UNDERSTANDING SPIRITUALITY FROM THE PERSPECTIVES OF JORDANIAN PEOPLE DIAGNOSED WITH END STAGE RENAL FAILURE: A PHENOMENOLOGICAL STUDY

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Abstract

Spirituality has been increasingly acknowledged in nursing literature as an important element of holistic care provision. The literature to date has investigated the meaning of spirituality in Western cultures, predominantly through positivist methodologies. Spirituality in Middle Eastern countries remains under-researched, and this study aims to address this gap and to better understand this concept. The main aim was to understand and interpret patients' perceptions, experiences, beliefs and practices associated with spirituality by exploring how spirituality is manifest in the lives of Jordanian End Stage Renal Failure (ESRF) patients.

A hermeneutic phenomenological approach was adopted informed by the philosophy of Martin Heidegger (Heidegger, 1962). Participants (n=27) were recruited from four different dialysis units: in a public hospital, a private hospital, an educational hospital and a refugees' hospital in Jordan. Data was collected through in-depth unstructured interviews.

Analysis was guided by the tenets of hermeneutic phenomenology, namely: gaining an immediate sense of what was said both during and after each interview, transcribing data verbatim, translating interviews into the English language, intensive reading and re-reading, seeking meaning units by line-to-line coding, developing situated structures (how spirituality was manifest in each text) and developing a general structure from the individual situated structures (how the phenomenon 'spirituality' comes into being).

The findings uncovered the phenomenon of spirituality and how the Jordanian ESRF patients experienced it during their illness. The nature of this phenomenon appeared to be complex and multifaceted. The three superordinate themes that emerged from analysis and interpretation of the participants' accounts clustered around *Religion*, *Relationships* and *Desperation*.

The study findings show how language, religion and culture were important elements and cannot be ignored in understanding Jordanian ESRF spirituality. The findings reveal that cultural issues such as losing employability, social stigma, social isolation and being tagged negatively are results of suffering from ESRF and are related to the meaningful way in which Jordanian ESRF patients viewed their spirituality. This has important implications for health care professionals. Should they use spirituality in care, there is a need to address wider issues such as stigma that patients face in society which impacts negatively upon individuals' spirituality. In addition, findings show a specific and crucial characteristic of spirituality was

the conflict between acceptance and rejection of the illness, and a sense of patients feeling that they are human and that life has not stopped. It is also evident that spirituality has played an important role in *Nafs* (inner self). It was part of the transforming process of *Nafs* from being *Nafs Ammarah (evil inside)* to *Nafs Lawamah (blaming)* to ultimately reach *tranquil Nafs (peace and comfort)*. These were the core spiritual needs of participants, who expected that health care providers, family and community should have the essential skills to address these needs. The role of nurses within the dialysis team is essential in enhancing patients' spirituality through spiritual and religious engagements. However, few participants highlighted the challenges in nurse-patient relationships, for example being in a busy unit, cultural boundaries, nurses' characteristics, lack of knowledge, lack of awareness, unbalanced power in such relationships, lack of support, lack of respect, and a lack of attention and psychological care. All these elements may affect a nurse's role in providing spiritual care.

This research prompts us to look at the important role pre-dialysis nurses can play in improving and addressing spiritual needs, increasing awareness, and educating patients, family and the public about ESRF in its early stages. It also highlights the important role for religious leaders, Imams, and psychologists in enhancing an individual's spirituality. The study argues that a "secular" concept of spirituality had no meaning for the participants in the study in the absence of religion. Spirituality is fundamentally part of religion and vice versa. The findings may have consequences for the use of spirituality in multi-cultural settings in Western countries. Additionally, findings highlight an important emphasis on the practice of spirituality, often underestimated in previous literature for Arab-Muslim Jordanian patients.

The study findings contribute to the existing gap in knowledge regarding how Arab-Muslim Jordanian ESRF patients experience spirituality during their illness. It provides valuable insights into the importance of spirituality for this patient group and suggests how nurses, educators and policy makers might help address ESRF patients' spirituality and spiritual needs in order to provide appropriate spiritual care. The study suggests the findings may have relevance beyond the Jordanian context in educating nurses on the importance of appreciating the religious dimension of spirituality. The study recommends further research in order to understand spirituality from the healthcare providers' perspective.

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Abbreviations

CKD	Chronic Kidney Diseases
CPR	Cardio-Pulmonary Resuscitation
DMD	Duchenne Muscular Dystrophy
DoS	Department of statistics
EBP	Evidence Based Practice
ESRF	End Stage Renal Failure
HIV	Human Immunodeficiency Virus
AIDS	Acquired Immunodeficiency Syndrome
ICU	Intensive Care Unit
NMC	Nursing and Midwifery Council
QoL	Quality of Life
RCN	Royal College of Nursing
UK	United Kingdom
USA	United State of America

Notation in Transcripts and Text Extracts

The actual names of the participants in this study have been substituted with pseudonyms in order to protect anonymity.

…	Natural pause
(Text)	Information about the participants or about the interviewee
[….]	Exclusion for part of the text
[Text]	Text added by the researcher to clarify

Glossary of Arabic Terms Used By Participants

Arabic Terms	**Meanings**
Ajer	Reward for good deeds from Allah
Al-Baqara	The second chapter of the Qur'an
Alfateha	The first chapter of Qur'an
Alhamdu lillah	All praise is due to Allah
Al-hamm	Worry and Sadness
Allah akbar	Allah is great.
Allah kareem	Allah is generous/the Sustainer
Almoawethat	Three chapters of Qur'an
Al-sakkeenah	A feeling of peace and tranquility
Al-weal	The maximum feeling of suffering
Amer	An order
Assalamu alaykom	Peace be upon you (Islamic greeting)
Assapeh- Tasbieh	A more specific form of *Dhikr*
Atarjal	Without preparation
Audhu billahi min Ashaytanir rajeem	I seek refuge with Allah from the devil
Awjrah	Materialistic Reward from Human
Ayah(at)	A verse(s) or sign (usually of Qur'an)
Ayat Alkursy	A particular verse of the Qur'an ('The Throne')
Azayem	Invitations
Azoma	Invitation
Balaa'	A test; a detrimental outcome of worldly fortune
Bismillah	In the name of Allah
Bismillah al-rahman al-Raheem	In the name of Allah, the Merciful, the Compassionate (conventionally used to introduce formal speech)
Dhikr	Remembrance (usually 'remembrance of Allah')
Du'a	Supplication to Allah
Dunya	The earthly world
Ebelaa	Being Tested
Estresal	Continuum
Fajr	Before sunrise
Fashelah	Sense of failure
Hadith	Any speech or action that comes from the Prophet Mohammad

Haraam	Prohibition
Hasanah	Good deed
Hasban Allah wa neama Alwakeel	Allah is Sufficient and the best Protector.
Ibadah	Worship
Iman	Believe
Insha Allah	God willing
Isha	The night prayer (one of five compulsory prayers).
Istighfar	Seeking Allah's forgiveness
Jamaa	Congregation; masjid *al-jamaa*, 'congregational masjid'
Juz'a	A portion (1/30th) of the Qur'an
Khalaas	Finished (slang)
La ilaha ila Allah	There is no God except Allah (declaration of faith)
Masha Allah	This is what Allah wills (exclamation of joy)
Mawaddah	Cordiality
MHasanahay	When you feel something great
Motmaenah	Wishing for
Nafs, Nafsyan	inner self, inner status
Neyalak	Good for you
Rabb	Lord
Rabb Al-Almin	Lord of the word
Raqaa	A unit of prayer
Riziq	Provision, or any income not necessarily a money
Ruqyah	Healing with the Qur'an
Ruzzaq	The Provider (a title of Allah)
Sahabah	Companions of the Prophet Muhammad
Salaamatuk	Peace to you (informal)
Salah	Prayer
Sali	Peace to
Sali aala Muhammad	Peace upon (Prophet) Muhammad
Sali aala Sayedena Muhammad	Peace upon our Noble Muhammad
Sayeaat	Bad deeds
Shahadah	Declaration of faith (*la ilaha ila Allah*)
Sheikh	An elderly respectable man (esp. a religious figure)
Subhan Allah	Allah be praised

Subhanahu wa ta'ala	Praised and Exalted be He (Allah)
Sunnah	The Prophetic tradition (derived from *hadith*)
Takbir	Praising Allah (esp. Allahu akbar)
Tasbih	Praising Allah (esp. *dhikr*, *subhan Allah*)
Tawakul aala Allah	Trusting in Allah
Tawhid	Oneness of faith (pure monotheism)
Tayyib	Ok (informal; lit. 'Wholesome')
Umrah	Minor pilgrimage
Wa alaykom assalam	And to you be peace (response to Islamic greeting).
Wuzu	Abolitions
Ya rabb	Oh Allah … oh Lord
Ya zalemah	Oh man…
Yeklef	Many thanks
Shafaqa	Pity look

CHAPTER 1: Introduction and Background

> *"A journey of a thousand miles begins with a single step"*. - Lao-Tzu(Speake, 2015, p166).

This chapter introduces my research and provides a brief background and an overview of the thesis. It also clarifies my ontological position and, as part of the reflexive process in phenomenological studies, explains my motivation for choosing a subject related to the care of patients in End Stage Renal Failure (ESRF). The research question that underpins this thesis is: "How is spirituality experienced by Jordanian patients with ESRF?" The term "phenomenon" is used throughout my thesis to refer to feelings and emotions that ESRF patients reported experiencing during their illness. The initial section is largely descriptive, as it is crucial to recognise the unique context within which this study was conducted.

Personal Ontological Position

Rossman and Ralllis (2012) explored the importance of researchers' biographies in constructing the understanding of the phenomenon under study. Denzin and Lincoln (2005) also suggested that presenting biographies situates the investigators behind and within the study paradigm and also demonstrates their interpretive perspective, research strategies, methodology and methods of data collection. All the processes of my study (e.g. the research interest, the formulation of the study questions, conducting fieldwork, and analysis of data) were influenced by me and are important in relation to my personal ontological positioning.

In this context, the study was largely motivated by my own needs and experience as a nurse, my own interest in spirituality and my role in care provision for renal patients. I am a Jordanian Muslim nurse and a father of four during the time I conducted this study. I was also diagnosed with ESRF. An important driving factor that inspired me to undertake this phenomenological research was my own biography and the gaps I identified from literature search in the provision of spirituality to patients in ESRF. I have worked as a renal nurse for the last seventeen years in different countries (Jordan, Iraq and the UK) and have cared for a large number of ESRF patients throughout their illness, often witnessing their grieving and its alleviation through various measures.

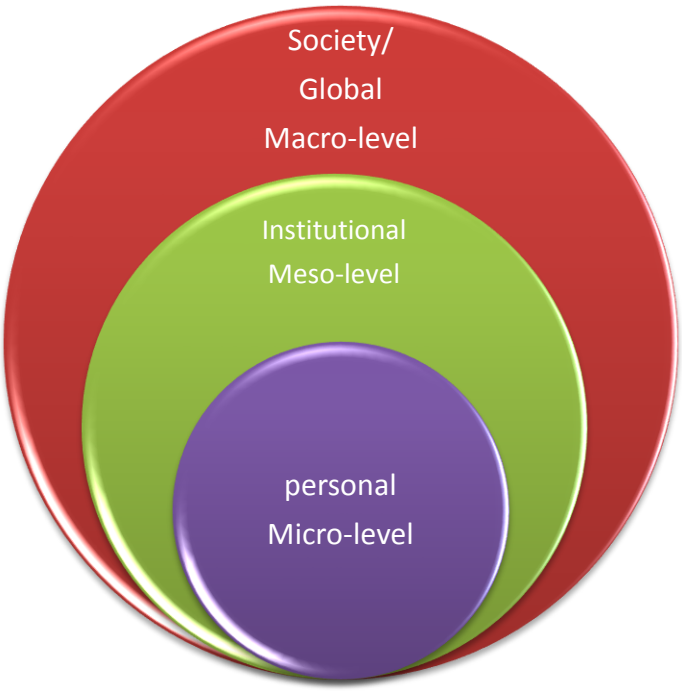
Working in different cultures has given me the skills needed to communicate with patients from different backgrounds (cross-cultural competence). Also, in Jordan, I worked in different hospitals, including private, educational and public hospitals. On reflection, I now realise that I had become part of a health care system which was largely dominated by doctors and was disease-orientated rather than patient-centred. During this time my intention was to develop my skills and knowledge and to progress my career further, with little consideration of what patients thought about the care I was providing for them.

At a later stage in my nursing career I worked as an emergency nurse in one of the busiest hospitals in Jordan. I found that emergency nursing was very different and more challenging, compared to working on medical or surgical units. Working with emergency patients required a special set of skills and a greater degree of autonomy. These skills were important to carry out various duties needed in emergency departments such as Cardio-Pulmonary Resuscitation (CPR), applying casts to broken limbs, giving injections etc. However, I found that it was very difficult to extend my focus beyond the physical injury; I became task-orientated about patients' physical injuries. This perception of incompletely identifying and meeting the psychosocial and the spiritual needs of my patients created internal dialogues and raised many questions about my ability to address these needs.

After my emergency nursing experience I moved on to work in the Intensive Care Unit (ICU) of another Jordanian hospital. During this period I decided to further my studies and obtain my Master's degree. I wanted to specialise in clinical cardiology and to become a clinical nurse specialist. However, I ultimately became a clinical nurse specialist in renal care. Courses in the Master's degree programme provided me with a background in nursing theories and clinical skills. However, during this period the main motivation to conduct this study came from the issues I encountered as a nurse and as a patient at a hospital in Jordan.

The decision to embark on this study was influenced by factors operating on three different levels: 1- Micro-level (personal level); 2- Meso-level (institutional); and 3- Macro-level (global) as shown in Figure 1.1.

Figure 1.1: My level of interest



Firstly: the micro level (the personal level). This describes my personal interest in the study. I was originally motivated by my own needs and experiences as a nurse, as well as my own interest in spirituality and its role in care provision for renal patients. This interest was later on amplified by another different experience, this time as a patient in a hospital in Jordan, the same hospital where I worked as an Intensive Care Nurse at a senior level. One day, whilst attending an educational meeting, I developed a sudden severe pain in my abdomen and was rushed to the emergency unit of the same hospital I was working in. The necessary investigations were carried out and I was given some treatment. However, I remained in pain and there was no urine output despite treatment. Suddenly, one of the senior doctors approached my bed and I could see in his face some bad news. With little introduction, the doctor told me "your kidneys are not working as they should be and your kidney function is seriously low". With little further explanation, he arranged for an urgent bilateral nephrectomy (an emergency operation to remove both kidneys). His words hit me like a sledgehammer and hurt me badly, demolishing any hopes, plans, or thoughts of the future and the meaning of life. I faced an acute physical, psychological and spiritual crisis. The doctor's diagnosis was extremely traumatic to me; I underwent what I can only refer to as a "spiritual experience".

I found it particularly challenging to inform my family about my condition when they came to visit me. I cannot forget how my mother broke down in tears when I told her about my condition. I remember her saying she would sacrifice anything and everything to relieve me of my ordeal. Within this nonverbal but fraught atmosphere, my uncle broke the silence and initiated what I would call "a spiritual care package". This incorporated religious talk with quotations from the Qur'an (the sacred Muslim book) and Hadiths (the sayings of the prophet Mohammed), reiterating family bonds and support, prayers and good wishes for hasty recovery and a bit of social counselling. He was quickly joined by support from my brothers and sisters, friends and relatives, in person or via my phone which kept ringing. However, when they all left, the exposure to this "spiritual package" remained alive and I was thinking about this "exposure" all night. This experience was pivotal in changing my views on the gravity of my medical condition.

The spiritual package I received enabled me to improve my own coping mechanisms; my mental status indicated an improvement in my mood and I became less stressed as my self-esteem improved. Furthermore, the level of pain had dropped to a minimum. I still remember that I deliberately refused a regular strong painkiller (Pethidine) that was prescribed for me that night. Although I was a practising Muslim and capable of reading and understanding the Qur'an and Hadiths, the meanings that I extracted from my family's spiritual and religious dialogue that night felt new and unforgettable.

Unlike many patients, my story did have a happy ending. In the morning I did manage to pass a small stone. The senior on-call consultant was informed and he came to see me. He was concerned when he was made aware of what I was told about my condition by a less senior member of his team and that I was misdiagnosed and potentially mismanaged without seeking his opinion. I stayed in the hospital for a few more days to achieve full recovery then I was discharged with the spiritual package that I will never forget.

I was continually asking myself why the spiritual care came spontaneously from my family and why it was not delivered by nurses or other health care professionals who were supposed to provide me with a holistic package; if this spiritual package helped me to cope with my illness, could it work for others? If I had a positive experience with a spiritual care package, were there any negative aspects of spiritual care? What

are the spiritual care dimensions of renal patients? What are other renal patients' views of spirituality and spiritual care? What is the importance of the supportive environment for the ESRF patients? Similar questions kept coming to me demanding answers and triggering various emotions. This was the beginning of my own experience with spirituality as a patient. As I later on discovered from my research, the provision of spiritual care for ESRF patients is still as pertinent today as when I first experienced "ESRF" many years ago. I also discovered in the course of my research that despite the scarcity in providing professional spiritual packages in modern medicine; ESRF patients tend to find the spiritual support from fellow patients.

Various studies have established that a supportive environment is an important factor in enabling patients to cope with chronic illness on the physical, psychological and spiritual levels (Baldacchino, 2010). In light of this, one may argue that patients cope better when they have a supportive environment that has the spiritual resources readily available for patients to use. From my Master's degree, I conducted a questionnaire study that evaluated nurses' roles in post-renal transplantation care. I concluded that nurses focus almost exclusively on physical care with little input in the psychological or spiritual care. It became clear to me that these important aspects of holistic care were being missed.

Following completion of my Master's degree I worked in dialysis units in Iraq, Jordan and the UK. I have noticed that the notion of spirituality and the spiritual care tends to be somewhere at the bottom of the list of priorities for nurses and other healthcare professionals. From informal discussion with colleagues over the years, the reasons for this appear to stem from the lack of awareness of spirituality and spiritual care to meet renal patients' spiritual needs. Certainly spiritual care and spirituality, as I uncovered from my research, are complex and multifaceted areas that are difficult to appreciate for many healthcare professionals across cultures.

Secondly: the Meso-level (institutional level). I queried why spiritual and religious dialogue such as Qur'anic verses and Hadiths' were not delivered by health care professionals in Muslim countries. If this support and spiritual dialogue helped me in coping with my illness and improved my psychological and spiritual status, would they work with someone else? If I had a positive experience, are there any corresponding negative aspects? What are other renal patients' views on spirituality

and how they received care? How does spirituality play a role in the experience of patients in ESRF? My communications with both patients and colleagues, and my personal experience of being diagnosed with renal disease, have led me to believe that spirituality is an important aspect of health care that has not been fully addressed by healthcare professionals. Some may argue that ESRF patients can be transferred to hospice care or end of life care pathways where they can receive spirituality and spiritual care. However, ESRF patients tend to live many years before they reach the terminal stage, thus requiring the institution of spiritual care during these years before reaching their final days.

Thirdly: the macro-level (global level). This had started after I graduated from the Master's degree when I developed my career in nursing around providing care to ESRF patients. I witnessed the effect of such illnesses on patients and their families and how it impacted on every aspect of their life. Wherever I have worked, I noticed a pattern of ignoring spirituality and spiritual needs for ESRF, even in hospice settings that are supposed to cater for these needs. The reasons for this were similar to those mentioned previously, regarding the lack of awareness concerning spirituality (Baldacchino, 2010; McSherry, 2007; Narayanasamy, 2004) and what roles spirituality can play in renal patients (Tanyi, 2002). A recent Royal College of Nursing (RCN) report showed that staff confirmed that nurses in the UK consider spirituality to be an important element and a fundamental aspect of nursing central to the delivery of high quality nursing care. However, staff in the RCN's study reported they needed more direction and support from professionals and policy makers to enable them to engage more meaningfully and confidently with spiritual aspects of care (RCN, 2010).

Against this background, I began to explore spirituality and nurses' roles in spiritual care for patients in general, and for ESRF patients in particular. Based upon my interest, my experience and the review of the literature, I designed and conducted this study to better understand the phenomenon 'spirituality' and to answer my own questions, with particular reference to the Jordanian context. It should be noted from the outset that "phenomenon" in this study refers to the object of experience, in this case spirituality, and "phenomena" refers to what ESRF patients say (their interpretation) of what they had experienced. This study seeks to address gaps in the literature regarding this subject. Therefore, I set out to answer the question: *How*

does spirituality uncover in the lives of Jordanian patients in End Stage Renal Failure? I realised that such a question requires a qualitative methodological approach (for further details, see Chapter Three).

Considering all of the above, I became motivated to understand spirituality and spiritual care and how I could apply them to the care I provide to ESRF patients. Despite the currently available knowledge about the positive role of spirituality in healthcare settings, I maintained an open mindedness to critics of spirituality who argue otherwise. For example, some could argue that spirituality is a constructed term which can lend itself to a more naturalistic approach. In other words, spirituality can turn into a gigantic conceptual magnet that attracts a host of extravagant meanings, such as: personal well-being, psychology and self-esteem, hope, cope, body image, positive feelings, negative feelings, music (McSherry, 2007; Ross, 1995). This view is supported by Paley (2008) who argued that spirituality can be conceptualised to an existential concern which can be reported in a scientific manner. Such critics helped me to refine my own thoughts and compare and contrast them with the debate in the literature.

When conducting the literature review for this study, I found that the majority of studies concerning spirituality in healthcare had been conducted with Western cultural perspectives, largely influenced by the faith traditions of Catholicism, Protestantism and Judaism (with research conducted primarily in Europe, North America, Brazil and Israel). Therefore, the provision of appropriate religious and spiritual care in health care settings may be restrictive for patients who come from a different cultural and religious background, such as Muslims, Hindus or Buddhists (Abu-Ras and Laird, 2011). The number of multi-faith chaplaincies and centres is growing in the NHS hospitals in the UK, providing information and guidelines to medical staff and patients about the different faiths that can help the staff to understand and address their patients' religious beliefs and spiritual needs during their admission to hospitals in the UK (NHS, 2014). However, I would argue that such information is still basic and inadequate in addressing Muslims' spiritual needs in terms of facing the illness. The religious and spiritual resources available from the UK hospitals chaplaincies are largely related to basic items related to issues that face patients during their hospitalisation such as: permissible food and drinks; mode of greeting; birth; examination of patients; particular sensitivities during washing and

personal hygiene; modesty; fasting; family planning; abortion; care in serious (or final stages of) illness; blood transfusion and organ transplantation. In addition, I would argue that the transitional move of the society in the UK and the shift from being a religious community to becoming a more secular society, as shown from the declining figures of people attending religious activities (Paley, 2008), is a clear indicator of the difficulties for health care professionals in addressing the above needs; especially when the staffs' faith or belief is different from the patient's faith.

In addition, it is important to note that the existing research considering spirituality tends to be part of wider positivist studies (Davison and Jhangri, 2010; McSherry, 1997; Ross et al., 2014). There have been very limited qualitative investigations of spirituality for Muslim patients either in Jordan or in Middle Eastern countries (see Table 2.3). Furthermore, previous researchers have recommended further studies to understand the Islamic view of spirituality and spiritual care (Clarke, 2009). A possible explanation for this scarcity of studies of Muslims' spirituality might be that western scholars are hesitant to examine and study Muslims' spirituality due to the sensitive nature of the subject and a notion that any criticism may be viewed negatively by the Muslim community. Another possible explanation for the paucity of literature on Islamic spirituality maybe related to the proliferation of Islamic sects in Western culture namely: Sunna, Shi'a, Mu'tazila, Shari'sim, Sufisim, Othmanis, Ahmadis, Brelw's, Wahabies, Baha'eis, Al Jumhor (Rahman, 1998). Some of these sects originated in Western cultures and some in Eastern cultures and the Middle East. Each sect has its own ideology and a unique way of interpreting Islam as a result of confusing religious teaching with the cultural norms, which has made it even more difficult for Muslims themselves to understand the basis for the differences between these groups. The magnitude of the confusion can be sensed from the hesitation of even non-Western scholars to address the topic of spirituality and religion among Muslims in Western cultures (Walpole et al., 2013).

Hall (2012) highlighted the need for healthcare providers and social workers to understand the spirituality of Muslims originating from different countries, for example: Pakistan, the Philippines, Indonesia and Malaysia. This is further complicated by the fact that certain Muslim culture and moral systems have been influenced by diverse historical influences, including Animism, Hinduism, Buddhism, Confucianism, Taoism; Shamanism, Christianity as well as Islam (Hall et

al., 2011). Such a complex amalgamation of spirituality arguably may represent acculturation status, which may not be applicable to Arabic-Islamic culture. In support of this argument, Khorami Markani et al. (2013) examined spirituality from a nurses' perspective in Iran and found that spirituality has religious and existential dimensions that relate only within the Iranian context. This conclusion, however, must be interpreted with caution because it only represents the Shi'as' view of spirituality which other sects maybe reluctant to accept. The phenomenon of spirituality remains largely unexplored for Middle Eastern Muslims, including Jordanian Muslim patients with ESRF, and more studies are required to explore spirituality in Islamic culture in the Middle Eastern countries.

As explained in details in Chapter Three, the four major qualitative methodologies used in nursing research are ethnography, grounded theory, narrative analysis and phenomenology. The fourth methodology – phenomenology – is concerned with the study of phenomena, for example: what people experience within a certain context (Crotty, 2009; Greatrex-White, 2004; Van Manen, 1990). Similar to a narrative approach, it studies peoples' stories, but the focus remains firmly on the phenomenon under study rather than the stories and narrators themselves. The understanding of the phenomenon results from the co-creation of a new level of understanding that involves both the researchers and the participants' interpretations, and not just the individual interpretation of either one (Flood, 2010). For the purpose of my research, I felt that hermeneutic phenomenology would be the most suitable methodology to answer the research question. Although my research question could have been answered using a different qualitative method, hermeneutic phenomenology appeared to be most suitable because it focuses on the way in which spirituality is experienced in reality for haemodialysis patients. From my literature search, this study appears to be first of its kind to focus on Jordanian ESRF patients' experiences of spirituality in care. In the absence of baseline information, it was deemed more appropriate to use an unstructured interview than a structured one in order to enable "probing" of participants' diverse experiences.

My study is appropriate and highly relevant research for Jordanian ESRF patients as well as the healthcare professionals, including nurses, in Jordan. It is hoped that this piece of hermeneutic phenomenological research will contribute to the understanding of the phenomenon of spirituality as experienced by people diagnosed with ESRF in

Jordan. In seeking to understand how spirituality uncovers itself in the lives of those who experience it during ESRF, this study builds on the findings of previous qualitative research and opens the door for further studies.

The thesis structure

My study has seven chapters. This opening chapter has provided a brief introduction to my own motivation in conducting this study and my own nursing background. I have explained how my unique experience and my desire to study this aspect of nursing care for renal patients informed this study of how spirituality is experienced during ESRF. It gives important background information and establishes the research motivations. The structure of my thesis is outlined below for each chapter.

In Chapter Two I highlight the context of the study by giving an overview of Jordan, the health care system in Jordan, incidence and prevalence of ESRF. I then identify the important factors that influence the treatment of ESRF in Jordan, including Islamic and ethical considerations, cultural considerations and financial considerations.

In Chapter Three I present a critical review of the relevant literature pertaining to spirituality, with an overview of spirituality and religion, characteristics of spirituality as they appear in the literature, spiritual care and spiritual needs, the influence of spirituality, challenges and boundaries of spirituality in Jordan, and a review of spirituality from lived experiences of patients who have survived chronic illness. I will also explain the search strategy and critically review a range of empirical studies that have been published on spirituality generally and for renal patients specifically. This chapter provides a variety of theoretical and clinical perspectives and it identifies the gaps in the literature and helps to justify the need for the proposed study.

Chapter Four outlines the methodology and methods focusing on justifying the research processes that underpin the proposed study. Importantly, it highlights the philosophical principles used to inform the research processes. An explanation for using a hermeneutic phenomenological approach is provided followed by research methods, including research participants, recruitment strategy and access, data collection and analysis, possible presentation and dissemination. It concludes with a

review of ethical considerations and the trustworthiness of the proposed study and how I conducted my study. All detailed access and personal reflexivity and decision trials are covered in this chapter. The chapter describes the research process and highlights some of the difficulties I experienced during different stages of the study.

In Chapter Five, which is the major empirical chapter in this study, I explore the phenomenon of spirituality and how ESRF patients experience it. This chapter reports the accounts of patients who participated in this research and describes the three themes that emerged from their stories: religion, relationship and desperation.

In Chapter Six I discuss ESRF patients' experiences of spirituality in this study and critically examine it with the wider field of nursing literature. The above three themes are discussed. The final section includes a summary of this discussion chapter.

Chapter Seven is the final chapter, where I draw conclusions and make recommendations, as well as explaining my own reflexivity on conducting hermeneutic phenomenology study and endorsement for future research. I will include a section where I reflect on my own journey experience in conducting this study, especially as I questioned almost everything during the process of this study. I will provide my reflection in the journey of this study.

Furthermore, the literature supports the researcher to write in the first person (Greatrex-White, 2004; Webb, 1992). Since my study was hermeneutic phenomenology; it is vital to illustrate any outcomes in the first person, as the reflexive account for the researcher is an important part of this methodology. Thus, I will use the first person pronouns to show how I directed this research and how I interpreted and understood the phenomenon of spirituality during this study. A brief description about the Jordanian healthcare system, the incidence and prevalence of ESRF, and factors influencing the treatment of ESRF in Jordan will be presented in the following chapter.

CHAPTER 2: The Context of the Study

> "Everybody is a genius. But if you judge a fish by its ability to climb a tree, it will live its whole life believing that it is stupid". Albert Einstein (Heisler, 2014, p9).

Introduction

This chapter highlights the context of the study by giving an overview of Chronic Kidney Disease, after which I focus on Jordan in the context of this study by giving an overview of the Jordanian healthcare system, and illustrating the incidence and prevalence of ESRF. Then I move to identify the important factors that influence the treatment of ESRF in Jordan, including Islamic and ethical considerations, cultural considerations and financial considerations.

Chronic Kidney Disease (CKD) is defined as an irreversible decline in the normal kidney function that steadily develops into ESRF (Gulati, 2011). The incidence of ESRF is rising worldwide (Welander et al., 2012). CKD causes abnormalities in and on the body (Molony and Stephens, 2011), which affect the patient's life and is difficult to treat (Talas and Bayraktar, 2004). ESRF also has an impact on patients and their families which can be very difficult to cope with (Lindqvist et al., 2000). The main treatment modalities for ESRF patients are renal transplantation and dialysis (Cases et al., 2011). The majority of patients with ESRF also face physical and psychological challenges in adapting to the chronic illness. Molzahn (1998, 271) and Reichsman and Levy (1972) highlighted these changes in three stages: "In the first, there is a honeymoon period of initial physical improvement; in the second, disenchantment and lack of support; and in the final stage, the patient starts to struggle, ending with long-term adaptation". Some might argue that the main focus of renal nurses and healthcare professionals should not only be on the clinical aspects of care; there should also be a requirement to understand the three stages outlined above in order to provide effective and holistic patient-centred care. Furthermore, it can be argued that by basing care on a comprehensive assessment of the patient's individual needs, it should be possible to minimise negative feelings.

Receiving a diagnosis of ESRF may have a shocking and life-changing impact upon patients and their families (Ziegert et al., 2009). In 2009, 2,666 individuals in Jordan received this diagnosis (Department of Statistics, 2009), compared to 1,711 in 2003 (Batieha et al., 2007). These numbers remain relatively low in comparison with other countries: 354,754 patients received dialysis in the US in 2006; 45,484 adults in the UK in 2007; and 250,000 in the rest of Europe in 2007 (Collette, 2009). However, the Jordanian Government's annual spending on renal diseases is relatively high, at JD 35 million (£35 million)(DoS, 2009).

A diagnosis of ESRF and the initiation of haemodialysis sessions are indicative of many forthcoming challenges in life for Jordanian renal patients and their families, examples of which include: financial aspects, transport considerations, changes in lifestyle, dietary restrictions, physical, psychological and spiritual alterations that may affect patients' worship behaviours (e.g. prayer). The diagnosis may also affect family structures and roles within the family. ESRF patients are required to cope with new and permanently stressful conditions which may significantly influence their quality of life (Baldacchino, 2010; Burra et al., 2007; Theofilou, 2012; Timmers et al., 2008). Renal patients often struggle to adapt to these issues on the one hand, and with their illness and spiritual issues on the other. Tanyi et al. (2006a) reported that spiritual support from nurses is an important element in enabling ESRF patients to cope with their long term illness. (Tanyi et al., 2006).

Jordan in Context

This section has two parts: the first part provides an overview of Jordan, focusing on its location, demographic characteristics, healthcare system and the incidence and prevalence of ESRF. The second part looks at the impact of important (non-medical) factors that influence ESRF treatment, including religion, culture and financial considerations.

Jordan and the Health Care System

Jordan is an Islamic country, located in the heart of the Middle East. Its capital city is Amman (see Appendix 1). The estimated population of Jordan by the end of 2011 was 6,249,000 (DoS, 2012), distributed within 12 governorates. The majority of the population (over 75%) live in three major cities: Amman, Irbid and Al-Zarqa (DoS,

2010). In 2009, 36.5% of the population were under the age of 15 (DoS, 2010). The Jordanian population comprises of 92% Sunni Muslims, 6% Christians and 2% Shi'a Muslims (The-world-factbook, 2012). Although Arabic is the official language in Jordan, English is widely used within the educational sector and among educated Jordanians.

Generally, Jordanian society adopts an extended family structure system, the average family size being 6-7 people. Association among members of the same family is very strong, especially in rural areas. Jordan has its own dress cultures for males and females, derived from the Arabic-Islamic and Western heritage. Respect, dignity and ethics are strongly associated with issues surrounding care, family and gender. Interaction between genders is culturally restricted especially in rural areas.

Jordan's healthcare system is a complex and advanced system compared with other Middle Eastern countries. In 1972, the first renal transplantation was performed in Jordan ahead of any other Middle Eastern country (Abboud, 2006; Chamsi-Pasha and Albar, 2014). The healthcare system in Jordan is under the auspices of six major public sector providers: the Ministry of Health (MoH), the Royal Medical Services (RMS), a large private sector, medical services at governmental universities; the National Centre for Diabetes, Endocrinology and Genetics; and the United Nations Relief and Work Agency (MoH, 2012). In 2010, there were 105 hospitals in Jordan (DoS, 2012). Different types of healthcare insurance schemes operate in Jordan depending on employment status and the type of employer. The unemployed still receive healthcare services at low costs at any Ministry of Health hospital, which are distributed across Jordan (Al-Hassan and Hweidi, 2004). They may also choose to receive their care from the private or the university sectors if the HCP cannot accommodate the patient within public hospitals.

Incidence and Prevalence of ESRF

In 2010, 21 out of 29 MoH hospitals included dialysis units within their service, providing dialysis for 921 patients in that year (493 male and 437 female). Almost all private hospitals (n=60) have dialysis units, where 1,247 patients were treated in 2010 (728 male and 519 female). Furthermore, 78 patients were treated for dialysis in the university hospitals (49 male and 29 female). The Royal Medical Services has capacity for 84 dialysis patients (45 male and 39 female). In total, there are 239

dialysis machines distributed among all Jordanian hospitals (Ministry of Health, 2010).

Unfortunately, because of the lack of registries, there are no figures on the incidence of ESRF in most countries in the Middle East. In Jordan there is no national registry collecting accurate data on ESRF patients. Moreover, there is a lack of national collaboration among hospitals to share figures on which an international comparison could be based. Thus, the true incidence and prevalence of CKD remains unknown (Akl and Said, 2010).

Hamed (2002) found in a retrospective study of Jordanian patients (n=202; 113 male and 89 female) covering the period from 1988 to April 2001 in one centre (the Jordanian University Hospital) that among the causes of ESRF, urological abnormalities and malformation accounted for 42%, hereditary renal disorder 29%, glomerulo-nephritis 14%, renal hypodysphasia 5% and haemolytic uremic syndrome 4.5%. Furthermore, he found that 49 patients received peritoneal dialysis, of whom 8 were moved to haemodialysis because of noncompliance or dialysis-related complications. Only nine patients underwent kidney transplantation. Hamed concluded that the estimated prevalence of ESRF in Jordan, according to his data, was 51 cases per million populations, based on the estimated population served by the centre during the period of the study. Abboud (2006) carried out a retrospective study to ascertain the causes of ESRD in the Middle East. Data extracted from published studies over 40 years indicated that diabetes mellitus was the most frequent cause of ESRF in the Middle East (20-40%), followed by hypertension (11-30%) and glomerulonephritis (Abboud, 2006). In Jordan, ESRF among children is also a concern and the prevalence appears to be higher compared with other countries (Hamed, 2002).

These results are the only statistics available in Jordan. Unfortunately, the data cannot be generalised to each individual centre, as the Jordanian University Hospital treats only 1.5% of the Jordanian population. Abboud (2006) stated that his results give only an indication of the prevalence of ESRF in one centre, as the sample selection was not nationally representative of all Jordanian cities and hospitals.

Factors Influencing ESRF Treatment Decisions in Jordan

The proposed research, conducted in Jordan, addresses some of the Islamic and ethical considerations, the social cultural issues that may affect ESRF patients and the financial considerations. These are explored in this section.

Islamic and Ethical Considerations

Muslims derive their religious values from the "Sharia", which is an a amalgamation of the interpretation of the Qur'an (the text form Allah to Prophet Mohammad, peace be upon him (PBUH) (Habibi and Labeebi, 2005), Hadith (the sayings of the prophet Mohammad) and the Sunnah (deeds, commands or approvals by Prophet Mohammad) (Sodiq, 2011). Sometimes, interpretations of the Sharia may not be straightforward. For example, the acceptability of renal transplantation among Islamic scholars has divided them into groups based on their different interpretation of the Qur'an. The first group approved of renal transplantation based on the generic permission stated in the Qur'an, "whoever saves the life of a human being, is as if he has saved the life of all mankind" (Qur'an 5:32). The second group prohibited renal transplantation on the basis that humans do not own their body after death and thus cannot donate his/her organs. In addition, the second group argued that Prophet Mohammad (PBUH) urged Muslims to seek remedy as Allah sent treatment for all diseases; therefore all Muslims have a duty to search for the actual remedy of ESRF. It had been narrated by one of the prophets companions, Abu Hurayrah, that the Prophet said "There is no disease that Allah has created, except that He also has created its remedy." (Pathan, 2015). Patients in a Muslim country like Jordan will normally incline to one of these schools of thought. Such uncertainty among Muslim scholars is not unique for ESRF and its therapy, but extends to some other medical conditions such as brain death diagnosis, termination of pregnancy etc. The controversy surrounding transplantation resulted in many Muslim-Arabic countries prohibiting renal transplantations from a deceased individual (Chamsi-Pasha and Albar, 2014). Chamsi-Pasha and Albar (2014) reported the factors that influence patients' decisions in selecting their ESRF treatment of choice which include: personal or family opinions, education level, socio-economic status, religion and cultural characteristics.

In addition, Uskun and Ozturk (2013) concluded, in a cross-sectional study aimed to examine the attitude of Muslim leaders toward donations, that Muslim leaders have either a positive or negative influence upon the donation process. It can thus be suggested that doctors need to consider the implications of the environment and culture in dealing with Muslim patients. The impact of the environment, individual values and beliefs and culture on human beings was addressed by trans-cultural theorists (Giger and Davidhizar, 2008; Leininger and McFarland, 2006; Narayanasamy, 2007; Sagar, 2012). It is generally accepted that the impact of religious beliefs and cultural values on study populations needs to be considered. In cross-cultural competence research, Liamputtong (2010, p 86) observed that:

> "Cultural sensitivity is an important issue in conducting research in different cultures. The researchers exhibit cultural sensitivity and competence through their knowledge of the key values of the social group. They also need to demonstrate culturally appropriate communication and ability to learn".

The importance of cross-cultural competence research and its sensitivity in the literature is well acknowledged (Liamputtong, 2010). Kulwichi et al. (2000) conducted a qualitative study (n=97), which aimed at discovering the professional perception of culturally competent care in the USA. One of the major themes that emerged was the difference between Arab and non-Arab research participants. Non-Arab health professionals stated repeatedly that "they treat everybody the same", while Arab health professionals stressed that treating Arab patients without addressing culture is an indication of culturally insensitive care. This lack of culturally competent care was also consistent with other studies conducted in Western cultures (Yosef, 2008). Culture is identified by Matsumoto and Juang (2012 ,p15) as "a unique meaning and information system, shared by a group and transmitted to generations. It allows groups to meet the basic needs of survival, pursuit of happiness and well-being and deriving meaning from life" (Matsumoto and Juang, 2012). Religion was defined by Balducci and Meyer (2001) as "a body of beliefs and practices shared by a commonality of people as necessary to establish a relation with the deity or to be in harmony with ultimate reality" (Baldacchino, 2010 pg 24).

As identified above, the majority of Jordanians are Muslims; the word "Islam" implies "submission and obedience to Allah" (Khatab, 2006; Mawdudi, 2000). These values and beliefs are the main sources for every individual's daily experiences in Arab-Islamic culture, particularly in medical treatment. Sometimes, various conflicting interpretations of the Islamic sources may arise. In Islamic religion (and Islamic cultures), health and disease are seen as being decided by Allah. Allah can maintain good health for people and can cure ill people. Muslims believe that illness is a test (*Balaa'*) from Allah. This belief is based on many verses of the Qur'an, and the general tone of the Islamic texts, for example:

> "of course you shall be tested in your wealth, and in yourselves" (Qur'an 3: 186);
>
> "No calamity befalls the earth or own selves, but it is (pre-destined) in a book before we bring it into being; indeed it is easy for Allah" (Qur'an 57: 22);
>
> "The one who created death and life, so that he may test you as which of you is better in his deed" (Qur'an 67: 2);
>
> "He (Allah) may test you in what he has given you" (Qur'an 6: 165); and
>
> "We test you through bad and good (situations) with a trial" (Qur'an 21: 35).

Therefore, Muslims are required to succeed in this test and they are encouraged to be stabilised through their *"Ibadah عباده"* (worship):

> "Seek help through patience and prayer" (Qur'an 2: 45).

Nevertheless, in the face of illness and disease, from an Islamic point of view, Muslims are encouraged to seek remedy and treatment. It is reported that the Prophet Mohammad (PBUH) said that Allah sent down disease and medicine, and medicine for each disease (Bahooti, 1982). Moreover, the Prophet (PBUH) urged Muslims to visit ill people, to express love, hope, sincerity, forgiveness and to relieve the distress and suffering. He stated that visiting the ill is a duty upon each Muslim (Abdul-Rahman, 2007). Given that Islamic ethics permeate society in the Arab World, Muslim patients' expectations when they are ill are consistent with these values. In the absence of religiously inspired cultural activities they will still feel spiritually strange which will add to their distress and compromise their healing.

Although for many ESRF patients, renal transplantation presented the treatment of choice (Devi et al., 2012; Neipp et al., 2009), in Jordan, non-related donors are scarce (as in other Middle Eastern countries), due to the cultural perception that it is the obligation of the immediate family to support their members before the rest of society. Therefore, rules and regulations prohibit renal transplantation from non-related donors. However, Jordanian patients are free to travel abroad to far East countries, namely India or Pakistan or to other Arabic countries, namely Syria, Iraq and Egypt, where renal transplantation from non-related donors is allowed (Abboud, 2006).

Cultural Considerations

In Jordan, a typical family rises in the morning and performs ritual ablutions before praying two units of prayer. They will then eat their breakfast, which will be in accordance with Islamic dietary laws (e.g. no porcine meat products or alcohol), saying the name of God before eating. Following the departure of the husband and sons to work, the mother and daughters, who are not at school, will attend to household chores, as their domestic role is highly cherished in Islam. The choice of career is typically informed by Islam. It would be considered shameful to work in settings involving the consumption of alcohol, usually due to Islamic prohibitions, whereas professions such as healthcare and education are highly prized and respected due to Islamic encouragement of such activities. At school and for women in the workplace, careful etiquette limits their proximity to men, for example, if a man and a woman who are not related by blood or marriage are in the same room, they will leave the door open; in healthcare settings, male family members of female patients always accompany them in the presence of male healthcare workers. This is due to the Islamic ethics that value the family above all other institutions in the life of the individual. As for children in school, Islamic rituals such as the noon prayer and religious and moral education which is informed by Islam are taken for granted. Although most men and women pray in their workplace or homes for the five daily prayers, many go to the mosque, and almost all men go to perform the congregational prayers on Friday. The great occasions for family and social reunion and interaction are based around religion - the underlying ethos of religious injunctions to visit and maintain ties of kinship, and the specific interactions encouraged by the two Eid festivals, Friday congregations, and breakfast parties

during the month of Ramadan. The way in which Islam permeates the society of Muslim-majority countries is perhaps seen most in the way in which all are able to forgo eating and drinking between first light and sunset for a whole month of the year.

This, from a Western prospective, might be seen as detrimental to women's rights and liberation and from a feminist perspective it might be seen highly inequitable. However, this is the part of the Jordanian and Islamic culture. For this reason, I chose to limit my study participants to the Jordanian context and most importantly to include both genders in my sample.

Al-Hassan and Hweidi (2004) reported how Islam can influence the interpersonal relationships and communications among family members and other Muslims. Socio-cultural elements are also seen as influential factors in facing illness among families who have ESRF patients. For example, in Arabic-Jordanian culture the communications between family members is important especially when the patient is a female. ESRF as an illness may be difficult to be accepted and revealed if the patient is a female member of the family. The family become more secretive about the illness in front of others especially when they are not first degree relatives. This secrecy is intended to protect the female patient's chances of getting married, which may be harmed should her illness become a public knowledge. Also, it is more likely that the female ESRF patient is accompanied by a family member every time she comes for dialysis. This is especially important during the time of cannulation for dialysis where she may have to uncover part of her body.

In contrast to female ESRF diagnosis, the family reaction may differ if the patient is male. By informing the extended family they see this as another source of support for the patient. Rambod and Rafii (2010) found that male ESRF patients receive more social support than female patients. As mentioned above, in Jordanian culture males are the breadwinners and consequently enjoy a better social support and community network.

Taken together, these Islamic and cultural values may limit the acceptance of such illness in Jordanian patients. Another important factor is the parental authority which may also restrict families with ESRF patients to share such information with other members of the extended family. Although, people in Jordan appreciate the western

way of living, families in Arabic cultures are classified as traditional (Al-Hassan and Hweidi, 2004). This means the eldest person in the family has ultimate power in deciding family matters. This often produces resentment and non-cooperation from those elderly members who perceive taking advice from younger relatives may damage their status. It is therefore imperative that healthcare professionals consider such Islamic and socio-cultural factors when treating ESRF patients.

Financial Considerations

The ESRF treatment decision is influenced by the financial status of the patients. The average monthly wage in Jordan is 250 to 300 JD (DoS, 2005). Financial considerations are always an issue in terms of choosing a suitable treatment, especially with regard to private hospitals. In Jordan, the cost of treating ESRF varies between 15,000 and 20,000 JD per patient, including admission to hospital, surgery and access formation (to create venous access to enable dialysis). As mentioned above, this amounts to approximately 35 million JD per year for the whole country (DoS, 2009). Each dialysis session costs between 120 and 150 JD (AlGa'ad, 2007). Although most ESRF patients are covered for treatments, they may have to pay other costs such as ancillary medications, transport, further medical investigation, dialysis access and any further treatment, which can exhaust the finances of patients and their families. As a result of the financial implications, some nephrologists in Arab countries shy away from discussing the possibilities of renal transplantation with their ESRF patients (Chamsi-Pasha and Albar, 2014).

Summary

This chapter presented the context of the study. The chapter highlighted Jordan and provided background information about the Jordanian healthcare system. It emphasised the important considerations that influence ESRF treatment in Jordan. The next Chapter will identify relevant literature on spirituality.

CHAPTER 3: Literature Review

"Ask the veteran not the expert".

An Arabic proverb to the effect that lived experience might be more valuable than professional expertise.

Introduction

The overall purpose of this chapter is to develop a strong knowledge base and to establish a solid foundation of spirituality and spiritual care for ESRF patients. This involved identifying, selecting and appraising all research studies that related to the research question as suggested by Booth et al. (2012). This chapter is divided into four main parts: the first part presents the search strategy for relevant literature and summary of the selected published studies (see appendix 3). The second part presents the definitions of spirituality and highlights the major debates in the literature about the relationship between spirituality and religion. It also reviews the characteristics of spirituality and presents the link between spirituality and holism. The third part provides an overview of how spirituality is experienced by patients with a chronic illness. The fourth part presents the evidence for the shortage of studies in this field and how the reviews have grouped relevant research studies conducted in ESRF. It also discusses the major themes that emerged from literature review such as: spirituality and coping, spiritual dialogue, boundaries of spirituality and cultural diversity, spirituality and quality of life (QoL) and finally spirituality and palliative care. The final section identifies the research gaps in the existing literature and sets out the research aims and objectives, concluding with a brief summary of the chapter.

The Search Strategy for the Review of the Literature

I began my search of the literature by using key words, then identifying new references through citation. I expanded the search by including studies that focused on spirituality in other fields such as palliative care, HIV, cancer, chronic illness and care of the elderly medicine. This initially produced 902 references, but after identifying duplicated studies, the number was reduced to 544 which I have included in my EndNote library. These studies were screened for relevance via their title and abstract.

I soon realised that the focus of my literature search was not targeted enough to yield the most relevant studies for my research topic, nor were the key references in my study field clear or identified. However, this initial search assisted me in developing a better understanding of "spirituality" in general and how it intervenes with other medical, psychological, socio-cultural and religious disciplines, but did not uncover the evidence I needed for my study in relation to renal patients.

Further reading was carried out on how to systematically search the literature. I checked Burns and Grove (2009), Cohen et al. (2011) and Booth et al. (2012) on how key references could be selected from the literature search on issues surrounding spirituality and haemodialysis patients. This enabled the identification of a focused search strategy that included a specific description of my search question, key words and also developed inclusion and exclusion criteria that could produce and maximise the research studies that were most relevant to my topic.

Search Question

Booth et al. (2012) draw on an extensive range of sources to highlight the importance of the search question in order to define the scope of the literature review process. In addition, they justify that this will support the researcher to develop a review protocol, plan the search process and adhere to it. Thus, my research question was set as: 'What are the English (and Arabic) language research studies that have been published on the topic of spirituality for renal lived experience?

Search Strategy

The search was guided by following the PICO criteria, where "P" describes the Population (i.e. the ESRF patients), "I" describes the phenomenon of Interest (i.e. the patients' experiences) and "CO" stands for the context of the study (i.e. Jordan). Thus, three main key concepts were nominated to structure the systematic literature search in order to identify appropriate research studies that were relevant to my research. I should have inclusion and exclusion criteria that to Identify the key references. The inclusion criteria were any research that focuses upon: Spirituality, Renal and Patient Experience together, Arabic or English language. The exclusion criteria were any studies that main focuses was in spirituality or renal without relating the two, commentary and opinion papers and paper published in a languge other than Arabic or English.

For the purpose of my study the concept of 'Spirituality' was constructed from the main heading:

> 'Spirit*'; 'Spirit* comfort'; 'Spirit* distress'; 'Spirit* state', 'Spirit* care'; 'Spirit* healing', 'Spirit* need'; 'Spirit* assessment'; 'Spirit* adjustment'; 'Spirit*support'; 'Spirit*well-being'; 'psychological well-being'; 'faith* care'; 'faith*comfort'; 'faith* faith* care'; 'faith* well-being'; 'religion*'; 'religion* care'; 'religion* comfort'; 'religion* state'; 'Heal*'; 'grief*'; 'hope' and 'belief'.

The concept of 'Renal' was built from these key words:

> 'Renal*'; 'kidney'; 'Nephro*'; 'Urology'; 'dialysis'; 'peritoneal dialysis'; 'Hemodialysis', 'transplant*; 'End stage renal failure'; 'Chronic renal failure'; 'kidney failure' and 'chronic kidney failure'.

The concept of 'Patient Experience' was developed after using these combinations of the heading words:

> 'Patient*'; 'life experience'; 'work experience' and 'lived experience*'.

