis machine (Gegory et al., 1998). The findings also add to knowledge by confirming that factors such as fear, dependence upon others, loss of familiar role functions, lowered self-esteem, feelings of helplessness, and alterations in family dynamics contribute to the psychological struggles of patients with ERSD (Kimmel et al., 2001; Walton, 2002; Yu and Petrini, 2010).

The finding in my study about identity loss and its potential impact on the psychological status of patients with ESRD contributes to knowledge by adding a new dimension to what is known in this field: an area that requires further investigation. Limited previous research was found to explore the relationship between identity loss and the health outcomes of patients with ESRD. This might be because previous research did not focus on assessing patients' identity and its role in their lives because it might seem odd that identity loss can be linked to poorer health outcomes. Therefore,

my findings add to those reported by Smith et al. (2009) who found that the different challenges and restrictions introduced into patients' lives because of ESRD can challenge their identity.

My study findings also show that, despite their psychological struggle, the near average overall MCS scores were not largely different from those of the general population, indicating that the mental health of my study participants is relatively preserved, which might be because the psychological adaptation usually occurs in patients with chronic diseases, who use rational strategies in order to face and accept the disease and its treatment on a daily basis.

My study is the first (to my knowledge) to examine and explore the impact of ESRD and HD treatment on patients' health outcomes and general well-being in Scotland. Although most of the findings about the impact of ESRD and HD treatment on patients' health status and well-being add to what is reported in the literature, they contribute to our understanding of the daily lives of this group of patients and provide insight into the many challenges that they are facing on a daily basis. My findings demonstrate that ESRD and HD treatment are all-encompassing, demanding and can have a negative effect on patients' health outcomes and general well-being. However, there remains a need to conduct further research to corroborate my study findings.

7.3.2 Spirituality

7.3.2.1 Meanings of Spirituality

For some participants, the spiritual experiences represent meaning and coping, which includes acceptance and fortification, maintaining a positive attitude and maintaining high levels of hope. Generally, spirituality was described as a multidimensional concept that incorporates different meanings, including connection with God, connection with the self, connection with nature/environment and having meaningful human relationships with others. The meanings of spirituality identified in my study and, in particular, connection with nature/environment, are more comprehensive than previous definitions of spirituality identified in the literature. In previous definitions of spirituality it was identified that it means having a connection with God or a Supernatural Being, connection with the self and others but the focus is rarely on the connection with nature or the environment. In addition, previous definitions of spirituality commonly represent the views and opinions of individuals, which cannot be generalized and applied to the general population (MacLaren, 2004), yet they do contribute to our understanding of the concept in that they provide us with insight into what people feel and think about spirituality. The meanings of spirituality identified in my study add to those identified in previous research where spirituality is described as an individual's search for meaning and purpose in life, which may include a sense of connectedness with others and/or the divine (Underwood and Teresi, 2002; Tanyi and Werner, 2003) and reflect the four domains of spirituality framework identified by Fisher (1998).

In my study, I found that connection with the self was identified as one meaning of spirituality. Connection with the self may have helped my study participants to find meaning and purpose in life and this might have a positive influence on their health outcomes and general well-being. Connection with the self evolves through patients' ability to adjust to their illness and demanding treatment and by coming to terms over time with the restrictions imposed on their lives. Adjustment appeared to follow a course that began with the diagnosis of ESRD, leading the initial phase of adjustment encompassed by uncertainty, depression, and support from loved ones, reliance on spiritual beliefs, and finally, acceptance of the disease. Most participants appreciated HD treatment as the only available option that keeps them alive, resulting in them continuing to receive HD despite its negative effects. Over time, their concerns changed from the initial shock and dealing with the disease itself, to facing the negative aspects associated with HD treatment and trying to live as normal a life as possible. These findings contribute to knowledge by exploring, for the first time, this meaning of spirituality and its role in the process of adjustment and add to the very limited amount of work exploring this process. Tanyi and Werner (2008a) agree that the process of adjustment to ESRD and HD treatment is under-researched. Current nursing literature reports that the adjustment process encompasses an initial phase of adjusting to ESRD and HD treatment, a second phase of appreciating the HD treatment, and a third phase of grappling with the negative aspects of HD and returning to a satisfactory life (Wright and Kirby, 1999; Tanyi and Werner, 2008a). Nevertheless, patients sometimes fail to adjust because of poor communication between them and health care professionals and therefore they might use self-protective strategies, such as refusing recommended

treatments, adjusting diet and medications, and refusing care from particular health professionals (Allen et al., 2011).

I also found that, for some participants, connection with the self as a meaning of spirituality evolves through engaging in art-making and creative outlets. This new finding is unique and contributes to knowledge by adding a new dimension to the adjustment process amongst patients with ESRD. No previous studies were identified to explore the relationship between engaging in art-making and creative outlets and the health outcomes and general well-being in patients with ESRD receiving HD treatment. My finding therefore adds to the limited amount of work exploring the role of art-making among patients with other chronic illnesses (e.g. cancer, stroke) which reports that art-making helps patients to restore self-worth, normalise everyday life, cope with cancer as well as remain actively engaged in daily life and address the uncertainty of their future (La Cour et al., 2005; Reynolds and Prior, 2006). Contrary to my finding, however, La Cour et al. (2005) found that engaging in creative activities is not always a positive experience as it can involve facing difficult existential issues.

In my study, I found that connection with others was identified as another meaning of spirituality. For some participants, having meaningful social relationships is important and often helps them cope with ESRD and HD treatment. Connection with others may therefore improve patient health outcomes and well-being through different mechanisms such as distraction, diffusing stress, and maintaining roles within the family and the wider society. These findings contribute to our understanding of this meaning of spirituality and give insight into how connection with others might help this

group of patients throughout their journey with ESRD and suggest that family, friends, and significant others are the most valuable source of support for them while receiving HD treatment. Previous research studies addressing social support in the lives of patients with ESRD were mainly carried out using quantitative methods and therefore lack the explanation of how perceived social support was used by those patients. Therefore, my findings are different from previous research because they explain that the conscious choices made by my study participants to look after their health in appreciation of the constant support from their family, friends, and significant others may have had a positive impact on their health outcomes and general well-being. Nonetheless, my findings add to those reported in a quantitative study by Patel et al. (2005) who found that greater levels of perceived social support reduce levels of depressive effects and correlate with a lower perceived burden of illness, greater satisfaction with life, and improved survival. However, they are in contrast to those reported in another quantitative study by Abbot (2009) who found that there was no relationship between social support and patients' health status and psychological stress.

In summary, the diagnosis of ESRD and the commencement of HD treatment lead to a process which disrupts peoples' daily lives and their sense of normality (Bury, 1982; Charmaz, 2002). Through spirituality, some participants managed to find meaning and purpose in life as described in the different meanings of spirituality identified by my study participants. Hence, it is unsurprising that most patients in my study managed to cope with being diagnosed with, and undergoing treatment for, ESRD and, as in any chronic illness, people attempt to reconstruct a meaningful sense of self that fits with

the changes that they have experienced in their lives (Bury, 1982). Through time, they learned to adapt and accept their illness by making sensible choices in order to live (i.e. attending dialysis) and thus they feel that maintaining a good QOL was within their own reach. Whether all patients receiving HD treatment share similar or different views about these meanings of spirituality and their roles in patients' lives remains a question that needs to be answered. My study might be a first step in identifying these different meanings of spirituality among this group of patients and, in particular, in Scotland where further research is required to corroborate what is reported in my study.

7.3.2.2 Spirituality, Religiosity and Quality of Life and General Well-Being

Findings from my study demonstrate that increasing importance of religion showed a small trend of improving overall MCS mean scores, suggesting that increasing importance of religion might help patients to be better psychologically adapted, or it might be that better psychologically-adapted patients can focus more on practising religion. This finding adds to those reported by Gilbar et al. (2005), who found that patients with ESRD who have a strong fighting spirit were less psychologically distressed and had better QOL and that higher levels of spirituality and religiosity were associated with better QOL, less depression and higher satisfaction with life (Nelson et al., 2009; Lucchetti et al., 2010). My finding, however, is contrary to what is reported by Haley et al. (2001) who studied 3,851 elderly patients and found that those who prayed, meditated, or read the Bible on a daily basis had greater physical disability and mental struggle than those who engaged in those practices weekly. In their study, however, causal relationships cannot be assumed (i.e. engaging in prayer causes poorer

or better health).

In my study there were weak, non-significant associations between spirituality and other domains of QOL (Bodily Pain, General Health, Vitality, and Social Functioning). The sample in my study may have been too small to examine for associations or that spirituality might have no associations with patients' QOL. However, synthesis of the findings showed that spirituality can have a positive influence on patients' health outcomes and general well-being. These findings contribute to knowledge and add to previous limited claims about the influence of spirituality on the health outcomes and well-being of patients with chronic illness and, in particular, they add to the very limited amount of work exploring the relationship between spirituality and the health outcomes and general well-being of patients with ESRD. In particular, to my knowledge, there have been no previous studies identified to address this important concept in the lives of patients receiving HD treatment in Scotland. My findings show that some participants emphasized that spirituality facilitates acceptance which was important and crucial in order to adjust their lives in the face of ESRD and HD treatment. Facing a challenging disease leads to a degree of reflection where participants view their health from a new perspective and start to look for balance in their relationships with God, the self, environment, and others, and this may have had a positive impact on their health outcomes and general well-being. Consequently, participants become adherent to their treatment and re-establish control over their lives. My findings add to those reported by previous qualitative studies about the importance of dialysis patients' quests to find balance in their adjustment processes which

highlights that spirituality is important and plays an integral part in improving the health outcomes and well-being of chronically ill elders or those receiving HD treatment (Walton, 2002; Harvey and Silverman, 2007).

I also found that spirituality and faith offer some participants the inner strength that helps them to overcome their challenges and facilitate adjustment to the daily requirements of ESRD and HD treatment. Inner strength comes from faith, prayers, and trust in God, which is a significant resource that encourages them to proceed with their treatment despite their struggles. Having inner strength empowers and helps some participants to be more confident about fighting their disease and therefore it may have had a positive impact on their health outcomes and general well-being. The near average mean scores of the Mental Health domain and overall MSC mean scores support these findings and suggest that participants in my study were able to adapt and adjust their lives accordingly. To date, the relationship between spirituality and how it helps in fighting a chronic illness is an under-explored area. The limited available literature suggests that spirituality provides inner strength and guidance in the face of a challenging disease and that having this inner strength could be essential in influencing the ability to cope with the changing circumstances of an illness and therefore leading to better health outcomes (Walton, 2002; Albaugh, 2003; O'Brien, 2003; Wright, 2005).

Spirituality encourages some participants in my study to maintain a positive attitude in the face of a challenging illness and treatment regimen. Spirituality may have moderated participants' stress and anxiety and consequently they become less worried about their illness and demanding treatment and, as a result, they manage to maintain

this positive attitude, which may have had a positive impact on their health outcomes and general well-being. Again, the near average mean scores of the Mental Health and the overall MCS domains of QOL support these findings. This finding contributes to our understanding about how patients with ESRD manage their lives by maintaining a positive attitude and suggest that if the ideas about positive thinking/attitude exist amongst patients with ESRD, it should be reflected in the literature. It has been established that a positive patient is far easier to care for than a depressed or angry one (de Raeve, 1997). Limited support for these findings was found in the HD literature. For instance, Beanlands et al. (2006) examined the strategies employed by individuals with ESRD to achieve balance in their lives and found that the importance of building a positive sense of self in the face of illness was a critical part of illness adjustment. Patients choose to reject talking to those people who are in a state of hopelessness and despair to maintain a positive attitude during the treatment and, therefore, patients consider dialysis as part of life and this positive view helps them increase their confidence in self-care, lessen their symptom distress and keep healthy (Yu and Petrini, 2010). In my study, however, it was found that maintaining a positive attitude can become a burden, especially for those who are always obliged to maintain this attitude in the face of illness even though they might not feel like it. Consequently, the expectation of being positive becomes a burden which can introduce more stress into their lives. de Raeve (1997) proposes that thinking positively has become a societal moral norm as it is expected from people with chronic illness to be positive all the time. Patients who do not want to fail their close relatives try to stay positive and this may create a sense of psychological oppression for them to think positively about their

disease (de Raeve, 1997).