Databases Searched

The following databases were searched using the key words above:

- CINAHL (Cumulative Index to Nursing and Allied Health Literature).
- Web of Knowledge : this database encompasses:
  - BIOSIS Citation Index
  - BIOSIS Previews
  - Medline (US National Library of Medicine)
  - Journal Citation Report
- Web of Science
- Cochrane Library
- Applied Social Science Index and Abstracts (ASSIA)
- PsycINFO (Ovid)
- Manual search for the grey studies through the University of Nottingham e-catalogues for related books and unpublished theses was viewed.

No date restrictions were applied on the publication date or on the type of studies included. However, the searches were refined by English and Arabic language. In addition, the entire search processes were individually saved within the databases used and transferred to my EndNote library.

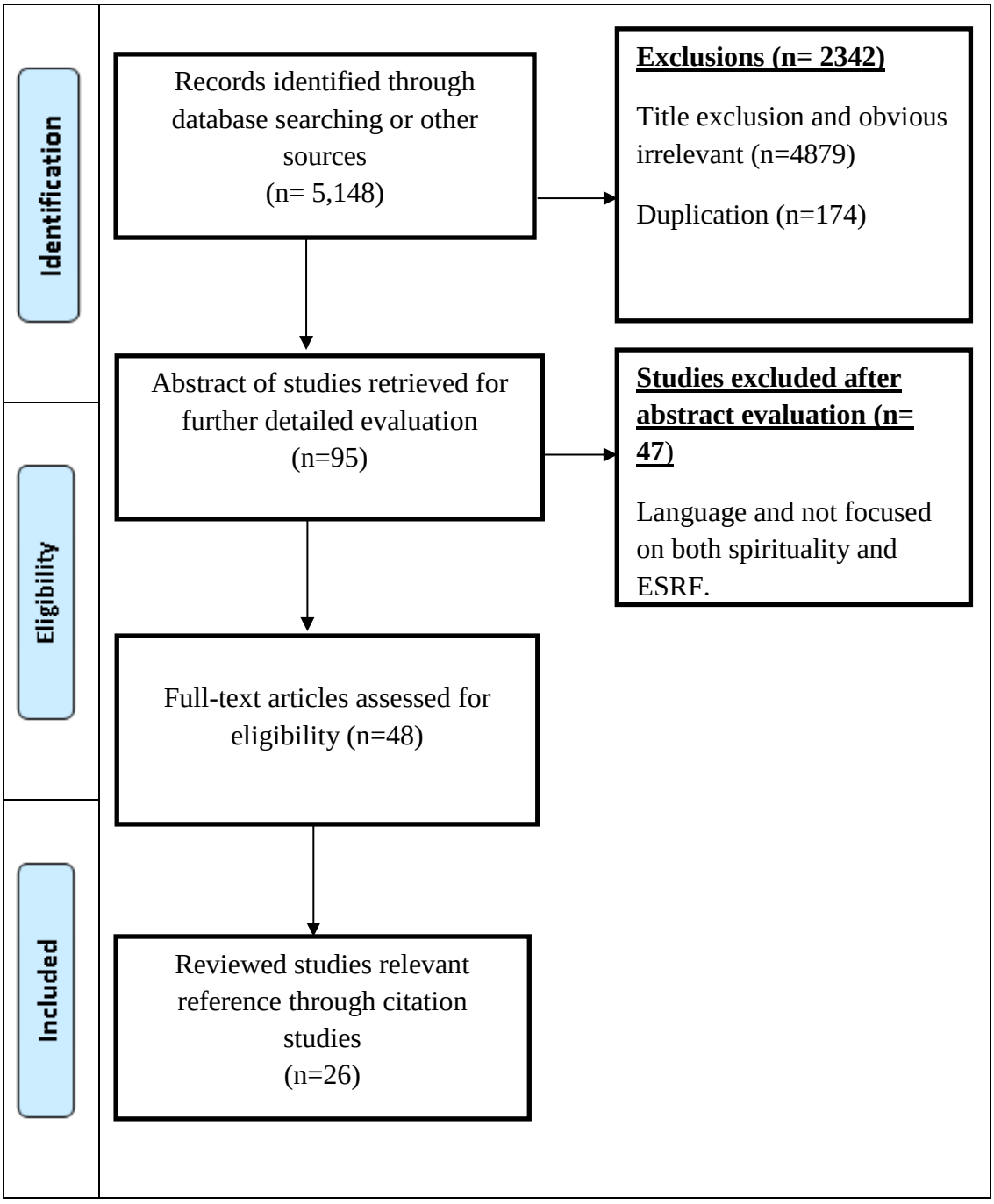
When the search of existing studies was narrowed down for ESRF, only 48 studies were recognised. The first study was from 1993 and the latest was from 2014. The majority of these research studies were conducted within North America and Europe, China, Brazil and Australia. All of them were exploring the meaning of spirituality from a Judaeo-Christian perspective. These studies were critically appraised by consolidated criteria for reporting qualitative research (COREQ) (Tong et al., 2007).

Table 3.1: Numbers of research studies published on spirituality for renal patients

Numbers of items published on:	Limits	Results
Spirituality*	Full Text, English and Arabic Language	518,820
Renal*		2,800,293
Patient experience*		42,810
Renal and patient experience		5,148
Renal and patient experience and Spirituality		74
Renal and patient experience and Spirituality and Jordan/or Muslim patient.		*NA Only 2 studies in Jordan that not focusing on ESRF.

* NA: Not Available.

Figure 2.1: Selection process for relevant studies



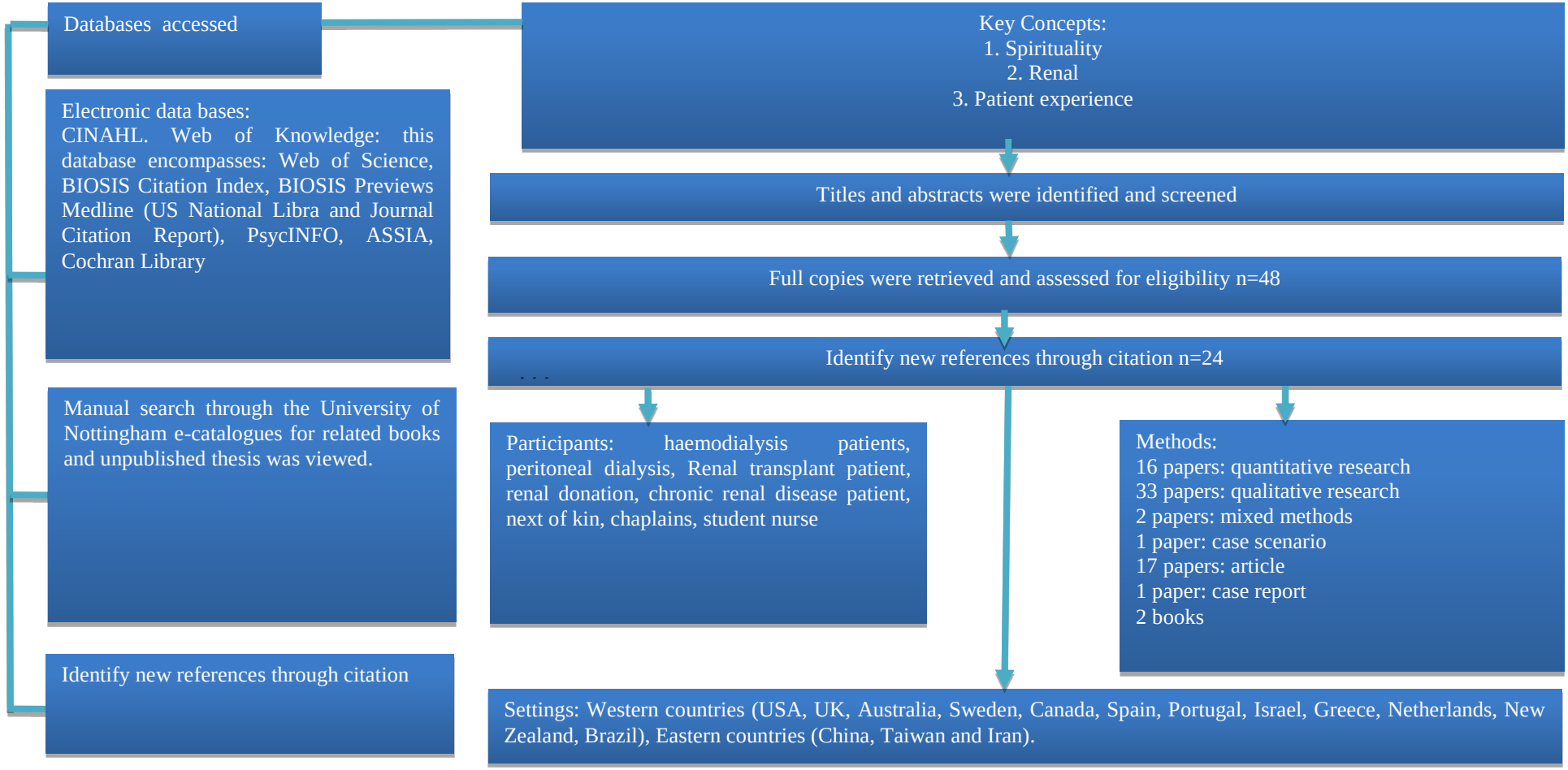
Summary of the Selected Published Papers

A summary and comments on the selected studies was tabulated into six columns which included: reference title, year and author; research study question or aim; sample setting and year; methods; focus area; findings, my thoughts and where I would refer the study back to my research see (appendix 3). The synthesis Table is presented at Appendix 3. After a consolidating criteria's for reporting qualitative study- i.e. COREC and CASP the rigorous in each study was identified then analysed. The main findings from the selected papers were collected separately and re-grouped for key themes according to their similarity, commonality, and differences. After a discussion with my academic supervisors, advice was given to include all of the nominated studies involved in the thematic synthesis from the above search because of the limited number that were found. The eight themes which emerged were obtained and presented under the following headings: Spiritual Coping and Spiritual Hope, Spirituality and A Sense of Fear and Uncertainty, Spirituality and Religion, Spiritual Help and Support, Spiritual Dialogue, Spirituality and Palliative Care, Spirituality and Quality of Life and Spiritual Boundaries and Cultural Diversity (see Table 3.2).

Table 3.2: Summary of themes that emerged after re-grouping of selected research

No.	Theme	No. of Papers
1	Spiritual Coping and Spiritual Hope	18
2	Spirituality and a Sense of Fear and Uncertainty	15
3	Spirituality and Religion	11
4	Spiritual Help and Support	11
5	Spiritual Dialogue	6
6	Spirituality and Palliative Care	6
7	Spirituality and Quality of Life	3
8	Spiritual Boundaries and Cultural Diversity	10

Figure 3.2: Summary for relevant the studies



The Definitions of Spirituality

This section is divided into five sub-sections. The first gives an overview of how spirituality has been defined as a concept in the literature and presents factors that lead to the ambiguity around spirituality. The second represents the debate in the literature in regards to the relationship between spirituality and religion. The third, introduces how spirituality is characterised in the literature. The fourth section presents the debate between spirituality and psychology and the fifth section presents the relationship between spiritualty and holism.

The review of the literature shows a wealth of studies concerning spirituality in nursing and in nursing care generally, presenting various definitions of spirituality (McSherry, 1997; Pike, 2011; Tanyi, 2002). Studies also suggest that there is an interest in spiritual needs (Balboni et al., 2011; Narayanasamy et al., 2004; Nixon and Narayanasamy, 2010) and emphasis on spirituality as a part of holistic care (Como, 2007; Ellis and Narayanasamy, 2009; Foster, 2006). In addition, researchers have noted the importance of spirituality in the healing process (Narayanasamy and Narayanasamy, 2008; Tanyi and Werner, 2008; Tanyi et al., 2006), improving coping mechanisms with long-term illness (Cotton et al., 2012; Narayanasamy, 2004), pain management (Delgado-Guay et al., 2011; Sato, 2011), psychological implications (Molzahn, 1998) and relationships between spirituality and religion (Brennan et al., 2008). Studies have also shown patients' strong need to include spirituality in their care (Davison and Jhangri, 2010). However, before giving the overall view of spirituality; it is important to define the term spirt.

According to the Oxford Dictionary (2012), "spirit" originated "from Anglo-Norman French, from Latin Spiritus 'breath, spirit', from spirare 'breathe'"; this meaning is consistent with other languages and religions (see Table 3.4) in terms of the following five different meanings and definitions in language:

> "The non-physical part of a person which is the seat of emotions and character; the soul. Also, it is the prevailing or typical quality, mood, or attitude of a person, group, or period of time. Additionally, it was described as the real meaning or the intention behind something as opposed to its strict verbal interpretation…. [chiefly British] strong distilled alcoholic drink such as brandy, whisky, gin, or rum… a highly refined substance or fluid thought to govern vital phenomena".

Spirituality has been identified and characterised differently according to different authors from different backgrounds (Clarke, 2009) (see Table 3.3). Several studies have thus proposed different interpretations of the meaning of "spirituality" based on the participants' demographic characteristic, religions, cultures and own understanding of the term of spirituality. The wide range of existing definitions of spirituality contribute to this debate (see Table 3.3), and different uses and meanings extracted from the concept by different studies have clouded the debate about what spirituality is and how it might be applied in nursing (McSherry, 2007). Nursing specialities including neuro-oncology and cancer (Albaugh, 2003; Nixon and Narayanasamy, 2010; Swinton et al., 2011); HIV (Tuck and Thinganjana, 2007); and renal failure (Duteau, 2010; Tanyi and Werner, 2008; Tanyi et al., 2006) have increasingly investigated the potential of "spirituality" over the last decade in many disciplines (Balboni et al., 2011; Nabolsi and Carson, 2011; Nixon and Narayanasamy, 2010; Whitford et al., 2008; Yang et al., 2010). Scholars of spirituality argued that existing definitions of spirituality produced misunderstandings (Baldacchino, 2010; Clarke, 2009; McSherry, 2007; McSherry and Draper, 1998; Mooney and Timmins, 2007). A possible explanation of this might be that previous researchers had investigated the influence of Christian theological traditions of Western spirituality from the broadest Catholic perspective, and hence the emergent understanding of spirituality may not necessarily be applicable to those of other beliefs, religions or cultural heritage. In addition, Clarke (2009) suggested that the main bias in research toward the identification of spirituality could be the attempt to find a broad, generic and existential definition. Furthermore, Clarke examined other reasons, for example, sources that nurses used to define spirituality, lack of research undertaken by healthcare researchers in theology and religion or even attempts to maintain a separation between spirituality and religion (Clarke, 2009).

All these factors have caused confusion in understanding spirituality. This confusion, according to Narayanasamy (2004), was identified as a barrier and a challenge to the application of research findings and recommendations in clinical practice. Moreover, it was a reason for the uncertainty surrounding the nursing role in fulfilling patients' spiritual needs i.e. the search for meaning, being loved, forgiveness, hope and strength (Narayanasamy, 2004). However, one common criticism that can be

levelled at most of the extant definitions is that their authors have not shown where their definitions came from (Clarke, 2009; Paley, 2008).

To better understand spirituality, I will provide an overview of spirituality as presented in the literature, divided into four important categories: Spirituality and religion, the characteristics of spirituality, the holistic approach and finally the influence of spirituality and the relationships between spirituality and psychology. The first category, aims to present the debate around the relationships between spirituality and religion, based on the existing definitions, the second part uncovers the characteristics of spirituality and presents the main dimensions of spirituality (the vertical and the horizontal dimensions) based on the definitions that attach our innerself to the world around us. The elementary characteristics of spirituality that can be extracted from the definitions in Table (3.3) are: inner person, appreciated to God, give and receive love, reflect on myself, inspiration, reverence, awe, meaning and purpose, understand their existence, meaning through sense relatedness to dimensions that transcend, relationship with the transcendental God, empowers and does not devalue the individual, faith, hope, peace, and empowerment, to be connected with others and our surrounding, as an inner source of power and energy, higher power, transcendence, community, religion, the mastery of creation and transformation. All these are extracted from the existing definitions of spirituality and can potentially provide different platforms and different frameworks to address individuals' spirituality and spiritual needs. The last part looks at the difference between psychology and spirituality and how they are influenced and connected with each other. Gaps in the literature in respect of ESRF patients are briefly presented at the end of this chapter.

Spirituality and Religion

Within the numerous studies that have discussed spirituality as a phenomenon in nursing (Albaugh, 2003; Ameling and Povilonis, 2001; Touhy et al., 2005), there are two major opposing paradigms: one supports the idea that spirituality is not part of religion (Béphage, 2008; Davison and Jhangri, 2010; McSherry, 1997; McSherry and Draper, 1998), and the other supports the notion of spirituality as a part of religion (Hall and Livingston, 2006; Nabolsi and Carson, 2011).

Table 3.3: Definitions of "spirituality" in healthcare

Authors	Definitions
Stoll (1989)	"Spirituality is my being: my inner person. It is who I am-unique and live. It is me expressed thought my body, my thinking, my feeling, my judgments, and my creativity. My spirituality motivates me to choose relationship meaningful and pursuits. Through my spirituality I give and receive love; I respond to and appreciated to God, other people, a sunset, a symphony, and spring. I am driven forward, sometimes because of pain, sometimes in spilt of pain. Spirituality allows me to reflect on myself. I am a person because of my spirituality-motivated and enabled to value, to worship, and to communicate with the holy. The transcendent".
Murray & Zentner (1989)	"A quality that goes beyond religious afflation that strives for inspiration, reverence, awe, meaning and purpose, even in those who do not believe in any good. The spiritual dimension tries to be in harmony with the universe, and strive for answer about the infinite, and comes into focus when the person faces emotional stress, physical illness or death".
Males & Boswell (1990)	"It is not easy to define spirituality since it concerns the way in which men and women may understand their existence and the action which comes from an understanding; the knowledge of things both within an individual and of the existence and importance of things beyond him or her. It is important to point out this knowledge is not the grasp of intellectual facts but rather a reverence for mysteries of life which no-one can fully understand. It is not, therefore, something which can be regarded as being unattainable for people with learning disabilities".
Reed (1992)	"Specifically spirituality refers to the propensity to make meaning through sense relatedness to dimensions that transcend the self in such way that empowers and does not devalue the individual. This relatedness my experienced interpersonally (in the context of others and the natural environment) and transpersonal (referring to a sense of relatedness to the unseen, God, or power greater than the self and ordinary source)".
Tanyi (2002)	"Spirituality is a personal search for meaning and purpose in life, which may or may not be related to religion. It entails connection to self-chosen and religious beliefs, values and practices that give meaning to life, thereby inspiring and motivating individuals to achieve their optimal being. The connections bring faith, hope, peace, and empowerment. The results are joy, forgiveness of oneself and others, awareness and accepted of hardship and mortality, a heightened sense of physical and emotional well-being, and the ability to transcend beyond the infirmities of existence".
(cited from McSherry, 2007, 28)	
Narayanasamy (1999b p 123-124)	"in the biological basis, Spirituality is rooted in an awareness which is part of the biological makeup of these human species. Spirituality is presented in all individuals and it may manifests itself as inner peace and strength derive from a perceived relationship with the transcendental God, ultimately reality or whatever an individual values as supreme".
Narayanasamy (2006a)	"The inner, intangible dimension that motivates us to be connected with others and our surroundings....the guiding force behind our uniqueness (that) acts as an inner source of Power and energy, which makes us "tick over" as a person.' Spirituality is the essence of our being and it gives meaning and purpose to our existence".
Broman & Dixon (1999)	"Spirituality .... Pertains to one's relationship with others, with oneself and with one's higher power, which is defined by individual and need not be associated with a formal religion".
Lapierre (1994)	"Six clear factors... appear to be fundamental aspects of spirituality... those of the journey, transcendence, community, religion, the mastery of creation and transformation".
(cited from Aldridge, 2000, 28)	

Paley (2008) argued for why spirituality should not be attached to a religion nor to any high-power based on his critical analysis of the above definitions of spirituality. On his historical analysis of the transition of Western society from being a religious society towards becoming a secular society, he argued that the lack of evidence and proof was an important reason why we should not relate spirituality to religion, since it cannot be scientifically justified. The key problem with the notion of "scientifically approved" is that there seems one specific way of knowing compare to other in which the scientists themselves keep the myth in epistemologically knowing anything (Aldridge, 2000). Furthermore, the literature suggests that individuals discover their way without scientific background. Also, individuals know their body's needs including their spirituality without resort to scientific measurements (Aldridge, 2000). Historically, the foundations of the relationship between spirituality and religion have been a subject of deep philosophical probing, as reflected in the studies of Otto and Laski (Cook, 2003; Gitre, 2006; Kristo, 1982; Poland, 1992)(see Appendix 2). For example, Otto (1950) suggested that:

> "In the crisis situations, such as illness, this connectedness may increase the individual's morale and may relieve spiritual distress. The numinous experience, the feeling of self-insufficiency may trigger self-transcendence. This enables the person to go beyond him/herself to reach God's help, with resultant empowerment to live through crisis situation, with a positive outlook toward life" (Baldacchino, 2010, pg 1).

As illustrated in Table 3.3 spirituality is seen as part of religion or appreciation to God (Stoll, 1989, Reed 1992 Broman & Dixon, 1999, Lapierre 1994, Tanyi 2002 Narayanasamy 1999b). The definitions of spirituality show that spirituality can lend itself to religion by using phrases such as: appreciated to God; the transcendent with high power; religious beliefs; values and practices that give meaning to life; relationship with the transcendental God – some of them even mention "religion" in their definitions. Thus, authors presented a link with God or a higher power as the vertical understanding of spirituality in which in vertical connectedness are very subjective terms as it can be varies from one to another. In addition, O'Connell and Skevington (2010) claimed that religious people had higher levels of spiritual quality of life.

However, from a secular society perspective, for those who categorise themselves as "non-religious", Baldacchino and Draper (2001p.835) argue against the aforementioned vertical understanding of spirituality. They claim that: "if spirituality is defined only synonymously with religion and belief in God, then several persons, namely the atheists, agnostics, humanists and hedonists, would be excluded from the possibility of using spiritual coping mechanisms. Therefore, spirituality applies to both believers and non-believers". This view was later echoed by Narayanasamy (2006a) who stated that such people typically claim to be "spiritual". This commonly deployed, but vague term, needs to be conceptualised and defined if it is to be used in healthcare literature and incorporated into nursing practice. It is argued that meanings from previous definitions of spirituality - such as: inspiration, reverence, awe, meaning and purpose, quality, hope, peace, and empowerment, surroundings, relationship , community - are all referring to the horizontal understanding of spirituality in which these terms can be tested and quantified.

Nowadays, while the above definitions may provide a generic and broad understanding of spirituality and the correlation between spirituality and religion, some might argue that the application and meaning of spirituality is subject to individual interpretations (Baldacchino, 2010). In other words, different meanings of spirituality can be extracted from different individuals (McSherry, 1997; McSherry et al., 2004). However, Compton and Hoffman (2013) suggested that religion and culture are the most influential factors that affect individual interpretations, thoughts, and actions with relation to the external world, although, some could argue that religion can form culture.

For example, in Jordan, religion plays an important role in shaping some community interactions and it has significant inspirations in forming and reforming the way in which Jordanian people, and other Muslims, interact with each other. Multiple aspects of the Jordanian day-to-day life activities are based on a set of religious obligations (Hall and Livingston, 2006) such as birth, meeting, greeting, personal hygiene, modesty, dress and decorum, special dietary requirements, fasting, family planning, sexuality and intercourse, abortion, care in serious (or final stages of) illness, blood transfusion / transplants, organ donation, spiritual advisor / counsellor, death, religious symbols, post-mortem and burial.

These aspects have become part of the social and cultural norm in Jordan. Furthermore, modesty for example, in both men and women has Islamic obligations: in the same that way Islam requires women to cover their hair and wear the Hijab and long dress, Islam also requires men to cover their body from the naval to below the knee. It became culturally unacceptable to see a man wearing above the knee shorts in the same way it is considered unacceptable to see women in miniskirts. In addition, Islam requires women and men not to expose their body to strangers (Zeilani, 2008). However, others argue that culture can form religion. For example, until recently, marriage was classified as a relationship between husband and wife based on the teachings of all of the Abrahamic religions which prohibited any sexual relationship outside matrimony (Gilbert, 2008). In Jordan it is acceptable for a Jordanian Muslim male to have sexual intercourse with his wife at any time after the marriage registration, but, it is not culturally accepted to have such relationship before the actual wedding day. Nowadays, the secular movement within society has forced religious leaders in some countries to accept gay, lesbian and transsexual marriages. In terms of spirituality, Lebron (2012) argued that the unity of civilians is important in spirituality regardless of their sexuality. In contrast, in Arabic-Islamic cultures, such unity with the same gender is prohibited and persecutors penalised people engaged in such relationships (Chapman, 2010).

Religion can be considered as contributing to the confusion in understanding spirituality (Paley, 2008). However, religion can also be seen as a platform from which to understand spirituality and to address the individual's spiritual needs according to their social interactions, values and beliefs. In fact, scholars highlighted how religion and religious practices could be the best way to offer the love, appreciated to God, the transcendent with high power, religious beliefs, values and practices that give meaning to life. (Narayanasamy, 2002; Ross, 1995). In the view of the holistic care approach, religion within the Arabic-Islamic culture is an integral factor that cannot be separated from culture as it influences the day-to-day activities of individuals (Nabolsi and Carson, 2011).

Taken together, scholars have argued that everyone can still enjoy their life meaningfully through love, work, human interaction, socialising, family, friends and by adopting the secular version or the horizontal dimension of spirituality, as well as

by transcending relationships - and here I am referring to the vertical dimension or the religious view of spirituality.

Before proceeding to examine spirituality further, at this stage, it will be necessary to define "religion" as Baldacchino and Meyer (2001) suggested as, "A body of beliefs and practices shared by a commonality of people as necessary to establish a relation the deity or to be in harmony with ultimate reality" (Baldacchino, 2010, p 24).

Table 3.4: The meaning of "spirituality" in different languages

The term Spirituality (which originated from Latin Word Spiritus)

Language	Version of "Spiritus"	Related word	Meaning
Greek	Pneuma	Pneumatum	Air, Breath, Spirit
Hebrew	Ruah	Nefesh	Spirit, Soul
Maltese	Ruh	Nifis	Breath
(Baldacchino, 2010 , pg25)			

As mentioned previously, Muslims extract their values, beliefs and understandings from the Qur'an. As a Muslim, while reading the literature concerning the conceptualisation and definition of spirituality, I became intrigued as to whether the term "spirit" had a corresponding word in Arabic, and whether it has any particular meanings in Islam or whether the "spirit or AL Rouh الروح" or "spirituality Or Al-Rouhaniay الروحانيه" is a matter of acculturation with Western culture. Before employing these meanings to examine spirituality, it is necessary to examine the notion of "Spirit" "الروح" and how it has been identified in numerous instances in the Qur'an. I conducted a more detailed search and identified different meanings in the Qur'an that could be useful, such as: command from Allah, reminder, hope, an expression for divine revelation, Archangel Gabriel, the victory of the faithful over their enemies in the world, sense of victory, inner comfort from worldly things, Allah's power and capabilities, support and strength, guidance, inspiration and warning (see Table 3.5). In addition, a broader understanding from those Islamic terms can be taken even from an Islamic view; it is fair to suggest that both vertical and horizontal meanings are acceptable.

Table 3.5: Representations of spirituality in the Qur'an

'Spirit' and related words	Verse	Meaning
"And they ask you about the (Al-ruh) spirit. Say, 'the Spirit is something from the command of my Lord, and you are given the Knowledge but a little'"	85:17	(Spirit- Al-Ruh) of the terms that fought people in their definition and statement nature, and floundering philosophers in determining the nature and stand up for what they are, which is at the end of the meanings that accounted for God's awareness was, and did not make a person a way to know, knew it from the known. **Spirit is the mastermind of the hull which are done of his life**
"He sends downs the angels at his behest with spirit (that is, the revelation), upon whom He wills from among His servants"	2:16	(Spirit-Bel-Ruh), **command from Allah to warn people** that there is no God but Allah, so fear Allah.
"In Similar way, we have revealed to you Ruhana from our command. You did not know what was the book (Qur'an) or what was the Iman, But we have made it a light which we guide whomsoever we will from our servant"	53:42	(Spirit-Ruhana) the term refers **to an expression for divine revelation conveyed** by the Archangel Gabriel, and the Qur'an, **an Inspiration, and a Mercy**.
"On the Day that Spirit and the angles will stand in rows. They will not speak, except the one who is permitted from the Rahman (Allah). And they speak right"	38:78 87:2	
"..And we gave clear signs to Isa, Jesus, the son of Marry) and we supported him with the Holy Spirit"	102:16	
"Say, "This has been brought down by Ruh-ul-Qudus (the Holy Spirit), from your Lord rightly, So that it may bring firmness to the believers and become guidance"	5:110	
"O 'Iesa (Jesus), son of Maryam (Mary)! Remember My Favour to you and to your mother when I supported you with Ruh-ul-Qudus"	16:102	(Spirit-Be Ruwh) this refers to the **Archangel Gabriel**
"Say Ruh-ul-Qudus has brought it (the Qur'an) down from your Lord with truth, that it may make firm and strengthen (the Faith of) those	26:193	

who believe and as a guidance and glad tidings to those who have submitted (to Allah as Muslims).	70:4	
"Which the trustworthy Ruh has brought down"	78:38	
"The angels and the Ruh ascend to Him in a Day the measure whereof is fifty thousand years"	98:4	
"On the Day that Ar-Ruh or and the angels will stand forth in rows, none shall speak except him whom the Most Beneficent (Allah) allows, and he will speak what is right"	19:17	
"Therein descend the angels and the Ruh by Allah's Permission with all Decrees"	19:91	
"She placed a screen (to screen herself) from them; then We sent to her Our Ruh and he appeared before her in the form of a man in all respects".	66:12	
"And (remember) she who guarded her chastity [Virgin Maryam (Mary)], We breathed into (the sleeves of) her (shirt or garment) through Our Ruh		
"And Maryam (Mary), the daughter of 'Imran who guarded her chastity; and We breathed into (the sleeve of her shirt or her garment) through Our Ruh"		
"they are such that Allah has inscribed faith on their hearts, and has supported them with a spirit from Him"	22:58	(Spirit-be-Ruwhen) in this verse refers **to the victory** of the faithful over their enemies in the world, and names them the **spirit of victory**; ordered them because it live. It was: (Spirit) in the sense of the verse here: the proof.
"O My Sons, go and search for Yousof and his brother, and do not lose hope in the spirit of Allah; in fact only, Only the infidels lose hope in Allah's Spirit"	87:12 171:4	(Spirit-Ruawh) refers to **the Hope and the Mercy of Allah.**

"…And His word that he had delivered to Maryam (Mary), and a spirit from him. So Believe in Allah"		
"then, Spirit there is comfort and fragrance and garden of blessing"	89:56	(spirit- Fa-Ruwhon)refers to the **inner comfort from worldly things**
" When I form him (Adam) perfect, and blow in him of my spirit, then you must fall down before him in prostration"	29:15	(Spirit-Men-Ruhana) refers to **Allah's Power and capabilities**
"He sends the A-Ruh by His Command to any of His slaves He wills, that he (the person who receives inspiration) may warn (men) of the Day of Mutual Meeting (i.e. The Day of Resurrection)	40:15	(Spirit-Al- Ruh) **Inspiration, warn**
"For such He has written Faith in their hearts, and strengthened them with Ruh (proofs, light and true guidance) from Himself"	58:22	(Spirit-Be Ruh) **Support and strengthened, guidance**
"Then He fashioned him in due proportion, and breathed into him form our Ruhana"	32:9	(Ruhana) Command from Allah, **Breathed of Allah spirit.**
"So when I have fashioned him and breathed into him (his) soul created by My ruhy, then you fall down prostrate to him."	38:72	

The Holy Quran, Translated to English using the Quran Explores apps. Free version Downloaded on February 2014.

Table 3.6: Elements of Al-Ruh (spirit) in different religions

Religion	Appearance	Meaning
Ancient Egyptian religion	Ib, Sheut, Ren, Ba, Ka and Akh	Heart, shadow, name, soul and vital spark
Hinduism	Ātman, Jiva or Jeev and Purusha	Soul, part of Prakriti (nature).
Buddhism	The body (physical), the senses, perception, karma (actions of the organism, and the ethical consequences resulting from actions) and conscience	Federation of time and emergence of these concepts
Judaism	Nephesh, Ruach, Neshamah, Chaya and Yechidah	Related to natural instinct, related to emotion and morality, related to intellect and the awareness of God, considered a part of God
Christianity	Soul	Spirit, soul
Islam	Al-Ruh	Breath, Allah's command
		Adopted from (Baldacchino, 2010)

In Jordan, Muslims facing illness strongly believe in nursing using a set of religious practices and beliefs, and they conceptualise illness, as with other life events, through the prism of religious belief; the exclusion of religious values and beliefs constitutes an exercise of failure (Nabolsi and Carson, 2011). In Islam, the body of religious beliefs are well established and known as the "Pillars of Islam". These pillars are the fundamental obligations required of every able-bodied and sane adult Muslim (they are waived in the case of those prevented from performing them, e.g. children or the disabled), comprising a comprehensive way of life and worship "Ibadah عباده". Practising Islam has implications for Muslims in every aspect of life (Nabolsi and Carson, 2011). The Five Pillars of Islam are: (1) the Shahada (declaration of faith that Allah is the only God, who is absolute and has no associate in divinity); (2) five obligatory daily Prayers (Al-Salah); (3) obligatory Fasting during Ramadan (Al-Sawm); (4) obligatory Almsgiving (Al-Zakah, 2.5% of capital maintained over a one-year period) and (5) one obligatory Pilgrimage to Mecca (Al-Hajj) (Mawdudi, 2000; Pierce, 2012). These ritual obligations represent the manifestation of belief in action in the life of a Muslim; thus, individuals' awareness is important in transcultural communication (Samovar et al., 2013).

In addition, the Pillars of Islam are supplemented by the Pillars of Iman (loosely translated as 'faith'), namely belief in: Allah, His angels, His books (e.g. the original Torah, Gospel and Qur'an), His messengers, the Last Day (the Day of Judgement) and Al- Qadar, the complicated notion of destiny (e.g. all good and evil occurs by divine decree, but action and free will are obligatory, and people must accept whatever happens with patience, resilience and gratitude) (Zeno, 1996 p 16).

Despite several research studies distinguishing the correlation between spirituality and religion (Davison and Jhangri, 2010; McSherry, 1997), in Arabic countries spirituality is overwhelmingly experienced in the form of Islam (Hall and Livingston, 2006). However, nursing literature suggests that there is a shortage of researchers studying and exploring the relationship between Islam and spirituality within Western healthcare settings (Clarke, 2009). This separation between Islam and spirituality means, that for this study, the spirituality discourse of previous studies related to this field needs to be reconciled with the spiritual meanings that Muslim patients attach to their illness and healthcare. By way of an example, three studies exploring the perceptions of spirituality and spiritual care among NHS nurses in the UK argued that spirituality can be separated from religion (McSherry, 1997; McSherry and Jamieson, 2011; Ross et al., 2014).

Although, McSherry (1997) stated that belief in God is no longer important to individuals; such crude generalisations are not applicable far beyond McSherry's own Catholic modernist/secular view within the West. Nevertheless, from the holistic approach, religion is part of being in the world, and for billions of people worldwide, belief in the Divine is a central part of their identity. As stated above, Islam has shaped the day to day activity for Muslims (Hall et al., 2011). Thus, I could argue that religion might still be an important part of spirituality and it will therefore be difficult to separate spirituality from those who are religious, since religions can offer much in terms of the vertical meanings I mentioned above. Despite this, from a secular view of spirituality, Paley (2008) argued about the false relationships between religion and spirituality. Since existing definitions of spirituality, such as shown in Table 3.3 fail to provide any scientific evidence of where how they were derived, Paley has assumed they represent the authors' preferences. To some extent I could agree with his argument especially the transitional movement of Western society from being religious to becoming a secular

society (Paley, 2008; Paley, 2008). In other words, religion has no influence on individuals where religion has no meaning to them. Thus, it could be inferred that to promote a relationship between religion and spirituality would be meaningless. I would however disagree with Paley, as his argument may have been built on the basis of such a transitional move within society and not in what vertical terms such as meaning and purpose, transcending and inner peace that religion can offer. In other words, he focused in the word of religion not on the function of religion. The question yet to be asked of Paley is how his argument would be compromised if the transitional move of western society was to shift back to being a religious society.

Secondly and in spite of the above, the studies by (McSherry, 1997; McSherry and Jamieson, 2011) proclaimed that their samples included the major faiths, and they provided justification to the validation process for their questionnaires. However, the questionnaires used were adapted to the Western (Christian) traditions of understanding spirituality and spiritual care. Hence, it seems likely that in both studies, the questionnaires will not have captured all the spiritual dimensions of the major religions. Markham (1998) indicated that in Western culture, individuals from different faith backgrounds may reflect a secular version of spirituality, or the horizontal dimension mentioned above. In phenomenological terms, this view could be seen according to Heidegger (1962) as the Das Man or "the they", concerning the relationship between the individual and society. In consideration of a recent study suggesting that 31% of nurses working in England are from oversees (Borland, 2014), the authors are unable to justify whether their participants' perception was a matter of acculturation with the Western understanding of spirituality (McSherry and Jamieson, 2011, McSherry, 1997), or was their enculturation view of spirituality. It is therefore possible that the questionnaires were not sensitive enough to detect such diversity in nurses' views of spirituality.

Thirdly, and most importantly, McSherry's studies were conducted within the NHS in England, where they contributed significantly to the growing body of literature in spirituality; however, it seems that the authors undervalued the use of language in their discussion of spirituality. The authors stated that questionnaires were administrated only in the English language and indeed it might seem reasonable to argue that there should be no requirement to distribute questionnaires in different languages when English is the main language in the UK. However, one major

drawback of using one language is that the word “spirituality” may not necessarily mean the same thing in different cultures. For example, if McSherry asked me my view of spirituality in English, I might give him a different answer than that I would give were he to ask me in Arabic, as my English answer would be coloured by thoughts generated from my understanding of the Western traditions’ understandings of spirituality (i.e. an acculturated answer). Conversely, my Arabic answer would represent enculturation and would reflect my clear intrinsic understanding of spirituality. On one hand, according to Swinton (2001), spirituality is a language: on the other hand, Waaijman and Vriend (2002) argued that spirituality can lend itself to the cultural language in which it expresses itself. Aldridge (2000) addresses this by drawing on an extensive range of sources to highlight the importance of language as a key tool in understanding spirituality; language enhances our repertoire of healing in both vertical transcending and horizontal dimensions. Thus, researchers and health care providers are required to consider this tool in understanding an individual’s spirituality. It follows that, those who argue for the separation of spirituality and religion fail to distinguish between the importance of cross-culture competence research and its implications in the participants’ responses. Draper and McSherry (2002) and (Markham, 1998) both state that any attempt to do so is perceived to be impossible, theoretically and culturally. Thus, it is fair to say that the ham-fisted attempts by previous studies to separate spirituality from religion to produce a cheap, one-size-fits-all paradigm does a disservice to the cosmopolitan and multicultural customers of modern healthcare systems.

Ross et al. (2014) using a cross-sectional, multinational, descriptive survey design aimed to describe how student nurses/midwives from 13 different EU countries perceived spirituality/spiritual care and how competent they perceived themselves to be in delivering spiritual care, I was fortunate enough to attend a spirituality conference where this study was presented in Lisbon (2013). After the presentation finished, I raised some concerns about the methodology of this study, arguing that the researchers failed to capture the subjectivity of the concepts of spirituality: I felt that the researchers needed to assess the correctness of their theoretical understanding of spirituality, including that of the healthcare providers. Although the authors presented some debate about the ambiguity surrounding spirituality, I was surprised to hear that all the participants in this study, from 13 different countries,

produced the same responses in the multiple questionnaires they used. Of course, some may disagree with my argument and claim that these questionnaires had already been validated and were therefore suitable for an exploratory study. Below is a summary of the question I raised. However I was unconvinced by the answers I was given:

- How could you explain the fact that all your participants from 13 different countries with different languages, religions, cultures, minds and even genetics were able to produce such homogenous attitudes toward so elusive a concept as spirituality?

All of these elements are phenomenologically important in terms of the unique spiritual experience presented by each participant, which could add other meanings to understanding spirituality in this context. This contradicts other studies conducted by the same authors. For example, Ross et al. (2013) stated that a student's own spiritual wellbeing, belief system and healthcare experience are important factors that affect the understanding of spirituality and competence in delivering spiritual care. In addition, McSherry and Ross (2002) specified that the phenomenon of spirituality is subjective, meaning different things to different people and having different elements for everyone. However, the main weakness of the Ross et al study was its failure to address how those elements can address spirituality differently for diverse participants. Instead, the authors in Ross et al. (2014) showed how the participants shared almost identical responses toward the meaning of spirituality and spiritual care! It should be noted that these tools comprised five different questionnaires based upon different theoretical assumptions. A qualitative study with detailed analysis (e.g. inductive approach) would have produced a more comprehensive and nuanced understanding of spirituality than that ultimately achieved by Ross et al. (2014).

Closer scrutiny of the methodology used in this study revealed that the authors sampled students at their own universities, thus raising the possibility of bias due to participants responding with a view to fostering social desirability. Moreover, it seemed that the authors share the same academic language in terms of choosing and constructing one definition of spirituality and spiritual care for their study despite the fact they all claimed in previous years that there is "ambiguity" and "subjectivity" surrounding spirituality (Baldacchino, 2010; Cone and Giske, 2013; McSherry et al., 2004; Narayanasamy, 2004; Ross et al., 2014; van Leeuwen et al., 2013). Authors

routinely pay lip service to the ambiguity of spirituality, while covertly promulgating a shared understanding of what they understand spirituality to be. They agreed about the ambiguity and the subjectivity of such concepts; in a recent study, they agreed to the objectivity and the quantification of spirituality. This fundamentally rooted from an attempt to construct amalgamated spiritual care for everyone. Aside from the impracticability of this in terms of spiritual care provision, there is an obvious methodological flaw given that surveys cannot provide accurate measurements of individuals' spirituality. Thus, I would argue that the academic model of spirituality used by the authors fails to capture the diversity of spirituality even across different EU countries. It is unclear whether the participants misunderstood what the above study aimed to achieve, or whether the academic model, surveys and questionnaires, failed to adequately incorporate the ways in which the participants viewed their spirituality. On reflection, the most important of these criticisms is thatRoss et al. (2014) failed to note that spirituality is very difficult to measure in positivist approach from a very diverse group.

However, in spite of studies that separated the role of religion in spirituality, it has been demonstrated that in patients with chronic illness, the use of religion and religious activities has provided inner comfort, help and support, finding meanings and purpose through illness (Cotton et al., 2012; Lagman et al., 2014; Walton, 2002; Walton, 2007). Cotton et al. (2012) and (Paula et al., 2009) conclude that religion is important for both patients and their family in coping with chronic illness. Rasic et al. (2009) examined the association between religious activities, spirituality and suicidal ideation and suicidal attempts in the general population in Canada. They found that attending religious activities was associated with decreased odds of suicidal ideation.

Considering the overall evidence that addresses the relationship between spirituality and religion together, it can be seen that religion has been viewed as part of the issue as well as a platform from which to address an individual's spirituality and spiritual needs. However, shortage of studies that addresses Islamic views in Jordanian ESRF patients more precisely leads us to speculate how spirituality can be addressed.

In summary, these results suggest that it is still acceptable to view spirituality from the vertical and horizontal understanding, which connects individuals to both the internal and external world. The literature suggests many models to understanding

spirituality such as Stoll's two dimensional model (1989) and Narayanasamy's ACCESS model (1999). These models and others will be explored in detail in the next section.

Characteristics of Spirituality As It Appears In Literature

Stoll (1989) shaped a model that emphasised the vertical and horizontal nature of understanding spirituality and how spirituality might be understood. Stoll referred to the vertical dimension as the transcendental connections between individuals and the high power or "God" or any values or beliefs that individuals may hold. She also referred to the horizontal dimensions to describe the interrelationships between the inner self and others. Stoll drew the attention to three main domains in her model which are love, trust and forgiveness as a way to help individuals in expressing their individual needs. This was later labelled in the literature as "spiritual needs". Stoll argued that these spiritual needs helped individuals to develop meanings and purposes in their life (Stoll, 1989). Stoll's model contributed significantly to progressing our understanding of spirituality and spiritual needs from the universal perspective.

Narayanasamy (1999) created another model, the ACCESS model (see table 3.7), based on studies conducted in 1999 (Narayanasamy, 1999; Narayanasamy, 1999; Narayanasamy, 1999; Narayanasamy, 2002). Narayanasamy suggested five domains in addressing individuals' spiritual needs. These are: communication; cultural negotiation and compromise; establishing respect and rapport; sensitivity and safety. These domains, to some extent, mirror Stoll's model in that both models explore the relationships between the vertical and the horizontal dimensions. However, the ACCESS model offers a comprehensive account to identify spiritual needs that are normally experienced by patients in order to guide nurses and healthcare professionals in healthcare sittings (Narayanasamy, 2001, p21).

Similarly, Otto (1958) referred to two important experiences of spirituality Holy and mysterium/wholly. Holy experience is related to the relationship between the behaviours and attitudes of individual's with the belief system. These include ethical, righteousness, abiding of the moral values and adhere to the belief of specific religion. The mysterium experiences yields an experience of awe, being in fear and sense of nothingness. However, Otto stated that the numinous experience feelings

may simulate individual's spirituality and inspired him to reach inspirations, tranquility and salvations and harmony in life. As a result, Otto (1958) reported that the "strange harmony of contrasts" of the numinous experience may have a positive and vital change in individual perception and attitude with appositive outlook to life. Thus, the notion of wholeness may refer to the spiritual dimension of individual (Baldacchino, 2010).

Table 3.7: ACCESS model to identify spiritual needs

Assessment	**Focuses on cultural aspects of patients' lifestyle, health beliefs and health practices.**
Communication	Be aware of variation in verbal and nonverbal responses.
Cultural negotiation and compromise	Become more aware of aspects of other people's cultures as well as understanding client views and explain their problems.
Establishing respect and rapport	A therapeutic relation that portrays genuine respect for clients' cultural beliefs and values.
Sensitivity	Deliver diverse, culturally sensitive care to culturally diverse groups.
Safety	Enable clients to derive a sense of cultural safety.

The copy right permission was verbally obtained from Dr Aru Narayanasamy in May 2014 to be used in this study (Narayanasamy, 2001, 21).

However, the above definitions do support the argument that a great deal of "ambiguity" and "subjectivity" surrounds spirituality. Given the fact that almost everyone appears to have vertical and horizontal elements to cope "spiritually روحانيا" with illness, it could be assumed that spirituality belongs to everyone (Baldacchino and Draper, 2001; Draper and McSherry, 2002; McSherry and Ross, 2002; Paley, 2008). However, in each model, the overall arching notion is that they both recognise important elements to understanding individual spirituality. These elements include meanings and purpose in life, horizontal and vertical dimensions, values, beliefs and culture. These elements will be discussed separately in the next section in relation to Arabic-Islamic views and ESRF.

A great deal of previous research into spirituality has focused on meanings and purpose in life. For example, Frankl (1984) and (Frankl, 2006) argued that finding meaning and purpose in his life was an important source to strengthen himself in his ordeal in the death camp during Hitler's regime. Frankl stated: "life is not for a quest

of pleasure, as Freud believed, or a quest of power as Alfred Adler thought; but a request of meaning. The greatest task for any one is to find meaning in his/her life" (Frankl, 2006, p2). Frankl claimed that he survived the death camp experience by maintaining hope, thoughts of his wife, and dreaming of lecturing after the war. However, in contrast, he noticed that those who lacked such hope and meanings of life died first. Gilbert (2011) added that signs of spiritual pain or distress include: anger, bitterness, regret, guilt, doubt, fear, isolation and loss of hope. Frankl also identified two levels of meanings, these are: meanings from the moment that we experience (existential) and ultimate meaning of our existential (ontology). In addition, Baldacchino (2010) stated that helping patients finding meaning and purpose is the aim of spiritual care. Baldacchino argued that identifying patients' spiritual needs and providing spiritual care accordingly led to spiritual well-being and enhanced patients' inner strength (Baldacchino, 2010). Therefore, it is vital to provide spiritual care to ESRF patients, especially when signs of spiritual pain or distress are evident. However, healthcare professionals may experience difficulty in understanding the belief and the value of individuals towards illness, especially when spiritual coping does not exclusively originate from religious beliefs (Paley, 2008). For instance, in the face of illness, Muslims turn to a set of religious practices and beliefs to find meanings and purpose and to enhance their inner strengths and find inner peace. They extract both vertical and horizontal meanings and purpose in life in every day-to-day activity. It is stated in the Qur'an that "the ones who believe and their hearts are peaceful with the remembering of Allah, certainly, the hearts find peace only in the remembrance of Allah" (Qur'an 13: 28). Aldridge (2000) argued that both the suffering and the nurture of illness have meanings and values; losing these meanings and values can lead to suicidal thoughts.

As per the discussion above, it appears that using a model like ACCESS is appropriate in providing a comprehensive assessment for both vertical and horizontal dimensions. As regards the horizontal dimension or the connectedness with others in spirituality, there has been an increasing interest in this concept as emphasised by Stoll's definition of spirituality (Stoll, 1989). Many studies highlighted the importance of the connectedness of patients (internal) with the others (external) (Molzahn et al., 2008; Tanyi et al., 2006; Walton, 2007). However, the internal and the external connectedness was also discussed by other nursing theorists resulting in concepts such as Johnson's behavioural theory system model, King's general system

framework, Neuman's systems model and Rogers's science of unitary of human beings (McEwen and Wills, 2011; Parker, 1998). They all highlighted the importance of the interaction between patients and their surrounding environment which can be reflected in the patients' coping and healing process.

The main criticism of much of the literature on Stoll's argument is that she relies too heavily on separating the meanings of vertical and horizontal dimensions from each other. In other words, she offers no explanation in the distinction between how vertical dimensions and horizontal dimensions are interrelated with the patient's own environment internally and externally (McSherry, 2000). I would argue that the vertical and the horizontal dimensions are inseparable and integrated to Muslims' internal and external relationship in their lived experiences. The main domains in Stoll's model for providing meaning and purpose were love, trust and forgiveness. Muslims believe that the Prophet Muhammad (PBUH) urged healthy Muslims to visit ill people (O'Brien, 2011). In expressing their love, hope, sincerity, and support, the inner peace and strengths of the patient could be enhanced. However, a few studies explored how Muslim spiritual dimensions, vertical and horizontal, could interact with patients' attitudes and the surrounding environment (Nabolsi and Carson, 2011) and how trans-cultural traditions could influence our values and beliefs (Narayanasamy, 2002; Narayanasamy, 2005). The ACCESS model appears to offer a better platform to addressing the cultural aspects in determining the patents' internal views and linking them to the external dimensions. It allows the patients to depict other elements, which could be important to their world view internally and externally, the ACCESS model offered the nurse a way to provide a more meaningful care to their patient.

Let me now turn to the experimental evidence on the transcending element in spirituality: as explained above, this term reflects the vertical dimensions in Stoll's model with the High Power or God, or even the trust in God in some studies (Al-Arabi, 2006; Albaugh, 2003). However, I would argue that it would be challenging for healthcare professionals to address such dimensions, especially in Western societies, as it may present ethical considerations for both patients and staff. These considerations are especially important when the professionals' healthcare beliefs or faith contradict those of the patient (Narayanasamy, 2014; Paley, 2008; Pesut and Thorne, 2007). In addition, it is important to note that it will be pointless to address

such vertical dimensions in a secular society (Paley, 2008). Nevertheless, Seale (2010) found that religious values and beliefs are important elements in addressing the care of individuals in life threatening situations. He found that patients were almost twice as likely to die if treated by non-religious doctors compared to those who hold a religion. Although Stoll's model of the vertical dimension could be seen differently based on the limited situations that individuals face, Karl Jasper argued that these limited situations are endless, interchangeable and unpredictable. He also claimed that from such limited situations, individuals may transcend in both vertical and horizontal dimensions to understand what is important in their lives to fight for it (Jaspers, 2011). This could also be interpreted as one of the top needs that Maslow identified in his motivational theory "the hierarchy of needs" such as self-fulfilling and self-actualisation (Maslow, 2011). Thus, healthcare professionals might have a far more effective role in addressing both vertical and horizontal needs for patients.