In my study, I found that some participants who have reported to be more spiritual often asked '*Why me?*'. It seems that the lack of understanding of the disease dynamics and the perception that ending up with ESRD was a punishment or test from God led those participants to ask this question, suggesting that they might struggle to cope at times. In particular, for those who are praying on a regular basis or talk to God frequently and who are regular church goers, ending up with a disease that requires a lifelong treatment was a major disappointment and, therefore, they often express some anger or dissatisfaction towards God. This finding adds to previous research about the *'Why me?'* mentality amongst patients with chronic illnesses. For instance, Nelson et al. (2002) suggest that when patients feel unprepared for their situation or unable to find guidance through their religious beliefs, the religion that was once a source of strength or comfort can become a source of stress, which may introduce a feeling of anger towards a God who has caused them and their family so much pain. Consequently, the resulting conflict between having strong religious beliefs and being unable to accept or express the anger the individual feels toward God may fuel the psychological distress that this individual is already facing. However, contrary to my findings, Tanyi and Werner (2008b) report that a diagnosis of ESRD and receiving HD treatment encourage self-evaluation among their participants, offering them a deeper insight into their illness and therefore they refrain from self-blame and the '*Why me?*' mentality.

In my study, I also found that, for some participants, spirituality instils hope in them and as a result they look positively at the changes that happened in their lives which

may have had a positive impact on their health outcomes and general well-being. Participants in my study remained hopeful that one day they will receive a kidney transplant which will positively transform their health status. The role of hope in the lives of patients with ESRD is an under-researched topic. My findings therefore add to the very limited claims about its role amongst this group of patients which reports that more hope was positively associated with reduced anxiety, depression, and improved mental health and QOL (Billington et al., 2008) and that keeping hope for a kidney transplant is an important factor in people's ability to cope with ESRD and HD treatment and links to better QOL (Dencheva, 2010; Moran et al., 2010). However, contrary to my findings, other researchers found that hope has been found to be negatively related to general maladjustment (Cramer and Dyrkacz, 1998) and symptoms of depression (Chang, 2003).

My study findings suggest that spirituality might have positive influences on patients' health outcomes and general well-being. However, contrary to my findings, other researchers reported that spirituality may have a negative influence on patients' health outcomes. For instance, King et al. (1999) found that stronger spiritual belief appears to be an independent predictor of poorer clinical outcome in patients admitted to the cardiology and gynaecology services and that people with strongly-held spiritual beliefs might be more vulnerable and hence do less well over time. Blumenthal et al. (2007) also found little evidence to support the notion that religion and spirituality can improve physical health outcomes in their sample of people recovering from myocardial infarction. The majority of these studies adopted a quantitative method to examine these

relationships and therefore it might be difficult to identify the true nature of the relationship between spirituality and health outcomes and general well-being (i.e. whether spirituality leads to better or worse health outcomes and well-being). Hence, using different methodologies may serve this purpose and explore in more depth the role of spirituality in the lives of patients with ESRD.

In summary, searching the literature, I found that studies exploring spirituality among patients with ESRD are sparse and mainly focus on examining the relationship between religion and mental health, but not other health outcomes (e.g. QOL). In my study, I explored the influences of spirituality on the health outcomes and well-being of patients with ESRD and, therefore, the findings from my study contribute to knowledge by offering insight into the potential role of spirituality and suggest that it might be an important coping strategy that helps patients find meaning and purpose in life and enhance their ability to cope with ESRD and HD treatment. This in turn might have a positive impact on their health outcomes and general well-being. Swinton (2009) agrees that actual empirical research that looks specifically at spirituality and patients' health is sparse. The implications of these findings for future research are discussed further in Section 7.8.

7.4 Strengths of the Study

7.4.1 Uniqueness

My study is unique because no other studies have specifically explored the influence of spirituality on the health outcomes and general well-being using a mixed method

approach, in particular, in Scotland, to date. Government policies and reports detail best practice in relation to providing spiritual care across the healthcare sector (Scottish Executive Health Department HDL, 2002; Scottish Government, 2009). However, most research to date focuses on examining the relationship between spirituality and mental health with limited studies available to examine this concept among patients with different types of chronic illnesses and, in particular, ESRD. In addition, there is a dearth of studies examining whether or not spiritual care policies are implemented across healthcare sectors, or whether staff within the NHS recognise their responsibilities and roles in providing spiritual care. The Scottish Government (2009) produced a report to review spiritual care within NHS Scotland and recommended that spiritual care is a significant NHS resource in an increasingly multicultural society and that spiritual care is given by many members of staff and by carers and patients, as well as by specialist staff appointed for that purpose. The report recommends that there remains a need to affirm the understanding that spiritual care is a necessary and integral part of the whole person care offered by the NHS in Scotland and to promote research which increases and enlightens an evidence base for the efficacy of spiritual and religious care in health. Consequently, my study is unique as it provides evidence that concurs with these recommendations and suggests that spirituality might be of particular importance for patients with ESRD receiving HD treatment.

7.4.2 Methodological Strengths

A sequential mixed method approach was used to address the study aim and answer the research questions in a real-life situation while participants were receiving dialysis

treatment. The qualitative and quantitative components were set out to explore the influence of spirituality on patients' health outcomes and general well-being (survey and interview questions). Had a single approach been used alone, it might not have revealed the depth of understanding of such influence, or captured the importance of spirituality in patients' lives, and may not have allowed an understanding of how the strengths and weaknesses of both data sets contributed towards this understanding. Therefore, this level of questioning of both data sets has helped to enrich the robustness of the study and the interpretations made from each data set (Moffat et al., 2006). In particular, the study established that, by using both approaches, the study aim was achieved, taking into consideration the complementary nature of the findings. For instance, first, the quantitative findings revealed that ESRD and dialysis treatment had a significant impact on almost all aspects of patients' lives. The qualitative interviews confirmed that ESRD and dialysis treatment introduce many restrictions and challenges into patients' lives. Second, the use of a mixed method approach helped to follow up patients' responses from the questionnaires and thus the interviews were more tailored to these responses. Third, the use of a mixed method approach facilitated a greater degree of follow-up of significant or unclear results. Specifically, the survey suggested that there were weak, non-significant associations between spirituality and patients' QOL and well-being, apart from the overall PCS mean scores. The interviews, however, revealed that spirituality was identified as an important coping strategy for the majority of the participants throughout their journey with ESRD and while receiving HD treatment (n=15).

Method triangulation also strengthened the study findings. In my study, I used a number of short, accessible, and straightforward questionnaires that served the purpose of achieving a detailed picture of the impact of the disease and associations between variables. All of these are validated and well-established measures. Some were used in this study for the first time with patients with ESRD, namely the Spiritual Well-Being Questionnaire (Gomez and Fisher, 2003). This measure was shown to be acceptable with good internal consistency and validity, suggesting that it might be useful in exploring spirituality among patients with ESRD. In addition, I used interviews and reflective accounts to strengthen the robustness of the study findings. Using one method of data collection may not sufficiently solve concerns around possible conflicting data, and can make the study more vulnerable to errors associated with that method (Patton, 2002). However, by using method triangulation in my study different types of data were analysed in the search for deeper meanings and explanations related to the influence of spirituality on the health outcomes and general well-being in patients with ESRD. In particular, method triangulation served the purpose of complementarity proposed for using a mixed method design in order to capture an in-depth understanding of such influence and give more depth to the analysis (Jones and Bugge, 2006).

7.4.3 Trustworthiness and Credibility

One of the main challenges in conducting qualitative interviews is to ensure that the findings are of high quality. Hence, many strategies were used in my study to ensure that the qualitative data were of good quality. Qualitative research findings should be tested for credibility or accuracy using criteria that have been developed exclusively for

this approach (Cutcliffe and McKenna, 1999). However, these criteria have been subject to debate by many researchers (Guba and Lincoln, 1994; Tobin and Begley, 2004). Lincoln and Guba (1989) identified a set of criteria for evaluating the trustworthiness of qualitative research, and these are often the most cited. These criteria are: credibility, in which the depth and scope of the phenomenon are understood; dependability, where the appropriateness of methodological decisions is demonstrated; confirmability, which means that the findings are grounded in the data; and finally, transferability, which means that the information created and lessons learned in one context can be useful in another.

Using ethically reviewed protocols enhanced the credibility of my study. As a PhD student, my protocols required review by the Ethics Committee in the School of Nursing, Midwifery and Health at the University of Stirling as well as by the NHS Research Ethics Committee. Consequently, two ethical reviews were undertaken. In addition, the use of semi-structured interviews, the use of neutral probing to minimise the possibility of leading patients towards a specific response, such as “Can you tell me what you mean?” and “Can you tell me more?”, and discussions with my supervisors, colleagues and an expert in mixed method research were helpful and offered me the chance to enhance the emergent themes and facilitated study credibility. My presence in the dialysis unit and the continual validation and verification of meanings and emerging themes during the interviews established credibility with participants. The verbatim transcription of the interviews and reading them several times alongside listening and re-listening to the tape recordings to check for any errors helped to ensure the reliability

of the transcripts (Robson, 2002).

Dependability and confirmability of a study may be addressed by the demonstration of an audit and recording of activities over time that other individuals can follow. The audit would include all documentation including audio files, transcripts, memos and anything concerned with the study. Hence, in my study, detailed records of the process of data analysis and how themes emerged from the data were made (section 3.4.5.1.1 through to section 3.4.5.1.5) to address the issue of dependability. The approach to qualitative data analysis which built up a coding framework from the interview and the use of multiple quotes from the interview data to illustrate themes confirming that the findings were related to participants and were not just a reflection of my viewpoint addressed the issue of confirmability (see Chapter 5). Transferability allows for the possibility that the information created and the lessons learned in one context can have meaning and usefulness in another. Transferability was achieved by providing a detailed description of the setting, the problem and the findings which should enable the reader to determine the relevance of findings to their own situation, for example, to other dialysis populations. Therefore, a detailed report of my study has been written providing examples of the analytical processes involved in order that a judgment of trustworthiness can be made.

7.4.4 Reflexivity

Being a researcher in a familiar environment is challenging. Researchers need to reflect on the process of their research and acknowledge that their own assumptions, biases and

experiences could influence the research findings. Awareness of this concern enabled me to focus my attention on it and, through a process of critical reflexivity, to note and question these assumptions. This allowed the participant's stories to be revealed and is discussed in more detail next.

Researchers should stay away from familiar settings in which they have direct personal or professional considerations. Taylor and Bogdan (1998) argue that, in such situations, the researcher will see things from only one point of view instead of the many possible ways of viewing the world. Spradley (1979) identified many problems arising from studying a familiar environment. The first is the language differences that seem to be slight and are easily ignored and may not catch the researcher's attention. For me, that was not such a problem, since I am not a dialysis nurse. Patients in the dialysis units were aware of my nursing background and did make assumptions about my knowledge. When they were talking to me they used terms that were understandable to medical personnel such as fistula, kidney transplant and peritoneal dialysis and so on. Often participants used the statement *"you know"* repeatedly while explaining something to me. Some participants asked me about my own definition of spirituality and, therefore, I repeatedly reminded them not to respond to me as a nurse or assume existing knowledge of the area under investigation. They were made aware that I was a student researcher who was at the dialysis unit for a specific reason. Language differences may have been an issue during the initial phase when I was conducting the interviews because English is not my first language and there were a few occasions when my accent was not understandable by some participants. Nonetheless, this was resolved in the subsequent interviews because I was more familiar with the different terms that

were causing these problems and I was able to communicate them to participants during the interviews. Also, by the time I undertook this study, I had been living in Glasgow for five years and therefore I was able to understand the different accents used by my study participants.