Both models of Narayanasamy and Stoll mentioned above view the transcending as recognition of personal beliefs and values; Neuman's systems model views the transcending as spiritual (Parker, 1998), whilst Aldridge (2000) suggested that religious activities may offer an outline to address the transcending needs. Thus, I would argue here that it is reasonable to say that spirituality might be already experienced on daily basis by individuals practising religious obligations throughout different times of the day. It is therefore not possible to extricate beliefs and values from an individual's daily activities. For example, in Jordan, as in other Islamic countries, most Muslims will aim to fulfil their religion obligations, especially to pray the five daily prayers, regardless of their other commitments or economic status and health conditions. This appears to be a "spiritually روحانيا" important need in so far as the transcending dimension is concerned. Such tasks may help in maintaining self-fulfilment and self-actualisation for individual. In this scenario, in contrast to Maslow's model, self-fulfilment and self-actualisation could happen even if the basic needs of the individual have not been met. Thus, the ordering of the needs within the hierarchy of Maslow's model is not necessarily correct (Tay and Diener, 2011). In addition, Muslims practice Islam in almost all everyday tasks. Religious obligations maintain the relationship of inner-self with both vertical and horizontal dimensions as well as with others around them.

Overall, there seems to be some evidence to indicate that the transcending dimension is not always vertical, as Stoll suggested in her model (Stoll, 1989). Such beliefs and values are continuous and changeable based on our individual experiences that are unique and unpredictable. From the previous discussion, it can be seen that beliefs and values are other important characteristics of spirituality. Numerous studies have attempted to explain how the beliefs and values of individuals are important when addressing spirituality needs (Chrash et al., 2011; Pesut and Thorne, 2007; Sessanna et al., 2007; Shih et al., 1999). However, Narayanasamy (2002) argued that in Western societies, health professionals are challenged by the cultural diversity of their patients making it more difficult to address their spiritual needs. Thus, the ACCESS model was used to address the transcultural issue of spirituality where factors such as values, beliefs and socio-cultural norms can be addressed. The failure to address such beliefs and values may affect patient's well-being, which in turn may lead to spiritual distress (Baldacchino, 2010; Timmers et al., 2008; Yang et al., 2012). According to recent figures, the estimated Muslim population worldwide was 1.6 billion in 2010, and this is expected to rise significantly to 2.2 billion (35% of the world population) by 2030 (Pew Research Center's Forum on Religion & Public Life, 2011). However, existing literature shows limited awareness in healthcare research of the practices of Muslims (Abu-Ras and Laird, 2011; Kulwicki et al., 2000). I would argue that such lack of awareness may lead to an increase in apprehension among healthcare professionals when trying to address spiritual needs for Muslims using tools such as the ACCESS model. Nevertheless, the rules and regulations, such as the Equality Act 2010 protected such spiritual needs from being dismissed for the ethnic minority groups. More importantly, it is vital to protect the way every individual interacts with his / her own beliefs and values in finding meaning and purpose in life.

As suggested above, "spirituality" can be interpreted in different ways by different people (McSherry, 1997). Despite the wealth of literature attempting to clarify what spirituality actually means to patients, relatives and healthcare professionals, the continuing uncertainty and confusion over the concept among scholars remains (Baldacchino, 2010; Clarke, 2009; McSherry, 2007; Narayanasamy, 1999; Tanyi, 2002). The impact of spirituality on personal, physical, psychological and social status is well documented. The Department of Health's Chief Nursing Officer's (Health, 2006) Recommendation 10 states that "all nurses must recognise and

respond to the spiritual and religious needs of all services users" (Gilbert, 2011, p194). This advice is consistent among all nursing professional bodies. The General Medical Council (GMC, 2008) stipulates that:

> "For some patients, acknowledging their beliefs or religious practices may be an important aspect of a holistic approach to their care. Discussing personal beliefs may, when approached sensitively, help you to work in partnership with patients to address their particular treatment" (Gilbert, 2011, 194).

Thus, from the above statements, it is clear that exploring patients' values, beliefs, religious needs and religious practices is a key element in identifying both the spiritual needs and the spiritual care that are needed to empower patients to cope with their illness. Almost every paper that has been written on spirituality includes a section relating to patients' inner strengths that can be utilised to empower patients to find meanings and purpose (O'Brien, 1982; Tanyi et al., 2006; Walton, 2002).

Having highlighted the importance of personal beliefs and values in general, I will now move on to discuss the impact of such factors on ESRF patient. A few qualitative and quantitative studies have explored the impact of spirituality in relation to personal beliefs, adjustment and religious faith in the lived experience of ESRF patients and on their QoL (Davison and Jhangri, 2010; Duteau, 2010; O'Brien, 1982; Tanyi and Werner, 2003; Tanyi, 2002; Tanyi, 2006; Tanyi and Werner, 2003; Tanyi and Werner, 2007; Tanyi and Werner, 2008; Tanyi et al., 2006; Tanyi et al., 2006; Tarakeshwar et al., 2006). Spirituality in haemodialysis settings was found only in three studies. However, these studies have remarkably aided our understanding of this phenomenon (O'Brien, 1982; Tanyi et al., 2006; Walton, 2002).

O'Brien (1982) cited (Kaye and Raghavan, 2002 , 234) examined the religious faith in ESRF patients in a three-year longitudinal mixed-method research found that patients' beliefs and spirituality practices were articulated through religion. Furthermore, dialysis patients who attended a church once or more scored higher on the Interaction Behaviour Scale and had better quality of life scores. In addition, the results indicated that haemodialysis patients who attend church more regularly complained more about the strict regime of dialysis treatment. O'Brien stated that not including spiritual aspects in care for dialysis patients would lead to incomplete understanding of their physio-psycho-social-spiritual being. Similarly, Davison and

Jhangri (2010) administered the Spiritual Beliefs Scale to 253 chronic kidney disease patients. The participants demonstrated that spirituality had a great impact on their QoL. Also, they reported that spiritual care has been identified as an essential domain of quality care by patients with ESRD, particularly near the end of life, and studies have indicated the strong desire of these patients to have spirituality included in their care. Whereas much of the early literature on spirituality in ESRD appeared in the nursing literature, the recent emergence of literature in major subspecialty journals reflects a shift in nephrology toward ameliorating suffering, whether physical, psychosocial, or spiritual. These patients reported that substantial existential distress and low existential well-being were associated with poor health related quality of life (Davison and Jhangri, 2010).

Walton (2002) conducted a grounded theory research study in the USA (n=11) aimed at exploring what spirituality meant to haemodialysis patients and how it influenced their lives. Walton claimed that for ESRF patients on haemodialysis, their faith, relationship with God, relationship with others and prayers were important resources in maintaining coping and in finding balance in their continuous struggle with their illness.

Tanyi et al. (2006) conducted a phenomenological study of women in haemodialysis (n=16), aiming to understand the perceptions of incorporating spirituality into their care. The study participants revealed that displaying genuine care, building relationships and connectedness, initiating spiritual dialogue and mobilising spiritual activities were significant elements in incorporating spirituality into their care.

Nevertheless, all of these studies explored spirituality from a Western cultural perspective and from non-Muslim religious backgrounds, therefore the insights gained from these studies in Evidence Based Practice (EBP) in the provision of appropriate religious and spiritual care in healthcare settings may not be applicable to Muslim patients (Abu-Ras and Laird, 2011).

Given the increased importance attached to spirituality in Western healthcare, as outlined above, where the culture is generally regarded as being less religious and “philosophically" more materialist, its importance can be assumed to be even greater in cultures where traditional religions still play a very important role in the everyday lives of people (e.g. Islam in the Arab world, Hinduism in India, or Catholicism in

South America). My views are supported by Kaye and Raghavan (2002), who wrote about spirituality in disability and illness and recommended further research inclusive of other faiths, such as Islam, in order to understand the implications of spirituality from a comprehensive perspective.

Together these studies provide important insights into the beliefs and values in spirituality. They also highlighted the importance of the transcultural nursing in addressing the beliefs and values.

As pointed out in the introduction of this section, different appearances of "spirituality روحانيا" have been identified in the literature. I will now move on to explore how help and support can enhance individuals' spirituality by improving the connections between the vertical and horizontal dimensions of spirituality. Eleven studies from the selected search attempted to understand spiritual help and support during ESRF especially when researchers reported that ESRF patients have difficulty in self-caring (Campos, 2007; Song and Lin, 2011; Tanyi et al., 2006). Five studies highlighted the important role that family plays in ESRF patients' spirituality (Cordeiro et al., 2009; Lin et al., 2005; White and Grenyer, 1999) and the remaining studies emphasised the importance of peer support that can mobilize spiritual resources (Al-Arabi, 2006; Hughes et al., 2009). Both religion and culture are vital components influencing ESRF treatment in Jordan, as well as the family structure. Thus, studies of this nature exploring Arab-Muslim patients may be illuminative about spiritual support in Arabic culture, especially since most of these studies recommended conducting further research in patients from different backgrounds.

Several studies thus far have linked spirituality with support (Davison and Jhangri, 2010; Hughes et al., 2009; Rambod and Rafii, 2010; Walton, 2007). Molzahn (1998) highlighted important stages that ESRF patients face during the illness (see Chapter One); in Stoll's Model addressing love, forgiveness, trust and in the ACCESS model addressing respect, communication, sensitivity and safety, all must be considered as important mechanisms in addressing an individual's spirituality. However, A key study aimed to discover what spirituality means to haemodialysis patients and how it influences their lives; Walton (2002) argued in his grounded theory that finding a balance in support for all the above spiritual characteristics was key in providing spirituality. However, the literature suggests that in Arabic-Islamic culture, such a balance could be very difficult to achieve due to the social support system that might

favour male over female patients, since males in Arabic-Islamic culture are seen as the breadwinners (Keister and Sherkat, 2014).

Again, failure to address the support needs of patients could affect their coping mechanisms and therefore their overall spiritual well-being (Rambod and Rafii, 2010; Tanyi and Werner, 2003). Although ESRF patients use hope continuously as a coping mechanism, either hoping to get renal transplantation or to recover from ESRF (Moran et al., 2011), support from the horizontal dimensions, the social and environmental factors, appears to be important in maintaining such hope.

In Jordanian culture, families and patients are treated as one unit by healthcare professionals. The family has social, cultural and religious roles and obligations to maintain the relationships among the family (Hussein Rassool, 2014). However, there are concerns in the studies that investigated how Jordanian women would like to perceive their support during their hospitalisation or when on dialysis, regarding how this could impact on their future role in the family (Zeilani, 2008). Furthermore, in respect to the vertical dimension, illness is viewed in Islam as a test form God (Allah) (Hussein Rassool, 2014). Therefore, the vertical hope in terms of finding meaning in suffering may enhance the individual's spirituality. It is therefore reasonable to say that the support from the surrounding environment and the connectedness in terms of reminding patients of the meaning of suffering could enhance the vertical hope. Uncertainty, worthlessness, hopelessness, fear from dialysis treatment and from the future as well as the severe dietary restrictions are some of the factors experienced by ESRF patients, resulting in a significant impact on their quality of life and their spiritual well-being (Davidson et al., 2007; Krueger, 2009; Lin and Bauer-Wu, 2003). A study that explores these factors and the help that is available for ESRF patients in Jordan would be very useful in this regard. Using the ACCESS model in determining both dimensions could be appropriate to adapt in such a study to identify ESRF patients' spirituality.

Collectively, the above studies discussed so far outline the critical role of personal beliefs, religious values and religious practices and the cultural concerns in understanding spirituality. These elements are sensitive and difficult to address and require a great deal of cultural awareness when trying to address them. In addition, the evidence presented in this section suggests that the spiritual needs of patients with ESRF are different than for other illnesses. McSherry (2007) categorised

spirituality according to its role in the literature into theistic, religious, language, cultural, political, social, ideological, phenomenological, existential, quality of life and mystical classifications. This was an attempt of McSherry to find a universal definition of spirituality from healthcare professionals and from different religious. Others, such as Baldacchino (2010), characterised spirituality into unifying life force, wholeness, connectedness and self-transcendence, becoming positive in life and meaning and purpose in life. However, both McSherry and Baldacchino have investigated spirituality from a Catholic perspective, based on the influence of Christian theological traditions of Western spirituality that permeate the European cultural milieu. This has resulted in framing the understanding of spirituality within a Western, Christian context that does not necessarily translate into application to other socio-religious environments, including the Arab-Islamic world, despite sharing the Abrahamic heritage: some scholars have drawn distinctions between Judaism, Christianity and Islam and other religions such as Hinduism and Buddhism; the previous being seen as monotheistic religions having the same roots (Abrahamic religions) and a linear eschatology, while the others are pantheistic with distinct sets of beliefs and traditions, including a cyclical concept of time. Original Pali Buddhism is doctrinally atheistic, but in folk practice Buddhism is more often practised as a form of polytheism and syncretic with other beliefs (e.g. Taoism in China) (Paterson, 2009)

In view of all the aforementioned, one may argue that spirituality has a broad meaning going beyond the boundaries of religion and impacting on various aspects of life such that it can be applied to both believers and non-believers. However, religion, family, environment, culture and language are all considered to be important factors that add complexity and confusion to the meaning of spirituality. This has forced some scholars to criticise spirituality and relate it to psychology, sociology or other dimensions(Paley, 2008). In the following section I am going to review spirituality and its relationship to psychology.

Spirituality and Psychology

There is literature that suggests an overlap between spirituality and psychology (Clarke, 2009; O'Connell and Skevington, 2010; Paley, 2008). Despite this, for both religious and atheist individuals, it can be seen from the above studies that elements of spirituality are manifest through: vertical meanings, transcending connections,

personal beliefs and values, religion, meanings and purpose, connect with others, help and support, inner peace and comfort, love, kindness, death and dying. The literature also suggests that inadequate attention to addressing spirituality and the spiritual needs may affect patients' well-being, which in turn may lead to spiritual distress (Baldacchino, 2010; Timmers et al., 2008; Yang et al., 2012). Such inadequacy in addressing these elements may be reflected in the individuals' psychology as a sign of anger, bitterness, regret, guilt, doubt, fear, isolation and loss of hope (Gilbert, 2011). O'Connell and Skevington (2010) further demonstrated that psychology and spirituality are different. Psychological symptoms can manifest as: positive feelings, negative feelings, cognitive, self-esteem, and change in the perception of body image. However, a key problem with this finding is that the authors did not include any Muslim participants. Thus, a study that can explore the meanings of spirituality in Jordan and Arab- Muslim culture is required.

In Jordan, the word "spirituality or الروحانيه" is commonly used in life, based on different meanings that can be extracted from the verses of the Holy Qur'an mentioned in Table 3.5. Nabolsi and Carson (2011) highlighted three important components in viewing the wholeness of individuals; these are: the Body (البدن), the Spirit (الروح) and the Emotions (النفس). In fact in Arabic-Arabic dictionaries "spirituality or الروحانيه" has four meanings: the spirit or soul (الروح) that gives life to the body; inner comfort and peace (الراحه) which is related to a feeling in the spirit (الروح) that gives inner comfort; the mercy (الرحمه) and the capacity (السعة); and the pleasant connections (الرابط اللطيف) between 2 items or more that give life (Al Basry, 2000; Al Fyrozabady, 2005). In Jordan the use of the word "spirituality or الروحانيه" can be reflected throughout different life experiences. The use of "spirituality or الروحانيه" is commonly used to describe the inner feelings of individuals. For example, if someone moves from one place to another, it is common to ask: how do you feel (spiritually or روحانيا) about this particular place? He/she might reflect his/her inner comfort by expressing feelings of being happy and peaceful, which can be reflected in their psychological status and spiritual well-being, or in contrast, he/she might become angry, upset or experience a sense of fear as a result of being uncomfortable with that place. These feelings may influence his/her psychological status (Baldacchino, 2010; Gilbert, 2011). In this case, the use of "spirituality or الروحانيه" refers to the meanings of inner comfort and feeling of peace that connect the Body (البدن), the Spirit (الروح) and the Emotions (النفس) to work in harmony with each other

to provide meanings for that particular place. Stoll's Model and Narayanasamy's Model have not identified such interrelationships between these three elements. Nabolsi and Carson (2011) argued that spirituality is part of the Jordanian culture and that each individual may have a prior understanding and experiences that differ from others and allows everyone to bring their own interpretation of "spirituality or الروحانيه". In other words, spirituality cannot be seen as a detached unit that can be switched "On" and "Off" as needed (McSherry, 2000). McSherry also indicated the risk of addressing spiritual needs and psychological needs separately (McSherry, 2000). However, O'Connell and Skevington (2010) do not support this view as they found that spiritual experience is a distinct concept and not identical to psychological experience. In addition, Fry (2000) reported that consideration of personal needs, meanings, religious needs and spirituality contributes significantly to the overall well-being of the patient.

Spirituality may have both vertical and horizontal meanings to individuals which is broader than religion (Narayanasamy, 2004); it can therefore be applied to both believers and non-believers (Baldacchino and Draper, 2001; McSherry et al., 2012; Narayanasamy, 2006; Narayanasamy, 2006). As stated earlier, meanings and purpose appear to be one of the elements of spiritual needs. The literature also suggested diversities in addressing spiritual needs. Narayanasamy (2004, p1141) highlighted other spiritual needs for example: meanings and purpose, loving, harmonious relationships, forgiveness, hope, strength, trust, and personal beliefs and values, spiritual practices, concept of God/deity, belief and practices, and creativity. This was in agreement with the RCN (2011) that guided healthcare professionals to address individuals' spiritual needs from the broadest definitions. All these spiritual needs appear to be related to the individual and connect the psychological and the spiritual well-being together (O'Connell and Skevington, 2010). Nevertheless, Gilbert (2011) argued that psychological signs include anger, bitterness, regret, guilt, doubt, fear, isolation and loss of hope are all indications of spiritual distress if the above needs have not been met. Thus, healthcare professionals are required to assess and address such spiritual needs. Narayanasamy (1999) suggested the ASSET model (Table 3.8) as a one possible way to address such needs and to provide spiritual care accordingly. Spiritual care is defined by the NHS education of Scotland as:

> "that care which recognises and responds to the needs of the human spirit when faced with trauma, ill health or sadness and can include

> the need for meaning, for self-worth, to express oneself, for faith support, perhaps for rites or prayer or sacrament, or simply for a sensitive listener. Spiritual care begins with encouraging human contact in a compassionate relationship, and moves in whatever direction need requires.' " cited from (Ross et al., 2014 , p698)

The literature emphasised that providing spiritual care is through being with individuals rather than only doing it (Baldacchino, 2010).

Table 3.8: The ASSET Model

Self-awareness	**Experiential learning** **Value clarification**	**Value clarification** **Sensitivity and tolerance**
Spirituality	Holism; perspectives of spirituality; broad aspects of spirituality	Knowledgeable practitioner in spiritual dimensions of nursing
Spiritual dimensions of nursing	Assessment Planning Implementation Evaluation	Competence in assessment of spiritual care needs Planning spiritual needs-based care Competence in counselling Positive nurse—patient relationship Competence in judging effectiveness of spiritual dimensions of nursing; enhancing quality of care; spiritual integrity; healing and relief from spiritual pain

Copy right permission was verbally obtained from Dr. Aru Narayanasamy in May 2014 to be used in this study (Narayanasamy, 2004, p1142).

Despite this, Paley (2008) argued against the use of the concept of spirituality in healthcare. He also suggested that spirituality should be combined with psychology, naturalistic approaches or even with sociology. I presented in the previous sections an argument for how spirituality is multifaceted and inseparable from all aspects of life (McSherry, 2007; Narayanasamy, 1999; Ross, 1995); However, Paley has a completely different view: he argues that spirituality is an artificial concept and Just-Word theory and that nursing literature has nothing to offer in terms of "spiritual concerns" to help patients when they raise questions like "why me?" (Paley, 2008 p,12). Paley claims that spiritual care is meaningless to the patients' needs. He builds his argument on the basis that he links spirituality with religion. He then

justifies his argument by quoting the steady decline in church attendance and the general move in the western societies towards being secular. However, I would debate against Paley's stance. For example, being a Muslim, one has to fulfil certain religious obligations whether at places of worship, work place or at home. Similarly other religions might have other religious obligations that are not necessarily linked to attending churches, temples or other places of worship. Personally, being a Muslim, most of my religious duties are performed outside places of worship. According to Paley's views, this practice renders me a secular Muslim. Thus, it is sensible to suggest that attending religious activities is not always an accurate indicator of the individual's religious connections. By drawing on religious practices, Aldridge has been able to show that individuals may regard themselves spiritually connected but not necessarily engaged in religious activities (Aldridge, 2000).

A key study comparing the overall QoL, including the psychological and spiritual Qol, is that conducted in the UK by O'Connell and Skevington (2010), in which they examined 285 individuals from different backgrounds. The study subjects differed in their religious orientations. The aim was to try and understand the theoretical debate on the contribution of spiritual, religious and personal beliefs to Quality of life. They compared five domains: the spiritual domain (spiritual personal belief and value, connections, meanings of life, wholeness, hope, inner peace, spiritual strength, awe and faith), the psychological domain (positive feelings, negative feelings, cognition, self-esteem, and change in body image), the physical domains the independence domain and the social support and environmental domain. They examined how these domains interact with each other and impact on the Qol. Their findings demonstrated that the spiritual domain made a significant independent contribution to the overall QoL, which was different from the psychological domain contribution to the QoL. In response to Paley's argument above, O'Connell and Skevington (2010) concluded that the spiritual domain is "a concept" that is not related to either the psychological or social domains. In this study, spirituality was scientifically proven to be a separate important object on its own. This finding corroborates the ideas of Goddard (2000), who suggested that psychology and spirituality are not similar. A further study with more focus on other countries and in different languages was therefore suggested.

Although there was some evidence to indicate that spirituality correlated with psychology, the evidence presented above suggests that spirituality is a completely different entity unrelated to psychology (O'Connell and Skevington, 2010). The section that follow moves on to explore spirituality as a part of the holistic care approach for individual's.

Spirituality and Holism

Several studies considered spirituality as part of the holistic approach to patient care (Balducci and Meyer, 2001; Carpenter et al., 2008; Chrash et al., 2011). As stated earlier, the policies and guidelines in Western medicine are well established in literature, and organisations such as the NHS, NMC, RCN, GMC and RCP do support the notion of spirituality and of spiritual care in nursing (Hemsley et al., 2006) in order to provide a holistic care approach that includes care for body-mind-spirit (Chrash et al., 2011; Narayanasamy, 1999). In addition, many nurse theorists put an emphasis on the importance of treating patients or individuals in a holistic way according to their physical, psychological, social and spiritual needs. For example: Levine's Conversation Model (Holistic being), Neuman's systems Model , Rogers's Science of Unitary Human Being, Heidegger Being in the World *"the Dasein"* (Heidegger, 1962; McEwen and Wills, 2011; Parker, 1998). By drawing on the concept of *the Dasein*, Inwood (2000) has been able to show that "*the Dasein* is important in the world, not in the essence that individuals occupied a single place in the world together or with other things, but in the sense that it continually interprets and engages with other entities and the context in which they lie, the environment or the world around us…. *The Dasein* brings the whole world along with it."(Inwood, 2000, p22) . He suggested however, before proceeding to examine spirituality and holism, it will be necessary to define what I mean by both holism and holistic care. The word "Holism" originates from the Greek word ''holos'', which meaning whole (McEvoy and Duffy, 2008). Human beings have multiple interacting subsystems including genetic makeup and spiritual drive, body, mind, emotion, and spirit which are a total unit and act together, affecting and controlling one another interactively (Erickson et al., 1983, p44). For holistic care, Ellis and Narayanasamy (2009, p886) suggested that "holistic care is based on the idea that there should be a balance between body, mind and spirit". Therefore, a holistic care approach to ESRF should include attending to the patients' body, mind and spirit. Thus, it could be argued that

ignoring one aspect within the elements of holistic care may have a negative effect on the others.

In the Jordanian traditions, the idea of holism is based on viewing individuals as three important parts, which are: the Body (البدن), the Spirit (الروح) and the Emotion (النفس) (Nabolsi and Carson, 2011). All the above theories highlight the importance of the interaction between individuals and their environment. For example, Heidegger argued that the interactions with the surrounding environment are so complicated and inseparable that he even found it difficult to detach himself from traditional daily formalities and interactions such as greeting people (Dreyfus, 1991). This view is supported by Yousif (2006) who reported that the traditional Islamic way of treating patients is by a mixture of spiritual and physical methods, with the use of natural substances and certain Islamic supplications for healing and cures. Since Islam is practised in day-to-day activities for Muslims (Hall, 2012), the concept of "whole" appears to be consistent with the Arabic-Islamic Jordanian culture. Furthermore, Mutair et al. (2014) highlighted the importance of the family in the Arabic culture to empower patients' inner strength during illness. Therefore, I would argue that the care provided by the family is an important element of the overall holistic care for Jordanian patients. However, when it comes to providing spirituality and spiritual care, Ross et al. (2014) highlighted that the belief system and the healthcare experiences of student nurses had implications upon their understanding of spirituality and competence in addressing spiritual care.

Two main criticisms of much of the literature on holism (body-mind-spirit) concern the separation between these needs from each other and the underestimation of the relationship between them. Raingruber (2003) pointed out that some healthcare professionals view individuals as a collection of biological, neurological and genetic systems but with more focus on the physical element. In doing so, the literature suggests that the care we provide to these individuals could become disjointed. By excluding other elements related to the mind and spirit, there is a higher risk of missing important items of care in order to treat the patient holistically (Bullard, 2004; McSherry, 2000). This is because the care may not take into consideration other important aspects in the individual's life such as the social, moral and cultural elements (Raingruber, 2003). It is therefore important for nurses to expand their knowledge to meet the three different needs and to consider other aspects such as

psychological, social and the cultural meanings, purpose in life and personal beliefs and values (McEvoy and Duffy, 2008). Such factors appear to be important to patients because they are related to their previous experiences, current needs, and their future objectives (Heidegger, 1962).

Unlike the Western model of nursing, which has progressed significantly towards more holistic care, I realised that in Jordan I became part of a healthcare system that was medically dominated by doctors and disease orientated rather than patient centred. Jordanian nursing remains very bio-medically focused with no model of nursing care to guide practice. Physical assessment is generally conducted by doctors with nurses just following the doctors' orders. This is despite the emphasis on a holistic care model in nursing and the increasing use of evidence-based practice in the Jordanian healthcare systems (Oweis, 2005). However, applying holistic care in Jordanian hospitals has its own challenges. My personal clinical experience suggests that spirituality in Jordan has it foundations outside the healthcare system and no policy has been found to contradict this assumption. Furthermore, the majority of the healthcare providers in Jordan are in the private sector where spiritual needs and spiritual care appears to be less important compared to physical needs. Nawafleh et al. (2005) found that nurses in Jordan have engaged in activities that are considered to constitute advanced practice, such as venepuncture, needling and suturing.

Together these studies provide important insights into how spirituality is an important component of the holistic care. Nurses in Jordan need to acknowledge and integrate their own spirituality with the care they provide to the patient. Narayanasamy (2002) stated that spirituality is a coping mechanism in holistic care during chronic illness. Nabolsi and Carson (2011) recommended conducting studies to explore meanings of spirituality in chronic illness in Arabic-Jordanian culture. The following section is an account of the literature on how spirituality is experienced during chronic illnesses.

Spirituality during Chronic Illness

The progress of phenomenology over recent decades has had a great impact on research aimed at understanding the experiences of nurses, patients and their relatives, carers and mourners of chronic illness (Adams-Leander, 2011; Albaugh,

2003; Brown et al., 2008; Cases et al., 2011; Herlin and Wann-Hansson, 2010; Kociszewski, 2004; Lin et al., 2005; Moran et al., 2011; Pehler and Craft-Rosenberg, 2009; Tanyi et al., 2006; White and Grenyer, 1999; Wright, 2003). These researchers used phenomenological approaches to reflect upon the lived experience of their study sample and "being in the world" living with chronic illness or providing care for someone with chronic illness. This approach allowed researchers to describe and interpret these experiences in order to gain a better and deeper understanding of the phenomena they investigated. The aim of the phenomenological study is to "gain a deeper understanding of the nature and meaning of our everyday lived experience, with the meaning of the phenomenon based on 'consciousness', which is considered the only point of access … [concerning] human 'being in the world" (Larsen and Johnson, 2012; Van Manen, 1990pg 9). These studies illustrate the impact of two major phenomenological philosophers (explained in detail in Chapter Three).

Several studies have examined spirituality from the lived experience of chronically ill patients, including neuro-oncology and cancer (Albaugh, 2003; Nixon and Narayanasamy, 2010; Noble and Jones, 2010; Swinton et al., 2011); HIV (Belcher et al., 1989; Tuck and Thinganjana, 2007); mental illness (Acton and Miller, 2003; Greasley et al., 2001; Hall and Livingston, 2006); heart disease (Beery et al., 2002; Nabolsi and Carson, 2011; Saudia et al., 1991); end of life (EoL) and palliative care (Baldacchino, 2010; Gijsberts et al., 2011; Hayden, 2011; Narayanasamy, 2007; Penderell and Brazil, 2010; Selman et al., 2011); post-traumatic stress (Hassouneh-Phillips, 2003; Wright, 2003); disability; and illness (Baldacchino, 2010; Kaye and Raghavan, 2002; McColl et al., 2000; Pehler and Craft-Rosenberg, 2009). A number of these studies reported spirituality as the primary source of coping amongst patients with chronic and terminal illnesses and as an important factor in the daily life experience (Albaugh, 2003; Kaye and Raghavan, 2002; Pehler and Craft-Rosenberg, 2009; Penderell and Brazil, 2010; Tuck and Thinganjana, 2007).

In the USA, Albaugh (2003) conducted a phenomenological study to examine spirituality in the lived experience of individuals diagnosed with life-threatening diseases, including breast cancer, colorectal cancer, prostate cancer, pulmonary fibrosis, and myocardial infarction. In this study participants indicated how their spirituality provided comfort throughout their journey and provided strength when

facing life-threatening situations. Although these findings could help me further understand the phenomenon of spirituality, due to the differences in the background and the belief system between the USA and Jordan, these results need to be interpreted with caution as the study viewed spirituality only from a Christian background. I suspect that Muslim ESRF patients in Jordan might have different experiences of spirituality. Furthermore, the patients in the above study were in the advanced stages of illness, whereas in my study I will explore the phenomenon of spirituality in patients with ESRF in various stages of dialysis.

The descriptive phenomenological study of Pehler and Craft-Rosenberg (2009) aimed to describe the lived experiences of spirituality in adolescents with Duchenne Muscular Dystrophy (DMD). They used structured interviews guided by Reed's (1992) theoretical framework of connectedness (that included intrapersonal, interpersonal, and transpersonal connectedness) to collect their data. The findings illustrated that the vital theme of spirituality was "longing"; the strong desire for something unattained. However, it is important to question Reed's framework of connectedness, which investigated spirituality from the Judeo-Christian perspective. In other words, I could argue that the participants in the study may have shared their experiences of ways of connectedness rather than sharing their experiences of spirituality. It is also important to appreciate that patients with DMD have dramatic language difficulties which may have impacted on their ability to verbalise their experiences. Furthermore, the researchers stated that most of the participants in this study had a difficult time explaining what they believed in, due to such disabilities. Since ESRF patients do not share the same speech disability, they may have expressed their spirituality in different ways compared to the participants in the study of Pehler and Craft-Rosenberg.

Numerous studies have attempted to explore the meaning of spirituality among HIV patients (Dalmida, 2006; Spinale et al., 2008; Szaflarski et al., 2006; Tuck and Thinganjana, 2007). Tuck and Thinganjana (2007) in their qualitative research aimed to explore the meaning of spirituality among people living with HIV (n=75) and healthy adults (n=25) in the USA. The findings from this study supported spirituality as a crucial human dimension. However, it seems possible that these results are due to the fact that Tuck and Thinganjana (2007) constructed their interviews on the assumption that there are positive spiritual effects of spirituality: they stated that

their questions were grounded in literature supporting spirituality as a component of holism, therefore inferring that it is applicable to all individuals, although, some could argue that such results represent the broader understanding of spirituality. However, it is important to bear in mind the possible ambiguity in participants' responses. As stated above, there are a number of important differences between spiritual needs for ESRF patients and the spiritual needs of patients with HIV (or HIV plus ESRF). For example, Spinale et al. (2008) using a qualitative approach concluded that the impact of spirituality may be mediated by social support. Further, they recommended multicentre, prospective studies with well-validated tools to measure religiousness and spirituality in order to determine whether there is an independent association of spirituality variables with survival in patients with ESRF.

Moreover, Spinal et al.'s analysis does not take account of how Muslim ESRF patients viewed their spirituality. A major criticism of their work is that the majority of their sample was from the African-American ethnic group (89%) in which it was not clear how many Muslims participated. It is encouraging to compare these figures with those by Tanyi and Werner (2007), who found that the African-American ESRF patients have higher spirituality scores than Caucasian-American ESRF patients. Similarly, another study found that spirituality provides a source of comfort, power and control, enabling HIV patients to understand and reflect on their experience of illness (Belcher et al., 1989). This sense of power was also experienced by patients suffering from chronic diseases and EoL illnesses (Kaye and Raghavan, 2002). Although some could argue that spirituality in its broader sense is the same, I would argue that the important elements of spirituality, such as the psychological, social, cultural meanings, purpose in life and personal belief and values, are all experienced differently.

Search results revealed only two studies looking at how Jordanian patients experienced their admission to either ICU or CCU (Nabolsi and Carson, 2011; Zeilani, 2008). Nabolsi and Carson (2011) conducted a hermeneutic phenomenological study aimed at understanding how Muslim men experienced their spirituality in CCU. They suggested that faith plays an important role in the choice of treatment by patients with heart disease during their healthy and unhealthy periods, and in accepting or rejecting their health and well-being. Furthermore, they found that both religion and culture were part of daily life for their participants. In

their conclusions, they recommended conducting further studies to explore meanings of spirituality in Jordanian patients suffering from other chronic illnesses.

Although the previous study could help us understand how spirituality is manifested in the lives of Jordanian heart patients, the method of analysis in this study using Colaizzie's steps has some limitations. Using Colaizzie's steps may bracket the researchers' experience of study from interpreting their participants' accounts. In addition, it calls for a validation of results by returning to study participants (Polit and Beck, 2008). I have been in contact with Nabolsi to clarify this further; however, she stated that this study was only a sub-theme from a bigger study, and she did not deliberately ask her participants about their understanding of spirituality. Thus, these results need to be interpreted with caution.

Likewise, Zeilani (2008) using narrative approach to explore women's experience of admission to the ICU suggested that cultural norms and religious beliefs shape women's experiences in ICU. Due to cultural aspects that differentiate men and women, I would argue that Jordanian men may have fundamentally different experiences from those of Zeilani's participants. In addition, Zeilani was not able to elaborate on whether her participants were using or relying on lifesaving machines. In addition, the sample in Zeilani's study was selected from an urban hospital; however, women in rural areas may have different experiences of ICU. Therefore, several questions remain unanswered at present concerning how Jordanian ESRF patients experience their spirituality.

Several studies have linked spirituality with palliative care (Delgado-Guay et al., 2013; Mako et al., 2006; Penderell and Brazil, 2010). Penderell and Brazil (2010) used face-to-face interviews with six practising palliative care physicians to gain a better understanding of physicians' spirituality and how it influences their care for the terminally ill. The results showed that spirituality was an essential element for providing compassionate care for the palliative patient. Spirituality was also uncovered as a powerful force for physicians to engage in self-care practices. Spirituality was not only important in the lives of palliative care patients, but also in those of healthcare providers. These findings were consistent with other researchers who examined spirituality from different healthcare providers in different settings (Touhy et al., 2005). Similarly, Delgado-Guay et al. (2011) highlighted the importance of spiritual assessment for both patients and the care givers. One

question that needs to be asked, however, is how we can provide spiritual assessments for Arab-Muslim patients as there are only limited studies that have explored the meaning of spirituality in the Jordanian context. Thus, a more comprehensive study that included Muslims in Jordan may provide greater insight into how spirituality and spiritual needs can be addressed.

To sum up, the results from the above studies identified the use of spirituality for diverse patient groups diagnosed with chronic and terminal illnesses. The empirical evidence from the reviewed studies showed how patients approved that their coping mechanism with their chronic illness was enhanced through utilising spirituality in their care. However, the participants in previous studies had different illness characteristics compared to ESRF patients. Before proceeding to examine spirituality further, it is necessary to uncover the existing literature on the manifestations of spirituality in ESRF. The literature related spirituality with ESRF identified six broad themes, which will be explored in the next section.

Spirituality in ESRF

A few qualitative and quantitative researchers have explored the impact of spirituality in relation to personal beliefs, adjustment and religious faith in the lived experience of ESRF patients and on their QoL (Davison and Jhangri, 2010; Duteau, 2010; O'Brien, 1982; Tanyi and Werner, 2003; Tanyi, 2002; Tanyi, 2006; Tanyi and Werner, 2003; Tanyi and Werner, 2007; Tanyi and Werner, 2008; Tanyi et al., 2006; Tanyi et al., 2006; Tarakeshwar et al., 2006). Few qualitative studies have been conducted in this area. Spirituality and its resources in haemodialysis were found only in three studies, which assisted remarkably in the understanding of this phenomenon (O'Brien, 1982; Tanyi et al., 2006; Walton, 2002).

O’Brien (1982)(cited in (Kaye and Raghavan, 2002, p234) in a three-year longitudinal mixed-method research, which aimed to examine the religious faith in ESRF patients, found that patents’ beliefs and spirituality practices were articulated through religion. Furthermore, dialysis patients who attended church once or more scored higher mean scores in the interaction behaviour scale and had better quality of life scores. In addition, the results indicated that haemodialysis patients who attended church more regularly complied more with the strict regime of dialysis treatment. O’Brien stated that not including spiritual aspects in care for dialysis patients would

lead to incomplete understanding of their physio-psycho-social-spiritual being. Similarly, Davison and Jhangri (2010) administered the ESRD Spiritual Beliefs Scale to 253 patients with chronic kidney disease. The participants demonstrated that spirituality had a great impact on their QoL.

Walton (2002) conducted a grounded theory study in the USA (n=11). This research aimed to explore what spirituality means to haemodialysis patients and how it influences their life. Walton establishes in his results that for ESRF patients on haemodialysis, their faith, relationships with God, relationships with others and prayers are important resources in maintaining coping and in finding balance in their continuous struggle with such illness.

Tanyi et al. (2006) conducted a phenomenological study of women in haemodialysis (n=16), aiming to understand the perceptions of incorporating spirituality into their care. The study participants revealed that displaying genuine caring, building relationships and connectedness, initiating spiritual dialogue and mobilising spiritual activities were significant elements incorporating spirituality into their care.

The majority of these studies explored spirituality from a Western cultural perspective and from non-Muslim religious backgrounds, therefore the insights gained from these studies may be inhibiting for Muslim patients (Abu-Ras and Laird, 2011). Further, these studies are applicable to ESRF patients as they shade light on the religious impact on coping with dialysis. However, since these studies were conducted on non-Muslim patients, further study on Islamic patients may reveal similarities or differences findings. Moreover, research that considered spirituality has tended to adopt a positivist methodological approach (Davison and Jhangri, 2010; McSherry, 1997). McSherry (1997) examined “spirituality” among qualified and unqualified nurses working on the wards in a large National Health Service (NHS) Trust (n=1026). McSherry’s methodology section shows that the data collection tool was developed and adequately described and the validity of the instrument and the reliability of the questionnaire were demonstrated: it is an example of the positivist approach. What is believed to be vital for this study, which examined sensitive issues in relation to understanding spirituality using a large sample from many ethnic backgrounds, is the translation of the data collection instrument. It seems that McSherry collected his data from different ethnic groups using one language, instead of using an adapted or translated instrument: this may

have affected the results of his study. For example, the notion of spirituality may differ greatly between Western and other cultures, which could lead to a construct bias. Thus, as a result, McSherry's findings are not necessarily culturally representative, especially for a study such as this one. Underestimation of the functionality of language was in McSherry's study.

Language is "a powerful tool" (Thies and Travers, 2009: 254) in exploring, reflecting, experiencing and communicating with others. It could be argued that overlooking the importance of this tool disabled research participants in McSherry's study from expressing their feelings, experiences, and understandings of spirituality. Expanding on this theme, I faced similar problems in my professional work in the UK, when other nurses would refer Bangladeshi dialysis patients to me in order to facilitate communication between them. Although I am an Arabic/English speaker with no knowledge of Bangli language, my nursing peers appeared to assume that because I had a similar sounding name to a patient, we must also share a language. A consensus of opinion prevails that language skills are an essential component for effective understanding of the application of spirituality in health and in nursing in multicultural communities.

Given the increased importance attached to spirituality in Western healthcare, as outlined above, where the culture is generally regarded as being less religious and (philosophically) more materialistic, its importance can be assumed to be even greater in cultures where traditional religions still play a very important role in the everyday lives of people (e.g. Islam in the Arab world, Hinduism in India, or Catholicism in South America). My view is supported by Kaye and Raghavan (2002), who wrote about spirituality in disability and illness and recommended further research inclusive of other faiths, such as Islam, in order to understand the implications of spirituality from a comprehensive perspective.

So far in this chapter I focused on how spirituality has been conceptualised and explored in the literature and its main characteristics, as well as patients' spiritual needs and spiritual care. I then presented how spirituality has been explored in the lived experience of patients with other chronic illness. I identified six themes from the literature; the following sections discuss how spirituality was uncovered during ESRF.

Spiritual Coping and Spiritual Hope in ESRF

In the literature review section, I identified eighteen studies on the subject of spiritual coping and spiritual hope in ESRF. Coping plays a major role in chronic illness and in ESRF on dialysis. In recent years, however, concerns have arisen about how coping can be defined. Bowling (2010) defined coping as an effort of an individual input to control or tolerate internal or external difficulties as a result of stressful experiences faced by an individual; this effort can be cognitive or behavioural. Many studies have investigated coping in life-changing situations, coping resources and types of coping such as religious coping (Koenig et al., 2001; Latifnejad Roudsari et al., 2014; Lindqvist et al., 2000; Lok, 1996; Narayanasamy, 2004; Pelletier-Hibbert and Sohi, 2001). For example, Lindqvist et al. (2000) presented important relationships between individual input and the consequences from that experience.

Success in coping relies on the positive outcome of that situation (Bowling, 2010). However, coping in the literature is largely presented in relation to stress (Koenig et al., 2001; Lok, 1996; Pelletier-Hibbert and Sohi, 2001). According to Lazarus (2006), individual responses to stress vary according to factors such as gender and age. However, there are two basic approaches currently being adopted in research into distinguishing between coping strategies. One is the problem-focused approach and the other is the emotional-focused means of stress coping theory (Lazarus and Folkman, 1984). The previous is aimed at problem-solving or doing something to alter the source of stress, whereby the stress can be eliminated or otherwise dealt with (Lazarus, 2006), while the latter concerns reducing or managing emotional distress associated with situations (Herlin and Wann-Hansson, 2010).

Several studies report that ESRF patients experience several stresses during illness, such as lifestyle-changing situations (Clarkson and Robinson, 2010; Herlin and Wann-Hansson, 2010; Moran et al., 2011; Sinclair and Parker, 2009; White and Grenyer, 1999) and uncertainty (Pelletier-Hibbert and Sohi, 2001). Patients face a number of physical, social, psychological, emotional and spiritual difficulties (Molzahn, 1998; Polaschek, 2003; Sussmann, 2001), dietary restrictions (Giaramazidou et al., 2005), constant struggling (Sinclair and Parker, 2009) and overwhelming sadness (Krueger, 2009). Other studies provided evidence of several boundaries and threats to the initiation of dialysis, as it restricts patients' lives with

sub-themes associated with feelings of being 'tied down', 'left out', and 'doing without' (Al-Arabi, 2006). These restrictions and challenges may be a cause for social separation and loneliness (Martin-McDonald and Biernoff, 2002), which can be a threat to the personal and family meanings of being in the world (Ziegert et al., 2009). However, there were several limitations among these studies. Firstly, they did not include many Muslim patients in their samples. Nabolsi and Carson (2011) also reported that studies on spirituality related to Arabic patients were mostly conducted in Western countries. Secondly, although there might be some similarity in the broader understanding of spirituality, the researchers' understanding of spirituality comes from Western or secular understandings where religion is understood as a diverse entity from spirituality (Paley, 2008).

Thirdly, the support system that ESRF patients have in Western countries may not be the same as in Jordan. Clarkston and Robinson (2010) used a structured interview to explore the lived experience of dialysis patients in the USA (four peritoneal dialysis patients and six haemodialysis patients). The results showed that coping helped ESRF patients to improve their strengths and actions toward dialysis. The authors reported sources of coping highlighted by participant, including church, prayer, support groups, family, God and other support. However, I would argue that Jordanian ESRF patients may have different cultural experiences to cope spiritually with ESRF. van Leeuwen et al. (2007) found that culture and religion significantly influence findings, meanings and purpose in the chronic illness situation. The researchers recommended further research to explore how spirituality can influence patients' health decisions. Therefore, these findings cannot be extrapolated to all ESRF patients.

Perhaps one of disadvantages of the methods that Clarkson and Robinson (2010) used is that the participants were directed by certain questions that might prompt them to answer in a certain way; this is known as the social desirability bias (Burns and Grove, 2009). In this bias the research subjects provide information which they think the researcher should or would like to hear. This would inhibit the trustworthiness of the findings. Furthermore, the authors did not show the audit trail or the reflexivity and how they analysed their data. In addition, the study participants were selected through dialysis support groups; such groups do not exist in the current Jordanian system, therefore, the recruitment for study may require a different

network. Additionally, data collection in Clarkson and Robinson (2010) study appeared to be through loaded questions and therefore may have missed other important factors pertinent to coping mechanisms.

There are several factors affecting coping which the previous study did not consider, such as the financial status and the financial support for patients in ESRF. Such financial issues may have an important impact on the Jordanian patients since most Jordanian patients with ESRF will require ongoing financial resources to pay for their hospital transport, medication as well as their general medical and non-medical needs. Therefore, as stated earlier, the financial concerns that may face ESRF patients in Jordan are challenging and may affect their coping with illness and the impact on their families.

Drawing on an extensive range of resources in spirituality, as mentioned in the characteristics of spirituality section, some scholars segregated religion from spirituality and created ways of understanding spirituality in order to include both believers and non-believers (Baldacchino and Draper, 2001; McSherry, 2007; Paley, 2008). Others recognised the importance of religion in coping and the positive role it plays in patients' QoL (Cordeiro et al., 2009; Tarakeshwar et al., 2006; Walton, 2007). Positive coping may be expressed in different ways, such as transition to acceptance, belief in life being worth living, willingness to engage in survival, improved sense of comfort, self-reliance or inner-strength of spirituality, positive attitude toward illness, honouring spirit, spiritual and religious beliefs and values, trust in God and praying (Albaugh, 2003; Burkhardt, 1993; Sinclair and Parker, 2009; Walton, 2007; Yeh and Yeh, 2007). Religious choices such as reading holy books, prayers and congregations have been found to be important in influencing dialysis patients' perception (Cordeiro et al., 2009).

Sinclair and Parker (2009) used a qualitative approach to explore the meaning of intradialytic weight gain for patients on haemodialysis using in-depth interviews. They described the living experience of dialysis as "constant struggling" trying to stay within their target weight. In Jordan, hot and dry weather may increase the need of ESRF patients to drink water, and potentially cause weight gain. As Islam urges Muslims to adher with their treatment, this might be another way to cope with strict diet. For example, Giaramazigou (2005) used a comparative quantitative approach in Greece to explore the relationship between patients' dietary compliance and

religion and educational level between Christian (n=33) and Muslim (n=37) patients. The results showed significant differences between the study groups. The findings indicated that, despite the better level of knowledge Christian patients had, Muslim patients had lower episodes of fluid overload, and no Muslim was admitted to the hospital for emergency dialysis. These findings indicated that the educational level of ESRF patients in itself is not the only factor in fluid overload, and other factors need to be explored more. Furthermore, the results indicate that Muslim patients had different coping strategies with fluid restriction and dietary issues compared to other patients. Such strategies can only be identified using qualitative methods according to the authors' recommendations.

A qualitative study by Walton (2007) conducted in American-Indians on haemodialysis (n=21) to explore spiritual thoughts, coping and healing from old traumatic experiences (building self-esteem, feeling loved, fighting addiction, caring for self). The researcher reported that patients' prayers played an important role in their daily lives, acknowledging their inner strength in staying connected with their communities, healing their old wounds and resisting dialysis. Also, haemodialysis patients' prayers helped them in coping with their illness (Walton, 2007) and increased trust in God (Albaugh, 2003). Both prayers and trust in God are ways of religious coping that enhance inner strength for patients. Walton also highlighted hope as an important factor in ESRF spirituality which has an impact on the ESRF patients, especially when they face various challenges. ESRF patients in Walton's study were able to transform their general outlook from negative to positive and to find resilience to cope and discover hope and balance in their life. This study reflects the desire that ESRF patients have to manage their day-to-day activities. This view is supported by both Rasic et al. (2009) and Garroutte et al. (2003) in cross sectional studies aimed at examining the relationship between spirituality and suicidal attempts. The two studies concluded that individuals who are spiritual and religious have lower suicidal attempts. However, for atheists, coping was aided by music therapy, aromatherapy and massage, which enhanced their inner strength (Yeh and Yeh, 2007).

In contrast to the above study, some studies found that religious coping negatively impacted upon patients' inner strength and increased the psychological distress, which resulted in increased suicidal attempts (Garroutte et al., 2003) and negative

religious coping (Rivera-Ledesma and Lena, 2007). Similarly, Ellison and Lee (2010) found the dark side of religious/spiritual coping which was strongly associated with spiritual struggle and psychological distress. In addition, several studies thus far have linked the negative effect of spirituality with suicidal ideation (Abdollahi and Abu Talib, 2015; Aho and Liu, 2010). However, limited studies have been conducted on the potential reasons of suicidal ideation among Jordanian and Arabic patients who suffered from ESRF. The result from above studies would have important implications in Arabic cultural for formulating prevention programs for ESRF patients. Therefore, understanding suicidal ideation is an important indication to prevent suicide among ESRF in Jordan.

The negative effects of religiosity/ spirituality in suicidal ideation are controversially interesting. As stated above, spirituality were defined as finding meaning and purpose in life and enhancing the vertical and horizontal relationships (Narayanasamy, 2006; Stoll, 1989; Tanyi and Werner, 2007). Spirituality may be viewed as multi-dimensional phenomenon that may create aim and purpose in life for individual's to fulfil (Abdollahi and Abu Talib, 2015). Nevertheless, in non-psychological illness, religious and spiritual coping have generally been found to help patients to find meaning in their illness and become more able to cope with any outcomes (Walton, 2007). Therefore, it would be predictable that any lack in finding meaning and purpose in life by spirituality/religiosity is likely to have negative sequences upon patients own coping mechanism. A further study with more focus on the relationship between spirituality and suicidal ideation is therefore suggested.

While the above studies illuminate some salient points about spiritual coping mechanisms, culturally oriented studies may provide a better understanding of how ESRF patients in Jordan cope spiritually with their illness. A focused study would provide more insight into their experience of spirituality.

Spirituality and Religion in ESRF

In the past two decades, a number of researchers have sought to determine the relationship between spirituality and religion during ESRF. In this respect, 14 studies were identified and are included in this section, consisting of nine studies using a qualitative approach (Adams-Leander, 2011; Ndlovu and Louw, 1998; Rambod and Rafii, 2010), five that adapted a quantitative approach (Cordeiro et al., 2009;

Davison and Jhangri, 2010; Fry, 2000; Rambod and Rafii, 2010; Tanyi and Werner, 2003) and one that used a mixed-method approach (Giaramazidou et al., 2005). All of them were conducted in Western countries with one exception that was conducted in Iran. All of the above studies emphasise the importance influences of religion upon ESRF patient in formulating perceptions of the illness (Cordeiro et al., 2009; Tanyi and Werner, 2003; Tanyi et al., 2006).

Tanyi and Werner (2003) in a descriptive correlated study aimed to investigate the differential impact of levels and relationships between adjustment, spiritual well-being, and self-perceived health in women with ESRF in the USA (n=65). Significant relationships were found between spiritual well-being and other adjustment domains and between self-perceived health and other types of adjustment. This research examined the influence of spirituality and self-perception of health for women suffering with ESRF. In addition, the researchers' objectives were to answer the following questions (Tanyi and Werner, 2003, p232): What are the levels of psychological illness? What are the levels of spiritual well-being? What are the levels of self-perceived health status? Moreover, the researchers examined the correlational relationships between psychological adjustment to illness, spiritual-well-being and self-perceived health status of the women undergoing haemodialysis. This empirical research mainly used a descriptive research design. Although this was justified (Tanyi and Werner, 2003, p233), the authors grouped almost fourteen variables into three main different groups: psychological adjustments, spiritual well-being and self-perceived health (Tanyi and Werner, 2003, p236). The results showed that spiritual well-being and self-perceived illness were positively correlated and significantly associated with the overall psychosocial adjustment. Furthermore, in terms of religion, the sample appeared to be heterogeneous. Albeit the P value of < 0.001 supports the assumption that the correlations are there and they are true, however, it is not necessarily a cause and effect relationship. It provides insight on these three variables (spiritual well-being, self-perceived illness and overall psych-social adjustment. It would have been more useful if the authors had considered combining a qualitative approach in their analysis which may have provided a better insight into this question.

In addition, it is important to note that the literature on spirituality in ESRF patients has included more women than men, with the majority being from an African or

Indian ethnic background. Such backgrounds tend to be relatively religious (Tanyi and Werner, 2003; Tanyi, 2002; Tanyi, 2006; Tanyi and Werner, 2003; Tanyi and Werner, 2007; Tanyi and Werner, 2008; Tanyi et al., 2006; Tanyi et al., 2006; Walton, 2007; Wright, 2003). Since the above studies highlighted the different spiritual experiences in this particular group with gender, religious and limited, a study that focuses on Arabic-Islamic patients might provide a deeper understanding of how spirituality is experienced in this culture.

Spiritual Dialogue for ESRF Patients

Six of the included studies indicated the importance of engaging patients in spiritual dialogue in the experience of ESRF (Campos, 2007; Finkelstein et al., 2007; Sinclair and Parker, 2009; Tanyi et al., 2006; Ziegert et al., 2009); all of these studies were qualitative in nature and conducted in the USA. Tanyi et al. (2006) in a descriptive phenomenological study aimed to understand how ESRF patients want nurses to address their spirituality (n=16, female ESRF patients). They found that most of their participants articulated that if nurses are keen to understand ESRF patents' spirituality, they must engage in a spiritual dialogue with their patients. However, a major criticism to Tanyi's work is that there seems to be an issue of data "accessibility": four researchers were involved in the study, but it is unclear who recruited the participants, who conducted the interviews, how the analysis was carried out and even how agreement was reached on the 83 significant statements in their research. In addition, the sample included only female patients, of whom 69% were African-American and the remainder were Caucasian, Hispanic and Asian. Thus, I would argue here that participants may have understood the context of spirituality in different ways. For example, the word "spirituality" in the English language may have different interpretations and meanings to spirituality in another language or culture. I would be concerned about how spiritual dialogue was implemented in such circumstances. Tanyi's study would have been much more convincing if the authors had included different languages in the interview. Moreover, the authors stated that there were breaks within some interviews, as a result of low blood pressure during dialysis, but they did not specify how these were handled or how long they were. I think it is vital in phenomenological terms to elaborate on these situations. Despite efforts from the researchers in the previous study to clarify matters related to the interview place, the duration of the interview

and data saturation, it was not clear whether the field notes were used by the researchers, which would have enhanced the conformability by showing the reflexive account and the audit trail. For example, in Tanyi et al. (2006, p534) study some of their participants became unconscious during the interview, yet the research team did not mention how many research participants experienced this, or the duration of each episode. My personal experience suggests that these events may last from 10 to 45 minutes before individuals are fully recovered. If so, this raises a number of important questions: How did the authors resume their interviews after the participants' regained consciousness? Was the time lost during these episodes compensated later on in the interview? Did the interruption in the flow of the conversation influence the research analysis or results? This study highlights an important consideration as it magnifies the importance of predicting special circumstances that may arise during interviews.

In conjunction with data analysis, Tanyi et al. (2006) cited that there were 83 significant statements, however, the basis on which the researchers agreed or disagreed and how they amalgamated these statements together into four themes was not clear. Also, the analytical process was inadequately described and documented. The researchers acknowledged that there were some issues surrounding the language in which interviews were conducted. This may affect the auditability[1] of their findings, as it was not explained how the findings were organised or how the researchers compromised on issues of contention amongst them especially when there were nine different religions in their samples. The findings of Tanyi's study would have been much more useful for healthcare providers if the authors had addressed how each religion included in the sample would have preferred to address the spiritual dialogue during dialysis. Aldridge (2000) highlighted the need to enrich our spiritual vocabulary in order to facilitate the understanding of spirituality, transcendence, forgiveness, hope, reconciliation and redemption. Enriching our spiritual vocabulary may help us in engaging with patients' thoughts and the process of suffering and healing from illness. Therefore, studies that focus on spiritual vocabularies for each culture may provide more insight into how spiritual needs and spiritual dialogue can be addressed by healthcare providers.

[1] Auditability: 'accountability as judged by the adequacy of information leading the reader from the research question and raw data through various step of analysis to the interpretation of findings' (LoBiondo-Wood and Harber, 2006, 168).

A broader perspective of understanding spirituality has been adopted by many scholars who have argued the universal aspects of spirituality, which includes both believers and non-believers. The literature suggests that both ASSET and ACCESS are valuable tools to initiate either spiritual or religious dialogue with patients or their families. However, several questions remain unanswered at present; how can nurses understand all the spiritual needs of patients and engage in religious dialogue with patients from different religious backgrounds?. However, what if the nurse's own religion contradicts the patient's beliefs? Is the nurse required to pray in her faith or in the patient's faith? For example, in 2009 a nurse called Caroline Petrie was suspended from her work and almost lost her NMC registration as a result of being spiritually engaged with her patients and offering to pray for them (Alderson, 2009). Thus, it seems that we are still far from integrating spiritual care even in the UK, where the importance of spirituality as a dimension of holistic care is more acknowledged academically. Thus, the healthcare professionals need to learn on religions/spirituality of their patients under their care through educational program and person initiative. As a result, in 2010, NMC conducted research with McSherry that majority of healthcare professionals agreed that spiritual care was an important component in their care. However, later in 2015, the NMC code has excluded spirituality and spiritual care from the nurses' role. This contradicts what McSherry recommended in the above study. Thus, it can be argued that in other secular societies, where the traditional biomedical approach prevails, there could be even more resistance to address such spiritual engagement, especially when there are very limited policies and guidelines in place.

Overall, these studies highlight the need for spiritual engagement in which spiritual and religious dialogue is viewed as an important element in spirituality. However, they also show that addressing such spiritual needs may be challenging to healthcare professionals. It is therefore vital for healthcare professionals to consider the diversity in culture and religion when addressing patients' spiritual needs. Further studies that take these variables into account are also needed to establish better ways to address such spiritual needs in different cultures and religions.

The following section will discuss some of the barriers and cultural issues when applying spirituality.

Barriers and Cultural Issues When Applying Spirituality for ESRF Patients

The challenges and the cultural issues when applying spirituality for ESRF patients have been highlighted by ten studies in my literature search (Burkhardt, 1993; de Gauna et al., 2008; Giaramazidou et al., 2005; Gibson, 1995; Madar and Bar-Tal, 2009; Matthews, 1998; Perry et al., 1996; Pesut and Reimer-Kirkham, 2010; Rambod and Rafii, 2010; Ruiz de Gauna et al., 2008; Walton, 2011; White and Grenyer, 1999; Ziegert et al., 2009). These studies were dated from 1993-2011 and the majority of them were conducted in the USA, Sweden, Greece, the Netherlands, Israel, Australia and Iran. The participants were patients, next of kin and healthcare professionals.

These studies identified two broad challenges: lack of knowledge and lack of support. Lack of knowledge was related to the treatment of ESRF and the uncertainty that ESRF patients and their families experience that is not always adequately addressed. These studies also discuss how spirituality can be addressed and how some ethnic minorities can become disadvantaged due to not having their spiritual needs met during their illness (Narayanasamy, 2007). This may lead ESRF patients to suffering and constant struggling (Molzahn et al., 2011). In order to overcome the prevailing lack of knowledge, some researchers suggested that spirituality can be part of healthcare students' curricula and that spirituality and culture should be increasingly acknowledged academically and legislatively (Gibson, 1995; Lay Hwa and Creedy, 2011; Lemmer, 2002). As mentioned previously, Giaramazidou et al. (2005) found that Muslim ESRF patients in Greece did not possess low dietary knowledge, but despite this lack of dietary knowledge, they had a low incidence of fluid overload, hyperkalaemia and hypophosphatemia, whereas Christian ESRF patients, despite their advanced level of education, had more episodes of fluid overload. This study highlighted the important role of spirituality and religion in ESRF patients' experience. However, the issue of tailored care for Muslims in non-Muslim countries is particularly complex due to the prevailing sensitivity concerning Islam-related issues (Narayanasamy, 2007). Muslim ESRF patients, and Muslim patients in general, are rarely mentioned in healthcare research (Clarke, 2009). Abu-Ras and Laird (2011) showed that the main challenges in addressing patients' spirituality were lack of cultural and religious awareness of healthcare providers.

With regard to the lack of support, the above studies reported factors that urge nurses and healthcare professionals to play effective roles in addressing spiritual needs of ESRF patients, either in the pre-dialysis phase or thereafter (Cases et al., 2011; Davison and Jhangri, 2010). This is congruent with findings that support, in any forms, enhanced positive outcomes of ESRF patients' spirituality and spiritual-well-being (Chaves et al., 2011; Davison and Jhangri, 2010; Finkelstein et al., 2007). Other studies have reported that peer support has influences on individuals' emotions and on their spirituality (Hughes et al., 2009). However, as stated in Chapter One, some cultures recognise males as the breadwinners and therefore more help and support is provided to male patients (Rambod and Rafii, 2010). The authors in the above studies drew attention to the distinctive categories of Stoll's model and the structural module of spirituality, in which the absence of showing love, trust, support and forgiveness from the horizontal dimensions may impact negatively on patients' spirituality. However, it was not clear whether such lack of support and the disconnection from the horizontal dimension and the surrounding environment has led patients to search for meanings and purpose in the vertical dimension. A broader study to explore what support systems are available in Jordan for ESRF patients, and what influence such support may have on patients' spirituality might be required.

Although family support is a crucial source in spirituality and spiritual coping mechanisms (Krueger, 2009; Weinland, 2009), in Jordan, as with other Islamic countries, the family has cultural and religious obligations to look after their ill relatives. However, with long term illness such as ESRF, the literature suggests that this may influence relationships between family members (Banning et al., 2009). ESRF patients may then feel disconnected and isolated from their own environment or left out as a result of such lack of support (Al-Arabi, 2006). In addition, the above studies indicated the lack of support may result in signs of spiritual distress such as fear, isolation, aggression, anger, substance abuse, psychological distress and suicidal thoughts (Banning et al., 2009; Garroutte et al., 2003; Noble, 2011). Aldridge (2000) pointed out that suicidal attempts and thoughts reflect the situations that individuals find themselves in, where they became disconnected, separated and isolated from their background and losing help and support. Thus, finding the balance in support may enhance ESRF patients' overall spirituality (Walton, 2002).

A more comprehensive study is therefore needed to identify spiritual resources for help and support in certain cultures in order to help patients to minimise possible suicidal thoughts.

Comparing the two overarching results in this section, it can be seen that these studies indicated that both lack of knowledge and lack of support may inhibit addressing patients' spirituality. However, I would argue that ESRF patients might additionally experience social stigma as a consequence of these factors. The literature suggests that stigma has been shown to have a negative influence on a person's sense of self and diminishes their self-esteem (Corrigan et al., 2009) which consequently impacts on the QoL of individuals. This will be explained in the following section.

Spirituality and QoL

Ten studies have attempted to explain the relationship between spirituality and ESRF patients' QoL (Al-Arabi, 2006; Chaves et al., 2010; Finkelstein et al., 2007; Gayle et al., 2009; Grudzen et al., 2010; Jablonski, 2004; Matthews, 1998; Song and Hanson, 2009; Steinhauser et al., 2004; Wesolowski and Szyber, 2004). These studies were conducted in the USA (n=6), Greece (n=1), Portugal (n=1), the Netherlands (n=1), and Iran (n=1). Furthermore, the quantitative approach was dominant in these studies (n=8).

The major themes emerging from these studies were the difficulties and the alteration that ESRF patients' face. For example, Al-Arabi (2006) in a naturalistic enquiry aimed at describing how ESRF patients experienced QoL using a sample of 80 dialysis patients in the USA found that "Life Restricted" was a major theme, with sub-themes such as "tied down", "left out", and "doing without". These themes and sub-themes gave the sense that ESRF patients had lost something that was never going to come back, including freedom, choices, physical appearance, rituals and decision-making opportunities (Al-Arabi, 2006).

Furthermore, Vélez and Ramasco (2006) emphasised the important role of healthcare providers in the pre-dialysis phase in Spain and how it can help in managing ESRF. In their study, they critiqued the focus of healthcare professionals on providing patients with ESRF with scientific information about their health, which may not

always be appropriate. They also argued that the lack of effective pre-dialysis care may have negative implications on patients' QoL. However, my personal experience suggests that such care is even less likely to be available in Jordan. This may contribute to the immense struggle faced by Jordanian ESRF patients trying to cope with the burden of their illness. Others have suggested that possible engagement with patients in discussions about their spiritual concerns and attending to their spiritual well-being may contribute to an improvement in their QoL and medical outcomes (Finkelstein et al., 2007). This is in agreement with other studies that showed that ESRF patients' perception of their illness was useful in understanding the impact of the treatment on the individual's QoL (Atkinson et al., 2004; Cordeiro et al., 2009; Curtin et al., 2004; de Gauna et al., 2008; Jansen et al., 2010; Madar and Bar-Tal, 2009; Ruiz de Gauna et al., 2008; Timmers et al., 2008). Furthermore, in a qualitative study conducted by Fowler and Baas (2006) in the USA and aimed at exploring the relationship between illness perception and QoL for ESRF patients on dialysis, it was found that nurses are in the best position to identify individuals' perceptions of their illness and help them to improve their coping mechanism and overall well-being. Similar studies showed that religious coping plays a significant role in enhancing the QoL of critically ill patients and that the style of religious coping could lead to better or poorer QoL (Tarakeshwar et al., 2006).

Together these studies provide important insights into the role of spirituality in enhancing ESRF QoL. It is important for future research to focus on studying QoL and how it interacts with coping mechanisms in different cultural backgrounds.

The following section will discuss the evidence on spirituality as part of palliative care during ESRF.

Spirituality and Palliative Care in ESRF

This section highlights the importance of spirituality in providing the palliative care for ESRF; six studies were included (Cases et al., 2011; Grudzen et al., 2010; Hine, 1998; Mast et al., 2004; Molmenti and Dunn, 2005; White and Fitzpatrick, 2006). Literature in the previous sections suggested that spirituality is an important element in caring for patients in a holistic way. The literature also highlighted the need to understand individuals with ESRF and life-limiting illnesses where the physiological challenges may override the psychological and spiritual needs (Bullard, 2004).

However, there is some evidence to suggest that spirituality and palliative care are overlooked by healthcare providers in the Middle East where the biomedical model of care prevails (Nawafleh et al., 2005). Bingley and Clark (2009) evaluated palliative care in six different countries in the Middle East: Cyprus, Egypt, Israel, Jordan, the Palestinian Authority and Turkey. They suggested that the key barriers to applying palliative care in these countries are lack of secure funding and government support, inadequate professional training, opioid phobia among professionals as well as patients, and a lack of awareness and understanding of palliative care needs at public, governmental and professional levels. These findings are congruent with a more recent study by Al Qadire (2014), which concluded that inadequate knowledge of palliative care among Jordanian nurses (n=220) was one of the main barriers to palliative care development and practice. He reported that 68% of his study sample received no palliative care education during their study. This indicates the need for incorporating palliative care training in the nursing curriculum in Jordanian universities. Despite the wealth of literature suggesting the importance of spirituality in palliative care, more studies are still recommended to understand better spiritual experience of ESRF (Bullard, 2004; Finkelstein et al., 2007) especially since limited studies conducted in Jordan.

Previous studies have been inadequate in trying to understand how spirituality is uncovered for Muslim patients. Both spirituality and palliative care were well structured within the healthcare settings in the Western countries where the studies were conducted. In other words, both spirituality and palliative care are generally regarded from a Western perspective. These findings therefore cannot be applied to all patients. Spirituality and palliative care differ not only in their meanings, but also in the way in which they are expressed in care outcomes informed by religion and culture. The findings of such studies would be more useful to my study if the authors had included Arab-Muslim participants' views on both spirituality and palliative care. Palliative care in Jordan, as in most developing countries, faces particular religious challenges and cultural obstacles.

To summarise, the findings of the above studies have a number of important implications for future practice. The evidence also suggests strong relationships between spirituality and palliative care; it seems that a lack of adequate knowledge about spirituality may negatively affect palliative care outcomes. In addition,

evidence suggests that ESRF patients may develop suicidal thoughts as a result of experiencing spiritual distress; therefore it is important to develop palliative care for ESRF patients. It is therefore important to explore and understand meanings of spirituality for Arabic-Muslim ESRF patients before palliative care can be applied to ESRF in Jordan.

Identification of Research Gaps

On the basis of how spirituality in my literature review was uncovered, a number of issues behind the confusion and complixity in understanding spirituality in general and its application in practice were identified. A better and more scientific approach to understanding this phenomenon in nursing care in general and for ESRF in particular is needed (O'Brien, 1982; Walton, 2002; Walton, 2007). Although religion and culture are deemed important to understanding individuals' spirituality, the studies that have been identified in the literature review were conducted in North America and Europe, China, Brazil, Israel and Australia, thus exploring the meaning of spirituality from a Judaeo-Christian perspective: it appears that the evidence on how spirituality is manifested in ESRF in general and in Jordan and Muslim culture in particular was limited in the literature. Only two studies in Jordan (Nabolsi and Carson, 2011; Zeilani, 2008) were found to mention spirituality (indirectly) in the lived experience of those who have been admitted to ICU and CCU. Both studies recommended exploring meanings of spirituality in other chronic illnesses, such as ESRF.

Proposed Research Question

"How is spirituality experienced by Jordanian patients with ESRF?"

Aim of the Study

The overall aim of this study is to understand and interpret patients' perceptions, experiences, beliefs and practices that are associated with the use of spirituality as a concept among end stage renal failure patients in Jordan as reported by patients.

Objectives of the Proposed Study

1. To explore patients' beliefs and practices toward spirituality in ESRF.

2. To explore and better understand how Jordanian ESRF patients characterise their spirituality.
3. To describe spirituality as depicted by the experience of Jordanian ESRF patients.
4. To understand how spiritual care is understood and experienced by ESRF patients.
5. To explore and identify the spiritual resources that ESRF patients can use to enhance their spirituality.
6. To understand how spiritual dialogue may enhance patients' spirituality.
7. To illuminate how spiritual help and support may enhance the quality of life for ESRF patients by nurses and HCP.
8. To identify the cultural barriers and cultural meanings of spirituality.

Summary

The above extensive and systematic literature search has provided a theoretical background for the present study by identifying the main themes in previous work in this field. Search terms, strategy and outlined results have been presented (Figure 2.3), and a variety of issues around spirituality and the previous research gaps that my study is aiming to fill, have been explained. I have explained the aim and objectives of the study, and its potential implications for nursing care for ESRF patients in Jordan.

Together, these studies indicate the importance of spirituality in the patients' experience of chronic illness. The literature illustrates that religion; culture, language and the support system are important factors in understanding individual's spirituality and spiritual needs. Thus, studies incorporating different cultures, religions and languages are required to enhance our understanding of spirituality from a wider prospective.

Another important issue that was recognised in the literature review was that previous studies on spirituality were carried out by academics with limited background knowledge of Middle Eastern culture. Furthermore, the majority of the studies were limited as a result of using one language in a diverse group of patients; this may hinder the participants in expressing their views.

The methodological review of the searched studies illustrates that qualitative approaches are suitable for understanding spirituality in the experiences of ESRF patients and for studying the spiritual care provided in Jordan. Since spirituality and spiritual care are relatively subjective and contextual in nature, it is suggested that qualitative approaches may be more useful to understanding such phenomena (Albaugh, 2003; Burkhardt, 1993; Tanyi et al., 2006; Touhy et al., 2005; Walton, 2007). The methodology and methods by which this research will be conducted are explained in the following chapter.

CHAPTER 4: Research Methodology and Methods

> *"If you don't have a refinery operating, it's hard to use oil that's available"*. (BOONE PICKENS, 2015)

Introduction

This chapter focuses on what I have done rather than on what I have not done. This does not mean I came to conduct my study with preconceived ideas regarding methodology and methods. This chapter represents a huge learning curve which was aided by my reading and understanding of qualitative and quantitative research methodologies and methods. I begin this chapter by describing methodology. Methodology is the theoretical underpinning of the research process (method). This chapter describes a series of decision-making processes that I undertook which eventually led me to an outcome. I justify why a hermeneutic phenomenology was chosen to conduct my study, followed by a description of the methods used, including participants, recruitment strategy, access, data collection, data analysis, presentation, dissemination and potential impact for stakeholders, and ethical considerations. This is an important chapter which indicates how I came to conduct my study and gives the reader an important audit trail.

My interests in ESRF and spirituality have developed from previous experience as a patient and as a nurse, and also from my review of the literature. These experiences led me to formulate a specific research question: How does spirituality manifest itself in the lives of Jordanian patients in ESRF? It has been well documented in the literature that the chosen research approach rests largely on the research question(s) (Bryman, 2012; Creswell, 2014). The research question above is posed on the understanding that we do not currently know and understand how spirituality comes to exist in the lives of Jordanian ESRF patients.

Spirituality could be explored using different approaches, with qualitative, quantitative or even mixed methodologies. From an early stage, I questioned such approaches in order to determine which would be best to address my research question, in part from my own ontological position and motivations, especially when I know nothing about how Jordanian ESRF patients manifest their spirituality. Thus, to answer my study question I argued that my research question would require answers that could give deep descriptions and interpretations. It appeared that the

answers would not be quantifiable; but I realised the answers to my study question would need to identify ways in which each individual experiences spirituality, which would not necessarily be same way that another views how spirituality is experienced. Furthermore, it will provide the opportunity to analyse spiritual experiences and to illustrate the phenomenon of spirituality structured from my study participants' accounts. Thus the understanding of the phenomenon of spirituality during ESRF that can be gained from such a process can be offered for the benefit of others, both practitioners and patients.

I discovered that the research question I had developed required an answer which would involve a qualitative approach to enquiry in order to maximise the understanding of individuals' experiences and most importantly to give a voice to the voiceless patient in describing how spirituality is manifested during their illness situations, and how they would like nurses to incorporate spirituality into their care. The following sections provide an overview of the two major research paradigms and a justification of why qualitative research (specifically hermeneutic phenomenology) is best suited to answer the research question posed by this study. This is followed by the methods employed, including a justification of each. In addition, I will elaborate on the process of decision making used to choose the appropriate methodology and methods to conduct my study.

Methodology

According to Crotty (2009), methodology is the theoretical stance taken by the researcher that underpins all research processes, including the methods employed. It locates the researcher and the research within a particular world view (ontology) and relates to views of epistemology (i.e. what can be known and who can know it) (Silverman, 2011). Following the completion of a number of courses and research modules in the first year of my PhD course, I have come to recognise that there are two major paradigms in research: quantitative and qualitative. The former is to do with seeking cause and effect relationships and involves quantifiable measurements (e.g. numerical data) (Polit and Beck, 2008). The second is often referred to as interpretation and refers to the way in which humans interpret their experience of a phenomena (Greatrex-White, 2004; Van Manen, 1990). Whilst the former paradigm assumes a static environment in which factors act in a specific way, comprising a truth that can be known and generalised, the latter is more to do with understanding,

and as such leads not to 'the truth' but to 'a truth', one of multiple possible interpretations of reality (Greatrex-White, 2008). Truth might be different for different people; this ideologically nuanced approach differs from the objectivism upon which natural sciences and positivist quantitative research are based. This is important for my study, because the aim is to seek a better understanding of the phenomenon of 'spirituality' from the perspective of people in ESRF who experienced it in Jordan. It can be argued that a study such as this requires a qualitative research approach as opposed to quantitative one. This first decision has helped me to refine a number of thoughts that I carried over years of experience in nursing; for example, around the existing questionnaires from the literature that have been used to examine the phenomenon of spirituality and whether they could be sensitively applied in a different culture.

Both healthcare providers in Jordan and the literature worldwide recommend a study to fill the gap in the existing body of knowledge regarding the meaning of spirituality from the Arabic-Islamic perspective, therefore, the purpose of my study was to explore the Jordanian experience of spirituality in ESRF. However, there are many different qualitative research methodologies and approaches within the qualitative paradigm (Bowling, 2010; Burns and Grove, 2009; Crotty, 2009; Polgar and Thomas, 2008; Silverman, 2011), as illustrated below, focusing on the four major qualitative methodologies: ethnography, grounded theory, narrative analysis and phenomenology.

Firstly, ethnography, according to Creswell (2007), focuses on the description of a group of people, their beliefs, language, and behaviours of culture-sharing. This approach would offer a description of ESRF patients and why spirituality is important to them from within a cultural framework. Ethnography may involve multiple methods of data collection, such as field notes, interviews, audio-visual materials as well as representation and observation (Silverman, 2011). However, such observation of ESRF participants in this research is not feasible for a number of reasons: the nature of this research is time-limited; in observing ESRF patients in the real world it would be impossible to record any spiritual interactions; and as stated above, the main aim of this study is not focused only on culture. The unsuitability of this approach was the second decision I made regarding methodology.

Grounded theory is applicable when the researcher's aim is to generate theory (Greaves, 2010; Wimpenny and Gass, 2000). A broader perspective was adopted by (Ke and Wenglensky, 2014), who argued that it would be impossible to begin a study and collect data in grounded theory without pre-existing data or assumptions. My personal experience of the phenomenon of spirituality and of being diagnosed with ESRF, and my professional experience of being engaged with ESRF for the last 17 years are all reasons which motivated me to conduct this research. I discovered in selecting a methodology that I must leave all of the above behind; in other words, I must bracket myself from the phenomenon of spirituality that I experienced myself. Bracketing myself from such powerful factors, which initially inspired my desire to undertake this study, influenced my first decision to conduct my study qualitatively. The purpose of my study was to seek better understanding of the question being asked: **"How is spirituality experienced by Jordanian patients with ESRF?"** Such a question requires a descriptive answer based on the interpretations of those who experienced such phenomena. Thus, the grounded theory approach was inappropriate for the purposes of the proposed study, which did not aim to produce theoretical perspectives but to analyse the existence ESRF experiences of spirituality and seek a better understanding of the phenomenon of spirituality in Jordan. This resulted in another decision that refined my thoughts further.

In examining the narrative approach, I came to face another important juncture in refining my thoughts. I discovered that narrative research arguably arose from phenomenology and is concerned with both the story being told by a participant and the way in which it is told. To elaborate this further, Frank (1995) observed that we can learn a great deal from people's narrative stories about healthcare and healthcare experience, and how these experiences can be transferable to other settings. Research participants narrate their stories based upon their understanding of their illness, their cultural and social background, and their educational level (Kleinman, 1988). Although this approach would be beneficial in answering the research question of this study, given that spirituality is experienced as a very personal phenomenon best recounted in the narrative of those who experience it, this research question aims as far as possible to encompass the general nature of spirituality in a specific healthcare context, thus the highly personal data typically yielded by narrative approach would prevent drawing general conclusions that would then be applicable to wider healthcare contexts. Additionally, narrative research can

generate unreliable data if participants narrate unreal or imagined events (Atkinson, 1998). Furthermore, creating a narrative can be challenging task, with people required to reflect their experiences in words as required by narrative research, resulting in chaotic data (Frank, 1995). This can be problematic, as illustrated in one of Frank's studies when interviewing a chronically ill patient:

> "If I'm trying to get dinner ready and I am already feeling bad, she's in front of the refrigerator. Then she goes to put her hand on the stove and I got the fire on. And then she's in front of microwave and then she is in front of the silverware drawer. And – and if I send her out she gets mad at me. And then, it's awful. That's when I have a really, a really bad time" (Frank, 1995 , p 99)

Such stories have no narrative sequence and contain nothing but life experience, which anyone may experience. Thus, the personal factors involved when engaging patients in narrative research make it impractical to use as a method for the purposes of my study, as they may compromise the validity of data narrated using this approach. Based on the above reasons, I decided to reject such a methodology.

Phenomenology

Phenomenology is concerned with the study of a phenomenon as experienced by people within a certain context (Crotty, 2009; Greatrex-White, 2004; Van Manen, 1990). Similar to the narrative approach, it concerns people's stories, but the focus remains more firmly on the phenomenon under study rather than the stories and narrators themselves; the understanding of the phenomenon results from the co-creation of the researcher and the participant, and not just the individual interpretation of either one (Flood, 2010). However, there are different forms of phenomenological research underpinned by two major approaches: Husserlian and Heideggerian philosophy (Ashworth and Greasley, 2009; Burns and Grove, 2009; Crotty, 2009; Greatrex-White, 2004; Koch, 1995; Polit et al., 2001; Silverman, 2011; Van Manen, 1990). Heideggerian phenomenology was chosen for the purposes of this study, for the reasons outlined below. The main differences between Husserlian and Heideggerian phenomenology are shown in Table 4.1.

Husserlian (or descriptive) phenomenology is seen as the "father" of phenomenology (Smith et al., 2009; Van Manen, 1990). Husserlian phenomenology necessitates that the researcher has to bracket out all that they know about the phenomenon, enabling them to approach the phenomenon in a pure form and to give an in-depth description

of the phenomenon, taking nothing for granted. According to Spiegelberg (1975, cited by Tani et al., 2006, p533), descriptive phenomenology is "the direct exploration, analysis and description of a particular phenomenon, as free as possible from unexamined presuppositions, aiming at maximum intuitive presentation". As observed by Greatrex-White (2004), this raises numerous problematic issues, since it essentially necessitates that so far as possible the researcher assumes the form of an automaton or *tabula rasa* with no pre-existing knowledge of the phenomenon under consideration. However, there are concerns about the practicality for this theoretical approach. For example, how could a nurse who has studied the phenomenon theoretically and worked with it practically negate all of their clinical knowledge and experience to consider it from the perspective of Husserlian phenomenology. Greatrex-White (2004) states that Husserl's main concern was pure objectivity (positivism), the paradigm associated with the natural sciences since the Enlightenment, and a very hard worldview to incorporate in modern studies of human phenomena. The implications of researchers bracketing themselves to conduct objective, positivist study of a largely relativist phenomenon like human spirituality in the context of this study are explained below.

Table 4.1: Comparisons of Husserlian and Heideggerian phenomenology

Husserlian phenomenology	Heideggerian phenomenology
Epistemological questions of knowing	Questions of experiencing and understanding
How do we know what we know?	What does it mean to be a "person"?
Mind-body person lives in a world of objects	Person exists as a "being" in and of the world
Starts with a reflection of mental states	We are already in the world in our pre-reflective selves
What is shared is the essence of the conscious mind	What is shared is culture, history, practice, language
Claim that adequate techniques and procedures guarantee validity of interpretation	Establish own criteria for trustworthiness of research
Bracketing defends the validity or objectivity of the interpretation against self-interest	The hermeneutic circle (background, co-constitution, pre-understanding)

Adapted from Koch (1995, p 832)

In my study the aim is to understand multiple social realities – the experiences, beliefs and practices associated with the phenomenon of spirituality among ESRF patients in Jordan – and according to Husserlian phenomenology I would have to bracket or somehow remove all things that I previously experienced throughout the research processes.

The question arises whether it is in fact possible to bracket myself, my mind and my knowledge. Heidegger argued that we are all born into the world that is not our own choosing and live in it through interpretations which he called "being-in-the-world". This hermeneutic phenomenological phrase demonstrates our interconnectedness with the world.

Reflecting on Heideggerian philosophy, in order to answer my research question I have to correlate with my ontological position, own experience as a Muslim person from Jordan, born and raised within the same culture that I examined, as a patient diagnosed with ESRF, a field I also worked in as a nurse in a haemodialysis unit. Thus, I understand the culture very well, I am part of the linguistic environment there, and I understand some of the values and beliefs of ESRF patients; in other words I have a high degree of commonality with Jordanian ESRF patients: this is my being-in-the-world.

It would not be beneficial for my study to bracket these elements, especially when the aim of the study is to gain a deeper understanding of such a complex concept as spirituality. I was not a stranger to the phenomena under consideration. It might be argued that this would enhance my connectedness with the research participants, giving them comfort and confidence to articulate and share more stories with the researcher (Hayman et al., 2012; Pringle et al., 2011). As we are embedded in an historical context, we are powerless to completely bracket ourselves (Koch, 1995; Koch, 1996). In addition, albeit bracketing is one way to maintain the objectivity of the researcher, this contradicts the subjectivity that phenomenology tries to achieve (Greatrex-White, 2004; Koch, 1995; Pringle et al., 2011) and what I aimed to achieve. The concept of phenomenology within Arabic tradition is manifest in the maxim that can be translated as "Ask the veteran not the expert" – an Arabic proverb to the effect that lived experience might be more valuable than professional expertise. I used this Arabic proverb to affirm the importance of lived experience over the abstract knowledge of expert "doctors".

Phenomenology was further developed by Heidegger, a student of Husserl, who was affected by Husserlian ideas; however, Heidegger argued against the idea of bracketing and suggested that it is impossible for a person to bracket their being–in-the-world (Greatrex-White, 2004; Koch, 1995; Van Manen, 1990).

Heidegger argued that we cannot bracket all we know and experience of phenomenon, but rather we utilise our experience as a part of the interpretive process, as we all live in an interpretative world, which he justified by the observation that a better understanding of the phenomenon emerges via our interpretative capacity: we all live in interpretation and make sense of our world by the fact that we are part of the world (Heidegger, 1962).

Heidegger's phenomenology thus suggests researchers use their background and experience to become part of the research process rather than act as a divorced entity, therefore hermeneutic phenomenology is more related to insiders than to outsiders (Crotty, 2009; Greatrex-White, 2004; Greatrex-White, 2008; Greaves, 2010). My interest and motivations in reviewing the spirituality and care of Jordanian ESRF patients, and my own spiritual experiences of being diagnosed with ESRF were positive experiences in this regard. I attempted to understand the phenomenon of spirituality from ESRF patients' individual experiences rather than trying to seek a single truth behind their experiences. My interest was in how ESRF patients experienced spirituality during ESRF: from their being-in-the-world. It is important to note that when I asked participants to recall their experience of spirituality, participants were reflecting upon and thus interpreting their experiences: I was not collecting the experiences themselves but the participants' interpretations of their experiences.

According to Heidegger the phenomenological understanding of phenomena can be achieved throughout the phenomenological methods that are inspected and the significance of their collocation. However, Heidegger engages the Greek dialect, making this extremely hard to understand and follow. My knowledge of Heidegger's phenomenological terms is as per the following. The Greek etymological components of the term are phainomenon and logos (Greatrex-White, 2004). Phainomenon, as indicated by Heidegger (1962 p.28) signifies, "that which shows itself', through which he explains his view that phenomenology speaks to a probability of deduction as opposed to only naming a strategy of data collection. In his investigation into the significance of logos Heidegger investigates the associations between the Greek words *logos* and *legein* (talking, saying). According to Greatrex-White (2004) Heidegger suggested that a more unique significance of *legein* is "to set down and lay before", therefore, *logos* communicates to the method of experience the phenomenon.

Phenomenology for Heidegger is to use of the expression "*essence*" indicates exactly the opposite of that which can be achieved by an analysis of day by day word-use. Rather it is that analysis by which the meaning of the various ways in which we come to exist can be translated from broad and vague language of everyday existing language into understandable and explicit language of ontology, without changing or destroying the way in which those meanings uncovered themselves to us in our everyday lives (Moran and Mooney, 2002). For example, Van Manen (1990) investigation of parenting where it is acknowledge that the term of parent can be defined however the essence parenting, how the parenting term understood by us is to reflect and sensing on the qualities that make parenting worthy in our thought and interest. In sum, how we consider what it means to be a parent. Essence is to be seen in an ontological sense and not a metaphysical sense (Greatrex-White, 2004; Greatrex-White, 2008). It appeared that Hermeneutic phenomenology go beyond the interpretation to extract the essence or the main structure that is central underlining the meaning of experience of spirituality and hence the essence of the common spiritual experiences among ESRF patients in Jordan. For my study, this meant that Hermeneutic phenomenology is not about the recognition of single covering definition of spirituality. It need to be understood in ontological rather than the metaphysical terms as it involving meanings rather than letting the merely letting the fact speak for themselves (Gayle et al., 2009). Thus, to understand individuals being in the world I have to enquiring into ways of being in the world. This led me to move from asking the “what” question to “how” question. I become increasingly aware that my inquiring into spirituality during ESRF was in a since ways to enquire the way being in the world. And this led me to pose the research question “how spirituality manifested during ESRF in Jordan.

I came to understand that a Hermeneutic phenomenology study includes an analysis of human experiences during the phenomenon that are under investigation (Van Manen, 1990). This meant that I should explore the phenomenon of ‘spirituality’ as situated in the encounters of the individuals who experienced spirituality. This meant I have to turn to ESRF patients who were and are still experiencing spirituality during ESRF.

The thought of intentionality is inseparably bound up with Heideggerian phenomenology, and on account of its significance requires further explanation.

Heidegger sees intentionality as the essential assumption of the phenomenological method. Intentionality for Husserl is the basic component of consciousness. The act of consciousness is constantly directed toward its object item (Husserl, 1964 p.79). Whilst Heidegger follows Husserl in his complement of the topic of intentionality, I discovered real tensions between the two. For Husserl the intentional relation of the act of knowing, and the things as known, is primarily a cognitive or theoretical operation which he calls consciousness. For Heidegger, the intentional structure is display not only in the domain of consciousness; understood in terms of a person's cognitive and theoretical relation to his/her world, but already in the whole of a person's being in the world. Individuals intend their world not only in seeing and judging, but also in their practical concerns and in their experiences and reactions to other individuals who their world (Greatrex-White, 2004).

To explain further, an individual to which Heidegger assigns the term *Dasein*, has what Heidegger calls a preconceptual understanding of *Being* in which the intentional structure of experience already operative. It is this preconceptual understanding that performs a revealing function in that it opens up ways for being in the world (Greatrex-White, 2004; Inwood, 2000). There is never an isolated "I" given without a world, which is then confronted with the task of formulating a hypothesis/theory of knowledge to account for both its own existence as well as the existence of an external world. Heidegger (1962, p211) stated that "The primary datum is not the thinking subject or the Cartesian cogito, but the sum or the act of existing, and this in the sense of an already being-in-the-world". Here Heidegger appeared to me to unite subject and object in one amalgam, organisation and structure; even hypothesis and practice in a major manner which I will now attempt to elucidate.

As per Heidegger there is a level of experience which precedes the split between subject and object. The recent is *a noetic* or theoretical distinction that arises later in an individual's experience and is itself grounded in an individual's fundamental awareness of being-with and having a world, in other words, there is a practical level of engagement before we reflect or theorised. This is important because it was the closeness to this pre-theoretical awareness that I needed to get at with respect to the experience of spirituality during ESRF. This is not an unproblematic proclamation, but rather I make this vital point because as a researcher I do not

believe that I can ever achieve pre-theoretical awareness of other people with other individuals without such platforms of awareness. Therefore, I likewise trust it ought not to stop a researcher or ESRF patients from attempting to get as close to the things themselves (the phenomena) experienced, and this requires a certain change in the orientation to method (Greatrex-White, 2004).

From a hermeneutic phenomenology perspective, to do phenomenology is to examine our being-in-the-world, the need to comprehend and understand the world in which we live as individuals (Greatrex-White, 2008). Furthermore, since to understand the world is profoundly to be in the world in a certain way, the act of researching is the intentional act of attaching ourselves to the world, to become more fully part of it. This inseparable connection to the world is then the principle of intentionality.

In Hermeneutic phenomenology, maintaining the understanding in the analysing the individuals' interviews requires forward and back ward connections between the part and the whole of the text. Thus, understanding the nurture of these connections requires continual dichotomy which known as "the hermeneutic circle" that continually connect the part and the whole together, in which individuals' social and cultural background should not be excluded from this understanding, in which pre-understanding of these norms is required (Howell, 2012). Hermeneutic understanding deals with such forward and back ward connections between the part and the whole through developing spiral approach where researcher moves in between the part and whole experiences (see figure 4.1). To elaborate this more, this require me to concentrate more in understanding part of the experience and understand its' relationship to the whole. Indeed, this will highlight the whole (in this case I mean the phenomenon of spirituality). Then, I have to return to either same part or other part of experience that under analysis and repeat the process. The interchanges in this process develop deeper and rich understanding of the phenomena under investigations. These new understandings then develop its own circle of understanding between the part and the whole based on both pre-understanding and the new understanding, which will co-creates a new level of understanding.

Although Heidegger demonstrated the above understanding through the Dasein; however, the hermeneutic circle according to Heidegger must not be reduced to the

lowest level of our basic understanding that accoure when the researcher continuing interpret without letting the fore-having, fore-sight and fore-conception to be presented in a popular conceptions (Howell, 2012). Heidegger distinguishes that the hermeneutic circle as “possesses an ontological positive significance’ and that all interpretation limitations of thoughts and ‘arbitrary fancies’ must be negated and the investigation concentrated on the phenomenon or thing itself and this incorporates ‘the first, last and constant task” (Gadmar, 2004, p269).

Reflecting on Being-in-the-world, it appeared that the understanding and being in the world are both established from the circle that provided us meaning of how thing around us is interpreted and understood. However, Heidegger stated that “interpretation is grounded in something we have in advance-in a for-having, fore-sight, pre-grasp or fore-conception”(Blattner, 2006, p96) in which this provides a dynamic for the circle of interpretations and understanding of the phenomenon under investigation. An implication of this is the possibility that the researcher has to have a dialogue with the individual’s interview transcript in a way that the researcher requires to listen to what the text has say while at the same time question the relationship between the part and the whole (Howell, 2012).

Heidegger utilizes the term das Man or “the they” to speak to the "levelling out" propensities of social reality (Lemay and Pitts, 1994 p49). In Heidegger's examination, the impact of das Man is specifically joined with the conclusion of interpretive structures of existence. "The 'they' prescribes one's state-of-mind, and determines what and how one 'sees' “(Heidegger, 1962 p213). According to Greatrex-White (2004) how the individual interprets the reality has to do not only with understanding on an abstract level but with action and existence. In this way "the ‘they’ endorses that method for deciphering the world and Being-in-the world which lies closest," and this creates "referential context of significance that governs our interaction with the entities we encounter" (Heidegger, 1962 p167). The immersion inside the interpretive methods for being recommended by *das Man* is alluded to by Heidegger as inauthenticity (Inwood, 2000).

The interpretive requirements of das Man are manifest in the very forms of language- use in which individual participate. Heidegger utilizes the term 'idle talk', to describe the forms of language that falls prey to the givenness of accepted interpretations and continues to foster those interpretive ways (Greatrex-White,

2004). He clarifies that idle talk is not intended to describe an isolation tendency within everyday language use but it is reflective of a dimension of language in general (Greatrex-White, 2004). Idle talk has a particular relationship with inauthenticity because it wards off alternate possibilities of discourse. It creates a closed interpretive world that excludes the possibility of being challenged by the new and outsider of the phenomenon, in my case spirituality. When the Idle talk becomes dominant in the discourse, Heidegger claims, "it serves not so much to keep Being-in-the-world open for us in an articulated understanding, as rather to close it off, and cover up the entities within the world" (Heidegger, 1962 p213). The interpretive determinations experienced by das Man upon the individual repress the potential for an authentic self by limiting and curtailing constraining existential possibilities. The individual is relieved of the burden of making decisions on fundamental level, and yet it is not some other individual who assumed this burden. of settling on choices at basic levels of decision making, but it is not some other person who expects such a burden. This seemed to me to parallel contentions shown in falling to underestimate the function of language (McSherry, 1997; Ross et al., 2014).

Heidegger offers a feeling of opportunity from inauthentic being through logical reflection and examination of the phenomenon under investigation. He builds up the thought of being by method for determination. Authenticity does not depict self-certain singularity yet rather "the opening up of individual" (Heidegger, 1962 p213). There is an enlightening relationship in the middle of determination and divulgence that backs the understanding of the phenomenon. Hence das Man speaks to a closed ontic process for being.

The issue of language, becomes progressively imperative to Heidegger as his work creates and gives the premise to the conjoining of hermeneutics as a way to deal with truth as disclosure (Greatrex-White, 2004). Heidegger investigates three viewpoints contained in the idea of statement: pointing out, predication, and communication (Heidegger, 1962 p196-198). Prediction serves to illuminate and further identify the demonstration of indicating out. Consequently Heidegger offers a general presentation of assertive language as "a pointing-out which gives something a definite character and which communicates" (Heidegger, 1962 p199).

Assertive discourse expresses the everyday way of language that is imperative for common sense issues. Heidegger does not attempt to examine its legitimacy accordingly yet rather looks to uncover what stays presupposed in assertive way. He argues that any such assertive determine of an object in an assertion essentially happens inside the structure of pre-given perspectives and points of view: "When an assertion is made, some fore-conception is always implied, but it remains for the most part inconspicuous, because the language already hides in itself a developed way of conceiving. Like all interpretation, assertion necessarily has a fore-having, a fore-sight, and a fore-conception as its existential foundations" (Heidegger, 1962 p200). language, while key for pragmatic objects, is unequipped for illustrating its interpretive fore-conceptions because the end that control it are both predetermined and, to a more noteworthy or lesser degree, covert or unconscious; consequently assertive language has a obscuring impact. It does not allow a transgression of its interpretive structures or an investigation into the way in which they shape objects.

Whilst assertive language dependably indicates something *as* either, that is, as interpretively delimited and decided, hermeneutical language questions the way or manner in which things are grasped as this or that, that is, into the structures controlling the disclosure of beings. This is an essential point in regard to hermeneutical phenomenology. Taking such a stance means that the researcher does not create orderly strategies for request with the foremost reason for absolutely protecting the subjective character of their information in place and untainted. Perhaps, the researcher asks into the route in which things are grasped; the focus is with phenomena and how it comes to exist or manifests, as opposed to simply relating subjective experience.

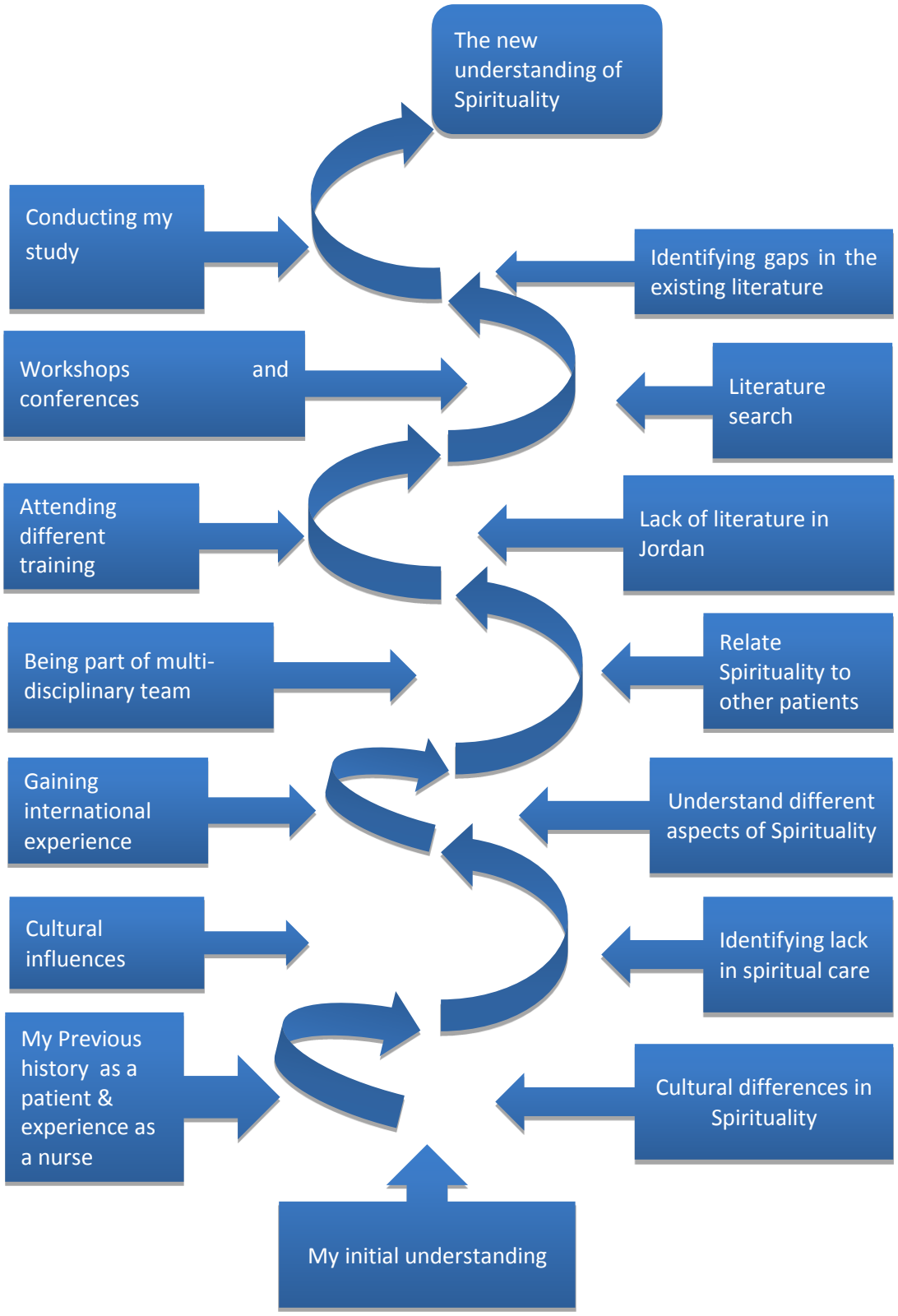
According to Greatrex-White (2008) and Greatrex-White (2004) hermeneutic phenomenology, as I now comprehend it is not about “giving voice to”, but rather is more concerned with figuring out how to hear the voices, for me this means learning to hear of those who experienced the phenomenon of spirituality during ESRF. Therefore, language permits the phenomenon to be exhibited; individuals cooperate with their understanding of being in the world by means for this understanding of the phenomenon and how they experienced it. Things are not given in a simply targeted way, but rather through dialect and, all the more particularly, through socio-cultural formed universes of discourse.

Further, language is not just a human item or device. The most obvious sense is that that language is not the result of the individual. Greatrex-White (2004) argued that language is mixed between history, culture and social interactions by nature and accordingly rises above any case of individual utilization. Also, Heidegger stated that "all language is historical" (Heidegger, 1962) (Heidegger, 1971 p133). The social and historical character of language implies that it shapes the universes occupied by individuals. For this specific reason, I decided to inform the research with a Heideggerian approach to understand better the relationship between Islam and spirituality, as this approach has a unique way to bring world and person together.

Greatrex-White (2004) argued that our understanding of the world that we live in relies on our understanding and meanings “to be” part of this universe, not only in the existential sense but also as human beings who are fundamentally part of the world through perception; hence the world mentioned above “being-in-the-world”. Furthermore, Heidegger (1962) reported that we all come to the world and we do not choose who we are. In the notion of Das Man or “the they”, he identified that the individual mirrors what other people are doing, which reflects on our behaviour and attitudes as being-in-the-world and how we perceive various things around us.

This is related to the spiritual perceptions of participants in this study within their milieu, to my own interpretation of my compatriots’ narrations, and the reaction of an outsider reading this paper – either with objective and open-minded consideration of the spiritual care needs of Jordanian ESRF patients, or with parochial disdain for the association between spirituality and religion (specifically Islam) which I have identified from the data, as will be unfolded further in the next chapter.