The second problem as identified by Spradley is that the analysis of field data becomes more difficult as researchers may fail to see things in the data because they are part of their own knowledge and so familiar they may be taken for granted. I experienced this problem while analysing the initial interviews. For the purpose of developing my study proposal, I conducted an initial literature review and this caused some concerns initially for me because I was linking my findings to themes or findings that were identified from the literature review and I was not seeing the real meanings of my findings. However, to overcome this problem, I had to be self-conscious and reflexive on my own perceptions and ideas about the impact of ESRD and spirituality and how it can influence patients' health outcomes and general well-being throughout my research process. This was important in order to be able to describe phenomena as they are, rather than as I perceive them (Hammersley and Atkinson, 2007). Bonner and Tohurst (2002) argue that it is important for the researcher to be reflexive and critical in examining his/her assumptions throughout the data collection and analysis phase. Hence, I made notes of what I know about the possible impact of ESRD and HD treatment on patients' health and about my own perceptions of spirituality in order to avoid being judgemental and accept patients' views on spirituality and present them as they emerged from the interviews. Also, participants were not made aware of my

religious background unless they asked me directly, which was the case for one participant. I then went back to the initial interviews and carried out a new analysis and by then I started to see the bigger picture and managed to identify the initial themes that constructed my final coding framework.

The problem of familiarity can be eliminated by the researchers acknowledging their subjectivity; they can then strive to maintain an "open-minded" approach through continuous self-evaluation (Hanson, 1994, p. 941). It is recommended that researchers should keep a research diary on their reflexivity from the start, as this will give a clearer picture of how knowledge is produced (Skeggs, 1994). For this reason, I kept a research diary of my personal reflections on methodological issues such as sampling, interviews and the analysis process.

The third problem that Spradley (1979) identified is the challenge participants from a familiar environment present for interviewing. This means that the participants believe that I know the correct answers to my questions and they might feel that I am asking them such questions to test them in some way. For example, in one interview when I asked the participant about his definition of spirituality and after he offered me his definition, he asked me about my own definition of spirituality. I had to make it clear to him that I was not testing his knowledge in any way and that I was seeking to understand rather than to criticise or offer any answers in order to avoid guiding study participants in any particular way. Throughout this study a respectful and mutual relationship developed between me and the study participants and none of them made any direct comments about me or my religious or cultural background.

Conducting research in medical settings leads to role confusion or ambiguities and ethical dilemmas (Goodwin et al., 2003). Goodwin et al. argue that the clinical role may take priority over the researcher role and therefore the collection of data. I experienced this myself when one of the patients I was interviewing felt tired and her blood pressure dropped because of her treatment. Initially, I tried to help her by asking her to lie back and elevate her legs; however, I realized that my role at the time was only as a researcher rather than a nurse and, therefore, I reported the problem to the staff nurse onsite who asked me to wait outside until the problem was solved. Consequently, I stopped the interview on that day and assured the participant that I would come back another day to complete the interview, which was the case. I learned from this incidence that every time an alarm goes off from the dialysis machine or if the patient becomes tired, to report it to the nursing staff. However, my nursing background working with patients on a one-to-one basis offered me a sense of comfort while I was in the dialysis units carrying out my research, and this allowed me to merge myself into the environment and the background without disturbing the situation.

In practice, any study will be affected by the researcher's values, as the researcher is the main instrument in qualitative studies. To minimize this influence, I followed a coherent approach in conducting the interviews. The richness of the data I obtained suggests that participants did feel comfortable disclosing information and expanding on it on their own terms. Although we cannot avoid having an effect on the social phenomena that we study, we only need to reflect on our roles as an active participant

in the research process and to acknowledge our influence on the research process and findings (Hammersley and Atkinson, 2007).

7.5 Limitations of the Study

This study has some limitations that should be considered. First, given the exploratory nature of this study, a cross-sectional survey was used in the quantitative component which makes it difficult to report causal relationships between variables. Nonetheless, well-designed cross-sectional surveys can play a vital role in supporting evidence-based practice for patient management (Ligthelm et al., 2007). Ruane (2005) argues that obtaining information from the population at a single point in time is seen as a reasonable strategy for pursuing descriptive and exploratory research projects. Therefore, a cross-sectional design was seen as the most feasible at this stage of my thesis.

Second, probability (random) sampling is the best way to give every individual the chance to participate in a study to decrease the chances of sampling errors (Meadows, 2003). Hence, all patients from all dialysis units were considered eligible to participate in the study, yet the small sample size in the survey may have reduced the power to detect statistically significant findings.

Third, the final response rate in the survey was 19.7% and the reasons behind this low response rate were not clear. However, it might be because patients who were given the study packs were not returning them to the nursing staff, or it might be because the nursing staff did not give the study packs to potential participants. Reliance on the

nursing staff as per my ethical and management approval may have raised the possibility of 'gatekeeping', where patients may have been subject to biased selection from clinical staff, and this may have affected the final response rate. Therefore, it was important to keep an on-going dialogue with the nursing staff to minimise this. Moreover, some participants may have declined to participate because they were involved in other research studies taking place at the same time I was conducting my study. To overcome this issue, participants were asked to complete the questionnaire on their own while connected to the dialysis machine to save them time. Although the response rate was low, it was relatively comparable to other studies conducted to examine spirituality. For example, Adegbola (2011) carried out a descriptive correlational study to explore the relationships between spirituality, self-efficacy, and QOL in 90 adults with sickle cell disease and reported that the overall response rate in her study was low (36%). Baetz et al. (2004) used a mail and online survey to recruit 157 participants to compare psychiatrists' and psychiatric patients' practice, attitudes, and expectations regarding spirituality and religion and reported that their overall response rate was lower than expected (42%).

While the final response rate (19.7%) is low and is acknowledged as a study limitation, the number of responses obtained (n=72) was sufficient to identify some differences of a certain magnitude between variables. All attempts, within the parameters of a PhD study and timeframe to maximise the response rate, were made. There is evidence that providing individual incentives can assist in increasing the study response rate (Kenyon et al., 2005), a strategy which was not viable in my study.

Fourth, the convenience sampling strategy adopted in the qualitative component might be considered as a limitation in generalising the study findings as it may not be representative of the general population of interest. However, the sample in my study was recruited from multiple dialysis centres within different Health Boards across Scotland which may increase the chances of the findings being representative of the whole dialysis population and, in particular, in Scotland.

Fifth, although the interviews used in the qualitative component were the most appropriate method to obtain insight into spirituality and its role in patients' lives, they are open to social desirability and acquiescence bias which is described as a participant's inclination to respond positively to questions without adequate evaluation of their content. It is possible that, considering the nature of my study, participants responded to questions to portray themselves as 'good' patients. Lack of privacy and the conduct of the interviews in the dialysis units may have created a barrier for participants to disclose sensitive information about their spirituality or their care. However, it was outwith my ethical approval to conduct the interviews in participants' homes.

Sixth, the sample was predominantly white, Christian, and English-speaking. The inclusion of non-English speakers or other ethnic groups may have ensured that the sample consisted of an appropriate degree of diversity. However, the characteristics of the sample could not be controlled, hence there was too little diversity within the sample.

Seventh, my ethical approval gave me no permission to approach potential participants myself and I was dependent on the nursing staff to recruit these participants and therefore it was difficult to monitor how many patients were given the study packs, or perform statistical analysis on those who declined to participate.

Finally, another potential limitation is the process of recruitment for the qualitative component which was carried out while conducting the survey by asking participants to indicate whether they were interested in taking part in an interview. This approach may have increased the risk of participants' bias as those who were more enthusiastic and more spiritual may have self-selected to be interviewed.

7.6 Recommendations for Clinical Practice

The practice of organising health care around the patient and the focus on improving their survival by providing HD treatment may have led to neglecting other risk factors, needs and concerns for patients, such as attending to their spiritual, psychological and emotional needs. If we are serious about improving the health outcomes of patients with ESRD and reducing their mortality and morbidity in Scotland, every opportunity must be taken to address some of these needs.

Current practice recommends that spiritual care should be provided across the health sector (Scottish Executive Health Department HDL, 2002; Scottish Government, 2009). Yet, there is no evidence available from Scotland or across the UK to examine whether or not spiritual care policies are implemented across the health sector and, in particular, in dialysis units, or whether the nursing staff within the NHS recognise their

responsibilities and roles in providing spiritual care. The Scottish Government report (2009) identified that there remains a need to affirm the understanding that spiritual care is a necessary and integral part of the whole person care offered by the NHS in Scotland and to promote research which increases and enlightens an evidence base for the efficacy of spiritual and religious care in health. Consequently, given the findings from my study on the potential positive influences of spirituality on the health outcomes and general well-being in patients with ESRD, I recommend that nurses in general and, in particular, those working with this group of patients should focus more on assessing patients' spiritual needs and that more efforts should be implemented to integrate these needs into patients' care plans. Furthermore, there is a strong emphasis currently on building the skills of health care professionals and in planning anticipatory care initiatives (Scottish Executive, 2005). Given the findings of my study and considering the findings from the Scottish Government report (2009), it is therefore timely to examine the expertise and skills sets of nurses in the dialysis units and, in particular, those skills that might help nurses to assess and identify participants' spiritual needs and how to implement them in practice, as a way of improving patient holistic care.

The findings from my study on the potential impact of ESRD and HD treatment suggest that they can have a great impact on all aspects of patients' lives. Indeed, the more that these patients are on HD, the more likely it is that they might have poorer health outcomes and well-being. Understanding how patients manage their daily lives and how they cope with HD treatment might help in shifting the nurses' focus from dealing with the physical effects of HD treatment into focusing more on the overall care of the

person. This is particularly significant given the importance of providing holistic nursing care (Nursing and Midwifery Council, 2004; Scottish Executive, 2005). Therefore, considering my study findings, I also recommend that nurses across the health sector and, in particular, those working in dialysis units as well as other healthcare professionals working with this group of patients (e.g. dieticians, doctors, patient support groups) should focus more on addressing factors like spirituality, social support, engaging in creative outlets/art-making activities and hope, which might help improve patients' QOL, symptom management and reinstate control and functional status. This might be achieved by combining a patient-centred care approach and developing and promoting a culture of care whereby patients can exercise control in certain aspects of their care while working in partnership with members of the nephrology team.

7.7 Recommendations for Patient and Nurse Education

The findings from my study can be used by healthcare professionals and educators to empower patients and help them throughout their journey on dialysis. Currently, there are different sources of information available for patients receiving HD treatment and for newly diagnosed patients like renal support groups who can provide support and information about the disease and HD treatment. In addition, several websites are also available on the World Wide Web which offer patients guidance and information about their illness and HD treatment. In addition, different websites are also available which talk about spirituality and what patients might gain from it. Nevertheless, studies examining these websites and the efficacy of support groups and how useful the

information they offer for these patients are limited. In addition, studies exploring whether these websites and the information they provide benefit patients either positively or negatively do not exist. Hence, I recommend that patients and their caregivers should be advised to seek information from sources that are trustworthy, such as the medical staff, nursing staff and licensed support groups who have the right type of information to offer and who would be accountable for their actions, so that patients can make informed choices about their care and treatment plans. Healthcare professionals and support groups information could then be updated and assessed regularly to ensure that it is up to date and meets patients' needs. Patient involvement in decision-making could also be discussed and assessed on an on-going basis as their condition might change at a time that is suitable for both patients and the nursing team.