Figure 4.1: My understanding of the spirituality phenomenon



Heidegger argued that the interpretations of human experiences always bring new meanings to understanding the phenomenon. As illustrated in Figure 4.1, I started with a meaning of spirituality before conducting my research; however, I end up with a different, new meaning of the phenomenon of spirituality, disclosed by my interpretations of what participants reflected upon their experience. Heidegger suggests that within an individual's engagement with a situation, the meaning is unfolded. And both the individual and the situation he or she faces constitute each other and this will create "Das Man" or "the they"(Greatrex-White, 2004). It could be argued that in this way it is possible to justify that "a truth" exists to the extent determined by the researcher (Cohen et al., 2011). In addition, engaging by reading for phenomenologists (Crotty, 1996; Greatrex-White, 2004; Koch, 1996; Van Manen, 1990). The aim of my study was to understand better the phenomenon of spirituality via the account of ESRF patients in Jordan. Because the presented phenomenon of spirituality is constructed by both participants and the researcher, it could be argued that truth is a spiralling upward, and the more research that is considered about spirituality, the clearer the phenomenon becomes. Thus, bias in Heideggerian informed phenomenology is arguably a point to celebrate, as it may invite other phenomenological researchers to explore and to gain deeper understanding of the phenomenon. Bias should not be seen as the positivist approach might understand it. As seen in Figure 4.1, such bias can be seen as a new way of uncovering a new body of knowledge, which is illustrated spiralling upward.

I acknowledge that my research might have been conducted using a different qualitative methodology. However, hermeneutic phenomenology appeared the most suitable approach for my study aim. It focuses on the ways in which spirituality is experienced and comes to be understood by those who experience it. Hermeneutic phenomenology is not a rationalist ontology, as it posits that truth does not exist in the abstract, and is not testable or objective; truth is rather subjective and experientially created, and might be understood by studying subjects' perceptions (Greatrex-White, 2004; Green and Thorogood, 2009).

Greatrex-White (2004) highlighted the important link between the research decision trials and the researcher's reflexive account during the process of conducting hermeneutic phenomenology, in order to examine and demonstrate the research fully. My reflexive account of doing this study will be discussed in a later chapter.

However, almost every paper I have viewed on hermeneutic phenomenology states that the process of understanding human experience can never be conclusive (Greatrex-White, 2004; Pascoe, 1996; Van Manen, 1990). Therefore, our understanding of the phenomenon of spirituality for Jordanian ESRF patients will develop further when investigated in future studies.

Methods

It is important to remember that the study is designed to answer the research question: *How is spirituality experienced by Jordanian patients with ESRF?* This question requires a specific research design, as presented above. Hermeneutic phenomenology was selected as the methodology to give direction to my study. The following sections: recruitment strategy, participants, recruitment process, data collection, data analysis, and rigour of the study will be discussed next.

Recruitment strategy

After ethical approval was obtained from the Ministry of Health in Jordan in July 2012 (see Appendix 1) and the University of Nottingham (see Appendix 2), I approached each hospital individually and applied to their ethical committees, where I presented my proposed study and underwent their application procedures accordingly (see Appendix 3).

The planning of fieldwork and obtaining consent was very important. Figure 4.2 shows how research participants were approached, how information sheets were distributed and how their consent was obtained. I stood in each dialysis unit reception area and distributed the research information sheet to the potential participants, creating a list of names. Two days after distributing the information sheet, I went back to each dialysis unit and checked whether the patients would like to participate in the study. Based on their decisions, I made further contact with them and asked them if they had any queries about the study (I made no further contact with those who did not express willingness to participate). Among the 180 potential ESRF participants, the information sheet was distributed to 80, of whom 27 replied and agreed to take part in my study. Five of them were from the largest public hospital; nine from an education hospital, seven from a refugee hospital PRC and six from a private hospital (Table 4.2).

All participants were assigned pseudonyms to maintain confidentiality. I hoped that I could recruit participants from other religious backgrounds, namely Christians, in order to explore how spirituality manifests among Arab Christians for comparative purposes. I did in fact manage to recruit one female Christian (aged 23), however on the day scheduled for the interview the woman was with her mother, and when I approached them to query if they had any questions before conducting the interview, the mother answered that her sons did not want the woman to participate in the study. After a discussion with her mother, it seemed that there was a misunderstanding of my study aim and objectives, and the potential participant's family thought that I was trying to proselytize Islamic religion. I explained the study and its aims and thanked her and her daughter for their time reading my research information sheet, then no further contact was made. I learned from this that cultural issues in interviewing participants are very important, and one must be particularly sensitive when approaching people from different cultural or religious backgrounds, particularly where this is pertinent to the research subject. This might be one reason why all participants in this study were Muslims (i.e. non-Muslim patients in Jordan may have presumed that this was an "Islamic" study). On reflection, it would have been useful to go back and check what the Christian participant thought herself. However, to avoid antagonising or pressuring the participant, discontinuation and withdrawal this participant from the study was made. Five months were spent in data collection from the beginning of January to the end of May, 2013. Organising this period was vital to maximise access to the research sample within dialysis units.

Figure 4.2: Data collection procedure

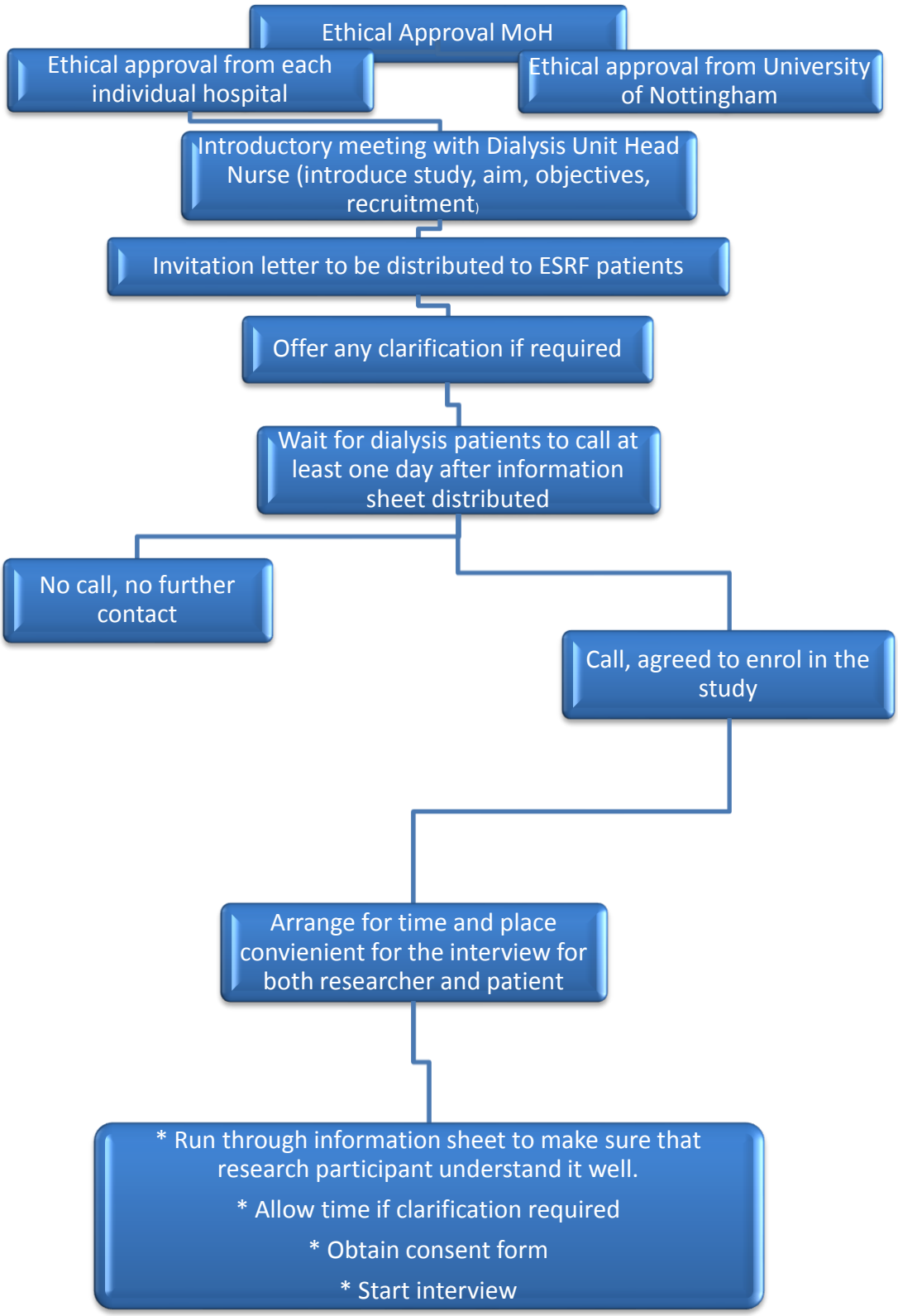


Table 4.2: Summary of the research participants' demographic characteristics

Participant	*Age*	*Gender*	*Marital status*	*Education level*	*Occupation*	*Employment status*	*Religion*	*No. of years*	*No. of transplantations*	*Time on dialysis*	*Healthcare setting*
Em Salem	57	F	Widow	University Level	Teacher	Unemployed	Islam	8	None	1200-1630	Private
Abo Ahmad	39	M	Married	University Level	Glossary	Unemployed	Islam	10	None	1600-2000	Private
Abo Malik	48	M	Married	Primary School	Farmer	Unemployed	Islam	2	None	0700-1030	PRC
Maha	22	F	Single	Secondary School	None	Unemployed	Islam	6	None	0700-1030	PRC
Abo Sara	75	M	Married	University & Above	Gynaecologist	Part-time	Islam	< 1	None	1200-1630	Private
Abo Hassan	57	M	Married	University & Above	Surgeon	Unemployed	Islam	3	None	1200-1630	Private
Abo Omer	59	M	Married	University & Higher Education	Anaesthetist	Unemployed	Islam	2	None	1200-1630	Private
Abo Shehab	64	M	Married	Primary School	Driver	Unemployed	Islam	10	None	0700-1100	PRC
Abo Sofyan	45	M	Married	Primary School	Driver	Unemployed	Islam	8	None	0700-1100	PRC
Abo Eizz	46	M	Married	Primary School	Business	Unemployed	Islam	10	once	0700-1100	PRC
Abo Sayef	24	M	Single	University Level	Student in medicine	Unemployed	Islam	3	Twice	1430-1830	Private
Abo Yaser	48	M	Married`	Secondary School	Catering	Self-employed	Islam	16	None	1200-1600	PRC
Abo Hussian	60	M	Married	Secondary School	Manager	Retired	Islam	2	None	0700-1200	Public
Abo Khalid	57	M	Married	Secondary School	Teacher	Unemployed	Islam	6	None	0700-1230	Educational
Abo Rami	53	M	Married	University Level	Teacher	Unemployed	Islam	3	None	0730-1100	Educational
Abo Saad	38	M	Married	Secondary School	Business	Part-time	Islam	7	Once	0730-1100	Educational
Abo Obada	54	M	Married	University Level	Accounting	Unemployed	Islam	9	None	0730-1100	Educational
Abo Saber	28	M	Married	Secondary	Restaurant	Employed	Islam	4	Once	0730-	Educational

				School	manager					1100	
Abo Khalil	40	M	Married	Secondary School	Business	Employed	Islam	5	None	0730-1100	Educational
Abo Hassan	38	M	Married	University Level	Nephrologist	Part-time	Islam	2	None	1600-2000	Education
Abo Ali	48	M	Married	Secondary School	Mechanic	Employed	Islam	4	None	1600-2000	Educational
Abo Rajab	76	M	Married	Secondary School	Teacher	Unemployed	Islam	1	None	0700-1130	PRC
Abo Ows	38	M	Married	University Level	Electrician	Unemployed	Islam	2	None	1200-1630	Educational
Abo Jamil	64	M	Married	University Level	Retired	Unemployed	Islam	2	None	0700-1130	Public
Em Ali	19	F	Single	Secondary School	None	Unemployed	Islam	2	None	1300-1630	Public
Em Alabd	21	F	Single	Secondary School	None	Unemployed	Islam	3	None	0700-1130	Public
Em Radi	24	F	Married	Secondary School	Housewife	Unemployed	Islam	2	None	1300-1600	Public

Participants

In phenomenology, participants are recruited to the study solely because they have experienced the phenomenon under study and are voluntarily willing to talk about it (Albaugh, 2003; Greatrex-White, 2008; Tanyi et al., 2006) in some cases write about it. (Greatrex-White, 2004). Thus, in my study I employed a purposive sampling technique (i.e. participants were recruited based on their experience of spirituality and their willingness to talk with the researcher about their experience). Such an approach seemed appropriate in phenomenological terms as only those who had experienced spirituality in ESRF would be selected. Bryman (2012, p418) defines purposive sampling as "a non-probability form of sampling", where the researcher aims to select the participants in his study on non-random basis. Bryman suggested that the advantage of purposive sampling is the ability to select the study sample in a strategic way so that participants are relevant to the phenomenon under investigation. Based on my inclusion and exclusion criteria, I had clear thoughts as to which potential participants could be recruited in my study. Critics of using purposive sampling argue that it does not provide equal chances to recruit participants; nevertheless, the selection of research participants was guided by the criteria outlined below.

In hermeneutic phenomenology, it is important to obtain as diverse a sample of participants as possible in order to generate a better understanding of the phenomenon in a broader perspective. This study is concerned with how spirituality is manifest in the lives of Jordanian patients in ESRF, thus participants will be patients in Jordanian healthcare settings. In order to allow the phenomenon of spirituality to be understood from the widest possible perspective, I decided to recruit from five different healthcare sectors as determined by hospital specialisation, insurance bracket, and geo-social context.

Since phenomenology produces large amounts of data from small samples, the inclusion of the broadest feasible range of patients allowed for optimum gathering of data (Greatrex-White, 2004; Smith et al., 2009). I hoped to recruit from both male and female ESRF patients from various age groups to enhance the comprehensiveness of the research results, facilitated by using multiple hospital

settings. As stated in Chapter Two, spirituality has been researched with regard to different chronic diseases, such as HIV, heart disease, mental illness, cancer, disabilities, post-traumatic stress, and end of life and palliative care (Albaugh, 2003; Hassouneh-Phillips, 2003; Hayden, 2011; Kaye and Raghavan, 2002; Saudia et al., 1991; Selman et al., 2011; Tuck and Thinganjana, 2007). In this study, my concern is with people with ESRF who are undergoing haemodialysis. This was the first study to do this in Jordan, and ensuring diversity of participants would maximise the variables and value of the study conclusions for the broader healthcare context. Thus, the following inclusion criteria were used to assess the eligibility of research participants from four different sectors: governmental hospital, educational hospital, private hospital and refugee hospital. All four hospitals were located in Amman. Criteria for participants who were valid for inclusion were:

1. Willing to participate voluntarily.
2. Could speak and understand Arabic.
3. Had ESRF and had been on dialysis for the previous six months.
4. Had stabilised dialysis access with no dialysis complications (e.g. bleeding, poor flow).
5. Willing to talk about their experiences.
6. Did not suffer from cognitive/mental disabilities.

The recruitment of the participants for the interviews was based up on the principle of good clinical practice (GCP). I waited for at least one day following the distribution of the information sheet to give the participants enough time to consider their involvement. Volunteers' eligibility to participate in the interview was assessed on the basis of the eligibility criteria above.

The study participants were recruited across four different healthcare sectors, the achieved sample was checked to ensure it was spread across the four dialysis units, and that both males and females and different age groups were included. The number of research participants is usually small in a phenomenological study, due to the voluminous and rich data generated by the approach (Greatrex-White, 2004; Tanyi et al., 2006; Van Manen, 1990). Paley (2005), Thomas and Pollio (2002) and reported that the norm of sample size in phenomenological research is between 6 and 12 and can be taken from one single institution. However, he was later critical of the small size in terms of generalizability and representativeness of the phenomenon. It

seems that Paley's understanding of phenomenology is questionable. A serious weakness with his argument is that he misses the important point that in phenomenology the main emphasis is on seeking understanding of the phenomenon rather than seeking generalizability. In addition, not all phenomenological studies recruit a small sample size of participants. For instance, Tanyi et al. (2006) recruited 16, Fouquier (2011) recruited 18, (Touhy et al., 2005) recruited 25, Greatrex-White (2004) recruited 26 and White and Grenyer (1999) recruited 44 participants. In my study I recruited 27 ESRF patients. In addition, it was decided to use multiple centres in a cross-sectional sample rather than a longitudinal study of participants, for practical reasons. Although a longitudinal study would generate data over the longer term, the serious illness of ESRF patients and the possibility of deteriorating health causing more drop-out for follow-up study, along with patients moving to different areas or dialysis units made a cross-sectional snapshot more appropriate. Furthermore, given the nature of ESRF, it was expected that patients' attitudes towards spirituality would not change significantly during the term of their hospitalisation. Another consideration was that I only had a limited time to recruit participants, collect and analyse the data. For these reasons, I felt that the inclusion of 27 ESRF patients in a cross-sectional study was practically feasible and sufficient to generate ample data to reflect upon the phenomenon of spirituality. As stated above, my main intention in conducting my study was to seek better understanding and I do not claim that the understanding that I gathered in my study is the end product; in fact, as I stated previously, my understanding was developed subsequently.

In Jordanian hospitals, the dialysis unit is an open place including between 3-12 dialysis seats. It is operated in two shifts and each dialysis unit may have an isolation area. The separation between dialysis patients who do not require isolation is by a curtain or glass door. For those who require isolation for medical reasons (e.g. hepatitis and HIV patients), separation is achieved by closing the door. For cultural and practical reasons, some units may separate male and female patients in dialysis areas.

Data Collection

In hermeneutic studies that aim to achieve a better understanding of a phenomenon by collecting data concerning people's experience of it, the main data collection tool for interpretive phenomenology is interview. Marshell and Rossman described interview as "a specific type of in-depth interviewing grounded in the theoretical tradition of phenomenology" (Wimpenny and Gass, 2000). Different types of research studies using phenomenology as a methodology collect data by different methods. For example, Greatrex-White (2004) adopted student diaries as a form of data collection in a hermeneutic study. Some researchers use structured or semi-structured interviews (Cases et al., 2011; Hess, 2004), or in-depth interviews (Cassidy, 2006; Tanyi et al., 2006). Interviews include face-to-face, telephone and electronic interviews, employing structured, semi-structured and unstructured interview protocols (Polgar and Thomas, 2008). Hermeneutic phenomenology aims to elicit participants' experiences of a phenomenon and to give a voice for their genuine views, feelings and opinions, without restriction or restraint to their thoughts (Lee, 2009). Furthermore, a number of studies have found that understanding of the phenomenon must result in co-creation between researcher and the participants (Flood, 2010; Greatrex-White, 2004; Greatrex-White, 2008; Van Manen, 1990; van Manen, 2014):. for this reason I decided to employ face-to-face unstructured interviews in order to explore each participant's perspective of the phenomenon, which is sound phenomenological practice (Silverman, 2011; Tanyi et al., 2006; Van Manen, 1990).

Using an unstructured approach means having one overall question: the participants' experience of spirituality. I discovered that this way provided the participants with control to express their thoughts in unique ways in describing the world after ESRF has changed it. All the participants were asked one question regarding their spiritual experience during ESRF. I asked them, "*Could you tell me, how does spirituality manifest in your experience during End Stage Renal Failure?*" No further directions or guidelines were given beyond this question. I encouraged the participants to raise anything they would like to raise that they considered to be important.

Prior to each interview, I thought it was important to "break the ice", thus I welcomed and thanked each participant for their time and effort. As Booth and Booth (1996) pointed out, it is essential in qualitative interviews to establish rapport with participants. I achieved this in different ways. Firstly, I organised the interviews at times and venues convenient to participants, where privacy could be ensured. All participants felt happy to be interviewed in the dialysis unit, except one participant who asked me to interview him at his house. This was important as it disclosed and challenged the power balance between myself and the participants (i.e. I empowered them). Secondly, before the interviews I recalled the purpose of research and reviewed the information sheet to make participants feel comfortable and happy to continue. Third, I listened attentively in order to prompt the participants to relate their experiences in more depth. For example, I used prompts such as:

> How did that made you feel? You mentioned this… what does it mean to you? Can you tell me more about it please? You described that as… When? How did it feel about…? You mentioned this… can you give me an example please? You stated this… What happened next? What did this experience mean to you?

Using probing questions during the interview is described as a useful technique to seek clarification from research participants (McConnell-Henry et al., 2011). Maintaining eye-to-eye contact provides positive reinforcement to participants and expresses interest, helping establish rapport and trust. Expressing my (genuine) interest in their stories also helped to build trust. Such steps appeared to be important for both myself and the participants.

I was assisted in this by my preparation. During the preparation phase, my supervisors kindly agreed to a number of mock interviews in order to hone my skills. I managed to interview two colleagues. In my first interview with Mr ML which lasted 60 min, I tended to interrupt him and kept engaging with my notes, neglecting eye-to-eye contact. Additionally, I did not allow Mr. ML to pause for reflection. In the second interview with Miss EG (74 min), I increased my awareness of issues raised from the previous interview and I maintained eye-to-eye contact that showed the participant how I was actively listening to her. In addition, I used some positive feedback utterances and Arabic reinforcements such as "*Allah Yerhamo*" and "*Aywah Aywah*". As a result, Miss EG was able to articulate and share more spiritual

stories and explore her experiences more deeply. Based on these pilot interviews, an interview was anticipated to last on average for approximately 1-1.5 hours.

In the next phase I recruited the first four participants from Jordan as a pilot (Abo Jamil, Em Ali, Em Alabd and Em Radi), I learned from them that they had no misunderstanding of the research question and aim, and they all reported that the information sheet was easy to understand and was very precise. As stated in Chapter One, in Jordan it is culturally normal to speak about religion and spirituality on a daily basis; thus, this might be a reason why participants engaged in deep conversation with me about spirituality more readily than would be expected in Western culture, wherein people are typically more reticent about such issues.

Culturally, I also anticipated that female participants may be reluctant / unable to be alone with the researcher, and for this reason I allowed female participants to invite a friend and/or relative to the interview. However, this proved not to be the case for any of the female participants in this study. In addition, I learned more from these participants as I noticed similarities and differences as I was recording the interviews. As I had my field notes with me, I let myself learn from the participants by capturing any meanings, expressions, thoughts, ideas and questions, verbal and nonverbal clues that were unique for each participant. I put a reflection for each participant in my diary that subsequently helped in my data analysis immediately after I had finished and listened to each interview.

A difficulty that I became aware of in the pilot study was that I became anxious if the patients came to a pause – I did not know what I should ask them or how I could separate my thoughts from the interviews. Although giving any direction to interviews is contrary to the essence of hermeneutic research, I was initially apprehensive about this when it came to application in the field. This anxiety was not rectified in the first interview. In conducting the second interview, I discovered that I actually gave myself extra opportunities to practise and to reduce the anxiety that I had in the first interview.

During the second interview, I maintained good eye-to-eye contact and took fewer notes. I learned that the use of the hands to explain things was important to give extra explanation to the words used. The participant in the second interview asked me for a transcription of the interview, which I later provided to him. Although I felt less stress in the second interview, I thought it was important to give myself extra opportunities to enhance my confidence step-by-step.

I found the third interview to be particularly problematic. The patient was open and appeared motivated about the subject initially, but proved to be very closed and reticent in the interview, and discussed spirituality directly for only a minute. Therefore, I decided to search for clues in what I had reflected in my research diary during her speech; this proved very helpful and enabled me to rescue and prolong the interview for an hour.

Although, my understanding of the phenomenon of spirituality in the first interview was superficial, I found I was making relationships between concepts, and another layer of understanding was unfolding (to be discussed in the next chapter).

I felt enthusiastic about the fourth interview in order to address my weaknesses further. Although I anticipated challenges during the dialysis session before the interview, the fourth session turned out to be extra-problematic in terms of the flow of thoughts and ideas, as the hospital staff kept interrupting, and the machine kept bleeping and distracting me and the participant. I learned from this experience that interviewing towards the end of the dialysis session was likely to be beset by more complications of this kind, thus I decided to conduct subsequent interviews during the first two hours of the dialysis session. By the end of the fourth interview, I was able to establish the context of each interviewee's experience and give reflection on the meaning it held. I was gaining a direct sense of conducting each interview during the course of this pilot study. Before the interviews finished, I asked each participant "would you like to add anything else before the interview finishes?" I then discovered the therapeutic effect of the phenomenological interview, as almost all of them disclosed how they felt spiritually both before and after the interview.

All the pilot interviews were video-recorded to enable me to learn more about my strengths and weaknesses. An initial analysis process was carried out and discussion was held with my supervisors for further directions and guidelines, which my supervisors suggested that I use only audio-recording during the fieldwork (among other benefits, patients may be more self-conscious and guarded if they know they are being video recorded). All the interviews in the actual study were audio-recorded on two separate digital recorders to prevent any data from being missed. This proved very useful when I had a very good interview and then discovered that one of the recorders had malfunctioned.

Data analysis

Guided by my reading in phenomenology (Greatrex-White, 2004; Smith et al., 2009; Van Manen, 1990), I started analysing and grouping my data from the moment I started each interview. I started consciously and sub-consciously making connections in my field notes, making relationships between different variables that were mentioned by each individual. This continually challenged my assumptions and judgments.

Figure 4.3 The process of data analysis

A number of nursing studies that claim to use hermeneutic phenomenology reveal on closer inspection of their methods of analysis questions regarding their understanding of phenomenology. For example, Colizzi (Nabolsi and Carson, 2011) and Giorgi (Herlin and Wann-Hansson, 2010) purport to be grounded on descriptive phenomenology (i.e. Husserlian phenomenology), and not hermeneutic phenomenology, which presents a complete mismatch of the philosophical assumptions that underpin these studies. As a novice interpretive phenomenology researcher I employed an analysis structure outlined below, following my reading of Van Manen (1990), Greatrex-White (2008) and Smith et al. (2009), all of whom present strategies within a hermeneutic phenomenology framework and recommend initially *understanding*.

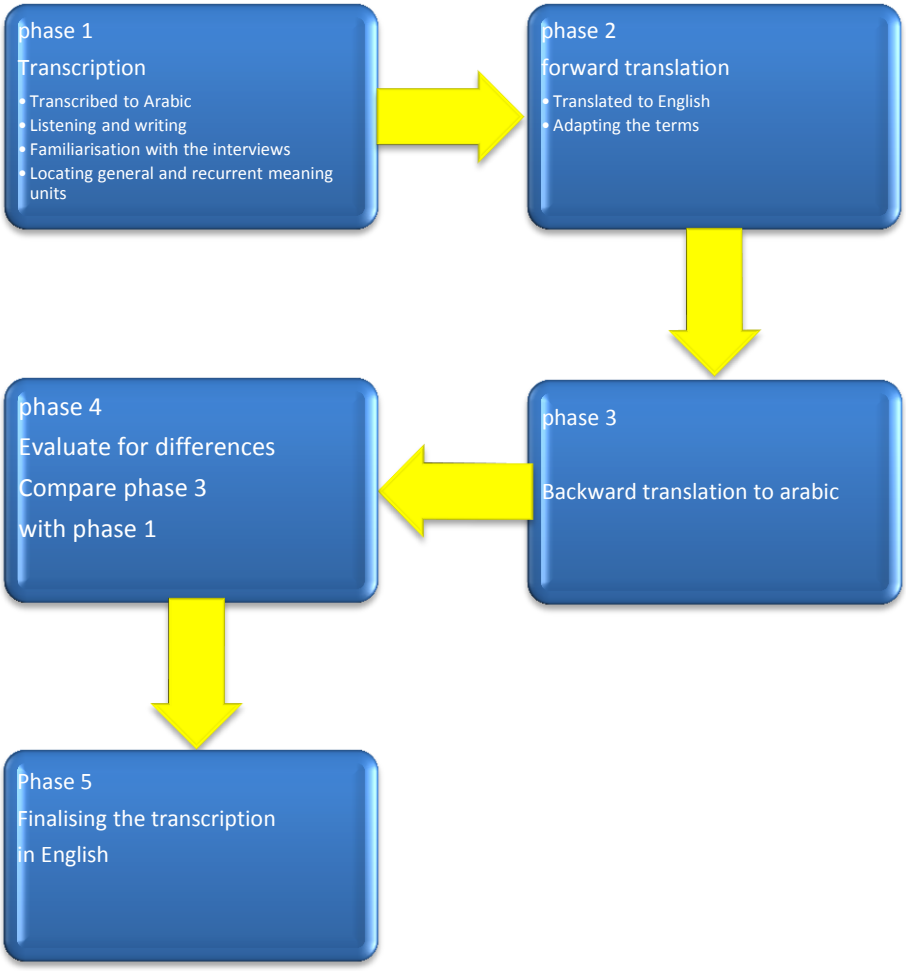
During the interviews I found I was obtaining an immediate understanding of the phenomenon of spirituality; for example, I was interpreting individual experiences from the moment the participants said something that was important to them. After the interview was finished I noted an overall understanding for each interview to gain the immediate sense of spirituality. Then, I listened and re-listened to each interview approximately three times immediately after the interview was finished and wrote my reflections. Thus, the analysis began during the interviews themselves and was formalised immediately after. I started to interpret the data from the minute I asked the questions, and wrote my reflections in my reflective diary during the interview.

Based only on my field notes, my first reflections after conducting all the interviews were that patients' beliefs, practices and values toward spirituality are part of their everyday routine lives. All the participants' interviews connected spirituality with respect, isolation, job, lack of financial support, praying, social anxiety, and social isolation, belief and believer, negative feelings, positive feelings, patience and connectedness to Allah, hope and tranquility, purification, test, spirituality and the effect of *Nafs* (specific aspects of the Muslim faith which will be explained in detail later) and its types. Furthermore, the family role and environment appeared recurrently to have an important role in participants' experiences of spirituality and I was able to identify some impact on patient spirituality exerted by community perceptions of and behaviour towards ESRF patients.

Additionally, participants talked about the lack of knowledge about their illness, feelings of being taken into the unknown, fear of death, the feeling of being excluded by others and the approaches taken by doctors and nurses (the negative, and the positive). As a result, participants shared numerous experiences about their illness and spirituality. Other important findings were addressed, such as cultural issues, which reflected what patients felt was vital for inclusion in their care. Again, I maintained field notes and captured my own reflections of the interview process for each individual interview and of the research process generally. This will be discussed further below.

Translating the transcripts, according to Van Manen (1990), also helps researchers to familiarise themselves with participants' perspectives. Thus, although this process of familiarisation will be presented separately, it should be viewed as a form of continuous engagement with the study data. All interviews were conducted in Arabic, transcribed, then translated into English using the cross-cultural competence translation technique (see Appendix 4) to ensure that each participants' experience was accurately and fully captured in the translation process (Beaton et al., 2000) (Figure 4.4).

Figure 4.4: Representation of the stages of cross-cultural adaptation in data analysis and translation



(Adapted from Beaton et al., 2000)

Stage one: verbatim transcription

Another level of familiarising myself with the data was by transcribing each interview verbatim. Listening to each interview many times enabled me to discover how ESRF patients shared very sensitive and personal information. I felt deep involvement with their stories and I was moved to tears twice while considering participants' stories. My interpretation and understanding of the phenomenon of spirituality was initially driven through transcribing each interview and by engaging with it many times.

Translation from Arabic to English

Although hiring an individual to translate my study's interviews would have been helpful, this was not possible due to the sensitive nature of the data, the bonds of trust I established with participants and the particular context of the content; all of these are important elements in phenomenology. Being bilingual, I felt that the onus was on me to conduct the translation myself. All the interviews were translated directly from the digital-audio recorder, not from the Arabic transcription. I spent three full days in translating each interview, working almost 12 hours each day. Finally, in order to minimise any issues in meanings and clarity during the translation, Beaton et al. (2000) suggests sending the translated version to two bilingual experts whose native language is that of the original participants, in order to confirm the fidelity of the translation and to make sure that the translated version is reflecting the same item content as the original version. This step often magnifies unclear wording in the translations. Thus, I sent two interviews to two bilingual and medically qualified as general practitioners, Dr. GH and Dr. FG, who suggested some minor corrections. During this process, I discovered similarities and commonalities between interviews and I noted these in my research diary, which exposed the data to different levels of familiarity. Again, while I was immersing myself within the interviews during the translation process, I was able to evaluate the breadth and depth of each interview in relation of the study aim and objectives.

By the end of this stage, I had finalised the English version from which I was able to select many meaning units in my diary and identify patterns to describe the participants' spiritual experiences, especially when they were in distressing situations such as "Being destroyed", "Being suffocated", "Being disabled", "Being tagged negatively" and "Sense of emptiness". I compared such patterns before and after the ESRF diagnosis. "Being suffocated" is an Arabic phrase used in this study to describe an individual's spiritual status in general.

Stage two: meaning units

During my extensive reading of the English text I compared the notes I had taken during each interview when I finished it, and the notes from the above stage, reading

and re-reading the text many times to immerse myself in the data. During this stage I also listened to the interview and read the transcript simultaneously. I was looking closely at what was being said, and immersing myself in the data enabled me to discover that a huge number of meaning units were emerging from the first interviews, where 321 meaning units were discovered. By "meaning unit" I mean part of a sentence or paragraph of any length forming a distinct item denoting a meaning or theme.

Since the data analysis was disorganised and unfocused at this stage, I consulted both my supervisors about the use of Nvivo Qualitative data management software to help me in organising and viewing those meanings. Both supervisors advised me not to use any software in *analysing* the data, but to use it in *organising* it; thus I used Nvivo to help in organising the huge volume of data produced from each interview. I therefore received training in how to use this software to organise my data. I started analysis of my first nine interviews manually on paper then transferred them to Nvivo. I realised that I could still analyse them the same way I did on paper, directly from the software, without replacing my analysis. This was a painstaking process, mining the raw data word by word, line by line, paragraph by paragraph and interview by interview to capture the essence of participants' experiences. Ultimately I saved time and effort in this way and I was glad that I used the software as I ended up with 3,804 meaning units.

Stage three: situated structure – emerging and ordering how spirituality in ESRF is manifested

Following the coding of meaning units for each individual interview, it is expected that overriding themes will emerge from the whole dataset. As Greatrex-White (2008) points out, although the general structure or themes may be present in each interview, it is important to note that they will almost certainly be experienced differently. Therefore, the meaning units from the stages above were classified under certain categories based on the importance of the study aim and objectives. When these meaning units become situated in structure, in a sense it was presenting situated ideas and thoughts. I used Mind-View software to help me in organising the large meaning units and situated structures. During this stage, I kept reorganising

those units whenever another layer of understanding the phenomenon of spirituality was unfolded.

I kept grouping and re-grouping those units. Indeed, for me, although I saw all 3,804 meaning units as important in understanding my study phenomenon of spirituality, I realised that I could not include all of them in my study. Thus, I kept refining and amalgamating the units based on resemblances and differences among them until the general structure started to take form, and three key themes emerged. These three themes reflected how spirituality was interpreted and thus understood from my interpretations of ESRF patients' reflections upon their spirituality. It represents a co-creation of new ways of understanding spirituality. By the end of this stage, I was able to present a map-view that presented all the themes and sub-themes together.

Stage four: moving situated structural narrative to general narrative

At this stage, I reviewed and examined the themes against the meaning units of their sub-themes and structures and considered whether they helped to meet my study aims and objectives. This stage helped me to refine and sharpen each structure within its own meaning units, clarifying many ideas and thoughts and querying the way it was structured. The three superordinate themes that emerged from analysis and interpretation of the participants' accounts clustered around *Religion*, *Relationships* and *Desperation*.

Greatrex-White (2004) suggests that these general structures cannot be regarded as distinct entities. Therefore, there is a large degree of overlap between the above three themes, but they are suitable for the interpretation of meanings emergent from the data, enabling great detail to be accorded to participants' experiences and providing thick contextual descriptions from participants' own words, my interpretation of their narratives based on my experience as an insider and drawing on the review of previous literature on spiritual experiences in ESRF (as I will present in detail in the next chapter, where detailed information on spirituality for Jordanian ESRF patients is presented). Indeed, it contributes to the gap in the existing body of knowledge that has been already identified on how spirituality is manifested during ESRF, whilst also generating new areas for future research.

From the three main themes I began to write my general narrative for each theme. In doing this I was creating an upward spiral of understanding, unfolding additional layers of the complexity of the phenomenon of spirituality. To achieve such an understanding, I attempted to point out all relevant information deemed to be important to participants, including thoughts from my reflective diary, and to question the ways spirituality was manifested by participants. See Table 4.2.

Table 4.2 Significant statements, formulated meanings, and themes

Significant statement	Formulating meaning	Sub themes	theme
"According to my experience, Allah subhanahu wa ta'ala created the world; He requested from the pen to write, and the pen asked "what shall I write?", you will have to write everything until Judgement Day, so the human illness, his eating, his drinking and his work, we know all of these as Muslims that we have to have believe. Iman in what has happened with him and in what will happen to him, and the Prophet, peace be upon him, said to Abdullah bin Abbas "oh boy, I am teaching you certain words: if you save Allah, Allah will save you, and if you save Allah you will find the other one is in your direction, and if you are going to ask for something you should only ask Allah, and if you need support you have to seek support from Allah, and you should know that whatever happened you wasn't going to miss you, and whatever misses you was not going to happen to you"; so any patient suffering from ESRF or liver disease or any other illness must know this is something Allah has written for him, so this person shouldn't feel sad, and he has to accept this matter with a good spirit".	The feelings, the believe and the sensing that Illness is from Allah	Acceptance and appreciation Balaa' Concept	Religion
"The family has got a big, big role in supporting the patient's spirituality in making his Nafs comfortable, and this will help with his illness, but if they undervalued him as a result of his illness, so that patient will feel that he been conquered by his family and by his illness, and in this case he is not only speeding his death, but Allah Rabb al-Alameen is going to make him	Family roles	Patient	

comfortable; on another hand, when you find that everyone around you doing their duties, you will find that the patient s' health will be maintained in a good condition, thanks to Allah".	in supporting patients' spirituality	engagements and interaction with social event	Relationship
"Secondly, the patient has to fulfil his emptiness, as you know the ESRF patient has got a big empty time, spiritually you can fill it with anything, with any activities, to allow him to re-run his brain and his mind, and not staying fixated on thoughts about "I am ESRF patient, I cannot go, I cannot do anything, I cannot work, even I cannot walk"... All those excuses, it's not good to have. To calm yourself and to be in excellent spirituality you have to fill your empty time". This responsibility will stop him harming himself. I might be going to be out from the context now, but look in Europe now: they have the highest suicide rate, as they don't have spirituality… even the healthy people; the suicides have completely lost their spirituality… Because the one who has good spirituality will never ever think about suicide at all…the one who claims to have good spirituality will never ever think about suicide at all…because he will know that he is going to meet Allah after committing"	Negative thought s and suicidal thoughts	Emptiness feelings	Desperations

Although I am bilingual, being a native Arabic speaker conducting doctoral research in the UK, I found writing the general narrative about spirituality in English to be very challenging, and indeed I thought it the most difficult aspect of phenomenology. My initial attempt to write the general narrative produced 280 pages, comprising over 143,000 words; the University of Nottingham regulations for doctoral research state that theses must not exceed 100,000 words. Thus I followed the advice of my supervisors to reduce the findings chapter to 30,000-40,000 words, but I found it to be a very painful and traumatic experience to reach 38,000. The result was a condensed general narrative that emerged from my interpretation based upon ESRF participants' experiences and articulation of their spirituality during their illness journey.

Ethical considerations

When I started my data collection in Jordan directly after the confirmation review, I faced a number of challenges regarding ethical approval from each individual hospital. As already mentioned, one of the hospitals I approached refused to give me approval, stating that phenomenology did not exist. This concern was addressed with my supervisors and a replacement hospital was advised and found.

In addition, I was able to ask research participants about their preferred venue for conducting the interview. Nevertheless, I experienced some issues that may have affected my data related to the place chosen by participants, which was the dialysis unit in all but one case. The sounds of dialysis machines, TV noise, and sometimes interruptions by healthcare professionals and visitors affected the continuity and flow of conversation. Furthermore, some of the participants were in tears when they recalled painful memories. However, I was able to give them reassurance and asked if they wanted to continue with the interview. In fact, many participants stated that they experienced catharsis from the experience of the interview. I documented all of this in my research journal and shared it with my supervisors.

As reported in the literature, in qualitative research the researcher can ask participants to recall sensitive and personal information which can potentially be a painful experience for them, thus ethical consideration is especially important in such cases. The following ethical issues considered in order to maintain participants' rights and wellbeing (Seymour and Ingleton, 2002). In almost all interviews the participants were close to (or broke down in) tears; even I became very emotional on several occasions. I encouraged participants to stop the interview if they wanted to whenever they became emotional, but all of them preferred to continue the interview. I supported participants in such situations by holding their hands, patting them on the back, and offering tissues or drinks.

Participant privacy is related to the place and time of the interview. Preserving research participants' privacy and safety is important in avoiding interruptions due to the presence of others (Walker, 2011). In real hospital settings, dialysis patients share big open units with other dialysis patients, separated by curtains or windowed doors. Tanyi et al. (2006) suggests that in order to minimise any interruption, these curtains are drawn during the interviews, doors are closed where possible, and staff

are asked not to disturb the patients unnecessarily during the interview. However, I found that this was another challenge during data collection as many participants refused to have the curtains drawn or doors closed, yet they appeared to talk openly. This might have been due to aspects of Jordanian culture and the topic of spirituality. The majority of participants expressed surprise when they read the privacy section in the information sheet, not considering the nature of the interview to warrant such precautions (see Appendix 5).

Indeed, one participant who had been enthusiastic to take part in the study during the recruitment day told me on the follow-up day that he had been deterred from taking part due to the patients' legal rights paragraph on the information sheet, despite my assurance that the legal aspects were designed to protect participants' rights. Although this paragraph was a requirement in the ethical application at the University of Nottingham, I felt that this paragraph was not culturally representative – the concept of "legal" can send different signals within Jordanian culture, and in the Arab world generally people view the state and law with suspicion; this should be noted for future research studied.

Furthermore, the hospitals that I included in my study had Syrian refugee patients present on the days of recruitment. Such potential participants were excluded from the study as their situation took them beyond my inclusion criteria. However, I realised that interviewing them in terms of spiritual care would have made for a study in its own right.

I emphasised participants' rights during the interviews and highlighted that their participation was voluntary and would not affect their dialysis treatment. Permission was sought and obtained from the participants to digitally record the interviews and consent forms were administered (see Appendix 6). Moreover, during the interview, I reiterated that the participants were free to ask any further questions at any time, and they could withdraw from the study at any point. Participants were free to terminate the interview if they wished, and no further contact would be made with them unless they expressed willingness to be re-interviewed. I gave my contact details to participants in case they had any enquiries at any stage.

Enhancing confidentiality is a challenging task in qualitative enquiry (Houghton et al., 2010). I assured the participants in my study that their names would not be included in the study and that pseudonyms and cipher codes would be used in substitution for names, and participants' identities would not be revealed outside the research team. Furthermore, in my study, there is no requirement to use participants' medical notes, or to take blood or other tissue samples; no one will access the original data except the research team. All the data including audiotapes, transcripts, and field notes were kept safe in locked facilities and password-protected computers within the University of Nottingham. All documents and files would be discarded two years after the end of the study.

The Study Rigour

Although the rigour and quality of research findings and data can be assessed through different criteria (Polit et al., 2001), it is evident in the literature that the validation of interpretation by participants is incompatible with phenomenology (Pringle et al., 2011). For example, an underling of assumption of credibility is that the overall aim of research is truthfulness. According to Brockopp and Hastings-Tolsma (2003), credibility is equivalent to the internal validity in quantitative criteria. The aim of the quantitative study is to discover a single truth that is exists in the reality. However, in qualitative studies the main findings is not searching for a single truth as the truth is appeared to be manifest in multiple and constructed (Howell, 2012). Heidegger argued that knowledge could not be separated from the interpretation. The aim of the hermeneutic phenomenology is to enhance our understanding of the phenomenon under investigation through multiple possibilities of interpreting meanings of human experiences. Thus, the multiple interpretations may be varying from one to another.

Confirmability is concern with assuring that, while recognising that complete objectivity is impossible in social studies (Bryman, 2004). Nevertheless, in Hermeneutic phenomenology, Schoolers argued that the findings are not neutral and value free (Crotty, 1996; Greatrex-White, 2004; Van Manen, 1990) in which they insisted that both credibility and confirmability is not relevant criteria in phenomenological studies.

Dependability in qualitative studies is parallel to for the reliability in quantitative studies (Bryman, 2008). Dependability aim is to establish the merit of research in terms of the trust worthiness. This involve a complete records of all research stages-issues and challenges, field note, interview transcripts, data analysis process, analysis decisions and so one (Bryman, 2004). In this study all records were kept and checked by both supervisors independently through all the stages.

Nevertheless, the main principle of judging in phenomenological study is by demonstrating trustworthiness (Greatrex-White, 2004; Van Manen, 1990). According to Koch (1995), this can be achieved by developing the audit trail over the research process. In my study, I enhanced credibility by making sure that the rationale and analysis were open to the reader.

It is important for researchers using a phenomenological approach to actually use reflexivity and to tell the reader what their ontological positioning is and to provide a credible plausible explanation of participants' accounts and avoid any assumptions (Clancy, 2013). According to Finlay (2003, p 108) reflexivity is defined as " a process of continually reflecting upon our interpretations of both our experience and the phenomena being studied so as to move beyond the partiality of our previous understandings and our investment in particular research outcomes." Greatrex-White (2008) argued that reflexivity is an important aspect in hermeneutic phenomenology.

My study was conducted within a health care system that I know inside out. I had experience from being a patient diagnosed with ESRF to becoming nurse caring for ESRF patients. Other important considerations I had to reflect on were my gender, age, general appearance, my language and accent, ethnicity, being from a middle class family, growing up in three different cultures, and my own motivations in conducting this research that I mentioned in Chapter One. All these factors might have influenced how the participants in my study perceived me and similarly how I might view them. Being a student from the University of Nottingham, or the UK, could be viewed by some of participants to be challenging. Participants might see me as a person from a Western country, an outsider, and unaware of their needs. However, such concerns decreased when I used face-to-face recruitment and interviews with them. I kept a reflexive diary throughout the research process which

allowed me to stand back from my own understanding and to view the phenomenon of spirituality from the participant's accounts.

In addition, I am able to show the reader how themes emerged and were developed, with evidential examples. Using reflexivity techniques may assist the researcher to eliminate many preconceptions (Pringle et al., 2011). I used the field notes to reflect on my research interviews and on the research process from the very beginning up to writing-up my thesis. This was a very useful tool that assisted me in developing my critique, viewing things in different ways to discover meanings, questioning every process, and examining my interpretations.

Developing a theoretical lens for viewing spirituality in ESRD

The influence that a conceptual framework may have in clarifying qualitative research findings and linking them to practice is evident in the literature (Johnson and Webber, 2001; Kim and Kollak, 2006; McEwen and Wills, 2011), in order to enhance the rigour in my study, to provide deeper understanding of the phenomenon of research, spirituality, and to identify the central area of research. Thus, I explored some theories which were used in spirituality which were important in formulating my understanding. Although the literature suggested a number of theories that I could adapt in my study, such as Frankl finding meaning and purpose, the Cognitive theory of stress and coping by Lazarus and Folkman and Parse's theory of human becoming, I would draw attention to the fact that the phenomena under consideration are culturally sensitive issues, and the abovementioned theories were fundamentally culturally constructed in a more or less twentieth-century, Western environment. Thus, special considerations were taken in adapting them to this research area. Such theories were presented accordingly in different sections in the next chapter.

Summary

This chapter has provided an overview and explanation of the proposed research methodology and methods. In addition, it draws attention to the philosophical underpinnings of the research methods, fieldwork, how the research participants will be approached, data collection process, research setting and study sample, and addressing the overall aims and objectives of the study. Reflexive account and audit trail were discussed and deemed to correspond with the process of my research,

enabling me to illustrate how my thinking was changing from one level to another through the decisions I made. Finally, this chapter pointed out the value of trustworthiness in the main study and highlights potential theoretical frameworks.

CHAPTER 5: Findings

"If you talk to a man in a language he understands, that goes to his head. If you talk to him in his language that goes to his heart". - Nelson Mandela

(LTL and Rosenstein, 2015, p63)

Introduction

This chapter presents the main findings of the thesis and explores the ways in which "spirituality or الروحانيه" was manifested during ESRF. Firstly, the participants' demographic characteristics are explained, which is important in a phenomenological study to provide a general view of the study sample and to show the diversity of themes from the study sample perspective. In addition, demographic characteristics give a wider view of the phenomenon of "spirituality or الروحانيه" in accordance with phenomenological practice. Secondly, an interpretation of participants' experiences of "spirituality or الروحانيه" of being ESRF patients is presented for different Jordanian healthcare settings. The study recruited 27 research participants, each of whom was asked "How is "spirituality or الروحانيه" experienced during ESRF?" ESRF patients were asked to share as widely as possible their experiences of how "spirituality or الروحانيه" can be manifested in different ways during their illness and how "spirituality or الروحانيه" had affected or influenced their feelings, attitudes or beliefs about themselves.

The presentation of data in phenomenological studies according to Greatrex-White (2004) and Smith et al. (2009) must be organised and maintained in a systematic approach to establish a robust report. Also, the presentation of the data should reflect the critical thoughts and understanding of existing literature (Silverman, 2011). The findings of this study uncovered the phenomenon of "spirituality or الروحانيه" or الروحانيه" and how Jordanian ESRF patients experience it during their illness. In addition, my interpretation of the interviews showed how "spirituality or الروحانيه" could be related to the wider literature. The nature of this phenomenon appeared to be complex and multifaceted. Situated structures were found to have patterns, which led to three superordinate themes emerging from the analysis and interpretation of the participants' accounts: Religion, Relationships and Desperation. These characterised the prevailing paradigm in which the phenomenon of "spirituality or **الروحانيه**" was manifested in the experiences of participants as interpreted by the

researcher. However, as mentioned in the previous chapter, these three themes cannot be regarded as distinct entities, as there is a large degree of overlap between them, but they are suitable for the interpretation of meanings emergent from the data (Greatrex-White, 2004). This will enable me to generate great detail according to participants' experiences and provide thick contextual descriptions from the participants' own words; my interpretation of their narratives based on my experience as an insider; and drawing on the review of previous literature on the spiritual experiences in ESRF.

The participants stated an important concept "*Nafs "النفس"* when they were referring to their inner self. As "*Nafs النفس"* and its derivatives were universal, it is necessary to elaborate upon this concept before explaining the three themes.

Nafs Concept

This section focuses on how all most all ESRF patients described the pattern of their inner self by using "*Nafs النفس"* or *"Nafsiyan نفسيا"* during their ESRF. Thus, it is important that I elaborate this concept to understand their "spirituality or *الروحانيه*". Participants demonstrated through their narratives that their *"Nafs النفس"* underwent changes through a range of different patterns. It also dramatically correlated with the ESRF patients' own "spirituality or الروحانيه", so whenever the patient's "spirituality or الروحانيه" became weak or absent, the "*Nafs النفس"* deteriorated from one pattern to another. Those patterns will be discussed as follows: ***Nafs Ammarah*** *النفس الاماره*, ***Nafs Lawamah*** *اللوامة النفس* and ***Tranquil Nafs*** *النفس المطمئنه*.

Nafs Ammarah النفس الاماره

Nafs Ammarah النفس الاماره is the concept that was used by almost all participants to describe their inner-self whenever it incites to evil (*evil inside)*. It appeared to be associated with negative thoughts attributed to the whisperings (*waswas*) of malevolent spirits, prompting humans to become intolerable in their behaviours. As the "*Nafs النفس"* starts inciting bad things to be committed (e.g. the numerous references to suicidal ideation expressed by participants, associated with the initial period after diagnosis with ESRF; see the desperation section), many participants expressed that this must be actively fought against, and they identified it as an index of their lowest "spirituality or الروحانيه" level:

> "As long as there is a belief or ideology, which is the basis of your life and which you aren't believing in, the stubbornness and force your "*Nafs النفس"* to do something different and even when the error comes out of you, and you insist it's not error, it is something normal, this will create too many problems for some people. But, they still believe in their ideology that they are still in the right path, and possibly it can lead to killing someone because he believed that this *"Nafs النفس"* has to be killed because he became like that, as he will not kill someone if he still has feelings of sympathy, or *haram*, or this is a mistake to commit, so at least the person shouldn't fight against his beliefs that he believes, and stored in his mind, as this can be interpreted as fighting against his *"Nafs النفس"* by all means". (Abo Hasan)

Abo Hasan described how there is as dialogue with his *"Nafs النفس"*; it appeared that the "dialogue with *"Nafs النفس"* for many participants essentially consists of the notion that the treatment/pain will be the same whether one wants it or not, so it is better to be patient and accept it, as Abo Shehab stated:

> "This is something that happened with me initially, but thanks to Allah this has finished, for me personally, all those thoughts have gone. [….] all these negative thoughts will be lifted out of his head But to keep thinking and thinking and thinking, he might kill himself by keep thinking, and there is no result [….] so negative thoughts - you shouldn't surrender to them (negative thoughts), but it needs some patience, and a tough will, as this condition will be finished". (Abo Shehab)

Similarly, Abo Sofyan stated that this pattern of *Nafs النفس"* involves the whispering of devils. This pattern appeared to be critical in ESRF patients' experience, especially in the initial period, as it will trick the patient as illustrated by Abo Sofyan:

> "If I would like to follow the devil's whispers, I might kill one of the kids, from my aggressive anger, or suffocate someone I don't know. No, I go back to Allah, *subhanahu wa ta'ala*. And saying thanks to Allah, and great thanks to Allah, this illness is what Allah has given

me, don't have ago at the kids, don't have a go at yourself, don't have a go at your wife, don't have a go at your family" (Abo Sofyan).