It is possible that nurses working in dialysis units are unaware of the available policies and guidelines that highlight the importance of providing spiritual care. In their healthcare strategy for improving the NHS services in Scotland, the Scottish Government (2010, p. 41) states that *"...important changes in culture and approach will be required to ensure that staff are equipped and supported..."* Therefore, I recommend that continuous upgrading of the healthcare system through continuous staff development, education and training together with the provision of resources are important for increasing the quality of healthcare services. Adopting a policy on how to assess and attend to patients' spiritual needs could be established as part of the dialysis unit philosophy and quality standards. Establishing such a philosophy may therefore help to reduce lost opportunities for attending to these needs which can have a positive

impact on patients' health and may improve their experiences.

The Nursing and Midwifery Council (NMC) states in its document, Standards of Proficiency for Pre-registration Nurses, that all adult nurses should have skills to meet "*the physical, psychological, spiritual and social needs of patients*" (NMC, 2004, p.23). Furthermore, the NMC states in its document, Standards for Pre-registration Nursing Education (NMC, 2010, p.18), that all nurses should be able to: "*carry out comprehensive, systematic nursing assessments that take account of relevant physical, social, cultural, psychological, spiritual, genetic and environmental factors, in partnership with service users and others through interaction, observation and measurement*". In addition, newly qualified nurses should "*demonstrate an understanding of how culture, religion, spiritual beliefs, gender and sexuality can impact on illness and disability*" (NMC, 2010, p.108). Seymour (2009) carried out a study to evaluate nurse students' understanding of spirituality and whether it is implemented in their education. She concluded as a lecturer in nursing that, despite the NMC educational requirements and expectations of spiritual care provision, there was not much spiritual education in the curriculum. Apart from Seymour's study, I could not identify any other studies that assess spirituality education across different universities in Scotland and, therefore, there remains a question whether spirituality is fully implemented in their curriculum and whether teachers, researchers and practitioners understand what spirituality means and how it could be implemented into practice. Hence, I recommend that modules addressing spirituality/spiritual care in students' curricula, if they are available or exist, should be re-assessed to establish

whether they are up to date and fulfil the needs of student nurses and the wider society, taking into consideration cultural differences.

7.8 Recommendations for Future Research

My suggestions for further research draw upon the principal findings I have identified in this thesis. The study has several implications for future research with the aim of improving patients' health outcomes and well-being and guiding clinical practice.

Considering the limitations of the quantitative component of my study, replicating this study with a large sample of patients undergoing different modalities of treatment (i.e. PD or home HD), or who are from a different ethnic, religious and cultural background, using a different approach (e.g. longitudinal design) is needed in order to: firstly, gain more statistical power as well as developing causal relationships to examine the associations between spirituality and the health outcomes and well-being in patients with ESRD; second, to establish whether they share the same views and insights identified in my study into the impact of the disease and the role of spirituality in order to understand the best way of offering the right level of care.

The majority of the studies examining the QOL of patients with ESRD that were conducted in different countries have a norm-based sample of a healthy population that was used as a comparative group, particularly for the SF-36v2 questionnaire (Davison and Jhangri, 2010; Thomas and Washington, 2011; Ibrahim et al., 2012). The SF-36v2 has not been tested with the Scottish general population's QOL which may be less than the norm-based standard compared to other countries. Continuous monitoring of

populations' QOL provides current data for policy makers and public health agencies to assess, protect, and promote populations' health (Moriarty et al., 2003). In addition, monitoring population QOL over time may help to identify health differences, evaluate progress on achieving broad health goals, and inform clinical practice (Moriarty et al., 2003). Therefore, there is a need in the near future to create a database in Scotland about the general population's QOL, either generic or specific. This database should be available for routine clinical care and for future research to study and monitor the QOL of patients with ESRD and other chronic illnesses.

The majority of studies exploring spirituality among patients with chronic illnesses or with ESRD that were conducted in different countries used a single approach, either quantitative or qualitative, and very few studies used a mixed method approach. My study demonstrated that using a mixed method approach might be useful in exploring and understanding the influence of spirituality on the health outcomes and general well-being of patients with ESRD. Therefore, further research using mixed methods is needed with the aim of understanding in more depth how patients perceive their disease, exploring how and why patients use spirituality in their lives and how it may influence their health outcomes (e.g. QOL) and general well-being.

In addition, studies exploring spirituality in the lives of patients with ESRD receiving HD treatment are limited globally and do not exist in Scotland. Therefore, more research is required in the near future in other similar contexts (i.e. different dialysis units across Scotland) to explore this important concept. My study findings, along with future research findings, may then be useful to inform the future development of

interventions for these patients and to ensure that these interventions are tailored to them and are therefore more likely to match their needs and preferences. Also, they might be useful as a guide for nurses to provide the right level of care and help in the development of nurse education (i.e. more focus on spirituality and spiritual care in the curriculum).

Although my study explored spirituality from the patient's perspective and was not aiming to assess nurses' views and perceptions on spirituality, further research is needed in recruiting nurses from different dialysis units to explore their views and perceptions on spirituality and whether or not it is implemented within their practice, and to explore how and what is the best way to attend to these needs.

7.9 Overall Conclusion

This thesis has provided a significant contribution to a very limited body of work. In particular, this study is the first 'to my knowledge' to examine the QOL and general well-being in patients with ESRD receiving HD treatment and to explore the influence of spirituality on their health outcomes and general well-being in Scotland. The findings from the study contribute to our understanding of spirituality and how people receiving HD treatment use it to manage their daily lives. In the main, the findings suggest that spirituality might benefit patients in recreating their sense of self and prevent the illness from controlling their lives, which in turn might have a positive influence on their health outcomes and general well-being.

Spirituality is of particular interest due to its connection with health outcomes in

patients with chronic illnesses. The link between spirituality and many chronic illnesses has gained some recognition, yet the identification of its influence on the health outcomes and well-being in patients with ESRD is still evolving. The incidence of ESRD and the need to undergo dialysis treatment is increasing, thus increasing the burden on the NHS and healthcare professionals. There is a need to understand patients' experiences and examine the factors that influence their QOL and well-being to ensure that the services available are adequately tailored to them. Hence, using a sequential mixed method design, the findings identified in my study generated detailed understanding of patients' experiences and highlighted the importance of spirituality and other coping strategies in their lives.

The thesis has demonstrated that, when faced with such demanding illness, most participants felt that their lives were taken away from them as a result of the psychological, physical, emotional and spiritual challenges of their treatment. Most participants continually strive to find ways to manage and cope with these challenges. Different meanings and perceptions of spirituality were identified. Most participants identified that spirituality was important and gave them the strength required to accept their disease and manage their daily lives. Most of them continued to adjust their lives, relied on their social network, and having a sense of humour, all of which may have contributed to an improved QOL and better well-being.

In completing this thesis, I feel that my awareness of the potential influence of spirituality on the health outcomes and well-being in patients with ESRD has been enhanced. Also, I feel that my awareness of the impact of ESRD and dialysis treatment

on patients' health status has been enhanced. I became aware that there might be a need not only to treat the physical impact of the disease but also to include other aspects in patient care (i.e. spiritual and psychological needs) that might have a positive impact on patients' health outcomes and well-being and that might make their journey on dialysis more acceptable and manageable. It is my hope that the results of this study will not only enhance the awareness of this need, but also enable action. Therefore, I consider this thesis as the start of a journey, rather than the end.

In conclusion, in undertaking this study, I hope that I have provided a novel and unique insight into the possible impact of ESRD and HD treatment on patients' lives and into spirituality and its influence on the health outcomes and well-being of these patients. The findings represent a unique contribution to knowledge because there is little research that has been identified to explore the influences of spirituality on the health outcomes and general well-being in patients with ESRD. Thus, I hope that this study has provided a stepping-stone and encourages other researchers to explore these concepts further.

7.10 Reflection on Being a Researcher

Initially, I embarked on this research with an optimistic perspective as I had little experience working with patients receiving HD treatment. Hence, my aim was to enhance my awareness of the experiences of these patients and hopefully contribute to better services and health outcomes.

I started with no specific methodology in mind. However, after reviewing previous

work around the area of study to be able to decide on the best possible approach to address the study aim and answer the research questions, I realised that undertaking one approach, either quantitative or qualitative, might not be appropriate in this setting. I felt that it was an opportunity to expand my choices and to learn and employ other research methods and skills. Hence, I have undertaken extensive training in qualitative research methods techniques (i.e. study design, data collection and analysis) to improve on the basics I gained while doing my Master's degree and, therefore, to become more competent in conducting mixed method research.

Throughout this PhD, I think I have developed well as a researcher by learning to be more patient, using different techniques such as interviewing to collect data, and valuing the unique perspective they provide in implementing research. I have learned that data analysis is a challenging process as I had two sets of data to make sense of. I have also learned that the relationship between the researcher and participants may have an influence on the research outcomes. As a middle-aged researcher and a practising Muslim, spirituality for me means mainly being religious with some focus on other aspects of spirituality, such as having a connection with others, the self and the environment. However, I made notes of my own perceptions of spirituality in order to avoid being judgemental and accepted patients' views on spirituality and presented them as they emerged from the interviews. In addition, I felt a sense of rapport with participants and the nursing staff as no explicit constraints emerged in our interaction. I felt honoured by the way I was treated by patients and staff alike wherever I went. People could not have been more helpful (well, perhaps by agreeing to complete a few

more questionnaires).

I found being a researcher quite a lonely adventure. While the support from my supervisors and colleagues who had empathy was invaluable, it was down to me in the end. I have also learned that research does not always go according to proposed plans, particularly when life and other issues get in the way. However, I feel that this PhD has considerably widened my research horizons and has equipped me with the research skills that will hopefully further enhance my future research endeavours.

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Appendix 1: Form used to Summarize Studies Retrieved from the Literature Review

Author, year, journal, vol. &issue, type	Title/Number of participants/country/period of data collection	Research aims/questions	Method /tools	Analysis	Key findings	Limitations

Appendix 2: Participants Invitation Letter

Version 3 (19th January 2010)

UNIVERSITY OF STIRLING

Invitation letter for participants

Title: The influences of spirituality on health outcomes and general well-being in patients with end-stage renal disease

Dear Sir/Madam

Thank you for considering participating in this study looking at how a sense of spirituality affects health outcomes in people with chronic renal failure. In particular we want to find out the kind of problems that people have to face on a daily basis and we also want to find out if there are factors that make daily living harder or easier.

I am writing to ask if you would be willing to take part in this study that I am carrying out as part of my doctoral thesis.

Your nursing team will give you this invitation letter and an information pack about the study. Please have a look at this information pack and if you agree to talk to me and to take part in the study, please fill the expression of interest form (enclosed), place this in the envelope provided and leave it with the nursing staff. I will then come and collect it from the dialysis unit and if you wish to take part I will come and speak to you at one of your next dialysis sessions.

What you will be asked to do?

The study will be over two phases.

Phase 1 asks some general questions about your experiences, behaviours, and health.

1

Appendix 3: Information Leaflet

Version 3 (19th January 2010)

UNIVERSITY OF STIRLING

Participant Information Leaflet

Title: The influences of spirituality on health outcomes and genera well-being in patients with end-stage renal disease

If you would like further information about this study please feel free to contact:

Ali Alshraifeen
Postgraduate research student
Department of Nursing and Midwifery
University of Stirling
Stirling, FK9 4LA, Scotland, UK
Tel. 07843280691
E-mail: ali.alshraifeen@stir.ac.uk

Or

If you would like to speak to someone who knows about this study who is an independent advisor please find his contact details below.