Nafs Lawamah النفس اللوامة

This concept was used by participants' to describe the second pattern of "*Nafs النفس*", which began with patients' blaming of themselves or the people around them. It seems that participants unanimously underwent such experiences and had to find their own ways to move beyond the first pattern, as several participants reported:

> "I started to think too many things… I started to think about my family, they don't deserve me blaming them [….] I started to question my "*Nafs النفس*" why do I need to cry every time?". (Abo Saad)
>
> "What the Prophet, peace be upon him, urged us to do is to leave the place. I will leave the house when I am angry, or sit and drink some water, and say *audhu billahi min ashaytanir rajeem*, and with everything if you follow the religion, you will find that you are doing the right things". (Abo Sofyan)

These strategies and practices enable ESRF patients to modify their "*Nafs النفس*" and to shift from *Nafs Ammarah النفس الاماره* to *Nafs lawamah*. This refinement of "*Nafs النفس*" was achieved by common courtesies and etiquettes in obeying Allah, increasing consciousness of "spirituality or الروحانيه" so that the patients reproached themselves for negative thoughts. For example, "this *Nafs النفس*" would cause the patient to question themselves: "you are a good man, how could you commit such and such?" or "how dare you think about something that would destroy you in the Hereafter?" (e.g. suicidal ideation which will be discussed later in this chapter). The motivation behind such blaming is that the instalment of "spirituality or الروحانيه" counteracts and modifies the *Nafs Ammarah النفس الاماره* to generate a kind of direction, as the participants expressed.

Tranquil Nafs النفس المطمئنه

This concept was used to refer to the refinement of the *"Nafs النفس"* over time which progressed during the course of ESRF until the participants reached the status of Tranquil Nafs النفس المطمئنه, whereby participants abhorred the concept of committing any deed that would incur Allah's wrath with them. Being in Tranquil Nafs النفس المطمئنه was defined by clearing negative thoughts and promoting a sense of being responsible, and patients who reached this stage exhibited remarkable resilience, self-efficacy and inner peace:

> "You will feel tranquility in your "*Nafs النفس"*. You will feel comfort in spirit. And a quietness in the patient's "*Nafs النفس"*. Which will give him a power, certainly, as long as you are comfortable in your *"Nafs النفس"*, and you feel peacefulness in your "spirituality or الروحانيه" , so now you will feel that it becomes a source of power for you [….] in the beginning, you will find this patient overtakes his mental status, and his "spirituality or الروحانيه" becomes comfortable, so being in this status, it will give you a powerful push, and very strong power which leads to do something that he never thought about when he was healthy". (Abo Eizz)

This concept of a source of power was echoed by Abo Saber when he stated the sense of victory over his limited resources:

> "I was able to open a project for my own, and get victory over the worldly things, over life, to have victory over the community, and to have victory over the able person, despite the fact that I'm disabled, and the community outlook has changed for me, it changed to become better". (Abo Saber)

The first theme, religion, reveals how Jordanian ESRF patients see phenomenon of "spirituality or الروحانيه" as a dimension of religion. Five important situated structures emerged which influenced their perspectives in identifying the phenomenon of "spirituality or الروحانيه" as religion: *"Balaa' بلاء"* concept; connectedness with Allah; "Balaa' بلاء" and ESRF patients' capabilities conflict, "Spirituality or الروحانيه and Religious Practices and spiritual coping mechanisms. The second theme, relationships, covers how ESRF patients highlight the importance

of “spirituality or الروحانيه” in the context of their relationship with the surrounding atmosphere. Four situated structures appeared for this dimension: family; community; other ESRF patients; and medical staff (including doctors and nurses). The third phenomena, desperation, reveals the spiritual distress of Jordanian ESRF patients and how it manifests during the illness, with particular regard to the danger of suicide among patients with low “spirituality or الروحانيه”. Structures related to desperation include: feelings of emptiness for ESRF patients and staff; deterioration and despair conditions; and finally rejection of the ESRF treatment.

Citations from research participants’ interviews are used to support the findings of this study. This affords the reader the opportunity to examine the validity of the analysis and study findings. All the data from participants are shown in indented quotations to distinguish their voices throughout this study. For purposes of clarification and to maintain anonymity, all participants were given pseudonyms. Any amendments made by the researcher are given in parentheses. It is Important to mention that it is part of the culture that individual’s referred to their experiences in “you” or “we” instead of “I”.

Demographic Findings

The demographic findings of the participants are summarised in Table 4.2. Twenty seven adult participants were recruited, five females and twenty two males. The age distribution of the participants ranged from 19 to 76 years old. Participants’ educational status was distributed between primary level (n=4), secondary level (n=12), and university level and above (n=11). The majority of participants were married (n=20). The participants included both employed and unemployed patients, representing the diversity of ESRF patients in the Jordanian healthcare system. All participants were receiving treatment in Amman (the capital city of Jordan) spread across four different hospitals. Even though the employability background of the participants represented a diverse sample of occupations and socioeconomic groups, it was universally observed that participants were greatly concerned with the challenge of finding and maintaining work in their current status, and the majority of participants (n=22, 81.48%) were unemployed. As a consequence of losing their employability due to their ESRF illness, the interviewees expressed the financial difficulties they faced related to their treatment. Only four had undergone renal

transplantation, which has great cost implications for ESRF treatment, especially when they all had haemodialysis as a first choice of treatment.

Regardless of the hospitals in which the participants received dialysis, all were receiving the treatment free of charge under the Ministry of Health rules and regulations. Additionally, one participant had 100% exemption from fees and could claim free medication.

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Religion

Historically, the foundations of the relationship between "spirituality or الروحانيه" and religion has been the subject of deep philosophical probing, as reflected in the studies of James Otto and Laski (Cook, 2003; Gitre, 2006; Kristo, 1982; Poland, 1992). Other studies have highlighted the impact of the environment, individual values and beliefs and culture on human beings, as addressed by trans-cultural theorists (Giger and Davidhizar, 2008; Leininger and McFarland, 2006; Narayanasamy, 2007; Sagar, 2012). As noted in Chapter two, it is generally accepted that it is important to recognise any religious beliefs and cultural values involved in the life of a population under study. However, despite the wealth of literature attempting to understand spirituality in Western culture and what spirituality means to patients, relatives and healthcare professionals, misinterpretations abound about the meaning religion can have in the lives of individuals in which the separation of religion from spirituality becomes obvious (Clarke, 2006; Tanyi et al., 2006).

Although religion could intuitively be analysed as the last theme, it was decided to consider it first as it was the most frequently cited concept by participants and they themselves spoke about it first. As outlined in Chapter two, unlike in Western culture, spirituality and religion are open subjects in the Middle East and are not considered to be sensitive. Participants unanimously correlated spirituality with religion. This corresponds with Frankl's theory (1958), which emphasised that people who believe in God have a continuous "invisible witness present", which belief they recall in challenging situations (Albaugh, 2003). It should be noted that all participants referred to God as "Allah", and searched for spiritual meanings of their illness through religious roots, despite the researcher studiously avoiding use of the word "religion" (*din*) in discussing "spirituality or الروحانيه". It was evident that for almost all participants the phenomenon of "spirituality or الروحانيه" was understood in terms of their religion or religious practices, which were found to be the most significant elements in their adoption status with regard to ESRF. There were numerous identifiable similarities and differences in their experience, as noted with regard to *"Balaa' بلاء"* concept and *"Balaa' بلاء"* and capabilities equations throughout the study. This was throughout all experiences with participants undergoing ESRF, as evident in the following example:

> "The first sources and the most important resources in "spirituality or الروحانيه" are the religion [….] as Muslims [….] we connect everything with the Islamic religion, and religious commitment to the provisions, or something ideological if you can describe it [….] whatever happened with me it was a caution or discipline". (Abo Hassan)

Abo Hassan's account showed that the meaning and purpose of his illness was perceived to be a checkpoint or a wake-up call from Allah about a transgression he had committed. According to his perception, the sense of a spiritual gap in his life precipitated the illness, and this gap was filled by being an ESRF patient. Such spiritual gaps were reported by participants during interviews in terms of their "spirituality or الروحانيه" and their obedience to Allah, comparing their religious observance before and after ESRF. This concept was repeatedly mentioned by many participants when they started to narrate their "spirituality or الروحانيه"; they invariably compared it before and after they suffered from ESRF:

> "I started to give more attention to my prayers, I became more conscious about my *" Ibadah عباده"*, I paid more attention to the Qur'an, I started to give serious thought while reading Qur'an, and when I hear the Imam reading Qur'an I give it meaningful thought. I started to realise that my judgement on things before was wrong; all the Hadith and the Qur'an refer to this *"Balaa' بلاء"* giving you comfort, and when I came back to my religion, *alhamdu lillah*, I found my condition was better, and to return to the religion is much better. Yes, I used to have weaker belief a little bit; thanks to Allah, after I got this illness my belief became stronger, so I've got the power of belief in my religion more, thanks to Allah and I mean a huge power". (Abo Sofyan)

> "I used to finish many chapters during dialysis, more than [….] when I was healthy, my obedience of Allah increased […] I always go to the masjid even fasting during Ramadan. I used to fast all month especially in the initial period, the first two years of dialysis [….] When my health started to deteriorate [….] I could not fast, so I fasted

> the following day… and walked with Allah step-by-step" (Abo Khalid).

As stated in Chapter 2, fasting is one of the five pillars of Islam. However, there are certain exemptions and permissions for not doing Islamic obligations when ill, despite having the strength to do so. For example, anything that can have any adverse effect on a patient, such as tiredness or fatigue, waives the obligation for a Muslim to perform religious duties such as fasting and the actions of prayer. With regard to fasting, the Islamic texts advises that the patient can feed a poor person in lieu of one day of compulsory fasting, or fast another day when he or she becomes healthy. This is cited in the Qur'an as: "Should any one of you be sick or on a journey, then (he should fast) a number of days (equal to the missing one); and those who have the strength (but still do not opt for fasting), on them there is a *fidyah* (compensation) that is feeding of poor person" (Qur'an, Al-Baqarah, V184). Nevertheless, it appeared from Abo Khalid's quote that he insisted on continuing to practise such pillars despite having permission not to, as he chose to remain attached to religious practices during ESRF treatment. In addition, the interviews revealed that all participants stated the importance of having an ideology and belief which encompassed a powerful sense of attachment to religion, thereby providing a sense of comfort to ESRF patients when facing their illness. They said the ESRF patient feels stronger in terms of coping mechanisms when he or she is attached to a religion (to be discussed later in this chapter), as exemplified by the following:

> "Something can help him. Some people believe in Buddha. Some people believe in Jesus, and as a Muslim, I have to believe in God, and all Islamic religion roots too [….] whatever your religion is, thanks to God before I reach this stage I was praying and following the Islamic habits, but nothing changed, I'm still the same as before, but maybe you feel a stronger attachment to religion, I don't know this feeling because you need God more than any time". (Abo Sara)

Abo Sara's account captured the comprehensive concept of "spirituality or الروحانيه" – of all religions offering spiritual solace and support to patients. Nevertheless, this view was narrowed by Abo Khalid when he stated that "spirituality or الروحانيه" is a sense of being with Allah, as stated previously, which he restricted to Abrahamic religions:

> "We in Jordan are 99 per cent Muslims. Even the Christian who is with us he has "spirituality or الروحانيه", he has his own "spirituality or الروحانيه", and you have to deal with him accordingly. "Spiritually روحانيا, it's not far off [from Islam] at all, unlike Buddhism or the one who prays to a stone. No, the Christian patient is walking with Allah too". (Abo Khalid)

Furthermore, Abo Obada, was very explicit about "spirituality or الروحانيه" being purely a religious issue that could not be separated from religion:

> "In the beginning, it [ESRF-illness] was really a very difficult matter, it wasn't easy. As it raises a contradiction between the religion matters and the "*Nafs النفس*" matters, I mean by contradiction that the religion matters will be a party of acceptance, and the "*Nafs النفس*" matters will be a party of rejection. Now from a religion point of view, we are Muslim, we must accept this matter, in fact, from Islamic views and from convictions, it will all refer to it being the best for the patient, and there are many hadiths that mentioned this, and this is something that has not come from nothing! And you know very well, being a patient this will be *takfear thonowb*, *maseh khataya* and even it will be *rafea' darajat*, as there are many hadiths saying that on Judgement Day there will be a gap for the person to enter Paradise. In addition, a gap will not be left without illness, so this is a religious matter or "spirituality or الروحانيه" purely, that I must accept. So, it becomes a terrible conflict between "*Nafs النفس*" matters and "spirituality or الروحانيه" matters, between what I see. In addition, I could not accept the illness. And the other side, You must accept this illness, This will take time a good time Until you will reach a new stage Where you will realise that this is what Allah has written for me, and you must accept it, whatever you did and whatever you become upset, you wouldn't have any new result, that's it". (Abo Obada)

In addition, later in his interview, he elaborated more by describing that "spirituality or الروحانيه" *is* religion:

> "Spirituality or الروحانيه" is almost 99 per cent based on religion, I wouldn't accept the idea of being a patient, unless after the surrender period. Rejection of this idea is consider as *kufr*, because you as a patient are refusing Allah's decision, you are refusing Allah's will, so this is something you must accept, so now, you will you will become connected with your degree of belief, and the higher the degree of belief you will have, the easier your acceptance will be. In general, all of the *almassaayeb* or other tests such as "*ibtilah* إبتلاء" the more degrees of belief you've got; the more easy you will accept such matters, and vice-versa, and in rejecting, you might be punished for it, not only during illness, according to *almoamen.*". (Abo Obada)

The foregoing two quotations of Abo Obada demonstrate the focuses of this study. He captured the salient features of all participants' experiences. He immediately conceptualised being an ESRF patient as if his illness itself is only a religious matter, and he conceptualised illness in terms of a source of benefit in the hereafter. Abo Obada emphasised the conflicting status between the acceptance and rejection equations and its implications, as discussed later in this chapter, and how the strength from "spirituality or الروحانيه" coincided with the acceptance status of being an ESRF patient. He also addressed that the illness is something "written" (i.e. predestined) by Allah, with no exception to anyone. However, this does not mean that the patient needs to leave his illness untreated or to be become determinism as result of such conflict, in which case he will refuse or become non-compliant with his treatment. As seen in Chapter 2, the prophets urge patients to seek remedy to any illness. Muslims believe that prophets similarly were tested with afflictions and challenges, enabling them to obtain a greater status than normal humans. As stated by Frankl (1992, cited in Albaugh, p594) "People forgot that often it is just such an opportunity to grow spiritually beyond themselves". In addition, the use of religious language to enthusiastically express feelings and the search for meaning and purpose in their illness was clear. Furthermore, it is evident that almost all participants immediately extracted verses of the Qur'an or the Prophet's hadiths to elaborate their spiritual experiences and to justify their spiritual practices to face illness, and in order to cope,

gain direction and achieve a sense of being blessed under the mercy of Allah to receive guidance from their illness. As stated in Chapter 2 with regard to Islamic and ethical considerations during ESRF treatment, the following accounts from two participants, Abo Shehab and Abo Malik, illustrated the use of such language and stressed the fundamental importance of being patient that is extracted from Islamic roots, in this case the Qur'an:

> "According to my experience, whatever has been written by Allah for you [….] you have to be patient with your *"Balaa' بلاء"*. As being 'patient is a key for *faraj*', as Allah will be with those who have patience, as it has been mentioned in the Qur'an: 'Surely we will test you with a bit of fear and hunger, and loss in wealth and lives and fruits, and gave a good tidings to the patient, who, when suffering visit them, say: 'we certainly belong to Allah and to him we are bound to return', those are the ones upon whom there are blessings from their Lord, and mercy as well; and those are the rightly guided', Qur'an, Al-Baqarah: 155-157], so it does mean that we have to be patient and have *hidayah*" (Abo Shehab).

> "According to my experience, Allah *subhanahu wa ta'ala* created the world. He requested from the pen to write, and the pen asked 'what shall I write?', you will have to write everything until Judgement Day, so the human illness, his eating, his drinking and his work, we know all of these as Muslims that we have to have belief. *Iman* in what has happened with him and in what will happen to him, and the Prophet, peace be upon him, said to Abdullah bin Abbas 'oh boy, I am teaching you certain words: if you save Allah, Allah will save you, and if you save Allah you will find the other one is in your direction, and if you are going to ask for something you should only ask Allah, and if you need support you have to seek support from Allah, and you should know that whatever happened you weren't going to miss you, and whatever misses you were not going to happen to you'; so any patient suffering from ESRF or liver disease or any other illness must know this is something Allah has written for him, so this person

> shouldn't feel sad, and he has to accept this matter with a good spirit". (Abo Malik)

Others justify the reason behind such behaviours and actions in terms of the search for deeper meanings and purpose in this life and the hereafter through religion. Heidegger considered the nature of being in the world to concern conformity, inauthenticity, lostness and authenticity, which could be inferred from participants' responses (Heidegger, 1962). ESRF induced the participants to consider existential questions concerning self and purpose. As such issues are ingrained in Islamic metaphysics: this was experienced as a realisation of intellectually dormant knowledge among the Muslim ESRF patients interviewed, developing the spiritual aspect in parallel with the performance of actions such as compulsory prayer, charity, fasting and eating halal food etc. This represents a much deeper and more complex experience of religion and "spirituality or الروحانيه" than that found by mainstream studies of spiritual care (i.e. their facile conclusion that "spirituality or الروحانيه" is not religion). For Muslim ESRF patients, "spirituality or الروحانيه" is religion. Religion appeared also to transform attitudes toward facing ESRF, as described in the previous and following quotations; participants received a sense of direction and guidance from their spiritual beliefs:

> "I can say is what happened with us, that the patient has to listen to the religion, has to listen to the Qur'an, has to listen to the Prophet's hadith. He has to listen precisely to those hadith with illness especially, and try not to make it general, so for example, search for the hadith that mentioned illness, for example, Prophet Muhammad told us that 'if Allah loves someone, Allah will give him *"Balaa' بلاء"*', and when he learned the Qur'an 'nor is there any blame on a sick person'. Allah will forgive you if you haven't fasted, Allah will forgive you with something you have done, these things that you are required to support the patient to do, you know what I mean, this is the "spirituality or الروحانيه" itself". (Abo Sofyan)

It was also noted by many participants that bearing illness patiently is a source of reward (and thus of hope) for reward Hereafter, as explained later in this chapter in the section concerning being tested and the reward of illness (purification). Such directions and guidance were found to be crucial for Muslim patients' "spirituality or

الروحانيه" to face ESRF, as some participants described their status of losing a sense of direction and facing a crossroads:

> "According to my own experience as a patient, with any illness and with ESRF, any person has got ambitions. But when he becomes a patient [….] he will reach a crossroads. Either he's going to fight against his illness, or he is going to cope with his illness and achieve his ambition and carry on". (Abo Sayef)

Other participants felt they had been dropped in a *magarah* or cave as a way to describe their existential predicament. All participants stated that their ESRF diagnosis was sudden and shocking. For example, Abo Khalid and Abo Saber described their initial feelings about ESRF as follows:

> "I was affected. As the illness came to me so suddenly, as I was never treated for kidneys, it came so suddenly at once. So it was shock to me". (Abo Khalid)

> "So when I knew from doctors that I had to start dialysis, it was like a shock, from my point of view and from my family's perspective and from community point of view [….] I'm still young, I wasn't married at that time, I felt as if I was falling in *magarah*, *fajwah*, where you don't know where you have to go, no left, nor right, or go ahead, or backward, like that, you will have complete silence". (Abo Saber)

Such feelings according to Heidegger are important as "the handle by which we can grip our own beings"(Heidegger, 1962). Nevertheless, due to the sudden appearance of ESRF illness all participants found themselves in a situation that limited all aspects of life, despite the power they previously had when they were in good health. This coincides with the observation of the philosopher Karl Jasper (1883-1996), who claimed that "humans are always in situations; some situations we can influence and change, others cannot be changed no matter what we can do about them" (Smith et al., 2013), such as the beginning of ESRF illness, as illustrated by the following:

> "I was feeling shocked from inside, I was shocked as I wasn't prepared for it to reach me at that stage, as I had a new contract with that hospital, and as you know if they discovered this they would have

> sacked me, and this was during the first month and a half of my existence in that hospital". (Abo Omer)

Abo Omer's narrative indicates that his own attitudes toward being an ESRF patient were shaken, as this limiting situation led him to discover the world around him to be unreliable, as he was subsequently made unemployed just after he had begun ambitious career plans. Thus, as narrated later in this chapter, he explained how he was searching for shelter and rescue from his limited situation.

The sense of losing direction and a need for guidance to face their status of desperation and limited situations was recurrently stated by participants to be a spiritual need for them, as explained throughout this chapter. The concepts of guidance and direction were repeatedly expressed by participants using a set of religious practices and beliefs. There was an Islamic philosophy underpinning the "spirituality or الروحانيه" of Jordanian ESRD patients to face the illness, which was reported by or was implicit in all participants' responses when they searched for meaning and purpose of their ESRF. This led to the identification of what amounts to a model that each patient follows, manifest in six situated structures: *"Balaa' بلاء"* concept, *"Balaa' بلاء"* and capability equations, *iman*, "spirituality or الروحانيه" and religion practices, "spirituality or الروحانيه" and Islam.

Although the phenomenon of "spirituality or الروحانيه" was equated by all participants with religion, all participants reported initial feelings of "why me?" during their initial reaction to ESRF diagnosis – questioning why Allah had afflicted them with the illness, which they subsequently attributed to a weak level of "spirituality or الروحانيه":

> "…the reception of my illness was very difficult, and once I knew that this is the illness I started crying and raising questions: 'why is it me?' [….] from all people Allah has selected me to be a patient and with something like that!". (Maha)

As seen from the above, the initial experience of ESRF negatively affected participants' spiritual status. This coincides with the observation that "sickness may have threatened the patient's faith in the ultimate goodness of life, he cannot believe that God can let terrible things happen; or may fear he has lost favour in the sight of God, considering the illness as a punishment for real or imagined sins" (O'Brien,

2003). With hindsight, the participants regarded such questioning as evidence of a lack of true belief and weakened spiritual status related to a lack of trust in Allah, which caused the *"Balaa' بلاء"* to be perceived as something beyond endurance. As Abo Ahmed described, ESRF patients start to raise such questions:

> "People with this condition will not have a *nur* [lightness] from inside them, they were switching it off, you will find those people who talk like this have drifted away from religion and far from Allah, and they will not depend on Allah in their hard times [….] the believer will not be affected". (Abo Ahmad)

Thus, when the *"Balaa' بلاء"* and the capabilities of participants to endure it were more balanced "spiritually روحانيا" almost all participants had internal conflicts between acceptance and rejection of their ESRF:

> "spiritually روحانيا as I told you it was very difficult, as it clashes between the acceptance and rejection parties, and this is what happened with me, acceptance that I must accept it as I am a believer in the *qadar* of Allah, and the rejection as it's difficult to accept it, especially when you are human, where he was high and now he is down, where you couldn't even lift a bag! Weak in your body, especially at the beginning when my movement was really very slow, now I can walk and go; but at the beginning it was difficult [….] for me it's like a catastrophe, it was like a catastrophe". (Abo Obada)

Subsequently, participants' capability to endure ESRF increased in parallel with their "spirituality or الروحانيه", which ultimately overcame the negative thoughts and eliminated bad imaginations and actions.

"Balaa' بلاء" Concept

Initially, all participants reported that patients must consider ESRF as a *"Balaa' بلاء"'* (test) written for them by Allah, a test which no one wishes to fail. Success in the trial was manifested through showing acceptance and resignation in a positive way. This appeared to be the ultimate ambition for ESRF. The interviews showed that no one objected to the status Allah wrote for them (although initial questioning of "why me?" was a common feature during the initial phase of ESRF diagnosis). Such concepts were repeatedly quoted by all participants, reflecting the deep

penetration of this concept in Arab-Islamic culture and can be traced to many verses of the Qur'an and hadiths. The interviews revealed the importance of initiating such feelings in querying their relationship with Allah as the first platform to understanding "spirituality or الروحانيه":

> "There are things that person has to keep in mind, that he will be having *"Balaa' بلاء"*. I consider this illness to be *"Balaa' بلاء"* and as Muslims, we all consider this as *"Balaa' بلاء"* from Allah, *subhanahu wa ta'ala*, I initially said thanks to Allah for this illness, as it is similar to other kinds of *"Balaa' بلاء"* that can happen to anyone, such as a car accident. As a Muslim, I consider this *"Balaa' بلاء"*. As long as it is from Allah; we accepted and welcomed it… and thanks to Allah I have reached this stage". (Abo Khalid)

> "I have a very strong ideology in Allah … this illness is something from *Qadar*, and it is written for me". (Abo Yaser, late 40s)

> "This illness is from the Virtue of Allah, at the beginning of this illness everything was getting worse, and after a short period, thanks to Allah that we know this is good for ourselves, this is very good for ourselves, and you know what I mean. And thanks to Allah that Allah selected you as a person. As Allah loved you, and this is *ibtila* from Allah, *subhanahu wa ta'ala*, Allah is the One who sent his *ibtila* to you, for your worldly life. And the Hereafter, *hasanah* for your worldly and *hasanah* for you Hereafter … And now, you feel mentally at rest, and very, very, very happy in this illness, and I hope from Allah to give me more than this illness". (Abo Sofyan)

This indicates find that Abo Sofyan started his illness with a feeling of being in a limited situation before he reached the abovementioned happiness status; he contradicted what he said earlier, as he only reached such a state after an initial regrettable period as he stated previously, which resulted in soul-searching. However Abo Khalid contradicted the wishes of any kind of *"Balaa' بلاء"* expressed by Abo Sofyan in the above quote, stating:

> "If the patient has any *"Balaa' بلاء"*, then he has to be patient and ask Allah to be patient in this illness. But never ask Allah to send *"Balaa' بلاء"* for you, as you may become weaker" (Abo Khalid).

Nevertheless, sensing that the *"Balaa' بلاء"* of ESRF is from Allah was perceived to entail certain spiritual provisos among ESRF patients, as outlined below. Although the majority of participants recounted that "spirituality or الروحانيه" was rooted in religion and consequently categorised ESRF as a *"Balaa' بلاء"*, it appeared that the experiences of the concept of the *"Balaa' بلاء"* appeared differently to participants . These experiences were: surrender, being patient, finding shelter and rescue (refuge), acceptance and being appreciative of Allah's selection, being comfortable, being tested and being purified, trust in Allah, being stabilised and being tranquil. All these different experiences were reported by all participants as religious aspects of "spirituality or الروحانيه" in the face of ESRF.

More than half the participants stated that by being patient and bearing any tightness and tiredness associated with the ESRF illness resulted in the latter becoming a source of reward, giving them a greater sense of appreciation, which was a religious tool to face the *"Balaa' بلاء"*. Thus, participants highlighted the need being patient as one of their spiritual needs and requirements. Again, these requirements were extracted by ESRF patients through religious roots. For example, the concept of enduring the illness patiently was perceived by the majority of participants as a source of reward (and thus of hope), as Allah urges them to be patient when they are compromised and in times of hardship in many verses of the Qur'an: "those who are patient in hardship and suffering win in battle! Those are truthful, and those are the God-fearing" (Qur'an, Al-Baqarah, 177); "…those did not lose heart for what they suffered in the way of Allah, nor did they become weaker, nor did they yield. Allah loves those steadfast" (Qur'an, Al-Imran, 146); "And be patient. Your patience is bestowed by none but Allah" (Qur'an, An-Nahla, 127); "So, observe patience, as the resolute messengers observed patience" (Qur'an, Al-Ahqaf, 35); "and be patient. Surely Allah is with the patient" (Qur'an, Al-Anfal, 46). Not being patient was perceived to incur Allah's punishment ("disciplinary"). All the participants noted this in facing their limited situation of ESRF. One participant addressed this need and requirement thus:

> "Without being patient there is nothing else you will have. As after being patient there are rewards, as always after the patience there is reward, and this is been mentioned in the Qur'an, 'verily with hardship comes ease', and it doesn't need any interpretation, and the one who is convinced about these things will live happlly, and the one who doesn't will feel upset always". (Abo Ahmad)

Another justifies the requirement of being patient according to Islamic belief as a spiritual need for ESRF patients:

> "As a Muslim, ESRF patient has to feel comfortable with that, that this has been written by Allah to him and he has to be patient, and if you become patient you will have the *ajr* and *thowab* from Allah, *azza wajal*, and if you haven't been patient then the discipline from Allah will be next to you, isn't it?". (Abo Malik)

> "What more than being patient with your illness do you need? Nothing will be bigger than this". (Abo Malik)

Abo Sofyan stated that a nurse engaging ESRF patients in spiritual discussions met such spiritual needs, particularly discussing:

> "The Prophet's hadiths are talking about *"Balaa' بلاء"*, patience, and actually it gives you a strong push forward; this is what I want, what the Prophet did, our Prophet is our role model, and when he gives us those pushes, actually it lifts our self-esteem" (Abo Sofyan).

The above quote by Abo Sofyan highlighted that attention to ESRF spiritual needs is a crucial though informal/unstructured component to nursing care in the dialysis unit. This was echoed in the literature with regard to the Frankl theory: "It's believed that spiritual values a person holds will determine, with great extent, his perception of illness. The spiritual values of the nurse or her philosophical beliefs about the illness and suffering will determine the degree to which he or she will be able to help in finding meaning in these situations" (O'Brien, 2003). Such interaction between patients and the surrounding environment, including nurses, is discussed with regard to the theme of relationships.

In addition, Travelbee revealed that religious practices are the facilitator to cope with distress and limited situations, discussed in detail later in this chapter ("spirituality or الروحانيه" and religious practices section), and as indicated in the following participants' narratives:

> "Of course first of all by *"Du'a دعاء"*, reading the Qur'an, being patient". (Abo Rami)

> "The *"Balaa' بلاء"* [….] is a step of "spirituality or الروحانيه" with Allah that the patient has to love [….] he has to be patient and ask Allah to be patient in this illness". (Abo Khalid)

> "We know that, as Muslims; the rewards of being patient… being in connection with Allah has a great reward… as long as you are patience… as Allah said, 'bid your family to perform *Salah* and adhere to it yourself' [Qur'an 20:132]". (Abo Khalid)

The association of reward being implicit in the status of being a patient was very strong among participants, as reflected in the Qur'an: "Certainly those who observe patience will be given their reward in full without measure" (Qur'an, Azzumer, 10), "And will give them, in return for their patience, Paradise" (Qur'an, Al-Insan, 12); "and give good tidings to the patient". (Qur'an, Al-Baqara, 155)

Turning now to other ESRF spiritual experiences, it can be concluded from the majority of participants' responses that the first step in the emergent pattern was for the ESRF patient to conceptualise ESRF as a test and *"Balaa' بلاء"*. This was a fundamental component of participants' "spirituality or الروحانيه", entailing the concept that it would either expiate for sins, as explained above, or increase reward (*ajr*). This was evident in the Islamic literature when the Prophet Mohammad (peace been upon him) said: "if Allah is going to do good for you, Allah will pour you in "Balaa' بلاء" as Allah will ultimately give good outcomes from such *"Balaa' بلاء"*, and relieve ESRF suffering. This was anticipated in the form of forgiveness for sins and spiritual purification. More than three-quarters of participants verbalised this consideration of *"Balaa' بلاء"*, which appeared to have important implications on their "spirituality or الروحانيه" and which generated inner comfort:

> "So, when Allah gives someone a chronic illness such as this, as long as he is a patient, Allah will erase his *sayeaat*, so once he is convinced about this thing the "spirituality or الروحانيه" will increase and the inner peace will increase too [….] We are sitting in this life as a test and we are going to see what will happen Hereafter, either you will be happy or you will go to Hellfire.". (Abo Ahmad)

Furthermore Abo Ahmad explicitly stated that a sense of comfort arose from accepting Allah's judgment (comfort in *Nafs النفس"*), which enabled him to conceptualise illness as a 'win' bringing compensation from Allah:

> "ESRF patient will feel that he lost everything, but if he understood properly he would realise that his illness is a win for him, as the patient when he is patient and copes with [endures] his illness for the sake of Allah, Allah will compensate him with many things and once he beliefs in this thing he will become comfortable in his "*Nafs النفس"* very much. And if he hasn't got this, nothing will give him comfort". (Abo Ahmad)

Participants also believe that only remembrance of Allah can a give sense of comfort and tranquility, as cited in the Qur'an: "the one who believe and their hearts are peaceful with the remembrance of Allah. Listen, the hearts finds peace only in the remembrance of Allah" (Qur'an, Alrad, 28). This belief was addressed by all the participants through their spiritual coping mechanisms, as described previously.

In addition, it is important to note that the conceptualization of the illness as *"Balaa' بلاء"* appeared insufficient in itself when facing ESRF; as stated above, it was experienced differently. More than two-thirds of participants expressed that this must be accompanied by a feeling of surrender and conviction of Allah's selection, not as punishment or to humiliate the patient. As reported by participants, a sense of being selected and favoured by Allah by being tested with ESRF outweighed the sense of punishment alluded of *why me?*

> "You have to have conviction that Allah is our Lord, and Allah told us that we have to be patient, as I mentioned; if you are patient you will get a reward, and even if you are upset about it you have to be

patient, you have to cope with it, and thanks to Allah that this is my absolute ideology, accepting it with a desire.". (Abo Yasser)

"My belief has increased in learning my religion, I came to believe 100 per cent in *Alqadaa wal qadar*, I'm not scared any more, and they said '*Sallamat Amry* to Allah" [surrendered myself to Allah], and this is something that has helped me a lot, in your "spiritually روحانيا and in your religion, it will help you very much". (Abo Saber)

Conviction that the illness is a test from Allah and a source of *ajr* in the afterlife promoted tranquility; lack of such belief resulted in frustration and depression, as discussed under the desperation theme later in this chapter. After a period of surrender and conviction, participants reported that they reached a stage of acceptance and appreciation of their illness, and perceptions of being loved by Allah. All participants showed their gratitude of being loved when they experienced tragedy and limiting situations during their illness. As stated in the Qur'an: "Who, when suffering visits them, say: 'we certainly belong to Allah, and to him we are bound to return" (Qur'an, Al-Baqara, 156), and as stated in the following:

"This is the "spirituality or الروحانيه" itself, as Allah sent this *"Balaa' بلاء"* to you, you have to accept the *"Balaa' بلاء"*. Yeah, why do you think Allah has selected you as the patient, because Allah He loved you, is there any better situation than that you are loved by the Creator?". (Abo Sofyan)

"So when Allah sends *"Balaa' بلاء"*, Allah has not asked us don't have it. Therefore, we have to take the reasons. The disease is from Allah, and Allah is the one who is going to take it from you and before the treatment starts we have to shelter ourselves to Allah. And make *"Du'a دعاء "*I have to realise as a patient that this disease is from Allah. In addition, no one can cure me except Allah we have to take it in a Tranquil Nafs النفس المطمئنه [….] Prophet Muhammad, peace been upon him, said: 'if Allah loves someone, Allah sends *"Balaa' بلاء"* to him". (Abo Khalid)

Following the condition of surrender, most of the participants experienced that the sense of acceptance and appreciation was necessary following the above stages, and was part of religion whereby they felt obliged to accept and appreciate their condition, showing their resilience by being thankful to Allah for their selection as ESRF patients, which promoted tranquility in their "*Nafs النفس*": Participants displayed remarkable resilience and self-efficacy in this regard when faced by ESRF:

> "I accepted and welcomed it, this is from Allah. And Allah is the One who is going to cure you and Allah is the One who gives you the illness". (Abo Rajab)
>
> "I have accepted my illness because it's part of religion. And I can stamp with my ten fingers that Allah has written this for me, and it is *takfear thonob* and *sayeaat* and so on. On the other hand, as I started on the religious way, I have to finish it in a religious way. So I don't have to take bits of religion and bits of social, correct? At the beginning I accepted because I knew that this is what Allah wrote for me, and it will benefit me in the Hereafter. Okay, halfway through my illness, I have to continue the religious way". (Abo Obada)

The above quote by Abo Obada distinguished between "*Nafs النفس*" matters and "spirituality or الروحانيه" matters (desires and "spirituality or الروحانيه"), and highlighted the importance of acceptance in dealing with the illness in a religious way. Similarly, all ESRF patients considered the sense of acceptance and appreciation to be "spiritually روحانيا" important, as Abo Khalid and Abo Sofyan reported:

> "I initially said thanks to Allah for this illness, as it is similar to other kinds of *"Balaa' بلاء"* that can happen to anyone such as a car accident [….] As long as it's from Allah; we accepted and welcomed it… and thanks to Allah I have reached this stage.". (Abo Khalid)
>
> "You are returning to Allah, if you are doing bad things in this life or if you do the right things in this life, as long as you are a Muslim doing the right things when you face Allah in the Hereafter, yes, these things are in your hands, so that I should face Allah with something right is better for me, and this is the good "spirituality or الروحانيه"

> […] I believe that Allah selected the good thing to happen to me, and thanks to Allah, I feel really comfortable". (Abo Sofyan)

Although the Qur'an affirms that "there are signs therein for those everyone who observe patience and gratitude" (Qur'an, Ibrahim, 5), Abo Sofyan contradicted his initial stance with ESRF in the above quote, as explained under the third theme later in this chapter. The above participants' accounts show that although surrender and conviction were experienced differently, generally speaking they gave patients a sense of relief and comfort. Following from the sense of accepting ESRF as a test from Allah to be met by trusting in Him, patients' acceptance and coping were facilitated by being thankful to Allah. Many participants displayed remarkable thankfulness for this severe medical condition, to the extent that some expressed that they preferred this status to normal good health because of its positive impacts on their "spirituality or الروحانيه":

> "Yes, this is when I was in the coma, so medically my matter was expired, but until now, what you make my *"Nafs النفس"* comfortable, Allah stands with the people around me, even with their prayers, their *"Du'a دعاء "*, the connectedness to Allah became very obvious not only with certain people, but even with my cousins' families, and the one who didn't pray before; he started to pray, and my condition was a motivation for them [call interruption to the participant], and this helped me to recover quicker than the medical treatment and tablets". (Abo Hassan)

In addition, participants frequently described their experience of acceptance as being fundamentally linked to the concepts of accepting the illness as a spiritual challenge and a test from Allah; more than half of the participants stated that trust in Allah's selection gave a sense of comfort if they met the challenge of their illness with trust in Allah:

> "…Spiritually روحانيا, it will give patient trust in Allah, *subhanahu wa ta'ala*. And it will give him a trust in *Alqadaa'* and *Al qadar* […] personally after a certain period of the illness, "spiritually روحانيا" I felt comfortable as I felt this is the mercy from Allah *subhanahu wa ta'ala* […]; I consider my illness as a mercy from Allah *subhanahu*

wa ta'ala, as may Allah will forgive me about some *thunoobs* that I have done". (Abo Eizz)

"The patient should fear Allah, trust in Allah, and ask Allah for recovery, and to follow up their illness normally and to accept with patience". (Abo Rajab)

"Of course without being with your religion commitments, you will start to say 'if this' and 'if that' and that "if" word is from the Devil's work, but when you have a belief in Allah, azza wajal, you shouldn't initiate any 'if matters. And as it's been mentioned in the Qur'an, 'say: 'nothing can ever reach us except what Allah has destined for us'. He is our master, and in Allah alone the believers must place their trust". (Abo Malik)

Abo Malik illustrated that using "if" is related to ESRF patients' avoidance of retrospective blaming (of self), and he mentioned it is from the devil's work. This has negative implications on ESRF patients' "*Nafs النفس*" as described under the "*Nafs النفس*" concept previously. Thus, trust in Allah and accepting the illness was a religious tool that enabled patients to circumvent cognitive processes of questioning leading to depression.

Also, "spirituality or الروحانيه" during ESRF manifested among participants' experiences in a perception of the importance of spiritual propagation and the need for appropriate strategies tailored to their interests. A sense of responsibility and consequences of empowerment were expressed by many participants regarding their successful spiritual coping with ESRF. Lack of such spiritual propagations and sensing of responsibility often appeared to trigger the negative thoughts associated with feelings of emptiness and depression:

"As a patient, initially, if he is well established within an Islamic environment [….] for example, praying five times a day [….] he has got good "spirituality or الروحانيه" he just needs a follow-up, but if he didn't [….] he will lose his "spirituality or الروحانيه" context if he stops performing *Salah* So here I would give him a motivation bring him back to performing *Salah*. And for those who don't perform *Salah*, I would approach them whenever they were calm and relaxed then I

> would ask if they perform *Salah* or not 'Why you shouldn't come closer to a Allah? You may die at any point any moment' and so on. If I pulled him back to performing *Salah* again as normal, I would give him some things a push forward that actually he needs to depend on Allah more Allah is greater than him Allah will send this *"Balaa' بلاء"*. This push will help him so he will reach tranquility; this pushes, will keep him away from feeling emptiness. Thus, when he start to think that when he needs to harm himself or others He will start to feel that he's got a responsibility This responsibility will stop him harming himself". (Abo Khalid)

Abo Khalid's experience echoed a concept found in the Qur'an: "O you, who believe, seek help through patience and prayer. Surely, Allah is with those who are patient."(Qur'an, Al-Baqarah, 153). This concept of being responsible was evidenced in some cases by remarkable resilience and self-efficacy:

> "I kept saying that my condition is great, and thanks to Allah for everything, and I kept insisting on that and kept coping with it, with pain, with tiredness with those problems, all of these pains, I coped with them". (Abo Yaser)

Also, Abo Yasser narrated that he refused offers to help with renal transplant from family and work colleagues due to numerous reasons, including hearing about people who had transplants that later failed after a few years. In addition, he stated that the disease is from Allah, and he expressed genuine happiness with his condition, and cited good health (with examples, such as his haemoglobin levels etc.) after 16 years on dialysis. Furthermore, Abo Yasser stated that it was not his right to cause suffering for someone not decreed by Allah to undergo such suffering (i.e. Allah decreed the ESRF for him; taking a donation from someone else would cause suffering to that person that would be attributable to him).

Despite this, a few participants experienced the *"Balaa' بلاء"* differently in terms of the feeling of being a refugee; those participants felt they migrated towards Allah, to whom they attributed the blessings of rescuing them from inevitable death. Abo Ows narrated that after he had renal transplantation, he walked on foot to the ICU department for a routine check and was discharged after nine months with multiple

disabilities: deafness, partial blindness and inability to walk. Despite all the challenges and the limiting situation he faced, he stated that observance of religious obligations rescued him, and that his only rescuer was Allah, by submitting himself to Him and feeling tranquility and comfort:

> "Reading both the Qur'an, and prophetic supplications I recited a large number of those I felt that these were a shelter and the rescuer (helper). This is the rescue for me and *subhan Allah*, actually, every time when I read the Qur'an, if I will go to an operation or surgical procedure I felt the tranquility especially when most of my operations were done under local anaesthesia, you see and you are oriented about everything happening around you of that event. I kept reading the Qur'an during the operation and I found it relieving [….] more precisely every time I come to dialysis, I must read *Almoawethat*, *Ayat Alkursy* and *Alfateha* [verses of the Qur'an] Essalat Al-Ibrahim's I must read all of these before I enter the dialysis unit I feel like I commend myself to Allah". (Abo Ows)

When I queried what Abo Ows meant by shelter and in what way he was rescued in his description (above), he replied: "In this situation, both; as the rescuer, it removed my fear. As a shelter, there are no other places you could go to except this, the only place" (Abo Ows). This expresses a common theme, whereby ESRF patients viewed their "spirituality or الروحانيه" as a shelter and rescuer. This helped ESRF many patients to overcome fears, phobias and spiritual distress that Abo Ows stated were associated with the illness:

> "So when you are approaching him on this religion way, the patient will receive everything from you, as he would like to shelter himself […] he will return to Allah, *subhanahu wa ta'ala*. You must give him such things. This is a "spirituality or الروحانيه" push". (Abo Sofyan)

> "Spiritually روحانيا my life changed as I never expected, doing things I never considered since I was given them at the school stage, such as making *"Du'a دعاء "*, or even being more insightful in my religion in my life I am an honest person [….] I thought the most appropriate

> thing to do was *Tasbih*, listening to religious radio for hadiths or *"Du'a دعاء "*; I found those things really helped me, they really relieved have relieved me very much for example, when they used to come to take blood samples, I didn't look at the needle; after I developed a phobia of the needle, I didn't need to look at it so I started making *Tasbih* and *"Du'a دعاء "*" Sometimes I *atarjal* when I am making *"Du'a دعاء*." I started to make my own *"Du'a دعاء*:" '*Ya Allah, Ya Allah*, relieve me…' And so on… And a kind of *estrersal*, I begged Allah until this fear was gone, and I found that the only friend in that situation was Allah. This feeling helped me and made me more comfortable". (Abo Ows)

The sense of a source of guidance and a sense of relief expressed by Abo Ows has its foundation in the Qur'an verses: "Be patient about your Lord's decision, because you are in front of our eyes. And *Sabah* (proclaim the purity of your Lord) along with his praise" (Qur'an, At-Tur, 48); "So, endure with patience what they say, and *Sabeh* (proclaim) the purity of and praise your Lord before sunrise and before sunset. And in some hours of night, *Sabeh* (proclaim His purity); and at that Point of the day as well, So that you may pleased". (Qur'an, Taha, 130)

As seen so far, participants frequently recounted that attributing the illness solely to Allah and corresponding remembrance of Allah generated feelings of comfort. Almost all participants verbalised that this consideration of *"Balaa' بلاء"* has important implications on their "spirituality or الروحانيه" and gives them inner comfort:

> "This is the most important thing that you are going to feel comfortable with, and if you haven't read the Qur'an and prayed, you will find that your *"Nafs النفس"* will you stay feeling tired. However, when you read the Qur'an, pray, and make commitments; you will have a spiritual status whereby you will not think about death or be scared about anything.". (Abo Shehab)

> "In your heart you will feel that you became comfortable [….] I started returning to Allah…" . (Abo Sofyan)

> "I feel comfortable in my "*Nafs النفس*", when you read the Qur'an and read the *Ayat* you will feel that your chest is *ansharrah* (put in peace and opened), especially when you face *ayaat* related to recovery". (Maha)

> "Yes, it might help... As it has helped me, it has helped me very much, especially when someone tried to remind me about such things, mercy and paradise, and to view my illness through religion, as I like to hear such things as I will feel comfortable and I become tranquil". (Maha)

The preceding quotes illustrate the concept of remembrance of Allah in an almost idealised form during ESRF, with patients stating that it evokes a sense of being comfortable. As can be seen in Table 4.2, all the participants were Muslims, thus this presents a clear indication of how Muslim ESRF patients enhance their inner comfort status through religious observances (as discussed below with regard to "spirituality or الروحانيه" and religious practices).

In addition, the perception of spiritual coping strategies and the common process undergone by few patients from shock to acceptance outlined above ultimately led to a feeling of stability and control over the illness and over other challenging life events:

> "Thanks to Allah I control myself [….] the restricted food - I keep away from it [….]. I have been ten years on dialysis, not one or two days, I have experience in such things". (Abo Shehab)

> "So the thing that stabilised me was my belief. That this is the life that being written for me, you are not going to leave it for something worse". (Abo Hassan)

Such stabilising is important and helpful for ESRF patients:

> "It has benefitted me in everything, thanks to Allah, as it makes me feel that I'm not a patient, as I feel myself that I'm coming to the hospital to sit with my friends for four hours, laughing and making jokes, I control myself completely, and thanks to Allah it has helped me in controlling my illness". (Abo Khalil)

As a result of the above experiences; it can be seen that "spirituality or الروحانيه" surfaced in that such acceptance and appreciation of the "Balaa' بلاء" gives the ESRF patient a spiritual dose in terms of their belief increasing, promoting a sense of tranquility. This sense of tranquility had implications on the patterns of ESRF patients' "*Nafs النفس*" (as discussed in the "*Nafs النفس*" concept above). As a consequence of having such a sense, the majority of participants reported becoming stronger, more comfortable and achieving the inner power they needed when reaching desperation stage during their illness (see desperation section), and even mitigating/overcoming suicidal ideation, changing their inner charges from negative to positive, controlling the pain. All of this has implications reflected in the different experiences and in the coping mechanisms of participants:

> "I let my "*Nafs النفس*" cope with it… As I am used to it… I convinced my "*Nafs النفس*" that this is something normal and usual, which it is - almost every day - and as I told you I rely on being patient. And sometimes, when I wake up during the night, I will start praying [….] this will make you feel the tranquility". (Abo Rami)

> "The benefit I will gain is it will give me the power and courage, it will give me the support from inside". (Abo Saber)

> "Then, if you ask him to perform *fajr* prayer in the masjid in *jamaa*, as the Prophet (peace be upon him) urged us, as it's mentioned that he said 'anyone who prays *fajr* in *jamaa*, he will be in Allah's mercy until the evening', so anything that happens during the day will be very merciful for him, it lets him believe that Allah is looking after him, and this will give him a big push to forget problems. Similarly, the Prophet said 'anyone who performed *isha* prayer in *jamaa* will be in Allah's mercy until the morning'… and you can give this patient more "spirituality or الروحانيه" [….] when the patient feels that he talks directly to Allah, this is a great "spirituality or الروحانيه", and he will start to think that his pain and his suffering are very meaningless things". (Abo Khalid)

> "And when you provide him with "spirituality or الروحانيه" for one or two times, once he responds with "spirituality or الروحانيه", you will find he already reached 50%". (Abo Khalid)

> "You will feel tranquility in your "*Nafs النفس"*, you will feel comfort in spirit, and quietness in his *"Nafs النفس"*, which will give him a power, certainly… As long as you are comfortable in your *"Nafs النفس"*, and you feel peacefulness in your "spirituality or الروحانيه" , so now you will feel that it becomes a source of power for you, and to add to this, there are some people who had the illness as other sources of power, and he might not achieve something in normal life, in healthy condition, but after they had the illness or had a certain disability, they might … do something that he never thought about when he was healthy." (Abo Eizz)

The spiritual "doses" alluded to above promoted feelings of tranquility among many participants in their *"Nafs النفس"*. This was evident in the majority of participants in the following examples:

> "The human *"Nafs النفس"* will become tranquil [when one asks] 'what else would you like to have?' and thanks to Allah you will stop wishing to die". (Abo Malik)

> "*Al-sakkeenah* is something you should have to get the tranquility; I'm not sure how to explain to you, as I explained to you it is peace of mind". (Abo Sofyan).

This was also echoed by Abo Ahmed, when he stated that:

> "It will be impossible to be *astakeen* from inside without Allah directing me to read the Qur'an, to remember Him and do something good, anything that will make Allah satisfied with me. And after that you will find that my "spirituality or الروحانيه" is high very much, and I will feel protection from Allah whenever I walk as He told me, and no harm is going to affect me unless Allah has written it for me". (Abo Ahmad)

On the other hand, one participant, Abo Ahmed, perceived "spirituality or الروحانيه" as the way in which a patient deals with and accepts the illness, related to belief in Allah, Judgment Day and patience. However, he thought medical professionals could not have a role in this, as he attributed it to patients' own *"Nafsiyan نفسيا*". He stated that ESRF patients would inevitably be despair and unable to cope without adequate "spirituality or الروحانيه". Correspondingly, he recounted that patients could reach tranquility by observing a lifestyle pleasing to Allah:

> "Nothing will feed the spirit except Allah and speech [the Qur'an] and Allah Himself, and these are the only things that are going to feed the spirit, as the spirit is from Allah, and you will find nothing else can feed it except something from Allah… Tranquility in *"Nafs النفس"* 'from Allah', but can be facilitated by reading the Qur'an, fasting, praying [specified "praying two *raqaa*" at night] and *dhikr* [especially in company]. If a patient does not remember Allah, Allah will not remember him". (Abo Ahmad)

The concept of such spiritual doses (i.e. religious/formalised spiritual actions) and their beneficial effects are an original and important contribution to the body of knowledge.