Professor William Lauder
Department of Nursing and Midwifery
University of Stirling
STIRLING FK9 4LA
Tel: 01786 46 6345 Fax: 01786 46 6344
Email: william.lauder@stir.ac.uk

1

Interviews can take place at the time of you receiving dialysis, or any other appropriate venue of your choice, whichever is more convenient.
Not all participants will be required for both parts, but you may be contacted and asked to take part in the interview.

You will be asked about various aspects of well-being such as your quality of life, emotional, psychological, physical, and spiritual status. However, we already know quite a bit about how people feel about these areas. This study wants to find out more about your views on your spiritual well-being. Spirituality means a lot of different things so we want to know what it means for you.

- ***What if I don't want to answer a particular question?***
  If there are some questions on the questionnaires that you do not wish to answer, you can leave them out. Also, you can decline to answer any of the questions at any point in the interview without giving a reason for doing so.

- ***Is the information confidential?***
  Yes. All of your information will be treated as strictly confidential and stored anonymously in a locked cabinet, in a locked room at the University of Stirling.
  Only members of the research team will be able to access this information. All names will be changed to ensure anonymity. Individuals will not be identified by any of the findings and your details will not be given to any other organisations or businesses.

  With your permission, the interview will be audio recorded to enable the researcher to transcribe the interview. All transcribed information will be stored on a university computer and only the Chief Investigator and researchers assisting in the study will have access. All tapes from the audio recordings will be stored in a locked and secured area. All information will be held in accordance with the Data Protection Act 1998.

- ***Do I have to take part?***
  No – but your participation would be greatly appreciated. It is important that we find out as much as possible directly from people who have experience of this condition. Taking part in the study is entirely voluntary. It is up to you whether or not you take part. If you wish to take part you simply complete and return the enclosed consent form to the unit manager or one of the nursing team in the provided envelope.
  If you change your mind you can withdraw at any time without this affecting your treatment.

- ***Will I benefit from taking part?***
  There might be no direct benefit for you but conducting the study might help to improve quality of care for dialysis patients in the future. Also it might help

to develop an evidence-based holistic plan of care for this particular group of patients.

- ***What about the results of the study?***
  The results of this study will be compiled and written to be submitted for a PhD thesis for the researcher. Results will be available for participants at the end of the study if they are interested to know the outcome of this project. Additionally results will be presented in national and international conferences as well as used to write publications in peer reviewed journals.

- ***Who is organising and funding the research?***
  This research study has been partially funded by The University of Stirling.

- **Researcher:**
  The researcher is Mr. Ali Alshraifeen. His background is nursing and has experience of looking after people with the same condition as you. He is carrying out this research as a doctoral project at the University of Stirling.

Appendix 4: Questionnaire Booklet

UNIVERSITY OF STIRLING

The influences of spirituality on health outcomes and genera well-being in patients with end-stage renal disease

I would like to take this opportunity to thank you for taking part in this questionnaire based study.

What is the survey about?
This survey is about your experience as a chronic renal failure patient currently on dialysis. You have been selected for inclusion in the survey because you have been on dialysis for six months or more.

This booklet includes seven sections. Each section asks you different types of questions about a different aspect of your health and well-being.

Completing the questionnaire:
For each question please tick clearly inside one box using a black or blue pen. Don't worry if you make a mistake; simply cross out the mistake and put a tick in the correct box.

Questions or help:
If you have any queries about the questionnaire please don't hesitate to ask as I will be available to help you if required. However, the answers should be given from your point of view – not the point of view of the person who is helping.
You should have been given an invitation letter and information sheet about the study by one of the nurses at your dialysis unit. However, if you have any questions about the study, please don't hesitate to ask me or you can contact the independent person whose details are provided at the front of your information sheet.

Taking part in this survey is voluntary
Your answers will be treated in confidence.

1

Section 1: 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. **<u>Compared to one year ago</u>, how would you rate your health in general <u>now</u>?**

Much better now than one year ago	Somewhat better now than one year ago	About the same as one year ago	Somewhat worse now than one year ago	Much worse now than one year ago
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

3. 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	<u>Vigorous activities</u>, such as running, lifting heavy objects, participating in strenuous sports	☐ 1	☐ 2	☐ 3
b	<u>Moderate activities</u>, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	☐ 1	☐ 2	☐ 3
c	Lifting or carrying groceries	☐ 1	☐ 2	☐ 3
d	Climbing <u>several</u> flights of stairs	☐ 1	☐ 2	☐ 3
e	Climbing <u>one</u> flight of stairs	☐ 1	☐ 2	☐ 3
f	Bending, kneeling, or stooping	☐ 1	☐ 2	☐ 3
g	Walking <u>more than a mile</u>	☐ 1	☐ 2	☐ 3
h	Walking <u>several hundred yards</u>	☐ 1	☐ 2	☐ 3
i	Walking <u>one hundred yards</u>	☐ 1	☐ 2	☐ 3
j	Bathing or dressing yourself	☐ 1	☐ 2	☐ 3

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 your physical health?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a Cut down on the amount of time you spent on work or other activities	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
b Accomplished less than you would like	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
c Were limited in the kind of work or other activities	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
d Had difficulty performing the work or other activities (for example, it took extra effort)	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

5. 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 Cut down on the amount of time you spent on work or other activities	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
b Accomplished less than you would like	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
c Did work or other activities less carefully than usual	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

6. **During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?**

Not at all	Slightly	Moderately	Quite a bit	Extremely
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

7. **How much bodily pain have you had during the past 4 weeks?**

None	Very mild	Mild	Moderate	Severe	Very severe
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6

8. **During the past 4 weeks, 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

9. These questions are about how you feel and how things have been with you during the past 4 weeks. 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 past 4 weeks...

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a Did you feel full of life?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
b Have you been very nervous?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
c Have you felt so down in the dumps that nothing could cheer you up?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
d Have you felt calm and peaceful?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
e Did you have a lot of energy?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
f Have you felt downhearted and low?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
g Did you feel worn out?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
h Have you been happy?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
i Did you feel tired?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

10. During the past 4 weeks, how much of the time has your physical health or emotional problems 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

11. How TRUE or FALSE is <u>each</u> of the following statements for you?

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
a I seem to get ill more easily than other people	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
b I am as healthy as anybody I know	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
c I expect my health to get worse	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
d My health is excellent	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Section 2: General well-being

We would like to know if you have had any medical complaints and how your health has been in general, over the past 3 months.

Have you recently:

12. Been feeling perfectly well and in good health?

Please ☑ one box only

- ☐ Better than usual
- ☐ Same as usual
- ☐ Worse than usual
- ☐ Much worse than usual

13. Been feeling in need of a good tonic?

Please ☑ one box only

- ☐ Not at all
- ☐ No more than usual
- ☐ Rather more than usual
- ☐ Much more than usual

14. Been feeling run down and out of sorts?

Please ☑ one box only

- ☐ Not at all
- ☐ No more than usual
- ☐ Rather more than usual
- ☐ Much more than usual

15. Felt that you are ill?

Please ☑ one box only

- ☐ Not at all
- ☐ No more than usual
- ☐ Rather more than usual
- ☐ Much more than usual

16. Been getting any pains in your head?

Please ☑ one box only

- ☐ Not at all
- ☐ No more than usual
- ☐ Rather more than usual
- ☐ Much more than usual

17. Been getting a feeling of tightness or pressure in your head?

Please ☑ one box only

- ☐ Not at all
- ☐ No more than usual
- ☐ Rather more than usual
- ☐ Much more than usual

Section 2: General well-being

We would like to know if you have had any medical complaints and how your health has been in general, over the past 3 months.

18. Been having hot or cold spells?

Please ☑ one box only

- ☐ Not at all
- ☐ No more than usual
- ☐ Rather more than usual
- ☐ Much more than usual

19. Lost much sleep over worry?

Please ☑ one box only

- ☐ Not at all
- ☐ No more than usual
- ☐ Rather more than usual
- ☐ Much more than usual

20. Had difficulty in staying asleep once you are off?

Please ☑ one box only

- ☐ Not at all
- ☐ No more than usual
- ☐ Rather more than usual
- ☐ Much more than usual

21. Felt constantly under strain?

Please ☑ one box only

- ☐ Not at all
- ☐ No more than usual
- ☐ Rather more than usual
- ☐ Much more than usual

22. Been getting edgy and bad-tempered?

Please ☑ one box only

- ☐ Not at all
- ☐ No more than usual
- ☐ Rather more than usual
- ☐ Much more than usual

23. Been getting scared or panicky for no good reason?

Please ☑ one box only

- ☐ Not at all
- ☐ No more than usual
- ☐ Rather more than usual
- ☐ Much more than usual

Section 2: General well-being

We would like to know if you have had any medical complaints and how your health has been in general, over the past 3 months

24. Found everything getting on top of you?

Please ☑ one box only

- ☐ Not at all
- ☐ No more than usual
- ☐ Rather more than usual
- ☐ Much more than usual

25. Been feeling nervous and strung-up all times?

Please ☑ one box only

- ☐ Not at all
- ☐ No more than usual
- ☐ Rather more than usual
- ☐ Much more than usual

26. Been managing to keep yourself busy and occupied?

Please ☑ one box only

- ☐ More so than usual
- ☐ Same as usual
- ☐ Rather less than usual
- ☐ Much less than usual

27. Been taking longer over the things do you?

Please ☑ one box only

- ☐ Quicker than usual
- ☐ Same as usual
- ☐ Longer than usual
- ☐ Much longer than usual

28. Felt on the whole you were doing things well?

Please ☑ one box only

- ☐ Better than usual
- ☐ About the same
- ☐ Less well than usual
- ☐ Much less well

29. Been satisfied with the way you've carried out your task?

Please ☑ one box only

- ☐ More satisfied
- ☐ About same as usual
- ☐ Less satisfied than usual
- ☐ Much less satisfied

Section 2: General well-being

We would like to know if you have had any medical complaints and how your health has been in general, over the past 3 months

30. Felt that you are playing a useful part in things?

Please ☑ one box only

- ☐ More so than usual
- ☐ Same as usual
- ☐ Less useful than usual
- ☐ Much less useful

31. Felt capable of making decisions about things?

Please ☑ one box only

- ☐ More so than usual
- ☐ Same as usual
- ☐ Less so than usual
- ☐ Much less capable

32. Been able to enjoy your normal day-to-day activities?

Please ☑ one box only

- ☐ More so than usual
- ☐ Same as usual
- ☐ Less than usual
- ☐ Much less than usual

33. Been thinking of yourself as a worthless one?

Please ☑ one box only

- ☐ Not at all
- ☐ No more than usual
- ☐ Rather more than usual
- ☐ Much more than usual

34. Felt that life is entirely hopeless?

Please ☑ one box only

- ☐ Not at all
- ☐ No more than usual
- ☐ Rather more than usual
- ☐ Much more than usual

35. Felt that life isn't worth living?

Please ☑ one box only

- ☐ Not at all
- ☐ No more than usual
- ☐ Rather more than usual
- ☐ Much more than usual

Section 2: General well-being

We would like to know if you have had any medical complaints and how your health has been in general, over the past 3 months

36. Thought of the possibility that you might make away with yourself?

Please ☑ one box only

- ☐ Definitely not
- ☐ I don't think so
- ☐ Has crossed my mind
- ☐ Definitely have

37. Found at times you couldn't do anything because your nerves were too bad?

Please ☑ one box only

- ☐ Not at all
- ☐ No more than usual
- ☐ Rather more than usual
- ☐ Much more than usual

38. Found yourself wishing you were did and away from it all?

Please ☑ one box only

- ☐ Not at all
- ☐ No more than usual
- ☐ Rather more than usual
- ☐ Much more than usual

39. Found that the idea of taking your own life kept coming into your mind?

Please ☑ one box only

- ☐ Definitely not
- ☐ I don't think so
- ☐ Has crossed my mind
- ☐ Definitely have

Version 1 (14th February 2010) Appendix 13

Section 3: Social support

In this section we are interested in how you feel about the following statements.
Please ☑ the box that indicates how you feel about each statement.

Items	Very Strongly Disagree	Strongly Disagree	Mildly Disagree	Neither agree nor disagree	Mildly Agree	Strongly Agree	Very Strongly Agree
There is a special person who is around when I am in need	1 ☐	2☐	3☐	4☐	5☐	6☐	7☐
There is a special person with whom I can share my joys and sorrows	1 ☐	2☐	3☐	4☐	5☐	6☐	7☐
My family really tries to help me	1 ☐	2☐	3☐	4☐	5☐	6☐	7☐
I get the emotional help and support I need from my family	1 ☐	2☐	3☐	4☐	5☐	6☐	7☐
I have a special person who is a real source of comfort to me	1 ☐	2☐	3☐	4☐	5☐	6☐	7☐
My friends really try to help me	1 ☐	2☐	3☐	4☐	5☐	6☐	7☐
I can count on my friends when things go wrong	1 ☐	2☐	3☐	4☐	5☐	6☐	7☐
I can talk about my problems with my family	1 ☐	2☐	3☐	4☐	5☐	6☐	7☐
I have friends with whom I can share my joys and sorrows	1 ☐	2☐	3☐	4☐	5☐	6☐	7☐
There is a special person in my life who cares about my feelings	1 ☐	2☐	3☐	4☐	5☐	6☐	7☐
My family is willing to help me make decisions	1 ☐	2☐	3☐	4☐	5☐	6☐	7☐
I can talk about my problems with my friends	1 ☐	2☐	3☐	4☐	5☐	6☐	7☐

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Section 4: Hope

This section assesses hopefulness in adults in clinical settings, and is designed to assess change in your levels of hope. Please tick the box to evaluate how you feel about each statement. Please ☑the response that applies to you.

Questions	Strongly disagree	Disagree	Not sure	Agree	Strongly agree
I have a positive outlook toward life	1 ☐	2☐	3☐	4☐	5☐
I have short, intermediate and/or long range goals	1 ☐	2☐	3☐	4☐	5☐
I feel scared about my future	1 ☐	2☐	3☐	4☐	5☐
I believe that each day has potential	1 ☐	2☐	3☐	4☐	5☐
I can see a light in a tunnel	1 ☐	2☐	3☐	4☐	5☐
I can recall happy/joyful times	1 ☐	2☐	3☐	4☐	5☐
I have a sense of direction	1 ☐	2☐	3☐	4☐	5☐
I feel my life has value and worth	1 ☐	2☐	3☐	4☐	5☐
I feel all alone	1 ☐	2☐	3☐	4☐	5☐
I have faith that gives me comfort	1 ☐	2☐	3☐	4☐	5☐
I have a deep inner strength	1 ☐	2☐	3☐	4☐	5☐
I am able to give and receive caring/love	1 ☐	2☐	3☐	4☐	5☐

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Section 5: This section measures how you cope when you are facing difficult situations at the time of your illness.

Please read the following statements and tick ☑ the number applicable to you in the box.

Items	I have not been doing this at all	I have been doing this a little bit	I have been doing this a medium amount	I have been doing this a lot	Not sure
I turn to work or other activities to take my mind off things	1 ☐	2☐	3☐	4☐	5☐
I concentrate my efforts on doing something about the situation I'm in.	1 ☐	2☐	3☐	4☐	5☐
I say to myself "this isn't real".	1 ☐	2☐	3☐	4☐	5☐
I use alcohol or other drugs to make myself feel better	1 ☐	2☐	3☐	4☐	5☐
I get emotional support from others	1 ☐	2☐	3☐	4☐	5☐
I give up trying to deal with it.	1 ☐	2☐	3☐	4☐	5☐
I take action to try to make the situation better.	1 ☐	2☐	3☐	4☐	5☐
I refuse to believe that it has happened	1 ☐	2☐	3☐	4☐	5☐
I say things to let my unpleasant feelings escape	1 ☐	2☐	3☐	4☐	5☐
I get help and advice from other people.	1 ☐	2☐	3☐	4☐	5☐
I use alcohol or other drugs to help me get through it.	1 ☐	2☐	3☐	4☐	5☐
I try to see it in a different light, to make it seem more positive.	1 ☐	2☐	3☐	4☐	5☐
I criticize myself.	1 ☐	2☐	3☐	4☐	5☐
I try to come up with a strategy about what to do.	1 ☐	2☐	3☐	4☐	5☐

Version 1 (14th February 2010) Appendix 13

Section 5: This section measures how you cope when you are facing difficult situations at the time of your illness.

Please read the following statements and tick ☑ the number applicable to you in the box.

Items	I have not been doing this at all	I have been doing this a little bit	I have been doing this a medium amount	I have been doing this a lot	Not sure
I get comfort and understanding from someone.	1 ☐	2☐	3☐	4☐	5☐
I give up the attempt to cope.	1 ☐	2☐	3☐	4☐	5☐
I look for something good of what is happening.	1 ☐	2☐	3☐	4☐	5☐
I make jokes about it.	1 ☐	2☐	3☐	4☐	5☐
I do something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.	1 ☐	2☐	3☐	4☐	5☐
I accept the reality of the fact it has happened	1 ☐	2☐	3☐	4☐	5☐
I express my negative feelings.	1 ☐	2☐	3☐	4☐	5☐
I try to find comfort in my religion or spiritual beliefs.	1 ☐	2☐	3☐	4☐	5☐
I try to get advice or help from other people about what to do.	1 ☐	2☐	3☐	4☐	5☐
I learn to live with it	1 ☐	2☐	3☐	4☐	5☐
I think hard about what steps to take.	1 ☐	2☐	3☐	4☐	5☐
I blame myself for things that happened.	1 ☐	2☐	3☐	4☐	5☐
I pray or mediate.	1 ☐	2☐	3☐	4☐	5☐
I make fun of the situation.	1 ☐	2☐	3☐	4☐	5☐

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Section 6: Spirituality

Spiritual health/well-being can be seen as a measure of how good you feel about yourself and how well you relate to those aspects of the world around you which are important to you.

Some people think that the following areas are necessary for spiritual well-being. We would like to know how important you think they are for your own well-being. Please give one response to each of the following items, by ticking ☑ the relevant numbers that applies to you in the columns.

Items	Very low	Low	Moderate	High	Very high.	Not applicable
A love of other people	1 ☐	2☐	3☐	4☐	5☐	6☐
personal relationship with the Divine/God	1 ☐	2☐	3☐	4☐	5☐	6☐
Forgiveness toward others	1 ☐	2☐	3☐	4☐	5☐	6☐
Connection with nature	1 ☐	2☐	3☐	4☐	5☐	6☐
A sense of identity	1 ☐	2☐	3☐	4☐	5☐	6☐
Worship of the Creator	1 ☐	2☐	3☐	4☐	5☐	6☐
Awe at a breathtaking view	1 ☐	2☐	3☐	4☐	5☐	6☐
Trust between individuals	1 ☐	2☐	3☐	4☐	5☐	6☐
Self-awareness	1 ☐	2☐	3☐	4☐	5☐	6☐
Oneness with nature	1 ☐	2☐	3☐	4☐	5☐	6☐

Section 6: Spirituality

Spiritual health/well-being can be seen as a measure of how good you feel about yourself and how well you relate to those aspects of the world around you which are important to you.

Some people think that the following areas are necessary for spiritual well-being. We would like to know how important you think they are for your own well-being. Please give one response to each of the following items, by ticking ☑ the relevant numbers that applies to you in the columns.

Items	Very low	Low	Moderate	High	Very high.	Not applicable
Oneness with God	1 ☐	2☐	3☐	4☐	5☐	6☐
Harmony with the environment	1 ☐	2☐	3☐	4☐	5☐	6☐
Peace with God	1 ☐	2☐	3☐	4☐	5☐	6☐
Joy in life	1 ☐	2☐	3☐	4☐	5☐	6☐
Prayer life	1 ☐	2☐	3☐	4☐	5☐	6☐
Inner peace	1 ☐	2☐	3☐	4☐	5☐	6☐
Respect for others	1 ☐	2☐	3☐	4☐	5☐	6☐
Meaning in life	1 ☐	2☐	3☐	4☐	5☐	6☐
Kindness towards other people	1 ☐	2☐	3☐	4☐	5☐	6☐
A sense of 'magic' in the environment	1 ☐	2☐	3☐	4☐	5☐	6☐

Version 1 (14th February 2010) Appendix 13

Section 6: Spirituality

Please answer the following question

What is your understanding of what spirituality is?

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Section 6: Spirituality

Please ☑ one answer that applies to you when answering the following questions:

1. How important is religion in your life?

Please ☑ one answer

☐Very low

☐Low

☐Moderate

☐High

☐Very high

2. How important is spirituality in your life?

Please ☑ one answer

☐Very low

☐Low

☐Moderate

☐High

☐Very high

3. How often do you go to church/religious group (apart from weddings & funerals)?

Please ☑ one answer

☐Never

☐once a year

☐2-3 times a year

☐once a month

☐most weeks

☐at least once a week

4. How often do you pray or meditate?

Please ☑ one answer

☐Never

☐only in times of real need

☐ 1-2 times a year

☐once a month

☐weekly

☐daily

5. Do you have a religious group with which you identify?

Please ☑ one answer

☐Yes ☐No

If yes please state your **religious affiliation**?

.....

Version 1 (14th February 2010) Appendix 13

Section 7: demographic information

Please ☑ one answer that applies to you when answering the following question:

1. Are you:

Please ☑ one answer

☐Female

☐Male

2. What is your age?

Please ☑ one answer

☐18-25 ☐26-35

☐36-45 ☐46-55

☐56-65 ☐66+

3. Please indicate period on dialysis:

☐6 months-5 years

☐6 years-10years

☐11-15 years

☐>15years

4. Do you live alone?

Please ☑ one answer

☐Yes

☐No

5. Do you work?

Please ☑ one answer

☐Yes: ☐part time ☐ full time

☐No

☐Retired

If yes please indicate your working area

.....

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Please ☑ one answer that applies to you when answering the following question:

51. Would you be interested to take part in an interview at a later stage of this study?

☐ Yes

☐ No

Version 1 (14th February 2010) Appendix 13

Section 7: Background information:

Name: .....

Hospital: .....

Dialysis session time: .....

Working area (if applicable): .....

OTHER COMMENTS

If there is anything else you would like to tell us about your experiences, please do so here.

THANK YOU VERY MUCH FOR YOUR HELP

Please check that you have answered all the questions that apply to you.

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Appendix 5: Expression of Interest Form

Version 1 (25th January 2010)

UNIVERSITY OF STIRLING

EXPRESSION OF INTEREST FORM

The influences of spirituality on health outcomes and general well-being in patients with end-stage renal disease

If you are interested in taking part in the above study, please fill in this form and return it to the researcher (Ali Alshraifeen) in the envelope provided.

Name: .....

Contact number: .....

Hospital.....

Dialysis session time .....

Dialysis session day .....

Date: .....

Signed: .....

Thank you

Appendix 6: Nurses Invitation Letter

Version 1 1st of June 2009

UNIVERSITY OF STIRLING

Cover letter for unit managers/nursing staff

Title: The influences of spirituality on health outcomes and general well-being in patients with end-stage renal disease

Dear Sir/Madam

Thank you for meeting with me and indicating that you would be prepared to facilitate me to complete this study. We very much appreciate the time you are giving to this.

As you are either the dialysis unit manager or working as a member of the dialysis team, you will have access to patients and your help would be appreciated to assist in identifying and recruiting potential participants for our study. We are asking you to distribute information pack and invitation letters to eligible patients and collect their responses in the envelopes provided.