In addition to self-efficacy in dealing with and managing their ESRF condition and their general lives, many participants expressed that their spiritual responses to their illness had endowed them with inner strength and an empowering sense of "spirituality or الروحانيه" that encompassed their whole outlook on life and the world:

> "This power … in your heart that you are with Allah, you are with Allah the *Azeem*, the *Ruzzaq*, the *Raheem*. You know, this is the power the power I threw up all my weight to Allah And when I pray I will say that my *rizq* is with Allah, Allah is the One who created me; I tell my woe to Allah, not to you or this one or that one or other people, that's it. All my weight [*amer*] is with Allah". (Abo Sofyan)

> "Praying.. Certainly…Praying on time [….] the religion will give you the strength; the religion will not weaken you.… It's the *nur* and the lifeline, which lightens the *mogharah*.". (Abo Saber)

This section has reviewed important aspects of different ways in which "spirituality or الروحانيه" was uncovered through the different experiences of ESRF that have been discussed with reference to the patients' search for meaning and guidance through immediate conceptualisation of their illness in terms of religion. The ways in which ESRF patients dealt with their illness in spiritual terms were related to belief in Allah and Judgment Day; these beliefs manifested in different ways to address their spiritual needs, such as concepts of being patient, being tested and rewarded for having such an illness, surrender and conviction, being thankful, trusting in Allah, being comfortable, being stabilized and in control, enhancing inner strengths and sense of being tranquil and *mostakeen*. All of these roles of "spirituality or الروحانيه" can be attributed to addressing what patients referred to as their *"Nafs النفس"*. Thus, it appears that ESRF patients would be desperate and unable to cope without adequate "spirituality or الروحانيه". It has been demonstrated that they correlated their "spirituality or الروحانيه" with the use of *"Balaa' بلاء"* concepts. This correlation is associated with their Islamic beliefs and philosophy.

Participants' spiritual understanding came initially from a direct perception of the connection of Allah and from religion. In addition, the spiritual practices supported them in learning and anchoring themselves in a more abiding sense to Allah. Such spiritual practices (as explained in later sections) contradict those of other studies that reported a dark side of religious "spirituality or الروحانيه" in western culture (Ellison and Lee, 2010). In contrast, Participants in this study reported that sense of spiritual distress was associated with lack of caring from healthcare professionals as a result patients experienced sense of guilt, negative feelings, and false impressions of providing spiritual care from only ticking the box in the nursing assessment chart to identify their spiritual/ religious status. Thus, the rudimentary understanding of spiritual beliefs and behaviours obtained from conventional studies tells us nothing of the complex and myriad phenomena of "spirituality or الروحانيه" among Arab-Islamic populations such as the Jordanian ESRF participants in this study.

"Balaa' بلاء" and ESRF Patients' Capabilities Conflict

Having interpreted how ESRF was reflected in what "spirituality or الروحانيه" meant to participants, I will now move on to discuss how the conflict between the acceptance and the rejection of ESRF in respect of *"Balaa' بلاء"* concept, as there was emphasis on this conflict from the ESRF perspective. This conflict was

uncovered as an indication of "spirituality or الروحانيه" during ESRF. The participants highlighted the stresses and challenges they had in adapting between their initial perceptions of ESRF illness and the "Balaa' بلاء" concept which could either strengthen or weaken participants' "spirituality or الروحانيه". Religion was found to have a remarkable influence on their adaptation to the illness in all its stages. Also, it became an indication of the relationship between acceptance and rejection of the *"Balaa' بلاء"* of ESRF according to the patients' own capability and experience of "spirituality or الروحانيه". Evidence for the relationship between *"Balaa' بلاء"* and spiritual coping capability is exhibited by the majority of participants:

> "The most difficult thing in this illness is not only one thing, but it is the balance and everything you face. As a patient, you've got a needs and you've got a requirements and to certain extent you are not capable of achieving most of them, as you wouldn't have strength in your body or strength in your "spirituality or الروحانيه" or you wouldn't have anything to help you, and to be honest with you, I reached the point where personal knowledge is not enough, the mind is not enough, the balance in everything has got positive and negative effect." (Abo Hassan).

Such conflict between acceptance and rejection of ESRF may have huge implications on patients' acceptance of treatment, and one participant related it to medical (possibly psychosomatic) outcomes on health:

> "If someone is tired in his *"Nafs النفس"* you will not accept any treatment, even the dialysis will not benefit him 100 per cent as the dialysis/clearance will become obstructed with being nervous… And the body will release some other toxicity when you become nervous". (Abo Ahmad)

The negative impacts of *"Balaa' بلاء"* on ESRF patient's spiritual coping capabilities was described by participants. One feature of how "spirituality or الروحانيه" during ESRF related to the *"Balaa' بلاء"* concept was the sense of tightness and tiredness which eventually influenced participants' coping with ESRF in the initial period. However, this according to Otto is followed by elements that empower and strength

their spirituality. This can be categorised of the numen, symbolised by willingness, force and activity in which this provide a direction that send him/ her away from such tightness and tiredness- mysterium experience toward(Otto, 1958). Nearly half of the participants characterise this concept, which was cited by the majority of participants:

> "Yes, that was initially when I started dialysis… And I didn't know anything about it… And I felt tightness if they didn't give me enough attention". (Abo Ahmad)

Furthermore, ESRF patients reported that they underwent too many challenges and limited situations throughout the illness that increased their stresses. As a result, a quarter of participants developed the sense of becoming a weaker person, which they linked this with their low levels of "spirituality or الروحانيه":

> "I used to do everything at home, but now I will start to rely on my wife and my daughters, and other workers to come and do whatever I have been doing, so you will feel the pressure that you become a weaker person, or sometimes you will interpret other's behaviour as they reckon you are a weaker person". (Abo Obada)

Similarly, more than half of the participants narrated that they expressed a sense of being "spiritually روحانيا" destroyed after they developed ESRF:

> "I used to feel destroyed when I saw people in dialysis unit, I felt myself… That the people will say that my life is destroyed by this illness...". (Abo Khalil)

Abo Khalil reported that social stigma due to ESRF status was an important domain that led him to develop the sense of being weaker. This was echoed by Abo Saber, who repeatedly emphasised the role of social stigma, social ignorance of ESRF and dialysis, and the popular misconception that ESRF results from alcohol abuse:

> "Yes, alcoholic… And this is what our community will attribute it to, and the only reason for ESRF is alcohol, which thanks to Allah I haven't even tried". (Abo Saber)

Such spiritual implications on ESRF patients are discussed in the Relationships and Desperation sections. However, the deterioration in "spirituality or الروحانيه" levels participants faced, undermining their inner strength, was related to perceptions of weakness due to ESRF status. This was referred to by numerous participants in terms of feeling suffocated or constrained:

> "No one will help you, No one will support you [….] I felt severely suffocated… Very much, as I would describe it to you, if the oxygen discontinued, and that's it". (Abo Saber)

> "I felt tightness. I felt tightness inside me as if I was going to suffocate". (Maha)

Nevertheless, many participants stated that the sense of suffocation was overcome through spiritual support from the surrounding atmosphere such as family and friends, as can be seen in the following exemplar:

> "As long as the surrounding environment is an Islamic atmosphere and can deal with him in a religious context… we, as Muslim patients, especially in Jordan, will feel it and be refreshed if treated in this way… these things can provide a comfortable status for us… The patient will remain connected with Allah". (Abo Khalid)

On the other hand, a low spiritual level encompassed a sense of fear and sense of being restricted, likened by some participants to being in jail. One-fifth of the participants expressed this experience:

> "It's like a jail for me [….] This is my first attitude to it". (Abo Sara)

> "We are in a compulsory residence; you cannot go anywhere without arranging for dialysis". (Abo Ahmad)

Furthermore, more than half of the participants reported that as a result of having low "spirituality or الروحانيه" during ESRF they experienced a sense of losing control.

> "spiritually روحانيا, when it has a negative impact on the patient's own house, when the patient has got this feeling everyone in the community look at him in *shafaqa* look [….] even your son, you will doubt that he respects you not because I'm his father but because I'm

> a patient and he is *taatof* with me only[….] slowly you will feel that you started to lose control in your home, not because your kids made you lose control, but because yourself… in your hand… As if you saw your son doing a mistake, you used to direct him to do the right things, but you will think that he will not listen to you because you are a patient now". (Abo Eizz)

> "Sure, I mean the feeling of being limited or in jail in certain moments [….] you will feel things go out of control". (Abo Hassan)

Bearing in mind that the majority of participants are men, the preceding quotations highlight the different experiences of men and women due to social norms in Arab-Islamic society, whereby men are obliged to work and earn as breadwinners (for their spouses, children and dependents such as parents), while women do not have responsibility for providing for their families. The majority of male participants strongly expressed the importance of work and employment in promoting self-esteem and spiritual fulfilment, and in overcoming social stigma. The participants suggested that the key to overcoming depression and despair is getting out of the house and working, to overcome the social stigma and *shafaqa* look, as discussed in the Desperation section. The obligations entailed by the traditional role of men thus exerts a significant cultural influence that affects male ESRF patients' "spirituality or الروحانيه" and ability to cope.

A great concern of ESRF patients is the economic constraint imposed by the illness. Many patients reported that they had lost their jobs due to their status. Despite being willing and able to work, employers in most cases (with some notable exceptions) did not want to give employment for ESRF patients because they required regular dialysis. The constrained means and apprehension about future financial stability, along with the collapse of their accustomed role as family breadwinners for the male participants, were dealt with as spiritual issues.

Some participants were inspired to achieve in academic studies or in starting business ventures, as suggested previously, due to the improved self-efficacy they experienced from spiritual coping strategies, and others were grateful to understanding and flexible employers whose beneficence was interpreted as a manifestation of Allah's help. However, the majority of participants experienced

genuine fear about their financial future at some point and viewed it with trepidation, but were surprised that they ultimately found the means to survive and continue with their lives (along with their families), which they attributed to the function of Allah as *al-Ruzzaq* (the Provider), who guaranteed them their provision (*rizq*):

> "See how the "spirituality or الروحانيه" is manifest, *subhan Allah*. At the beginning, I was really very sad, and mentally I became very uncomfortable, in a way that you wouldn't imagine, why? As I've got small children. I've got a house, I had a job, I had my social life, I had all of these things, I carried their *hamm* in *rizq[*….]but after a short period, thanks to Allah, I realised that Allah is the All-Sustainer [….] *Rizq* is from Allah [….] I swear that I am unemployed and sat in my house; they knock on my front door and they will say 'please take this [money]' exactly as I said [….] Where is this money from, isn't it from Allah?! Have you not seen that Allah has subjugated these people?! Yes Allah, subjugated them for whom? Isn't it for me because I am poor?". (Abo Sofyan)

As a consequence of a lack of spiritual fulfilment, a sense of being disabled and losing self-dependence in fulfilling family obligations were reported by some participants:

> "spiritually روحانيا I felt that I'm going to stay at home without any job, and I will become unable to help my family, and fulfilling my role with my family, and as a result in my *"Nafs النفس"* I feel tightness, and there is the possibility that certain people will go away from me". (Abo Rami)

In addition, it is important to note that *Iman* was uncovered as a key way for "spirituality or الروحانيه" during ESRF. Perhaps the most significant question regarding the effect of "spirituality or الروحانيه" on coping with ESRF is the extent to which patients were able to improve their capabilities and to enhance how they dealt with their illness. Many participants themselves defined their level of *Iman* to be the level of "spirituality or الروحانيه". Following the acknowledgement and acceptance of ESRF as a *"Balaa' بلاء"* from Allah, as described above, and corresponding belief in and acceptance of *qadar* (one of the six pillars of *iman* in Islamic religion), it

naturally followed that patients regarded the ESRF as something from Allah's *Qadar*, which was fundamental to shaping how their "spirituality or الروحانيه" enabled self-development (i.e. preparing their *"Nafs النفس"*) to deal with the illness:

> "The pillars of *iman* and praying, fasting, *zakat*, pilgrimage, and to have *iman* in the *qadar* and its *"Khayr خير"* and its *sharr* and the illness is a kind of *qadr* of course it has prepared my *"Nafs النفس"* for such things, Allah is the *Rabb* who we worship, and there is no god except Allah". (Abo Malik)

> "spirituality or الروحانيه" to me is *qadr*". (Abo Shehab)

> "I have a very strong ideology in Allah, and as I mentioned to you that this illness is something from *qadr*, and it is written for me; I have to cope with it, and Allah has given me this *"Balaa' بلاء"* and I have to cope with it, and as a told you once I started dialysis, and even before I started dialysis". (Abo Shehab)

However, many participants highlighted the importance of feeding the *"Nafs النفس"* (i.e. developing and changing its pattern) to prevent its decline, which could result in the re-emergence of negative thoughts and *Nafs Ammarah النفس الاماره* (i.e. a relapse from developed spiritual status and coping to spiritual despair, hopelessness and even suicidal ideation associated with the initial phase in the typical course of progression outlined in patient narratives):

> "If you left the patient without any "spirituality or الروحانيه" , you are actually helping him to collapse quicker and stay on this chair without anything to do from the first years of his illness, or even from the first month he will not be able to walk and move at all". (Abo Khalid)

In the section that follows I will present how ESRF participants "spiritually روحانيا"challenged the stresses and what spiritual practices they did during their illness.

"Spirituality or الروحانيه" and Religious Practices

Although implicit throughout patients' discussions of their "spirituality or الروحانيه", the role of spiritual practices must be explained explicitly in terms of their role in patients' self-efficacy regarding their *"Nafs النفس"*, particularly as this study is the

first to target Muslim ESRF patients. In addition, the participants' experiences uncovered how spiritual practices can empower their individual coping style in different ways. The role of certain religious practices and symbols are experienced in different ways by participants. Many participants reported that reading the Qur'an was very beneficial in enhancing their "spirituality or الروحانيه" in terms of improving their tranquility in *"Nafs النفس"* during their limited situations, and as such it was revealed to be a great helper to them.

The first religious practice cited by many participants was that of reading the Qur'an and hadith, which are the fundamental texts of the Islamic religion:

> "Reading the Qur'an, prophetic supplications, I recited a large number of those…. I felt that these were a shelter and the rescuer (helper) … I had a feeling that making *"Du'a دعاء "* and reading the Qur'an improved my status better than the transplantation at that time". (Abo Ows)

Secondly, Du'a' which is a kind of supplication to Allah was cited by almost half of participants who stated that it was one of their important spiritual practices. This was revealed as another way to improve their "spirituality or الروحانيه" and to reduce their fears, and gave them inner comfort during treatment:

> "By reading the Qur'an, and from increasing my awareness by other people's advice and directions, and they advised me by religion – *"Du'a دعاء* "and religious talk, which gave me a comfortable feeling". (Maha)

> "I developed a phobia of the needle, I didn't need to look at it so I started *Tasbih* and *"Du'a دعاء"* [….]This feeling helped me and made me more comfortable". (Abo Ows)

Both Maha and Abo Ows explained how the Qur'an and *Dua'* can promote spiritual comfort and can enhance tranquility, helping overcoming the phobias associated with ESRF treatment.

Thirdly, few participants reported that *dhikr* was a key domain to empower their "spirituality or الروحانيه". *Dhikr* literally equates to "remembrance" (i.e. remembrance of Allah), and it is a condition of all acts of worship in Islam. It

denotes a greater degree of reflection while engaging in acts of worship rather than formulae and mechanical observance:

> "Without the patient getting up at night and praying two raqaa' or making *dhikr* to Allah when he is in the middle of the people, Allah will not remember him as well [….] the hearts find peace only in the remembrance of Allah". (Abo Ahmad)

Fourthly, a more specific form of *dhikr* is *Tasbih*, which literally means glorifying Allah (i.e. *subhan Allah*) by repeating formulae to that effect in all situations. It was expressed by many participants as a source of empowerment. This was demonstrated by Abo Ows when he greatly emphasised the benefits of this spiritual activity:

> "I thought the most appropriate thing to do was *Tasbih*, listening to religious radio for hadiths or *"Du'a دعاء"* I found those things really helped me, they really relieved… have relieved me very much [….] Well, for me and in my view this was my very important experience". (Abo Ows)

Abo Ows stated the sense of joyfulness in practicing *Tasbih*, which was found to be a platform to direct his thoughts away from morbid thinking.

Fifthly, another aspect of *dhikr* was *Istighfar* ("repentance"). As mentioned previously, part of the acceptance and gratitude for ESRF status was related to the concept of purification from sins. Consequently, *Istighfar* was cited by many patients as a useful religious activity to fill emptiness and spiritual gaps:

> "Here I'm talking about being Muslim, not about other religions; performing *dhikr*, performing *Tasbih* or performing *Istighfar*... Or performing *Salah*; as you know, we have many *dhikr* we can't even count [….] With all these things, the patient will occupy his time and fulfil the emptiness". (Abo Khalid)

Sixthly, prayers and fasting are two of the five pillars of Islam and were valued in dealing with ESRF "spiritually روحانيا. This was reported by many participants. It should be noted that prayer was associated by some participants with going to the

masjid and learning from religious scholars, which implies a socialisation role that could be useful in overcoming isolation during ESRF:

> "I consoled myself, and then I started to look to others whose condition is worse than my condition, and as you know, with praying and other things, like going to the masjid, starting to see people, and when you talk with him [a sheikh], he lifts your morale up, and gives you a talk on how to be patient, and how to go to paradise by your illness". (Abo Saad)

Seventhly, the *Sadaqah* which is the act of giving charity is fundamentally linked to spiritual, financial and bodily wellbeing in Islam. Seen as the purification of wealth and expiation for sins, ill people in particular are often moved to give charity in Islam. Various spiritual experiences for ESRF patients were manifested in *Sadaqah*, which fundamentally provided a source of spiritual tranquility. One participant highlighted the importance of such activity in enhancing his "spirituality or الروحانيه":

> " I believe if someone from his inside finds a patient who was being destroyed, and makes a donation for him without anyone knowing, this can be treating the patient by donation[….] The Prophet (peace be upon him) said 'treat your patient by making donations' and this made a big change [….] You have to be optimistic about Allah very much, and he will be kept happy and feeling well, sort of a winner, regardless of whether he dies or remains alive, he will be feeling tranquility and happiness". (Abo Ahmad)

Abo Ahmad indicated his belief that donating *Sadaqah* during his illness would be rewarded, either by improved health outcomes or spiritual rewards, and that it expiates *thunoobs* (sins).

Eighthly, some participants experienced "spirituality or الروحانيه" through religious journeys (i.e. pilgrimage) such Hajj and *umra*, which they found empowered their "spirituality or الروحانيه":

> "The *umra* is fantastic, there I used to feel as if I'm not no longer a patient, as I was always in *"Al- Haram الحرم"* doing *"Du'a دعاء"* and so on and praying then I go out, I used to feel that I was being pulled

> to a very strong power, I mean the Divine, to do the *umra*, and in fact I have done the *umra* twice during my illness [….] It improved me a lot, I started to like going out, it has change my ideas 90 per cent, it changed a lot of my own ideas, especially when I started my illness, and it has changed my idea even on dialysis, to come and go, and to go to hospital to seek treatment for the illness itself'. (Abo Saad)

Furthermore, Abo Eizz suggested that the hospital should organise more extra-therapeutic activities (e.g. social outings for patients and nurses, and educational events during dialysis) so patients have a more varied lifestyle and experience (less dialysis-centric) to share with their families. This ESRF patient had been instrumental in such attempts, but cited government bureaucracy as a major barrier to implementing such extra-therapeutic care.

It is also worth noting that the spiritual practices reported above were meaningfully attributed to ESRF patients' "spirituality or الروحانيه". Also, all of the spiritual practices outlined above were expressed by patients as strategies that enhanced their spiritual power / immunity to the challenges of ESRF. "Spirituality or الروحانيه" appeared to be strengthened after performing such practices, and the participants reported a feeling of receiving guidance and comfort to face their challenges. This is mentioned in the Qur'an: "No calamity befalls (one), But by the leave of Allah. And whoever believes in Allah, Allah guides his heart" (At-Tagabon, 11). This concept appeared to be important in promoting tranquility and calming patients' fears about the impacts of ESRF. Given the manifest benefits of increasing such spiritual power / immunity, activities must be considered that are perceived (or rather, identified) by patients as feeding the spirit, and activities that feed their *"Nafs النفس"*. In contrast to studies conducted in a Western context, which frequently cited the benefits of music in spiritual therapy most participants cited the benefits of listening to/reading the Qur'an:

> "Nothing will feed the spirit except Allah and speech [the Qur'an] and Allah himself … as the spirit is from Allah, and you will find nothing else who can feed it except something from Allah". (Abo Ahmad)

One unanticipated finding was that of the role of music in "spirituality or الروحانيه". Participants in my study appeared to indicate a dark side and a negative effect of music on ESRF patients' "spirituality or الروحانيه". The ESRF patients expressed that music was not a cause for calmness or tranquility but rather of distraction and depression, which they related to satanic *waswas.* Therefore, music was an undermining force in their "spirituality or الروحانيه". Hence, although some participants stated that listening to music helped them temporarily forget the illness, this was perceived by them to be a form of avoidance that prevented their authentic spiritual coping with the illness and it resulted in an absence of "tranquility"; additionally, intermittent feelings of sadness were engendered by music. In this respect, my findings do not support previous research conducted in a Western context (Atkins and Schubert, 2014; Cook and Silverman, 2013; Westermeyer, 2013), which frequently highlighted the benefits of music in spiritual therapy. A key difference in my study was that participants cited the benefits of listening to and/or reading the Qur'an as a source of comfort and tranquility (i.e. spiritual care). This difference might be attributed to the absence of Muslim participants in studies conducted in a Western context, and the cultural diversity of the use of music between Western culture and other Eastern religions (e.g. Hinduism). Music has a history of spiritual application in the European/Christian tradition (e.g. church music and hymns) which is relatively unique. While Jews occasionally use a shofar (horn), music is not a part of religious observance in the other Abrahamic religions. Islamic culture particularly abhors the use of wind and stringed instruments; albeit the muezzin's call is comparable to chanting (and drums have been used on occasion in some Islamic traditions), music as it is commonly understood is not perceived as a "spiritually روحانيا" helpful phenomenon in Arab-Islamic tradition.

Furthermore, Maha stated that listening to music helped her to temporarily forget the illness, but she did not consider this to comprise spiritual care due to the absence of "tranquility" and intermittent feelings of sadness engendered by music:

> "No, it won't make you feel tranquility. But it will make me laugh and be happy, but sometimes it can make you feel even more sad". (Maha)

It could be argued that music may be perceived to be a dark side of an individual's "spirituality or الروحانيه". Such findings may prompt healthcare providers and

policymakers to consider that music may not be a preferred aspect of spiritual care. In addition to the negative associations of music in the context of "spirituality or الروحانيه" in the Arab-Islamic context, music is a matter of taste, and it has numerous varied psychological impacts. Indeed, the same piece of music can be 'heard' differently by different listeners, having different behavioural and neural impacts (Virtala et al., 2014). Even in cases when music can be assumed to benefit patients (e.g. people with motor diseases), the "overflow of music into the motor system, can easily go too far, becoming irresistible and perhaps even coercive." (Sacks, 2006). These complex considerations indicate that any attempt to use 'music' in a therapeutic context is fraught with the possibility of failure, undermining its efficacy as a practical therapy in spiritual care. Therefore, further research should be done to investigate the implications of music in Muslim ESRF patients' "spirituality or الروحانيه". In the next section, I will present some of the findings of my research on the impact of "spirituality or الروحانيه" for Muslim ESRF patient and how it can be seen in the context of spiritual coping.

Spirituality and Coping

As mentioned at the outset, Islam/religion and "spirituality or الروحانيه" were inextricably linked in the minds, perceptions and experiences of participants, despite the conscious avoidance of conflating the terms on the part of the researcher. Although the existence of "spirituality or الروحانيه" and Islam as distinct concepts was linguistically implicit throughout, many participants particularly addressed this issue when asked if they considered any other meanings of "spirituality or الروحانيه" other than those addressed, and if they thought the terms of religion and "spirituality or الروحانيه" could be divided:

> "I wouldn't accept! I wouldn't accept it. But, I have accepted my illness because it's part of religion… And I can stamp with my ten fingers that Allah has written this for me, and it is *takfear thonob* and *sayeaat* and so on. On the other hand, as I started on the religious way, I have to finish it in a religious way. So I don't have to take bits of religion and bits of social, correct? At the beginning I accepted because I knew that this is what Allah wrote for me, and it will benefit me in the afterlife". (Abo Obada)

> "Spirituality or الروحانيه" is something to do with the religion itself, and hasn't got any other sides, as it's the relationship with Allah, and following what the Prophet told us, and his followers, and your relationship with Allah is the best thing, and this is the "spirituality or الروحانيه", that you are walking with Allah, and that's it. You will feel tranquility, and your heart will be in tranquility, and you will have peace of mind". (Abo Sofyan)

> "More than the religion dimension!! The most important thing I have got is the religion dimension, and all other dimensions are not important for me". (Abo Malik)

Almost all participants described the importance of the religious dimension in their "spirituality or الروحانيه". Based on the above discussions, religion appeared to be the bedrock of "spirituality or الروحانيه", and the prevailing paradigm in which the latter was understood. As it appeared that the spiritual practices differed among participants' experiences, so too coping mechanisms varied between them, but all were grounded in Islamic terminology, religious language and ideology. Their spiritual coping mechanisms included the following techniques.

First, dependence on Allah and being appreciative were uncovered as a way of spiritual coping. The sense of depending on Allah was reported by almost all participants. This sense was considered to have important implications on the fears associated with their illness. Rather than promoting fatalism, the concept of dependence on Allah empowered ESRF patients' "spirituality or الروحانيه" in facing their challenges during all illness stages:

> "I went to the blood examination with my friend I told him seriously that I feel my kidney has gone, as we were going to take the results, but he was doubting me by saying 'oh no, *"Ya Zalameh* يا زلمه*"*, depend on Allah'. When I told him that I am already depending on Allah, and accepting whatever comes from Allah, and it was my expectation I would have ESRF, and not be bothered by it". (Abo Ahmad)

Part of dependence on Allah was the concept that one still enjoyed many great advantages in life as an ESRF patient compared to others who were less fortunate (e.g. cancer patients):

> "But when you compare it with other people who had cancer for example, you will find cancer even worse than ESRF, and the one who lost his vision will be even worse and worse … Then he really has true conviction that he is in mercy". (Abo Obada)

> "When I witness a patient being carried by two or three people, I look to myself and I will say thanks to Allah, that I am still in *"Khayr خير"* … I look to myself, I haven't got anything apart from ESRF, and thanks to Allah that I am much better than others and there are others much better than me. This will help you to have tranquility and it will give you advancement you need ahead of your illness, and thanks to Allah this is exactly what happened". (Abo Ali)

The preceding quotes give the reader an idea of the various styles of spiritual coping mechanisms used in the dimension of dependence on Allah by the ESRF patients interviewed. Such styles adhered to the adaptive model of coping mentioned earlier. This appeared very effective and advantageous to spiritual coping. In the last quote, Abo Ali highlighted one of the most remarkable and moving things I experienced in the interviews, this constant series of "*Khayr خير"*. Many patients expressed the concept of feeling grateful to Allah that others were in worse conditions than them, reflecting on the hadith about looking at those with less in *dunya* and more in *akhirah*, but Abo Ali was the only one to state that he was genuinely really happy that some others have a better situation than himself: as a researcher, this struck me profoundly. His happiness was evident to the researcher and to others, and he reported that doctors and students kept informing him that he did not look like "a patient".

Second, fundamentally, "spirituality or الروحانيه" during ESRF was a means of overcoming despair and promoting hope. However, hope itself was cited as a distinct theme by almost all participants as a method of spiritual coping. Hope was considered by the participants to be essential to motivate them and to provide meaning and purpose through their illness. They also stated that it can enhance their

"spirituality or الروحانيه" and their emotional feelings toward their illness. It was noted that the sense of hope was embedded in religious concepts, implying to the rejection of hope from medical science among some participants:

> "Yes, that was from my inner-self telling me that with the will of Allah I'm going to recover, and I hope with time I'm going to recover". (Maha)

However, other patients felt that hope should be linked to the hope for a biomedical cure, specifically transplant, which could promote tranquility even if it is a false hope:

> "You will give him a hope… you will become comfortable mentally, and have tranquility [….] you can give him the hope and the tranquility on the treatment by giving him a hope for transplant". (Abo Khalid)

Another source of hope was the normalisation of dialysis and ESRF status together with the concept that patients could still lead fulfilling lives. However, the most fundamental aspect connected with hope was a resigned attitude toward the prospect of cure. As shown below, some patients felt that people ask too much from life (e.g. a longer lifespan), and most referred to the root concept of Abrahamic religions, namely that the purpose of the transient worldly life is to worship God in preparation for the eternal Hereafter:

> "So I accepted this even though I reached the age that I would be this July, 75 years old; Prophet Muhammad lived only 63 years, so these things when you remember them, they make things easier for you. Our Prophet lived only 63 years you see. We are demanding too much". (Abo Sara)

> "You can remind this person of life after death, you are giving him hope… And to come out from the pressure/tightness that he is in…. There is something bigger… there is heaven, there is hell… there is discipline… there are rewards…". (Abo Khalid)

It can be concluded that although hope has individual meanings to each participant, it generally functions to overcome negative thoughts and a sense of failing or being destroyed, thus empowering them to carry on in their lives.

Third, having accepted and conceptualised their ESRF status in terms of religious terminology and concepts, patients expressed a sense of being loved by Allah and preferred in being selected to have the illness. This was reported by almost half of the participants, and is aptly summarised in Abo Sofyan's narrative. Such senses of being loved by Allah provided the participants with meaning and purpose in their illness and gave them a balanced and positive self-perception. Participants were overwhelmed and showed a remarkable sense of comfort. This spiritual concept empowered them and their coping styles in accepting his illness.

Fourth, many participants considered work to be a form of worship; hence it is included under religion in this study. Work empowered the "spirituality or الروحانيه" of patients to face the challenges of illness and overcome all negative feelings and emotions associated with social stigma and the loss of their socially constructed role as breadwinners. Work also appeared to give participants a sense of spiritual meaning and purpose in their lives:

> "spiritually روحانيا I have to go out from the house, then I will try in any way to keep myself busy, either I will go to the market, walk to the market [….] thanks to Allah that I have got a cousin … he has helped me a lot [….] This has helped me mentally and "spiritually روحانيا, as I felt [….] people still care about me, there are people still consulting you [….] Even searching for goods in marketplaces you will see different things and different events, it will be a change of atmosphere to you [….] You wouldn't have an emptiness any more, you will start to think strange thoughts, thanks to Allah that I went out from this emptiness, and I feel much better in my "spirituality or الروحانيه" and my mentality". (Abo Eizz)

> "The patient has to try… has to try to find a job... Has to work… Has to change his life with his own hands and not wait…". (Abo Saber)

There is an apparent discrepancy between the two preceding quotes and the account of Abo Sofyan concerning the predestined source of *rizq* mentioned earlier. Although almost all participants stated that *rizq* is something written by Allah, most stated their worries about not working. Additionally, some participants recounted remarkable efforts to find work because of the Islamic belief that it is sinful to sit and wait for *rizq* without making any effort: this is a common concept in Arab-Islamic culture related to the effort of Mariam (the Virgin Mary), who was inspired by God to make the effort to get dates from a tree in the desert (Qur'an, Mariam, 19: 24-25). In the Islamic metaphysical belief in *al-qadar*, this is an example of how one is obliged to make effort (e.g. to find work or to seek medical treatment) while trusting in Allah.

Finally, it was evident that more than half the participants experienced a sense of relief and comfort from the interview itself as a form of spiritual dialogue. The interview process thus can be seen as fulfilling the multi-therapeutic role of phenomenological study for the interviewees, as it gave participants spiritual comfort. They expressed this in terms of the following dimensions.

Providing spiritual comfort:

> "I will give you 9 out of 10 from such talk because I felt comfortable when I find someone to talk with. We feel that the future period is going to be much better than the previous period we had, as it will be comfortable in all aspects in everything". (Abo Omer)

Being helpful:

> "Yeah, I do appreciate this and I'm really happy that you coming and opening this subject with me, because I feel there are some people who care [….] which is a great feeling". (Abo Sara)

Providing spiritual push/ motivation:

> "I'm very delighted that I made this interview to be honest with you I swear to Allah that I am very happy as it gives me a boost". (Abo Ali)

Providing missing care:

> "I'm delighted with the discussion that happened between us, which has really benefitted me, really benefitted me, and I'm delighted about it. Honestly I loved your idea [….] The other important thing is patient "spirituality or الروحانيه", as it will help patients to cope with his illness much quicker (and the other thing is the law)". (Abo Sayef)

Opening the mind:

> "Seriously Thanks to Allah [….] I feel myself stronger during dialysis … it has opened my mind in many things". (Abo Saad)

Promoting optimism:

> "I become more optimistic... You become relaxed physically and mentally, your *"Nafs النفس"* has been changed by such spiritual dialogue [….] to get out of this *mogharah*, which injures patients who fall in it, and I'm telling you that every patient falls in it". (Abo Saber)

Counteracting fear:

> "Before this discussion I was feeling normal. I like to talk about my life; I don't like to talk to everyone about it. I am not scared anymore and I haven't got any fears, and I am not irritable anymore, now I have got enough bravery. From having hope and being optimism in life, you will overcome the illness in all its aspects". (Abo Saber).

Sense of relieved heart:

> "I will feel comfortable in my *"Nafs النفس"*, as we are both going to benefit from it, you as a researcher will gain benefit from it, and I as a patient will feel comfortable and you will feel something budge from your chest". (Abo Shaba)

The spiritual engagements highlighted in above quotes show that spiritual dialogue has a major impact in empowering patients' "spirituality or الروحانيه". Participants reported multiple feelings such as a sense of spiritual comfort, a sense of helpfulness, spiritual push, addressing a gap missing from formal care, opened their mind to new elements of care, become optimistic, encountering their fears and relieving their hearts.

In summary, this general structure (religion) is greatly correlated (synonymous) with "spirituality or الروحانيه", as uncovered from participants' responses. The narratives of "spirituality or الروحانيه" from ESRF patients revealed the multiple roles of religion that directly relate to "spirituality or الروحانيه" and beliefs. The implications of such exposure to the multiple uses of "spirituality or الروحانيه" during ESRF were viewed by almost all participants as methods of finding meaning and purpose in illness through religion. Participants' experiences illustrated how the *"Balaa' بلاء"* concept, the *"Nafs النفس"* concept, *"Balaa' بلاء"* and capabilities relationships, *Iman*, "spirituality or الروحانيه" and spiritual practices and Islam all play important roles in the ways in which patients deal with their ESRF status. The findings make essential contributions to the existing body of knowledge about "spirituality or الروحانيه" for ESRF patients, and more precisely for Muslim patients. Due to the importance of beliefs during ESRF, participants raised numerous important issues concerning their experiences which related either directly or indirectly to enhanced "spirituality or الروحانيه". These important associations will be presented in the following general structures of 'Relationships' and 'Desperation'.

Relationships

The previous theme, religion, addressed how religion played an important role during ESRF in finding meaning and purpose through illness. It also showed how religion empowers participants' "spirituality or الروحانيه" and how it can enhance their inner strengths and inner peace, consequently influencing their choices and experiences during ESRF. Such experiences were also reflected in their relationships, which were correlated with their "spirituality or الروحانيه". This theme gives more insight into the study participants' experiences of relationships and how they were related to their "spirituality or الروحانيه".

In this section, the construct of relationships is divided into four main situated structures. The first situated structure focuses on ESRF participants' perceptions of how their families had an impact on their "spirituality or الروحانيه"; the second presents and discusses how the phenomenon of "spirituality or الروحانيه" was manifest through community relationships; the third focuses on how "spirituality or الروحانيه" can be manifest in relationships with other ESRF patients; and the fourth addresses how "spirituality or الروحانيه" was manifest in relations with medical staff.

Family

The family is the primary environment in which the ESRF patient lives, and it is required that this environment is prepared mentally, morally and *"Nafsiyan نفسيا"* as part of holistic care so that ESRF patients have help and support in coping with their illness. The family attitude and behaviour was found to profoundly affect the experience of illness among patients in numerous ways, either positively or negatively. It was found that family reassurance and spiritual observations relating to the purification function of illness was found to be very helpful among patients. This increased their "spirituality or الروحانيه" levels and promoted the "Tranquil Nafs النفس المطمئنه", enabling patients to accept and deal with their illness. In particular, conceiving of the illness in spiritual terms overcame perceptions that the illness was an obstacle, fundamentally preventing patients from living normal lives. This enabled them to be more active and positive and consequently improved their morale (which in addition to being desirable in itself has been found to encourage compliance with medication regimens etc.). When patients conceptualised the illness as a divinely decreed purification and something to be borne patiently, they frequently expressed that they came to view it as a reward. Thus, the family environment has a huge impact on morale and numerous care outcomes stemming from the dimension of patient "spirituality or الروحانيه". The importance of spiritual propagation and the need for appropriate strategies tailored to patient interests was reported by almost all ESRF participants, as it could enhance their "spirituality or الروحانيه" by giving them sense of comfort and opening/ widening their chest as summarised by Abo Khalid:

> "As long as the surrounding environment is an Islamic atmosphere and can deal with him in a religious context [….] anyone surrounding this patient, including nursing staff, doctors or even at home [….] might be able to give him religious motivations to be with Allah [….] for example, arranging for an *Umrah* trip, and so on, to improve his belief and "spirituality or الروحانيه" among people". (Abo Khalid)

Such interaction between the ESRF patients and their environment, as demonstrated in the above quote by Abo Khalid, presented four important elements that can help the participants to cope with the ESRF in a very resilient way: family, community, other ESRF patients and healthcare professionals. The role of the family attention

and interest in patients' condition was highly important - virtually all ESRF participants expressed a very significant positive effect of family interest on their *"Nafs النفس"*. It also showed that the importance of spiritual reinforcement from family (e.g. advice and Islamic expressions), as well as care and concern by visiting was a dynamic of tranquility and conferred a positive influence on the ESRF experience, as reported by the following participants:

> "These are the important factors, family and the community around him, that they have to reassure him that whatever happened it's not a problem, at the end of the day you will find that the patient will improve, and whatever Allah has written for you will happen. These are the things that will give him tranquility". (Abo Sayef)

However, there was a tendency among families to cuddle and suppress the autonomy of patients by over-concern, despite their generally positive role in enhancing patients' "spirituality or الروحانيه" and self-confidence. Overall, a pattern occurred whereby intense interest from family and friends during the initial shock of diagnosis and dialysis treatment was followed by normalisation, which was usually, welcomed but which in a minority of cases caused increased feelings of isolation. Abo Eizz suggested that patients should regard the intense concern of family and friends during the initial period of ESRF as equivalent to taking paracetamol, which he suggested was a healthy approach for ESRF patients to conceptualise decreasing attention. He also suggested that family and even hospital visitors should treat the ESRF patient as "a person", not as "a person on dialysis", to avoid focusing on the illness:

> "At the beginning… in the initial period of the illness, in the first moment, the people around you would be shocked to hear that you started having dialysis, so everyone likes to pay attention to you, especially when you have many people who don't know what dialysis is [….] When the dialysis become routine, it will become like anyone taking paracetamol tablets [….] so the family should deal with you as a normal person. For example, at home, they deal with me as *a normal person*, not like *a person having dialysis*". (Abo Eizz)

Abo Eizz emphasised an important point that emerged concerning his family

rebuilding his confidence, as well as treating him as a normal person without undervaluing him as a result of his illness. This concept was repeated by many participants:

> "the family has got a big, big role in supporting the patient's "spirituality or الروحانيه" in making his *"Nafs النفس"* comfortable, and this will help with his illness, but if they undervalued him as a result of his illness, so that patient will feel [….] conquered by his family and by his illness, and in this case he is not only speeding his death". (Abo Rajab)

> "They are all standing next to the patient, and everyone was supporting me in anything I want, they even offered their kidneys for me, and whatever I asked them to do they are willing to do it, so in this perspective I felt comfortable, that thanks to Allah there are people standing with me". (Abo Malik)

Abo Rajab and Abo Malik in the above quotes demonstrated that the sense of being supported by family members is important in giving patients a sense of comfort in their *"Nafs النفس"* and *"Nafsiyan نفسيا"* This was also addressed by Abo Sofyan when he illustrated the importance of being attached to family members as this attachment could rectify any issue that he faced and prevent him from feeling loneliness. As mentioned in previous chapter, the family has a social obligation to look after their ill member. In a situation such as ESRF, it seems that family centeredness and collectively is central to Jordanian culture:

> "From a "spirituality or الروحانيه" point of view and from a social point of view [….] they've got major roles in assisting me, supporting me with my illness, and if you've got a really good brothers and good family, they will support you; financially they will support you, morally they will support you, and if you become tired, they will lift you up and they transfer you from here to there[….] "spiritually روحانيا" it's exactly the same, you will have to accept Allah's decision [….] The life is not very nice when you live alone. I really feel comfortable with them as they stand with me; as you know this illness

> has many falls, today I feel fine but after two hours I am not sure what will happen!! Allah knows". (Abo Sofyan)

Family also appeared to have crucial role in lifting ESRF participants' morale as stated by many participants:

> "To be honest with you the family role was in advices, [….] and they advised me to take my medication and not mix up the medication. "Spiritually روحانيا"they were supporting my morale, and helping me if I needed anything to help me. Just in case I needed some money; they would give it to me. In addition, if I needed to be in hospital, they would help and go with me so there is support from my family". (Abo Rami)

As noted above, Abo Rami highlighted the important role of the family in improving adherence to the treatment regimen. Despite the above participants' positive views, some participants believe that the family and community can have a negative role, in terms of social stigma, which can lead to deterioration in an ESRF patient's "spirituality or الروحانيه" and mentality, as stated below. The concept of "power" or energy derived from surroundings (i.e. friends and family) and influencing health outcomes was a recurrent theme among participants:

> "The thing is that the people around you, who love you, will become very disappointed even more than yourself, and all of these problems will create a negative power, as everyone has got a negative power and positive power, and this already exists in science; they will send power… And negative power to the patient that every time he would see his brother, or his mother or any member of his family, seeing they are disappointed more than him, even if he is already disappointed a little bit, he will become worse than them and disappointed even more with himself". (Abo Sayef)

Nevertheless, a few ESRF patients were very appreciative of their spouses, who as well as providing practical assistance (e.g. with food and bathing) were a source of spiritual comfort:

> "The person who helped me in my illness is my wife [patient weeping]. She tolerated she stood by me perfectly. She has relieved me a lot when I was in ICU I mean after Allah. I have a huge appreciation and thanks for her standing". (Abo Ows)

> "In every week… I will go to visit her…. In every week I will go with my kids to visit her [….] when I go to visit her graveyard, and read *Al-Fatiha* to her, I will go home happy". (Abo Saber)

The most common and important aspect patients discussed with regard to the role of their families in their spiritual care was the concept of being (or feeling) supported, which was expressed by almost half of the participants:

> "As my family used to ask here and there, as all my family were tested [….] I felt my mentality being lifted up, as I started to love to see people and to love going out, I started to eat more and my weight gained a bit, when it reached 55 to 57kg". (Abo Saad)

> "As I told you, the family have a big role to play… Which was supportive of everything that may happen with you as something from Allah, and to make *"Du'a دعاء" to* Allah to make you recover, otherwise you haven't got any other option". (Abo Rajab).

However, despite the optimum role participants ascribed to their families in providing care, a delicate balance was involved between practical and useful spiritual assistance and emotional support and coddling and over-protection, which patients found stifling and negative:

> "The least that is required from them "spiritually روحانيا"is to consider this illness like other illnesses, they shouldn't exaggerate it [….] following his every move, and stop asking the patient 'do you need anything?… Can I do anything for you?… I will help you with your clothes' [….] to prevent the patient feeling tightness, or becoming very weak". (Abo Obada)

Furthermore, another role of the family in "spirituality or الروحانيه" was their important role in the rehabilitation of patients, which involved monitoring their psychological symptoms. As mentioned previously, many patients expressed having

experienced suicidal ideation during the early period of diagnosis due to life changes. The following quotes show how patients felt that families have an important role in monitoring the psychological wellbeing of patients undergoing such difficulties. They also illustrate that the family can play an important role in helping patients to reintegrate themselves into society and in becoming more independent and useful contributors to their families and others. All of this can be attributed to the concept of "power" or energy emanating from surrounding relationships:

> "If his family noticed or the community… We go back to the society… And the family is the most important thing, if his family started to notice that this patient started to withdraw himself or become isolated from his friends, he must seek psychological treatment, he must seek a specialist… to rehabilitate him and return him to re-enter his own life, it has an impact on the patient during his treatment". (Abo Sayef)

A more direct form of family support reported by many patients was assistance in monitoring their treatment, although others preferred to undergo dialysis independently. One participant stated that his wife accompanied him to dialysis for five years to monitor him, as he frequently lost consciousness due to blood pressure changes. He related that his family constantly checked his whereabouts to prevent any mishap, and he felt tranquility when his wife was nearby. Abo Shehab was singular in wishing to have close assistance from his wife/family while undergoing dialysis (largely due to his relatively complex medical history), but even he resented over-protection from family members and restrictive behaviours towards him, rooted in the way in which Jordanian families view their elderly members as people requiring extra protection. However, both participants reported that this cultural factor has negative implications on their "spirituality or الروحانيه", despite being intended to have the opposite effect:

> "As a patient and for example if I need to do anything at home, in the street, or anywhere - they will view me as a patient". (Abo Shehab)

Similarly, others complained of being "forced" to eat food (due to traditions of hospitality), complicated by trying to conceal their "patient" status. This has very

serious implications in terms of preventing compliance with treatment regimens and exacerbating other problems associated with dialysis due to inappropriate diet. Indeed, this was reported by one participant as a lack of knowledge from both family and patients about ESRF:

> "I knew nothing about it [ESRF] - what does it mean? [….] No one was conscious about what I would do or what I should avoid [….] when you go visiting other people and they forced to you to eat something. And to be honest with you I pretend that I'm not a patient, and everything [blood parameters] is sky-high". (Abo Yasser)

The above quote from Abo Yasser highlights the challenges that ESRF patients face when engaging with their families, which either directly or indirectly affects their "spirituality or الروحانيه". Another challenge that faced ESRF participants' "spirituality or الروحانيه" was addressed by Abo Obada when he narrated the conflict he experienced between compromising his needs as an ESRF patient and his family's commitments:

> "You will face two options, either you prohibit the food in your home or prohibit the medications! And the latter option will be more likely, as the commitments for your home will be stronger than your own. It reached the point where you have to sacrifice". (Abo Obada)

Moreover, patients collectively expressed that family and even hospital visitors should treat the patient as a person, not as a person on dialysis, and avoid focusing on the illness. They were particularly resentful of expressions and mannerisms expressing pity and condescension (*shafaqa*), which were intended to be "spiritually روحانيا" supportive but which in fact negatively affected patients' "spirituality or الروحانيه". Such effects were reported by many participants:

> "… The family and the people surrounding the patient must deal with the patient as a normal person, this will return the confidence back to the patient…the *taatof* look and *shafaqa* look, "spiritually روحانيا" you will feel shame, you will feel shame about this look". (Abo Eiz)

Despite being well-intentioned, and indeed seen as socially appropriate responses to encountering someone with serious illness, such *shafaqa* behaviours adversely

affected patients' "spirituality or الروحانيه". This could weaken them or socially isolate them and prevent them from interacting with others, as summarised in the following quotation:

> "The overwhelming support will make the patient feel his weakness, and he became an inactive member of his family; the patient will start to interpret in terms of *shafaqa*, and this hurts the patient, but after some time, his perception will be changed [interruption by staff] … and the attitudes of his family toward him will change, as they will view it from the point of view of loving him, but at the same time it will have adverse effects on the patient, and when they decrease their support, his acceptance to his illness will increase. Certainly, they've got an important role, as if they didn't understand it… They will hurt the patient very much". (Abo Obada)

Such strange views have implications for ESRF patients' "spirituality or الروحانيه", as discussed further in the section regarding social stigma and isolation. Exploring the meanings of "spirituality or الروحانيه" attached to the family by participants gave more insight into their perceptions about the phenomenon and how it is interpreted. Many participants indicated that at the time of diagnosis, both patients and their families were totally ignorant about ESRF and dialysis, which seemed to be associated with their spiritual status:

> "When the day came that I had to start dialysis, it was a miserable day for me, because most of the doctors outside the field of kidneys are ignorant about dialysis, they never talk about it [….], all this fear from the lack of general knowledge about dialysis, no one bothered to give a lecture for example, or to reach doctors, only the people who work in this field, who know exactly about it you see… And this is the problem, even the community they look at you as… As you finished your study…. Or finished your work in this life… *khalaas*. As I have retired from doing anything, and people look at you as helpless". (Abo Sara)

> "In my early career, I used not to bother about kidney problems. I spent my life on surgery and this is why I am interesting in surgery

> only [….] It's [“spiritually روحانيا] very important that ESRF patients understand what's going around him”. (Abo Hassn)

The above quotes indicate that the lack of knowledge about ESRF for both patients and their families was associated with feelings of low “spirituality or الروحانيه” in the initial period of the illness. Participants who were unable to fill this knowledge gap (either for themselves or their families) were more prone to a state of “despair” in their spiritual status, as explained in more detail with regard to the theme of ‘Desperation’.

In contrast, the most fundamental role of families in spiritual care for ESRF patients, which underpinned the particular issues they raised, was the concept of being loved. Almost all participants expressed the importance of this sense on their “spirituality or الروحانيه”:

> “In case he loves that, and his family loves that, it will surely make a difference, as when someone sees the one who loves him come and shake hands with him he will be feeling happy, so you will find his body will release plus, plus, plus [+++] charges inside him”. (Abo Ahmed)

The perception of being loved by family and others appeared to have a positive impact on participants’ “spirituality or الروحانيه”, and it appeared to change their negative feelings and emotions to positive ones, and indeed to empower their “spirituality or الروحانيه” by replacing their negative interpretations with positive ones about the changes that happened around them as a result of ESRF. This can be achieved when family and others give patients opportunities to sense that they are loved. The most basic expression of this is visiting, as discussed later.

It was clear that the fundamental stressor experienced by male ESRF patients – concern about how they would provide for their families and their family role – was intertwined with masculinity, and the perceived change to their masculinity due to ESRF resulted in spiritual impacts with regard to their families and communities. In this section, it has been explained how families could either enhance or diminish ESRF patients’ “spirituality or الروحانيه”. The section follows moves on to consider the role of community and its implications upon ESRF patients’ “spirituality or الروحانيه”.