This study aims to widen our understanding of the experiences of end stage renal disease patients, and to establish an idea of their quality of life, mental well-being, social support they receive, and whether being spiritual has effect on their lives. I hope this study will be able to contribute to the development of Evidence Based Practice and knowledge in the field of providing holistic care to end stage renal disease patients.

The study involves two stages.

1. Patients will be asked to fill 6 questionnaires. Part 1 asks general questions about patient quality of life, hope, mental well-being, social support, spiritual well-being, and coping strategies. Filling the scales should take no longer than 1 hour to complete.

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2. Patients at a later stage will be invited to take part in an in-depth interview for about 1 hour to obtain a better detailed understanding of their experiences with this disease and to try and find the effect of being spiritual or not on their general well-being and health outcomes.

What is required from you?

You are being asked to help by giving patients an invitation letter and study information pack and if I am not present, to explain to patients that they have 2 weeks to think about the study and whether they want to take part or not. When I attend the unit to interview patients, you are also required to guide me in identifying if any potential participant is distressed or does not wish to fill in the questionnaires. This will then be reassessed at a later date on another visit.

Inclusion criteria for the study:

- Patients diagnosed with ESRD or chronic renal failure.
- Hospitalised or receiving haemodialysis.
- Been on dialysis for at least 6 months (to measure the impact created by the disease on their lives).
- Aged between 18- 65 years old.
- English speaking.

Exclusion criteria:

If a person is experiencing distress and participating would exacerbate the distress then they will not be asked to take part in the study.

Please see the attached patient's information sheet for more information about the study.

This study has been granted ethical approval from the NHS Greater Glasgow and Clyde Health Board, and from the University of Stirling Ethics Committees.

Version 1 1st of June 2009

If you need any further information please don't hesitate to contact me at:

Ali Alshraifeen
Department of Nursing and Midwifery
University of Stirling
Stirling, FK9 4LA, Scotland, UK
Tel. 07843280691
E-mail: ali.alshraifeen@stir.ac.uk

Or

Professor William Lauder
Department of Nursing and Midwifery
University of Stirling
STIRLING FK9 4LA
Tel: 01786 46 6345 Fax: 01786 46 6344
Email: william.lauder@stir.ac.uk

Yours sincerely

Ali Alshraifeen

Appendix 7: Consent Form (Quantitative Component)

Version 2 (19th January 2010)

UNIVERSITY OF STIRLING

Consent Form phase 1

Title of Project:

The influences of spirituality on health outcomes and genera well-being in patients with end-stage renal disease.

Name of researcher: Ali Alshraifeen

Contact details:

Ali Alshraifeen
Postgraduate research student
Department of Nursing and Midwifery
University of Stirling
Stirling, FK9 4LA, Scotland, UK
Tel. 07843280691
E-mail: ali.alshraifeen@stir.ac.uk

Or

Independent person contact details

Professor William Lauder
Department of Nursing and Midwifery
University of Stirling
STIRLING FK9 4LA
Tel: 01786 46 6345 Fax: 01786 46 6344
Email: william.lauder@stir.ac.uk

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Version 2 (19th January 2010)

Please initial box to demonstrate that the question has been asked by the researcher and that you understand the questions.

1. I confirm that I have read and understand the participation information sheet dated (version 1) ..... ☐

2. I confirm that I have had the opportunity to ask questions. ☐

3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason and without it affecting my care ☐

4. I give my consent to be part of the study ☐

5. I understand that all personal information will be coded and kept confidential by the investigator. ☐

6. I agree to the use of anonymised data from the study (including direct quotations) in any publication arising from this study. And that I understand that I will have a 'cooling off' period when I can contact the researcher should I wish to remove/withdraw a quote/quotes ☐

.....	.....	.....
Name of participant	Date	Signature
.....	.....	.....
Name of researcher	Date	Signature

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Appendix 8: SF-36v2 Licence

QualityMetric Incorporated

24 Albion Road
Building 400
Lincoln, RI 02865
USA

SALES QUOTE

Sales Quote Number: QM003831

Sales Quote Date: 02/24/10

Page: 1

Sell
To: University of Stirling
Ali Alshraifeen
40 Craigton road
flat 0/1
Glasgow, G51 3RA
Great Britain

Ship
To: University of Stirling
Ali Alshraifeen
40 Craigton road
flat 0/1
Glasgow, G51 3RA
Great Britain

stomer ID C005037

Ship Via

stomer Contact	E-Mail	Telephone	Terms	Sales Contact
Alshraifeen	alshra25@yahoo.com	00447843280691	Due on Receipt	Lynda LaPlante

m No.	Description	Unit	Quantity	Unit Price	Total Price
30220	SF-36v2, Standard Recall Unfunded Professor	Years	2	90.00	180.00
ANG0450	Great Britain (English)	Each	2		
OMINS	Administrations	Each	200		
M019	Users Manual for the SF-36v2 eManual	Each	1	45.00	45.00
ANG0590	United States (English)	Each	1		
3020	Scoring Software v3	Each	1	75.00	75.00
3026	SS v3 Key: SF-36v2	Each	250		
S997	SS v3 Add-on: MSE	Each	250		
S999	SS v3 Add-on: RCI	Each	250		

SOFTWARE FOR ONE COMPUTER.

25% DISCOUNT APPLIED IN

APPRECIATION OF YOUR PATIENCE!

THANK YOU!

Amount Subject to Sales Tax	Amount Exempt from Sales Tax		
0.00	300.00	Subtotal:	300.00
		Tax:	0.00
		Total in USD:	300.00

Appendix 9: Scoring the SF-36

SF-36v2 items are scored so that a higher score indicates a better health state. For example, functioning scales are scored so that a high score indicates better functioning and the mental health scale is scored so that a high score indicates better mental health. After data entry, items and scales are scored in four steps:

1. Item recoding for the 10 items that require recoding
2. Computing raw scores by summing across items in the same scale (raw scale scores)
3. Transforming raw scale scores to a 0-100 scale (transformed scale scores)
4. Transforming 0-100 scale scores to have a mean of 50 and standard deviation of 10 in the general U.S. population (norm-based scale scores).

(Ware et al. 2002:28)

Item recoding

Ten items from the questionnaire are recoded. This is carried out to ensure that a higher item value will indicate better health in all SF-36v2 items scales. SF-36 items that are reverse scored are worded so that a higher pre-coded item value indicates a poorer health state (Ware et al. 2002).

Missing Data

An advantage of multi-item scales is that a scale score can be estimated even though responses to some items are missing. The method for scoring missing values is to substitute the average score within the same scale for the question missed (Hayes et al.

1995; Ware et al. 2002). This method of completing scores is adequate when one or two questions are missed, especially when this occurs within a dimension with several questions, which was the case for the current data set. However, such a method becomes problematic when respondents repeatedly miss questions, which was not the case for the present study.

Computing raw scale scores

After item recoding, including handling of missing data, a raw score is computed for each scale. This score is the simple algebraic sum of responses for all the items in that scale, as shown in Table 1. This straightforward method is possible because items in the same scale have roughly equivalent relationships to the underlying health concept being measured and no item is used in more than one scale. Therefore, it is not necessary to standardise or weight items (Ware et al. 2002:42). These assumptions have been thoroughly tested and verified for both Versions 1.0 and 2.0 of the SF-36 (McHorney et al. 1994; Ware, 1993; Ware et al. 2002).

Table 1. Formulas for Scoring and Transforming Scales

Scale	Sum Final items Values (after recoding items)	Lowest and highest possible raw scores	Possible raw score range
Physical Functioning	3a + 3b + 3c + 3d + 3e + 3f + 3g + 3h + 3i + 3j	10, 30	**20**
Role-Physical	4a + 4b + 4c + 4d	4, 20	**16**
Bodily Pain	7 + 8	2, 12	**10**
General Health	1 + 11a + 11b + 11c + 11d	5, 25	**20**
Vitality	9a + 9e + 9g + 9i	4, 20	**16**
Social Functioning	6 + 10	2, 10	**8**
Role-Emotional	5a + 5b + 5c	3, 15	**12**
Mental Health	**9b + 9c + 9d + 9f + 9h**	**5, 25**	**20**

(cited in Ware *et al.* 2002:43)

Transformation of Scale Scores

Transforming each raw scale score to a 0 -100 scale using the formula below is the next step in scoring the SF-36. Table 1 provides the necessary information to apply this formula to each scale.

$$\textbf{Transformed Scale} = \textbf{100 x} \frac{\textbf{(Actual raw score - lowest possible raw score)}}{\textbf{Possible raw score range}}$$

(Cited in Ware et al. 2002:43)

This transformation converts the lowest and highest possible scores to 0 and 100, respectively and the scores between these values represent the percentage of the total possible score achieved (Ware et al. 2002).

Norm-Based Scoring of Scale Scores

The next step involves the norm-based scoring of each 0-100 scale score using a list of formulas which are described below. The means and standard deviations used in norm-based scoring come from the Oxford Healthy Lifestyles Survey (OHLS) (Wright et al. 1992) (see Table 2). A linear z-score transformation is used so that all eight SF-36 scales have a mean of 50 and a standard deviation of 10 (Ware et al. 2002:44).

The advantage of the standardisation and norm-based scoring of the 8 SF-36v2 scales is that results for one scale can be compared with the other scales and their scores in the UK population. More precisely, all scores above or below 50 are above or below the average, respectively, in the UK general population (Jenkinson et al. 1996).

The first step in norm-based scoring consists of standardising each SF-36v2 scale using a z-score transformation. A z-score for each scale is computed by subtracting the UK population mean (Table 2) for each SF-36 scale and dividing the difference by the corresponding scale standard deviation (Table 2) from the UK population (Jenkinson et al. 1996).

Table 2. General U.K. Population Means and Standard Deviations Used to Derive SF-36v2 z-scores

SF-36 Scale	Mean	Standard Deviation
PF	88.40	17.98
RP	85.82	29.93
BP	82.93	31.76
GH	88.01	19.58
VT	73.77	17.24
SF	61.13	19.67
RE	81.49	21.69
MH	73.52	19.90

cited in Jenkinson *et al.* 1998

Step 1. Formulas for z-score standardisation of SF-36v2 scales

PF_Z = (PF – 88.40)/17.98

RP_Z = (RP –85.82)/29.93

BP_Z = (BP –82.93)/31.76

GH_Z = (GH – 88.01)/19.58

VT_Z = (VT – 73.77)/17.24

SF_Z = (SF – 61.13)/19.67

RE_Z = (RE – 81.49)/21.69

MH_Z = (MH – 73.52)/19.90

Step 2. Norm-based Transformation of SF-36v2 Z-Scores

The second step involves transforming each SF-36v2 score to the norm-based (50, 10) scoring. This is achieved by multiplying each z-score from Step 1 by 10 and adding the resulting product to 50.

Norm-Based PF: PF = 50 + (PF_Z * 10)

Norm-Based RP: RP = 50 + (RP_Z * 10)

Norm-Based BP: BP = 50 + (BP_Z * 10)

Norm-Based GH: GH = 50 + (GH_Z * 10)

Norm-Based VT: VT = 50 + (VT_Z * 10)

Norm-Based SF: SF = 50 + (SF_Z * 10)

Norm-Based RE: RE = 50 + (RE_Z * 10)

Norm-Based MH: MH = 50 = (MH_Z * 10)

Scoring SF-36v2 Physical (PCS) and Mental (MCS) Component Summary Measures

Scoring the SF-36v2 PCS and MCS summary measures involves three steps. First, the eight SF-36 scales are standardised using means and standard deviations from the general UK population. Second, they are aggregated using weights (factor score coefficients) from the general UK population. Finally, aggregate PCS and MCS scores are standardised using a linear T-score transformation to have a mean of 50 and a standard deviation of 10, in the UK general population (Jenkinson et al. 1996).

The advantage of the standardisation and norm-based scoring of the PCS and MCS is that results for one can be meaningfully compared with the other and their scores have a direct interpretation in relation to the distribution of scores in the general UK population (Jenkinson *et al.* 1996). Again, all scores above 50 are above average and all scores below 50 are below average, respectively, in the UK general population. The standard deviation is 10 for both PCS and MCS measures and therefore each one point difference in scores also has a direct interpretation. A one point difference is one-tenth of a standard deviation.

Steps in scoring the PCS & MCS

Step 1

In order to compute the PCS and MCS, each of the 8 SF-36 scales is standardised using a z-score transformation. This is the same as Step 1 used in the norm-based scoring of the 8 SF-36 scales. A z-score for each scale is computed by subtracting the mean 0 – 100 general UK population score (see Table 3 below) for each SF-36 scale and dividing the difference by the corresponding scale standard deviation (Jenkinson et al. 1996).

Table 3. Means and Standard Deviations for the eight SF-36 dimensions for the OHLS Survey and Factor Score Coefficients used to Derive PCS and MCS Scale Scores

			Factor Score Coefficients	Factor Score Coefficients
SF-36 Scale	Mean*	Standard Deviation	PCS	MCS
PF	88.40	17.98	0.78846	0.04933
RP	85.82	29.93	0.75177	0.25943
BP	82.93	31.76	0.77944	0.20436
GH	88.01	19.58	0.63623	0.42003
VT	73.77	17.24	0.37507	0.73390
SF	61.13	19.67	0.51227	0.65439
RE	81.49	21.69	0.10733	0.78364
MH	73.52	19.90	0.12527	0.88495

* The means and standard deviations for each SF-36v2 are based on the 0-100 scoring (cited Jenkinson *et al*. 1996:40)

Step 2

After a z-score has been computed for each SF-36v2 scale, computation of aggregate scores for both the physical and mental components using the physical and mental factor score coefficients from the general UK population, as given in Table 3, is carried out.

In order to compute an aggregate physical component score, each SF-36v2 scale z-score is multiplied by its respective physical factor score coefficient and then the eight products are summed, as shown below. In the same way, to obtain an aggregate mental component score, each SF-36 scale z-score is multiplied by its respective mental factor score coefficient and then the eight products are summed.

Formulas for aggregating scales in estimating aggregate physical and mental component scores

AGG_PHYS = (PF_Z* .78846) + (RP_Z* .75177) + (BP_Z* .77944) + (GH_Z* .63623) + (VT_Z* .37507) + (SF_Z* -0.65438) + (RE_Z* -.78364) + (MH_Z* -.88495)

AGG_MENT = (PF_Z* .04933) + (RP_Z*.25943) + (BP_Z* .20436) + (GH_Z* .42003) + (VT_Z* .73390) + (SF_Z*.65439) + (RE_Z*.78364) + (MH_Z* .88495)

Step 3

Transformation of Summary Scores

Transforming each component score to the norm-based (50, 10) scoring is achieved by multiplying each aggregate component scale score by 10 and adding the resulting product to 50.

Formulas for T-score transformation of component scores

Transformed Physical (PCS) = 50 + (AGG_PHYS*10)

Appendix 10: Consent Form (Qualitative Component)

Version 2 (19th January 2010)

UNIVERSITY OF STIRLING

CONSENT FORM for phase 2

Title of Project:

The influences of spirituality on health outcomes and general well-being in patients with end-stage renal disease

Name of researcher: Ali Alshraifeen

Contact details:

Ali Alshraifeen
Postgraduate research student
Department of Nursing and Midwifery
University of Stirling
Stirling, FK9 4LA, Scotland, UK
Tel. 07843280691
E-mail: ali.alshraifeen@stir.ac.uk

Or

Independent person contact details

Professor William Lauder
Department of Nursing and Midwifery
University of Stirling
STIRLING FK9 4LA
Tel: 01786 46 6345 Fax: 01786 46 6344
Email: william.lauder@stir.ac.uk

Please initial box to demonstrate that the question has been asked by the researcher and that you understand the questions.

Version 2 (19th January 2010)

1. I confirm that I have read and understand the participation information sheet dated (version 3) ……. ☐

2. I confirm that I have had the opportunity to ask questions. ☐

3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason and without it affecting my care … …. ☐

4. I give my consent to take part in the study ☐

5. I understand that I might be asked to be interviewed by the researcher ☐

6. I give permission for the interview to be audio-recorded ☐

7. I understand that all personal information will be coded and kept confidential by the investigator. ☐

8. I agree to the use of anonymised data from the study (including direct quotations) in any publication arising from this study. And that I understand that I will have a 'cooling off' period when I can contact the researcher should I wish to remove/withdraw a quote/quotes ☐

……..	……	……..……
Name of participant	Date	Signature
……..	……	……..……
Name of researcher	Date	Signature

Appendix 11: General Memo

Main points arising after the analysis of the 5 interviews

1- **Stressors**:

- All participants agreed that the disease had a great impact on their lives from a physical, psychological and an emotional point of view. Main physical stressors reported were reduced mobility, reduced physical strength, feeling weak, tired, washed out. Also, other associated problems were reported such as pain and swelling.
- Most of them share the point that at the beginning going on dialysis was a shock for them and they found it very difficult to cope with it, especially with the restrictions on life and with the diet and fluids restrictions. The illness affected the whole family.
- Denial and stressors because of the dialysis treatment were some emotional responses/ stressors identified by some participants.
- Feeling vulnerable: some of them felt that they were indebted to their caregivers because they have to rely on them sometimes.
- Uncertainty about the effects of the disease was reported by some patients.

2- **Coping mechanisms**: different coping strategies identified

- Optimism: hope, being positive, humour
- Engaging in life: doing things they enjoy
- Building social partnership: social network
- Social comparison: comparing with others
- Spirituality as a coping mechanism

3- Definition of spirituality

- Transcendental spirituality: belief in God, or someone
- Personal spirituality: own values, beliefs,
- Communal spirituality: loving family, friends, loving life
- Environmental spirituality: nature, beach, green

Appendix 12: The Topic Guide

The Topic Guide

Can you tell me a bit about you?

Where do you live, about your family (husband/wife, children),

What do you do for living? (Where did you work?)

Talk me through a typical week (i.e. what do you like to do during the week, weekends/free time?)

How did you become on dialysis? How did you feel since you started on dialysis?

Can you tell me about the effects dialysis had on your life? (Physical, Psychological, Emotional, Social, Financial)

How did you cope with your disease (demands)? What helped you to deal with these demands? (optional)

Family support, friends, medical team, Any other sources of support?

I'm interested in spirituality/religion can you tell me what you know about spirituality?

What it means to you? (religion/ not related to religion)

Has spirituality helped you to cope with your illness? In what way?

Questions to explore quantitative study findings

In what way has being on dialysis for a long period affected how you cope with dialysis?

In what way has growing older changed/affected how you cope with dialysis?

In what way has religion affected the way you cope with your disease and being on dialysis?

If you go to church/attend services (and praying), how has that affected the way you cope/adapt with dialysis?

How has support from your family and others affected you throughout your disease?

Has having hope affected your way of coping with dialysis? In what way?

Demographic characteristics: age (D.O.B), sex, marital status, employment, education level, religion, period on dialysis

Appendix 13: Ethical Approval - University of Stirling

BP/TS

16 July 2009

Ali Alshraifeen
Postgraduate Student
40 Craigton Road
Flat G/1
GLASGOW
G51 3RA

UNIVERSITY OF STIRLING

DEPARTMENT OF
NURSING AND MIDWIFERY

Email: nursingmidwifery@stir.ac.uk
Web: www.nm.stir.ac.uk

Dr Brodie Paterson
Deputy Chair
Departmental Research Ethics Committee

Department of Nursing & Midwifery
University of Stirling
Stirling FK9 4LA

Tel: +44 (0) 1786 466350
Fax: +44 (0) 1786 466333
Email: b.a.paterson@stir.ac.uk

Dear Ali

Influences on well-being and health outcomes of end-stage renal disease patients: Mixed method approach

Thank you for your letter (undated) in response to my letter to you of the 13 July 2009. Having read your proposal and the revised sections I am happy to grant approval.

Please note with reference to your proposal to contact health boards across Scotland that this means that, in addition to pursuing ethical approval via IRAS you will still need to negotiate access via each health boards R&D department.

Good luck with your research.

Yours sincerely

DR BRODIE PATERSON
Deputy Chair
Departmental Research Ethics Committee

Highland Campus:
Centre for Health Science
Old Perth Road
Inverness IV2 3JH
Tel: +44 (0) 1463 255655
Fax: +44 (0) 1463 255654

Stirling Campus:
Stirling
FK9 4LA
Tel: +44 (0) 1786 466340
Fax: +44 (0) 1786 466333

Western Isles Campus:
Western Isles Hospital
MacAulay Road
Stornoway Isle of Lewis HS1 2AF
Tel: +44 (0) 1851 708243
Fax: +44 (0) 1851 706070

The University of Stirling is recognised as a Scottish Charity with number SC 011159

Appendix 14: Ethical Approval - West of Scotland

West of Scotland REC 4
West of Scotland Research Ethics Service
Ground floor, Tennent Institute
Western Infirmary
38 Church Street
GLASGOW
G11 6NT
e-mail: evelyn.macfadyen@ggc.scot.nhs.uk
Telephone: 0141-211-1722
Facsimile: 0141-211-1847

NHS
Greater Glasgow and Clyde

28 January 2010

Mr Ali Alshraifeen
40 Craigton Road
Flat G 1
Glasgow
G51 3RA

Dear Mr Alshraifeen

REC reference number:	**09/S0704/85**
Protocol number:	**2**
Study Title:	**The influences of spirituality on well-being and health outcomes in patients with end-stage renal disease: Mixed method approach**

Thank you for your letter of 19 January 2010, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Vice-Chair.

Confirmation of Ethical Opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation, as revised, subject to the conditions specified below.

Ethical Review of Research Sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the Favourable Opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Continued...../

28 January 2010

Letter to Mr A Alshraifeen.....continued/

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk. *Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.*

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved Documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering Letter	-	15 December 2009
REC application	-	17 December 2009
Protocol	2	11 August 2009
Letter to Unit Managers/Nursing Staff participants	1	1 June 2009
Letter to patients participating in study	2	16 September 2009
Letter from Mr J Stuart, Head of Nursing supporting the study	-	30 October 2009
Questionnaire: SF-36 Questionnaire	2	21 September 2009
Questionnaire: General Health Questionnaire	2	16 December 2009
Questionnaire: Multidimensional scale of perceived social support	2	17 September 2009
Questionnaire: Herth Hope Index	3	14 December 2009
Questionnaire: SHALOM Questionnaire	2	21 September 2009
Participant Consent Form: Phase 2	1	14 July 2009
Evidence of insurance or indemnity	-	27 July 2009
Letter from Sponsor	-	27 July 2009
Questionnaire: COPE Scale	2	21 September 2009
Letter from University of Stirling Research Ethics Committee	-	16 July 2009
Interview Schedules/Topic Guides	1	24 June 2009
Investigator CV	2	19 January 2010
Participant Information Sheet	3	19 January 2010
Participant Consent Form: Phase 1	2	19 January 2010
Participant Consent Form: Phase 2	2	19 January 2010
Letter of invitation to participant	3	19 January 2010
To whom it may concern - contact details	-	-
Response to Request for Further Information	-	19 January 2010

28 January 2010

Letter to Mr A Alshraifeen.....continued/

Statement of Compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After Ethical Review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

09/S0704/85	**Please quote this number on all correspondence**

Yours sincerely

for **Dr Ken James**
Vice-Chair

Enclosures: "After ethical review – guidance for researchers"

Copy to: Professor William Lauder
Dr Josie Evans, University of Stirling