Community

The extended family structure of Arab-Islamic societies naturally extends into the community domain, with associated spiritual impacts for ESRF patients with regard to community relationships. As discussed previously regarding *"Balaa' بلاء"* and relationships with family, ESRF patients recounted undergoing different patterns of negativity, which manifested in feelings of being suffocated, tiredness and tightness, weakness, feeling destroyed, frustrated, restricted, being in "imprisoned" and being disabled. In addressing these negative perceptions, almost half the participants expressed that the community can play an important role in lifting patients "spirituality or الروحانيه" both by helping them and their families:

> "The spiritual stand of the community has helped me a lot, as I would like to mention that I came from a family with seven members, and over fifty people very close to me, and more than a thousand personally ask about you, and they come to visit you, and when they visit me, they laugh with you and they try to make you to stand again on your feet". (Abo Hassan)

> "If the community views this person, [as] a man or a woman, not as someone whose condition is being destroyed [….] Conversely, they should lift his morale up [….] the community can help at least in fifty percent of patient "spirituality or الروحانيه" , and the doctor 25%, and the remaining twenty five percent would rely on the patient himself". (Abo Khalil)

> "As our community has to be with her [his wife] as well, and to support us as well, and if they don't need us to be at work, they have to create something for us, to support us[....] I witnessed the Islam in non-Muslim cities, as these cities will look after the person from being born to his death, but in our Islamic countries we haven't got such things, they haven't got the practicality of it, as our religion urges us to look after the person from being born until death, but what we have to do, as we are responsible for everything as you can see, electric bills are accumulated, water bills are accumulated, taxes every day, petrol increasing [….] They have to give mercy to those

> who are on the floor first, before asking Allah to give them mercy". (Abo Omer)

In the above quote Abo Omer mentioned some form of state provision for patients and their families (e.g. equivalent to carer's allowance in the UK), however he also articulated that the community should open avenues of career opportunities for ESRF patients and give them a chance to work in some form of employment. This relates back to one of the most commonly reported spiritual dimensions that ESRF patients' experience – the fear about *rizq* and being unable to work due to social attitudes and stigmas surrounding patient status:

> "This [employment] is something that patients cannot have, the ESRF patients who have dialysis [….] without help and support from the community [….] They have to find us a solution, either to find us a job, and we accept to do any job, and that's it. And we are not asking for any benefits". (Abo Omer)

A more general emotional problem was the lack of awareness among the community about ESRF and dialysis, which led to feelings of isolation and being destroyed:

> "Anyone in the community, as a person, when he knows that someone is on dialysis, he shouldn't destroy his morale, he should lift it up, not destroy it". (Abo Khalid)

Furthermore, others emphasised the important role the community could play by allowing patients to actively engage in it, which empowered their "spirituality or الروحانيه" to cope with ESRF, although one patient specifically described the negative role of the community in depriving patients of employment opportunities: Abo Saber stated that the world around him completely changed as a result of ESRF illness. Numerous ESRF patients stated that they were unemployed because of their illness, despite their willingness and self-perception of ability to work in most cases, as highlighted in the following section

> "As when I went to search for work in any hospital that I went in… they would refuse to give me any job opportunities". (Abo Omer)

Abo Omer added that he was actively searching for work but employers refused him due to his illness, despite the recommendations of colleagues. As a result of losing

employability, patients' "spirituality or الروحانيه" was badly affected by being unable to work or study, which directly undermined their "spirituality or الروحانيه" and self-esteem, prompting them to withdraw from the community and to feel a sense of emptiness:

> "In regard to self-esteem, and most important thing is that ESRF patients shouldn't be isolated and withdrawn or lonely". (Abo Sayef)

Similarly, it also appeared that being unemployed had a deep impact on ESRF patients' self-esteem and their "spirituality or الروحانيه" generally due to becoming isolated and withdrawn from society, to the extent that one participant mentioned the development of agoraphobia:

> "spiritually روحانيا I felt that I'm going to stay at home without any job, and I will become unable to help my family, and fulfil [….] my role with my family, and as a result in my *"Nafs النفس"* I feel tightness, and there is the possibility that certain people will go away from me". (Abo Rami)

Even the self-employed Abo Saad reported such despondency due to being restricted in fulfilling his professional role, which was instrumental in his "spirituality or الروحانيه" deteriorating and in his experience of feeling destroyed:

> "I became tired again, when I went to the doctor at the Jordan Hospital, where he told me that the transplanted kidney started to deteriorate, he changed the tablets. But it didn't work, I started to be absent from the shop, I really reached a point where I had to sell out, where I started as I used to be, I had a commitment to stay at home, I didn't like to see anybody, and I become very nervous with my family, and became the same where I used to be; I lost my appetite, and then my mentality was destroyed completely". (Abo Saad)

Correspondingly, the minority of patients who were in some form of employment reported that it aided their "spirituality or الروحانيه": such perceptions seem to have originated from Islamic and Arabic culture, particularly when the community often use professional status as a criterion for respect. As noted earlier in the first theme, the importance of work, many participants strongly expressed the importance of

work and employment in promoting self-esteem and spiritual fulfilment and in overcoming social stigma. This was suggested as the key to overcoming depression and despair and in getting out of the house and walking. Many participants highlighted different experiences relating to the social gender construction in Arab-Islamic society, whereby men are expected to earn due to their obligation to support their families:

> "The patient has to try… has to try to find a job... has to work". (Abo Saber)

As stated in the previous theme, hope was very important in spiritual coping with ESRF. Abo Saber later in his interview narrated that work was viewed as a source of hope that could empower ESRF patients' "spirituality or الروحانيه" and also as a topic to initiate spiritual dialogue with ESRF patients. He stated that he supported a new ESRF patient by telling him:

> "I told him go back to your job, return to your own work, keep the hope with you, you are still young, forget anything else". (Abo Saber)

Some patients included the barriers to employment among the general lack of community support in numerous life aspects:

> "Of course… As they will return my trust and self-confidence to my *"Nafs النفس"*, and when you become self-confident in your *"Nafs النفس"*, in any operation you do, or in any work, he will feel that he will become productive for his community and he will not be burden on his community. When the person becomes a burden on his community it will be very difficult, or he will become *yashahad* on the street, and this is something wrong, as they can give us office work, for example". (Abo Omer)

The sense of being a burden on the community due to being prevented from working was a very important phenomenon universally reported by patients (particularly relating to the initial stage of diagnosis), and it has huge implications for the mental state of ESRF patients, as discussed later in this chapter. With regard to the psychological effect of ESRF due to being unemployed, participants expressed very deep emotions relating to despair, psychotic conditions and religious dilemmas.

Patients were very concerned about financial burdens, which were prominent among their spiritual responses to ESRF. In addition to being unable to work (a major impact for those who had hitherto been breadwinners for their families), the cost of treatment and transport were significant problems for many patients. Most patients related their financial struggles to the concept of *rizq* and divinely predestined provision, after a period of initial anxiety about how their families (rather than themselves) would cope "spiritually روحانيا". Such perceptions seem to emanate from Islamic culture, as the ESRF patients used term of *rizq* to connect their financial status with their belief in what Allah has written for them. It also appeared that almost all participants viewed work as a worship that links them to Allah. Thus, the appearance or absence of this connection appeared to have implications on patients' "spirituality or الروحانيه". The attribution of provision to Allah was conceptualised as the meaning of *rizq*. Although this is a mainstream aspect of thought in Islam and in the other Abrahamic religions, participants expressed a realisation and deep conviction in this concept that had previously been an ethical consideration:

> "My brother in Jerusalem has got ESRF as well, honestly there is a huge gap between here and there [….] When the ESRF patient feels he has his humanity, it will help him to accept the illness". (Abo Obada)

The quote from Abo Obada, after he compared his ESRF condition with that of his brother in Jerusalem, raised very important questions related to the perception of acceptance of ESRF and the perception of spiritual coping, which requires special consideration from the healthcare providers in Jordan. ESRF patients in this study questioned how they could adapt to living with ESRF whilst fulfilling their obligations when the community turned its back on them. As a result of this burden, their spiritual wellbeing was affected.

As stated earlier, the majority of the study sample was men, who are expected to support their families (spouses, children, parents and extended family). Many participants compared their financial status before and after ESRF and how they used to fully fulfil their family obligations. Their accounts were associated with having been previously active members of society and being financially productive. Work

itself was a key to spiritual wellbeing, enabling those with jobs to find happiness in satisfying/contributing to family requirements and generally raising morale.

However, the accounts of participants revealed that being an ESRF patient generally means being perceived as an unemployed and unproductive member of the community. This status created a sense of stress in patient's mentality and a sense that "something is missing" in life as an ESRF patient. Many participants reported that were relying on family members or the community and were unable to autonomously fulfil their family requirements. Being disabled from fulfilling such requirements had a negative influence on the participants' "spirituality or الروحانيه", which reflects the role of the community in enforcing the construct that financial commitments must be fulfilled by men, thereby projecting onto male ESRF patients a weak and dependent role.

There is substantial evidence to support the spiritual distress that ESRF patients faced when their needs clashed with those of their families. More than half of the participants stated that they faced challenges which led them to fail to fulfil their family obligations. As a result, participants experienced spiritual distress during ESRF. At least one participant, Abo Omer, stated that he missed some of his dialysis sessions due to lack of financial support, which affected him "spiritually روحانيا":

> "I have missed some dialysis sessions because I didn't have the money to go there; what about giving the patient a lift or [….] sending an ambulance to bring you in and out?" (Abo Omer)

Furthermore, patients employed numerous spiritual self-efficacy beliefs and practices to address their financial uncertainty, and many participants stated that work can promote their "spirituality or الروحانيه" independent of its financial implications due to a sense of hope and motivation to keep "coming and going", which was a formula cited by many participants with regard to enhancing their "spirituality or الروحانيه" . This is summarised in the following citations:

> "That is a fault in our community, they don't help you "spiritually روحانيا", they wouldn't help you, because you are a patient… And… on dialysis… To give two nice words to the patient; this can lift his morale up, but instead "spiritually روحانيا" they will destroy you, the

> dialysis itself is something "Nafsiyan نفسيا", and they have got in their hand either to lift the "Nafsiyan نفسيا" or to destroy you". (Abo Khalil)

Despite the fact that Islamic foundations of community life urge members to care for ill and vulnerable people, being cast into a vulnerable role was universally resented by participants. Consequently, the community reaction to ESRF patients was generally negative, as narrated by almost all the participants. As seen from Abo Khalil's quote above, the sense of being destroyed by the community was found to change participants' *"Nafs النفس"* patterns. As presented earlier under the first theme, *"Nafs النفس"* patterns are considered by participants as being significantly important in their "spirituality or الروحانيه".

In contrast, numerous research participants identified positive aspects in the role of the community, such as being pleased when they were visited by their friends and relatives. A common theme was that isolation and withdrawal from others had very negative mental implications, from depression to suicidal ideation. It has been found that individual isolation can be catastrophic on individuals' mentality (Grassian, 2006). This can be manifest in a sense of being abandoned by and a burden to others, the implications of which are discussed later in this chapter and concern feelings such as being broken ("break you down" or "they will break your rowing"- see below) and a sense of being destroyed. Participants viewed such isolation either as the outcome of their own negative actions (particularly during the early phase following diagnosis), or as a manifestation of social negligence by the community. All participants mentioned being very sociable before being diagnosed with ESRF and most reported becoming completely isolated (by self or others) shortly after their ESRF diagnosis.

However, receiving visitors as an ESRF patient was seen as a different way of experiencing "spirituality or الروحانيه"; the analysis showed that visitors to ESRF participants could mobilise and increase "spirituality or الروحانيه" by expressing fondness and enhancing the confidence of participants by reminding them that the illness is a test and that they must be patient et cetera in order to discover the rewards. This can be likened to spiritual care provided by the community, which helped ESRF patients to fortify their spiritual self-efficacy and give them a push and the motivation to cope with their illness more than when they were not visited:

> "When suddenly people don't continue seeing you then you will feel the hit… A very tough hit. For example, when your neighbour hasn't come to see you yet and say thanks to Allah for your health, this will make you feel it in your *"Nafs النفس"*, and that's about it as I haven't got any other thing". (Abo Omer)

> "From the first moment that they felt it… I'm still living with my parents, I was married and living with my family, and when they say that I am patient they never left me alone for a moment [….] everyone asked about me, I was very delighted and very happy in a very great way, you see, no one left me at all". (Abo Ali)

As noted, being visited generally has a positive effect on patient morale. However, some participants expressed the opposite view, reporting that they had negative experiences arising from being visited:

> "The community don't help you at all 'they will break your rowing' [Jordanian proverb] [….] they'll say 'that's Allah's decision... what you have to do? Nothing you can do, you need to cope with it'. You wouldn't hear from them anything that reminds you that you need to depend on Allah, leave it with Allah… Allah will help you. Imagine – I even used to hate my mother's visit. I didn't like anyone to come to visit [….] I used to keep my eyes on the sky *Assapeh*, making *"Du'a دعاء"*… I don't know how the days passed". (Abo Ows)

The narratives of participants explore the meanings they attach to ESRF and being visited, and they provided more insight into their spiritual perceptions and thoughts. As stated in Chapter One, the Prophet (peace be upon him), urged Muslims not only to visit ill people, but also to instil confidence and show support for them, and not to make them frustrated about Allah's mercy. Such visitors are enjoined to make the patient feel optimistic about their illness.

As explained previously, the perception that Allah has selected patients to have an illness gives them the sense of being loved by Allah and others, encouraging feelings of pride and contentment which overcome negative emotional responses such as frustration, depression, loneliness and emptiness and the "why me?" feeling. The

normative analysis also shows that visiting can promote a sense of inner comfort which enhances participants' "spirituality or الروحانيه":

> "Visiting the patient by friends or brothers or others, as it's mentioned in our Islamic religion, it is a *Sadaqah* [….] this will give him comfort in his *"Nafs النفس"*, as he will see that friends kept asking about him, and he was able to do many things, to laugh, to play… all of this will give him a comfort in his mentality, and it will give him a comfortable feeling "spiritually روحانيا". (Abo Khalid)

In addition, visiting could bestow the frequently mentioned feeling of "tranquility" which uncovered different forms of "spirituality or الروحانيه":

> "They were giving me tranquility always. They are not doctors, they used to say '*tawakal* on Allah… *insha Allah* you will recover, and this is to purify you… And it will go… And *Masha Allah* on you… Your *"Nafs النفس"* looks great' and so on… such talk will lift your morale […] So I used to feel very tranquil in a great way once they visited me". (Abo Ali)

Visiting also had the immediate effect of making patients feel supported:

> "It [visiting] will support your morale… It will make you feel that you've got *hema*, as the visits are something very good. You will feel better and it will make you feel "spiritually روحانيا" better than before. You will feel that there are people around you. There are people who care about you; there are people who pay attention to you". (Abo Rami)

The manifestation of interest and concern for patients' wellbeing by visitors helped to dissipate negative thoughts, and in some cases allowed them to forget about the illness altogether during the visit event which uncovered different ways of experiencing "spirituality or الروحانيه":

> "The spiritual dimensions in visiting any patient it will show the interest and the attention [….] if he has got "spirituality or الروحانيه" [….] The notion of visiting cancer patients or ESRF patients is really

> important, as it will relax patients' mentally and ease the relationship with his family". (Abo Khalid)

> "As I told you it will make you forget the illness that you are already in. It will make you forget about it… you will forget the illness that you are in, and you get their support and their prayers and *"Du'a دعاء"*. (Abo Malik)

Taken together, the narratives of my study further associate the need for ESRF patients to be visited, facilitated in their re-emergence in the community, and helped to overcome feelings of being isolated and cast away from social events. Connections between the ESRF patients and regular engagement (e.g. visiting) with the community, friends and family had a great positive role in supporting patients' "spirituality or الروحانيه". As illustrated above, many participants expressed that being visited gave them a sense of comfort, support, hope and tranquility that enhanced their "spirituality or الروحانيه" and prevented them from becoming isolated and lonely during their ESRF experience. The spiritual dimension of being attached to social life and community events thus had a significant impact on patients' "spirituality or الروحانيه" especially when the support came from other ESRF patients, which will be explained in the next section.

Other ESRF Patients

Patients found a sense of solidarity among themselves, particularly within the context of dialysis treatment. Abo Sara stated that the dialysis atmosphere engendered a system of mutual support, fostering camaraderie and general positive emotions. Many participants felt that their relationships with other ESRF patients strengthened their "spirituality or الروحانيه":

> "I feel good… I mean if you are not here; you will find the other man [ESRF patient] from there talking with me with jokes [laughs], we share everything you see, the other has got phones, he rents cars [laughs], and he tells everybody what happened in his phone, the other doctor there [ESRF patient],… that doctor used to work in Saudi Arabia as well, he is funny, he's a nice man, he tells you about his work in Saudi Arabia. Socially it is a nice atmosphere". (Abo Sara)

As a result of having such an atmosphere in the dialysis unit, Abo Sara added that he felt very comfortable, as if he were sitting in a garden during his dialysis session. This was a "spiritually روحانيا" joyful experience for him, to make friends instead of thinking of the one he lost as a result of his illness:

> " Since I started doing it [dialysis], I found it's a type of the treatment and I enjoyed the people here, I mean they asked me to go to a separate room, the private room, for dialysis but I refused to, because here you feel like… as if you are in garden or something like that you see… You're making your friends here, and the staff [nurses] here are extremely excellent". (Abo Sara)

Mutual participation of ESRF patients in any events outside the dialysis unit appeared to have very positive results due to feelings of social solidarity engendered by such activities among participants, as Abo Khalid narrated:

> "You will find many people at the event itself, you will feel a social solidarity between all of us". (Abo Khalid)

Furthermore, Abo Malik stated that such trips for staff members and patients make them all feel like one family. The solidarity promoted by interacting with other patients sharing the same illness gave a sense of comfort by being with the group, and ESRF participants no longer felt loneliness in facing illness:

> "It [a trip] has given me comfort in my *"Nafs النفس"*, feeling comfortable being with others and meeting others, and meeting new people who are on dialysis but not at the same time [….] you wouldn't feel lonely in this illness. As you will have staff and other patients standing with you. So this will give you a comfortable feeling". (Abo Malik)

"Spirituality or الروحانيه" was manifest in different ways through mutual support among patients, helping them to cope with their illness, as two participants stated:

> "I started to explain to him, and his morale was lifted up, but my morale used to be lifted up more than his, as I feel I am stronger now whereas he was weaker [….] I kept saying to him you have to pray and be patient, I kept reminding him about so many things, I even

> started to think about what I was going to do with my family after I finished my dialysis, what do I have to do… I started to think about so many things". (Abo Saad)

> "For example, we are now watching the television; as we suggested last year, the dialysis unit has to arrange a trip, a leisure trip, [….], so they arranged it for nurses and patient. Some time ago, I suggested to them to create something called "Association for ESRF Patients' Friends", which has got two responsibilities, financial and educational, to increase awareness. The duty of this association is to increase awareness among those who are not suffering from ESRF, and for those who know got ESRF patients, to tell them that the life hasn't stopped here, for patients and for their families, and ESRF patients can be active members of society again [….] Medically, yes I have received my treatment, many thanks, but we still need something else, as it will affect patients' "spirituality or الروحانيه" , it will make the patient outgoing in life, he will feel comfortable in life [….] this is what we actually would like, not only for ESRF patients but for all patients, especially for those with chronic illnesses". (Abo Eizz)

As reflected in the above experiences, the participants of this study considered that their relationships with other ESRF patients in the dialysis unit had positive impacts on their "spirituality or الروحانيه" in different ways. Many participants narrated the importance of the support from and to other ESRF patients within the dialysis unit, which played an important part in accepting the illness, and gave them a sense of comfort, relief and hope. As described earlier, the conflict between accepting the illness and rejecting it was the main challenge that faced ESRF patients. They also described that being with a group (i.e. other ESRF patients) helped them to share their experiences together, and prevented them from feeling lonely and isolated, which addressed the sense of emptiness commonly associated with ESRF. Additionally, as Abo Yaser noted, patients could share their experiences with each other (particularly long-term dialysis patients with new patients), promoting comfort in biomedical progress. Thus, a key policy priority should therefore be to plan for the long-term spiritual care for ESRF patients and their families. Having uncovered how ESRF patients' "spirituality or الروحانيه" was affected and enhanced by other

ESRF patients, I will now move on to discuss the implications of healthcare providers upon ESRF participants' "spirituality or الروحانيه".

Healthcare Providers and the Spiritual Trust

Participants' accounts revealed how "spirituality or الروحانيه" can be an important aspect of the relationship between healthcare providers and ESRF patients, despite there being no acknowledgement or provision for this in the Jordanian healthcare system. Many ESRF patients manifested having a sense that the nurse or the doctor is a person or human with good characteristics and not a weak personality. Such perceptions arose when the healthcare professionals displayed or articulated trust in Allah and regarded the patients as creations of Allah with a certain destiny (*qadar*); not viewing illness and other phenomena as random things but as part of a cosmic order administered by Allah. Thus, the context of ESRF in this worldview is that the Creator has determined a certain scenario in which both patients and healthcare professionals have certain roles and obligations to fulfil.

Therefore, in this paradigm, it has been uncovered to be important that ESRF patients must trust the doctor or nurse and appreciate the care they provide, leaving the outcome to Allah: this can be reflected in healthcare professionals' behaviours, honesty, sincerity and good talk and good deeds. The optimum healthcare professional (as perceived by most patients) approaches patients and their families in a good manner and softly and gently discusses the situation, with confidence in their abilities. The role of confidence emerged from many participants, reflecting the cultural appreciation of certainty and mistrust of vagueness, which is reflected in the Qur'anic verse: "Let us know its interpretation. We see you are a man of good deeds" (Yousof, 36); this verse relates to people trusting the Prophet Yusuf (Joseph) due to his good deeds, which inspired confidence to ask his expert opinion. Otherwise, regardless of any specific qualifications or expertise, they would not trust him or ask him, or accept his interpretation. This cultural phenomenon is very deep and pervasive in Arab-Islamic culture, reflected in the fact that the fundamental determinant of the authenticity of any statement is who said it, rather than what it imports or how likely it is in itself. Therefore, confidence in health professionals' personality and character was uncovered to be key for building spiritual trust among healthcare providers and patients which will determine patient satisfaction, compliance with treatment and general spiritual outlook.

> "Especially when he is not mumbling, or hesitant if we did this or that… But to have a doctor telling you that you have got 1 to 4, the confidence from the doctor's side will be transferred to the patient's confidence, and this will give me a great deal of tranquility [….] sometimes I ask some nurses and they will answer me the same way that the doctor will answer, and in the future I will keep asking the same person, as I will know that this person is very clever, and he faced many cases…Whatever he did with me I will feel tranquil with him". (Abo Ali)

The analysis demonstrated the patients' experiences and knowledge of how healthcare professionals' behaviours influenced their perceptions of care (and by extension, clinical outcomes). A staff member considered to be characterised by good deeds is one who does his job in the best possible way he can. Undoubtedly exhibiting genuine care and concern goes a long way in helping patients' "spirituality or الروحانيه". Conversely, if a patient has had negative experiences, they will be untrusting, and will not feel inner comfort. Thus, there must be an exchange of trust and confidence between the ESRF patients and healthcare professionals, and the latter must be perceived by the previous as being characterised by integrity and experience. Such encounters affected "spirituality or الروحانيه" in positive and in negative ways. Especially, whenever ESRF patients feel that the person who provides care is someone capable of looking after their needs, they will feel comfortable in their *"Nafs النفس"*; it was found that when a patient knew they would be cared for by certain members of staff who were able to identify ESRF spiritual needs, they would feel more tranquil. The ESRF participants stated the importance of a trust relationship between themselves and healthcare providers as a source of tranquility which enhanced their "spirituality or الروحانيه". On the other hand, some patients ultimately had an apathetic regard for the role of health professionals due to their overriding fatalism and belief in destiny. Once trust in healthcare providers was lost, there was an enduring sense of discomfort "spiritually روحانيا" among patients:

> "Once the ESRF patient has lost his trust with the doctor who treated him [….]. Mentally he will become mentally uncomfortable and more sad, and he will feel more insecure from this doctor, until there will

> be no trust between them, and whatever the doctor tells him, the patient won't accept it and will start to think about something else, as he thinking that this wrong and this is will be similar to the scenario that he experienced before with this doctor, and this doctor is worthless. He will reach the stage where he will start to move from one doctor to another doctor to another doctor and so on, and at the end he will lose trust in all doctors". (Abo Sayfe)

Such negative relationships had impacted badly on the participants' "spirituality or الروحانيه", and many participants narrated numerous examples of such experiences where they felt destroyed and weakened in their inner strengths:

> "It will affect the patient negatively [….] a relationship between the patient and doctor with a negative impact on the patient is not positive, and it has got an impact on patient "spirituality or الروحانيه" very, very, very much, as the doctor will be the lifeline for the patient, and when you find out that this doctor is worthless, what should you do with him?! And this is the effect on us". (Abo Saber)

Furthermore, many participants frequently cited that the main barrier to trusting relationships with healthcare professionals was the perception that health systems in general, and particular personnel, were motivated purely by financial considerations, which had a negative impact on their "spirituality or الروحانيه" in itself, as well as the secondary impacts caused by lack of trust in treatment:

> "When the doctor has got financial concerns more than the caring side, yes it will have an effect on the patient, especially when the patient feels that the doctor has reached a progress stage, where he becomes a businessman, the patient feels that he has become merchandise". (Abo Sayef)

Many participants narrated examples of insensitive care (e.g. the delivery of health- and treatment-related information discussed previously) or even negligence amounting to gross misconduct from healthcare professionals. One participant considered an official complaint but decided not to pursue this for spiritual reasons (i.e. patience and forbearance). While most negative experiences of health professionals were associated with doctors, some participants narrated a perception

that both doctors and nurses were unconcerned with the patient except as a case, and their professional concern was only to evade blame for patients' deaths. Failing to show genuine care appeared to have implications on patient's "spirituality or الروحانيه" as many participants reported. In addition, aside from medical issues like medication, health professionals were perceived to be insensitive in relaying information that affected patient's "spirituality or الروحانيه". Furthermore, the general behaviour of health professionals in and around the dialysis ward was uncovered to have a significant relationship with their "spirituality or الروحانيه". This, as well as the deficiencies of general hospital infrastructure and organisation, appeared to be a source of distress for some patients:

> "As I sat here as a prisoner and you [staff] are taking your complete freedom from eating and drinking and talking, coming and going, you're making me feel that I am actually in a prison [….] if you request to see a doctor, he will not come, and if he came, he will start making jokes 'Ha ha ha', then he will leave you and that's it". (Abo Obada)

Another different way of experiencing "spirituality or الروحانيه" from the relationship was through healthcare providers displaying genuine care and making ESRF patients feel that they were genuinely responsible and accountable for patients' conditions. Displaying such genuine care was revealed to be important in enhancing ESRF patients' "spirituality or الروحانيه" and inner strength. This provided a source of power for ESRF patients to overcome any challenges that they faced. The general approach adopted by healthcare professionals toward ESRF patients played an important role in their "spirituality or الروحانيه", particularly when displaying genuine care. Likewise, nurses' attitudes also appeared to be important in "spirituality or الروحانيه": Tanyi et al. (2006) concluded that displaying genuine care was highlighted as a way for nurses to incorporate "spirituality or الروحانيه" into ESRF care. In my study, this was reported by participants to be a source of tranquility. Similarly, staff competence and honest care emerged as situated structures among all participants, with effective care being described as "genuine" and "compassionate". Thus, this can be seen as a way for nurses to individualise ESRF patent's spiritual needs and playing the spiritual dose accordingly.

> "spirituality or الروحانيه" is tranquility; personally, the tranquility for my illness precisely is that I'm still a believer in Allah's capabilities, and this is my luck in this life, as you can see, and when you go to the hospital or to see the doctor, and their approach with me personally [….], where I found very, very, very good care, including the doctors and nurses, they were frightened for me more than myself, and the treatment I received, I was feeling very comfortable with it [….] This gave me tranquility from the doctors around me". (Abo Ali)

For other participants, healthcare providers were a source of peacefulness and stability of their "spirituality or الروحانيه"; however, a clear theme emerged whereby nurses were generally viewed as friendly and approachable partners in managing the condition, whereas doctors were perceived as aloof and generally uncaring. This relates to the universal nursing role as patients' advocate, nurses being the professionals who spend the most time with patients and their families; but it also touches on a deeper problem in the Jordanian context whereby doctors are habitually condescending and even cruel toward patients, as reported by many participants:

> "Personally, nurses play a 90-100% role in patient "spirituality or الروحانيه", as they wouldn't have staleness towards the patient, or destroy his morale. They come to you, they will give you the spirit for life again [….] even when they cover you with a blanket, and when you ask them to change something they will change [….] I personally will give them 100%, not 90%, but the doctor I will give them 25% [….] all of the nursing staff here will lift you your "spirituality or الروحانيه" up, and they will answer all your queries and whatever else you would like to have, thanks to Allah, and that He gave us nurses, *Masha Allah* on them, they lift our heads up and honour us". (Abo Khalil)

Moreover, lack of displaying genuine care appeared to be one of the important factors that led ESRF patients to feel "spiritually روحانيا" distressed. In some cases, participants reported that healthcare professionals failed to communicate effectively about treatment; as a sequence this led to mental pain among some participants:

> "At home, I stopped talking with everyone, I became very nervous, I couldn't take a single word from anyone, didn't accept to see any friends, relatives, not even calls, nothing at all, as I was mentally destroyed". (Abo Saad)

However, being informed also helped ESRF patients to accept and adjust to their illness. Some participants specifically stated that their "spirituality or الروحانيه" was strengthened by their relationships with healthcare professionals, who raised their morale and had a positive impact on their spiritual condition:

> "The doctor has an important role on the patient's illness, as the doctor will be number one, and *Masha Allah* you will find them here coming and laughing with us, and lifting the patient's morale, in a very beautiful way, and the doctor is a friend to the patient, not his doctor". (Abo Ali)

Thus, to enhance patient "spirituality or الروحانيه" during ESRF, the participants themselves highlighted several requirements from health professionals, such as being informed, initiating spiritual discussions and reminding them about spiritual practices. Some participants reported that their "spirituality or الروحانيه" was enhanced by such a relationship with the medical staff as it gave them a sense of comfort and inner peace. One possible explanation for such feelings might be that staff helped the participants to strengthen their connectedness with Allah, aiding the process of surrender and conviction that enabled acceptance and of the illness and consequently better coping and self-efficacy (as explained exhaustively above). Thus, nurses in particular have a role in the promotion of the Tranquil Nafs النفس المطمئنه:

> "….it will give the patient a large dose.... Especially when the patient reaches the despair situation. For example, even if it was a small headache… and the patient has got belief in Allah… and this is a *"Balaa' بلاء"* from Allah, subhanahu wa ta'ala, and this is something beyond his control… then his mentality will be more accepting [….] but in the unit everyone was helping him … it will be a very good to initiate "spirituality or الروحانيه" with him from the start of this illness… as it will help much in the treatment... as staff, whenever I

give the patient a physical treatment, I must give him spiritual dose together, as it will have a better results, as long as the doctors that I have seen so far give me "spirituality or الروحانيه" , as long as I felt comfortable with my illness"

"You [nurses] have to expect the worst things that the patient can do. And when you provide him with "spirituality or الروحانيه" for one or two times, once he responds with "spirituality or الروحانيه", you will find he already reached 50% [….] with one single dose of "spirituality or الروحانيه" you would not be able to increase patients' "spirituality or الروحانيه" [….] before you introduce "spirituality or الروحانيه" to anyone you have to know the educational level for this patient, and this is very easy to assess through conversation. From this stage, you have to activate his "spirituality or الروحانيه" which already exists as a source within him but which is not activated as yet [….] So as a nurse or someone who is going to work with patient "spirituality or الروحانيه" , I have to start with the aim of my work being for the sake of Allah, forgetting about any other secular benefits; as a Muslim, your aim is for the sake of Allah and to improve this patient's "spirituality or الروحانيه" , as long as you are convinced or believe in your own "spirituality or الروحانيه" , it is very easy to transfer it to someone else, as long as you were with it. You will find for example that one word can lift a patient's "spirituality or الروحانيه" from the earth to the sky… and actually it can lift patient "spirituality or الروحانيه" … and at another times, if you explained it to him in many words, such as what is in the newspaper, you wouldn't lift his "spirituality or الروحانيه" anywhere, because you entered the wrong entrance for this patient's personality". (Abo Sara)

Abo Khalid reported finding meaning and engagement in the home, rather than isolation, due to performing religious rituals and helping with household work. Also, it was a notable feature from almost all participants' narratives that they linked their relationship with healthcare providers to their overall spiritual experience of ESRF. Their "spirituality or الروحانيه" was generally empowered by positive relationships with health providers, which encouraged them to change their initially negative (e.g. despairing) views about their illness and engage with it more

constructively. As a result of a spiritual dose from staff; many participants reported that such relationships motivated them and gave them a sense of hope:

> "You will feel tranquility in your *"Nafs النفس"*, you will feel comfort in spirit, and quietness in his *"Nafs النفس"*, which will give him a power, certainly… As long as you are comfortable in your *"Nafs النفس"*, and you feel peacefulness in your "spirituality or الروحانيه". (Abo Eizz)

The interpretation of participants narratives shows that the personal (non-clinical) engagement was also highly useful to patient "spirituality or الروحانيه" , whether by providing extra care and assistance (as reported above) or by simple personal interactions and engagement, given that ESRF patients typically spend a significant amount of time in hospital receiving dialysis treatment. Abo Khalid explicitly emphasised that spiritual care can be provided using a simple but effective approach when he addressed the mobility of such spiritual care within the dialysis unit, and the fact that the unit becomes a home away from home for most patients, who spend more time there than they do in their typical social and extended family life:

> "When the nurse says *bismillah*, at that precise moment I will come back to Allah... I might be oblivious that time, but the words *bismillah* and *tawakal aala Allah* will give you refreshment… even though we are all Muslims, grown up in an Islamic culture… with the severity of illness and the pressure, the patient might become oblivious; such words will act as moisture for our atmosphere… it will give him a spiritual injection… it's much better than giving him a painkiller… really, I'm very serious [….] to reach the tranquil *"Nafs النفس"*… it will ease everything is around him". (Abo Khalid)

Participants suggested detailed ways in which they thought nurses could approach ESRF patients' spiritual care, based on their own experiences:

> "First of all you have to give him the complete physical care, and secondly you need to sit with his family and talk to them, and let them understand that these things are the consequence of such things. And if they are not aware about the importance of a psychiatrist, then you have to say "listen to me", you have to explain to them, that they

> shouldn't keep the patient withdrawn or isolated [….] you will find some nurses come to the dialysis unit and connect the patient's dialysis machine and disconnect him, and that's about it, he wouldn't bother whether the patient is depressed or even worse. But you will find other nurses who come to the patient and talk to him and are more caring than the others". (Abo Sayef)

> "…but if you left the patient without any "spirituality or الروحانيه" , you are actually helping him to collapse quicker and stay on this chair without anything to do from the first years of his illness, or even from the first month he will not be able to walk and move at all". (Abo Khalid)

> "…They [nurses] will say 'you look good, *Masha Allah*' and [….] the nurses are the ones who come and start asking me what I want, making jokes with me, and this is what lifts my morale up, and makes us feel that we are not patients" . (Abo Khalil)

A particular nursing role that emerged from numerous interviews was the concept of giving patients a spiritual 'dose' analogous to medication. Such spiritual doses were described as increasing patients' sense of connectedness with Allah through initiating spiritual discourse and reminders of spiritual activities to help reach Tranquil Nafs النفس المطمئنه. Some participants cited particular nurses who offered more direct and traditional spiritual care in ward settings. Abo Sofyan was particularly elaborate in describing this concept:

> "I would talk to him [another ESRF patient] about religion, as I mentioned to you I will talk with him in *hadith*, I would talk to him about the Qur'an, I would talk to him that Allah selected you and so on. He will be a hundred per cent not tranquil, but once he knows such things he will feel tranquility [….] it has given us a push in religion". (Abo Sofyan)

Many patients perceived themselves to be affected by positive and negative forces that they often explicitly compared to electrical charges and toxins. Numerous pieces of advice were given in this regard by patients when they were asked how healthcare personnel could "spiritually روحانيا" care for ESRF patients. It was clear

that patients equated their spiritual wellbeing/state with medical outcomes; whether this represented medically improved outcomes or psychosomatic/placebo effect, patients' associated positive spiritual status with improved health:

> "As if you will find if someone is tired in his *"Nafs النفس"* you will not accept any treatment [….] it does feel actually as if you have a toxin inside you, that is released after being nervous, and you will find others make you happy and you will find that your body releases other things which are sweet, which helps you from inside, so there is a positive and negative substance in our glands which have a huge impact very much". (Abo Ahmad)

Many patients elaborated on this concept with regard to engagement with spiritual stories and religious practices. The concept of remembrance of Allah (*dhikr*), as explained previously, is implicit in all of Islamic religious concepts and practices. Some patients mentioned that healthcare professionals can play a role in communicating this remembrance. Abo Khalid and others mentioned positive roles undertaken by health professionals in this regard (which affected him so positively he compared it to painkillers, possibly indicative of a placebo effect), whereas Abo Ows complained of a lack of such regard. He elaborated more about the spiritual value of such Islamic remembrances by saying:

> "It would be better to turn to the side and see a sign reminding you that you need to say 'Allah *sally aala Muhammad*' it will remind you that you need to keep connected in saying so…. Is that wrong?! Or though *takbir*…. You will keep yourself saying those things… it may open new doors for you… and to make *"Du'a دعاء"* for something else…. Entering this place is like entering a different world [….] there is no "spirituality or الروحانيه" to be found here. Here, nothing will remind the ESRF patient to be connected with Allah.... Nothing at all [….] if his eye spotted that reminder with '*Allah akbar*', it may help him to keep thinking about it not only for four hours… but even for ten hours". (Abo Ows)

When probed, some participants elaborated on the connection enabling spiritual care to be delivered by staff members to ESRF patients, which they indicated was mutually beneficial (partly due to the long-term clinical relationship between

professionals and dialysis patients). Being compassionate was identified as the most important aspect of spiritual care; to be treated well, in a friendly way with Islamic colloquial terminology, and a jocular tone. It was also frequently mentioned that the people around, including staff members, should inspire hope and ambition among patients which can have a beneficial effect on the pain:

> "The spiritual role is that you have to reassure him by telling him that this is something normal, don't be scared[….] you have to assure him that everything is under control and this is normal [….] which will lead the patient to be mentally comfortable and "spiritually روحانيا comfortable, which will lead his body to win against the pain, and *subhan Allah*, it seems to me that there is something going out from your brain to the centre of the pain and relieving the pain every time someone supports the patient, and assures the patient that his condition is under control, 'don't worry, don't be scared, don't be frightened'… this will send a signal to the pain centre and will you some things which relieve the pain [….] you start to feel less pain; you [already] know the hope is in Allah, but such things increase your hope, the pain will not continue and it will disappear, but you have to do certain things… move your legs… and *tawakal aala Allah* and everything will be fine". (Abo Eizz)

In summary, the theme of relationships is linked to ESRF patients' "spirituality or الروحانيه" as manifest in their engagement with their families, the community, other patients and medical staff. Perhaps the most important aspect to emerge from the latter was the patients' perception that health providers should display genuine care and concern, initiate spiritual conversation to activate patients' "spirituality or الروحانيه" to raise their morale and make the dialysis unit (and thus treatment) a comfortable and amenable situation, improving their "spirituality or الروحانيه" and their experience of medical treatment. Almost all participants reported the importance of "spirituality or الروحانيه" links between staff members and themselves, particularly nurses, whose spiritual care for ESRF patients during dialysis was revealed to be associated with the element of religious support that facilitates the acceptance of the illness and enhances coping mechanisms. It was repeatedly identified by participants that a sense of hope was generated by the above elements,

while their absence (e.g. negligence or apathy on the part of health providers) caused despair and was identified with poorer health outcomes. This lead to desperation which will be discussed in the next theme.

Desperation

The themes of religion and relationships were addressed in terms of their impacts on ESRF participants' "spirituality or الروحانيه" and *"Nafs النفس"* patterns as sources of comfort and tranquility and enhancing their inner peace. The theme of desperation provides a deep insight into ESRF patients' perceptions about the state of despair in their "spirituality or الروحانيه" that they reported reaching during their illness, often as a result of social isolation and exclusion, assigning them a position of vulnerability within the Jordanian community, and in some cases discriminating against their rights in terms of: losing their employability status, losing their residency, loss of their role in community, loss of respect from others. The theme of desperation was reported by almost all participants and consists of two main sections, namely: ESRF patients' perceptions about their feelings of emptiness during their illness that deterioration and despair conditions and the sense of rejection of treatment.

One feature that became apparent as a common theme arising from the interviews was that the feelings associated with desperation were particularly associated with the early phase of diagnosis and initial treatment; although the time that this stage lasted varied between patients, from a few months to years, it was indication from the data that some measure of despair was a common experience during the initial engagement with ESRF. Patients themselves were well aware of this phenomenon among ESRF patients, but it should not be regarded lightly, as thoughts relating to suicide or suicidal ideation (along with murderous feelings, at lower frequency) were frequently cited by patients, having grave implications for care during the initial period (i.e. months or years) of ESRF:

> "I felt tiredness initially, and I swear it was for one or two years [….] I used to sit with my *"Nafs النفس"* where I really feel I am going crazy [interruption by staff] … so it's not like everyone is going to accept his illness as you would imagine; [….] for others it will be difficult for them… Where he would like to stay alone… And he doesn't like

> to stay with others, where his *"Nafs النفس"* is being destroyed". (Abo Yaser)

In addition, "spirituality or الروحانيه" as desperation surfaces in a number of ways, one of which was negative insinuations. The stream of consciousness or internal monologue has been understood in many different ways; current cognitive science centres on 'Buddhist meditative psychology', phenomenology and psychoanalysis (Varela, 1993). Such concerns are beyond the scope of this research, suffice it to say that the Arab-Islamic tradition is based on the Abrahamic concept of the human which is that of a transcendent soul incorporating a material body that is subject to positive or negative influences of the self (*"Nafs النفس"*) and supernatural beings. Thus, while Western atheists hold that they, their thoughts and their actions are random physical and chemical phenomena, followers of Abrahamic religions believe that they are subject to positive and negative influences of demonic and divine natures, and their function in life is to resist negative thoughts and perform good deeds. These negative influences on the psyche are understood to result from the interplay of negative internal thoughts the whisperings (*waswas*) of Satan (i.e. temptations of the devil) by Muslims. Thus the majority of participants perceived and expressed their state of despair and depression concerning ESRF in terms of *waswas*:

> "if I would like to follow the devil's whispers, I might kill one of the kids, from my aggressive anger, or suffocate someone I don't know. No, I go back to Allah, *subhanahu wa ta'all*". (Abo Sofyan)

According to Abo Sofyan, this was related to the general milieu and period of flux and confusion that ESRF patients undergo during their initial diagnosis and treatment, and patients emphasised the need for nurses to understand such things but did not seem to think such understanding was inherent in the care they received. Similarly, Abo Saad stated that the concept of the inevitability of disease (i.e. the concept of destiny) was related to the importance participants attached to being reminded to be patient, particularly when they became anxious:

> "…Certainly it [spiritual dose/push] helped, as you know without such things, that give you a little push to be patient [….] If the patient stayed by himself, very nervous, not talking with others, he wouldn't

> last for a year on dialysis, as something would happen for him that Allah has forbidden [i.e. suicide]". (Abo Saad)

As stated in the literature review, the relationship between "spirituality or الروحانيه" and psychology is well documented, particularly with regard to depression (Ellison and Lee, 2010; Lin and Bauer-Wu, 2003). "Spirituality or الروحانيه" as desperation surfaces in a number of psychological challenges. One of the participants narrated the plethora of psychological challenges typically faced by ESRF patients and the spiritual aspects related to them:

> "…During the negative mental effects which lead the patient to believe that he reached the point where his life has ended, and let's say "spiritually روحانيا" and religiously it is well known that ending someone's life without any sin or corruption in the earth, it is forbidden and *mogharah*, and this is at least in our culture, where we are born and brought up and where we exist, without such things, I reached a stage where my life had ended... As there are no other opportunities for him to continue and keep going in life… So he will question himself, 'Why should I continue?!' And even I asked myself what kind of life am I going to have, and to live!!" (Abo Hassan)

This participant, Abo Hassan, even related rejection of treatment (discussed in more detail later in this chapter) to the concept of suicide and self-destruction arising from despair, and also highlighted that the main paradigm through which patients viewed the issue of suicide was the spiritual aspect related to religious prohibition. As illustrated in the theme "religion", this may resonate with fatalism in which it appeared to be a feature of Jordanian spirituality:

> "Now the suicide attempt…The suicide itself is killing *"Nafs النفس"* after premeditation and monitoring; can we say that the patient is free to do so?" (Abo Hussan)

"Spirituality or الروحانيه" desperation also surfaced in different ways as a sense that related suicidal ideation and despair to the dialysis treatment itself, during which patients felt empty and anomie from their surroundings. One third of participants reported such a sense:

> "We are here in the dialysis… we are all ESRF patients… we talk to each other - this and that… and from this interaction you know the mentality of the person you are talking with…. You'll hear sometimes things such as 'If I drink a chemical cleaning detergent (hypix), will I feel anything?'… This will give you an indication that this person is considering suicide for example… even if it was only kidding". (Abo Ows)

The complexity and ambivalence of patients' experiences of suicidal thoughts are reflected in a subsequent statement by the above participant that he had never reached the stage of contemplating suicide. This reflects the social stigma and taboo of suicidal thoughts in Islamic society, the concept that the antidote to such thoughts is "spirituality or الروحانيه" ("relationship with Allah") and through the spiritual dose. (as explained earlier) the patients are themselves confused and perplexed about such feelings and thoughts:

> "Even if it wasn't "spirituality or الروحانيه", I haven't reached that stage where I start to think about it; indeed, you will have the inner tranquility inside you: why do I have to think about these things? Suicide will kill you and the illness will kill you too; either way you are going to die, thus it is better to die in a way that Allah is happy with rather than dying in a way that will make Allah angry with you" (Abo Ows)

> "You will feel something broken inside you [….] tightness, something affecting your breath, and you would like to go out from this life in any way, you even think 'If I die, it will be better". (Abo Saber)

> "People with this condition will not have a *nur* from inside them [….] people who talk like this have drifted away from religion and far from Allah, and they will not depend on Allah in their hard times". (Abo Ahmad)

The participant cited above, Abo Saber, also related suicide to the concept of being a burden and an unproductive family member due to ESRF status, considering it to be alleviation not only for himself but for the "community", and he implied that

marriage (itself conceived of in Arab-Islamic culture as a spiritual exercise) helped to overcome suicidal thoughts. Another participant explicitly linked the suicide theme to non-compliance with treatment, which was overcome by the concept of Divine Providence. Abo Khalid expanded on the concept of suicide at length, outlining that "spirituality or الروحانيه" is a direct antidote to suicidal thoughts because of the promise of punishment for the one who commits suicide in the Afterlife:

> "Any person who has *Balaa' بلاء* and reaches the despair stage will do exactly the opposite of what he is asked to do [by medical professionals] … he will try suicide… or do it by other methods… in order to harm himself. And he might say that I would like to harm others as well… but in the end he will only harm himself". (Abo Khalid)

He also related an anecdote about another, a young 24 year-old male, who ceased coming for dialysis due to feelings of despair and consequently died, thus illustrating the link between desperation (amounting to suicidal ideation in its most acute form), emptiness feeling and death. Abo Khalid believed that the patient had a poor connection with Allah as well as his family, enabling him to lose meaning and purpose in life, and thus leading to suicide.

Emptiness Feeling: ESRF Patients & Staff

Despite the fact that all of the ESRF participants interviewed were living with their families (one became a widower during his illness), all participants experienced a sense of emptiness due to ESRF. Many participants related the emptiness to not having a role, usually an area of professional activity, which profoundly affected how the participants were perceived socially and consequently how they perceived themselves. Almost all participants felt despair due to the absence of work because of a lack of professional satisfaction; for others their despair arose from panic at the prospect of being unable to provide for their families, which was only overcome by the concept of *rizq* and the actuality that they ultimately managed to sustain their families. One patient explicitly outlined the correlation between loss of work/career due to ESRF, social condescension and feelings of inferiority and despair, and consequent isolation and depression. Essentially, a sense of keeping busy or having

some non-ESRF related activity proved a source of spiritual comfort for many patients in overcoming the emptiness left by the loss of their previous assumptions about their roles and responsibilities. While most patients viewed a job as the ultimate comfort, others mentioned things such as exercise and academic study; notably, all of the activities that proved "spiritually روحانيا" helpful involved getting away from the home (and the stifling pity often associated with the domestic environment) to engage in challenging activities concerning goal setting, perseverance and feelings of achievement. Furthermore, Abo Khalid stated that performing the prayers was a source of spiritual comfort that could dispel feelings of emptiness, and he equated neglect of prayer to losing "spirituality or الروحانيه". As described earlier with regard to the *"Balaa' بلاء"* concept, ESRF patients generally undergo a similar pattern in initiating and moving on from the concept of *Balaa'* to overcome emptiness:

> "But those who will feel emptiness – how they cannot give you what they don't own?! [….] Allah will send this *"Balaa' بلاء"* [….] this push will help him… He will reach tranquility". (Abo Khalid)

Also, such sense of emptiness can lead to self-harm as stated above, however the sense of responsibility among ESRF participants often blocked such feelings. Almost one third of participants reported this to be one of their spiritual needs during ESRF; as stared earlier with regard to the *"Nafs النفس"* concept, the idea of being responsible was important in patients' self-efficacy and general spiritual condition. Losing the sense of being responsible was an indication of moving the *"Nafs النفس"* pattern from the positive tranquil *"Nafs النفس"* to the negative *Nafs Ammarah النفس الاماره* and into the orbit of suicidal thoughts and feelings:

> "They have the highest suicide rate, as they don't have "spirituality or الروحانيه" … even the healthy people; the suicides have completely lost their "spirituality or الروحانيه" … Because the one who has well "spirituality or الروحانيه" will never ever think about suicide at all…". (Abo Khalid)

There is a manifest link between feelings of emptiness and ESRF patients' psychological state, *"Nafs النفس"*, "spirituality or الروحانيه" and religion. This interaction creates a complex amalgam of needs that reflecting very specific

psychiatric symptom that presented consistently among ESRF patients as a result of the spiritual gap produced by the emptiness status. This amalgam adds another layer of complexity to Jordanian ESRF participants' "spirituality or الروحانيه". However, a common feature of this amalgam was the pattern of isolation and obsession due to morbid thinking which many patients felt was best cured by addressing their spiritual needs in terms of orthodox religious practices such as praying and reading the Qur'an and interactions with others (e.g. visiting friends and family), with the common theme of keeping busy and avoiding isolation. This was reflected by the majority participants:

> "spiritually روحانيا, the patient must not have an emptiness status; once he has an emptiness status, he will start his own obsessions[….] Being Muslim, it's really easy to fulfil the "spiritually روحانيا that the patients have… this comes from remembering Allah, reading the Qur'an… Performing *Salah*… Away from the dialysis machine, ESRF patients can perform *Salah*, socialise and visit relatives such as reading Qur'an, he will fill his emptiness". (Abo Khalid)

Some patients stated that spiritual care was more important than medical care in relation to above psychological symptoms (a plausible assertion given the widespread evidence that depression and negative emotions have been associated with non-compliance with treatment, and may develop into an issue with fatalism as a consequence.):

> "So the "spirituality or الروحانيه" matters are massively important to the patient… Very much important… We don't need to say it's parallel with the medical treatment; it is more important than the medical treatment". (Abo Obada)

In contrast to Abo Obada, who referred to psychological and spiritual care synonymously, two other participants cited the need for psychiatric assistance as part of the spiritual care for some patients who are particularly vulnerable to depression and other psychiatric symptoms, although, as mentioned earlier in this chapter, "spirituality or الروحانيه" was generally perceived by participants as the way in which patients deal with (i.e. accept) their illness, related to belief in Allah, Judgment Day, and patience. Further, Abo Obada

highlighted a deeper problem within nursing model in Jordan. It might be that in the Jordanian nursing model "spirituality or الروحانيه" is being left out, and yet the participants' experiences showed how "spirituality or الروحانيه" is important to their well-being. One participant, Abo Ahmad, stated that medical professionals should not have a role in this, attributing it to patients' *"Nafsiyan نفسيا"* and a journey each patient must make alone, although he later modified this view during the interviews, perhaps as his understanding of spiritual care evolved. Many participants stated that patients would be despairing and unable to cope without adequate "spirituality or الروحانيه". Conviction that the illness is a test from Allah and a source of *ajr* in the afterlife promotes tranquility, while a lack of such belief results in frustration and depression:

> "I consider "spirituality or الروحانيه" as the belief of an individual about his illness, and if there is no belief I don't think there is "spirituality or الروحانيه" at all, and the person will become negative and despairing about his illness [….]and I don't think the doctors are going to have anything to do with it". (Abo Ahmed)

In summary, two main patterns in the experience of ESRF patients emerged; in one, the initial diagnosis was a terrible blow to their psyche, self-perception and roles in the family and community, creating a spiritual crisis which was gradually overcome; in the other, the initial period saw a (not unwelcome) flurry of excitement, interest and support from family and friends that later gave way to feelings of abandonment and loneliness. This what Heidegger described as ways to discover the world around us when we can determine the conformability, lostness and inauthenticity of the culture in which we live (Heidegger, 1962). This was seen as a powerful beginning for all of the participants to start their authentic existence individually. As explained previously, the most traumatic initial period following diagnosis and beginning treatment varied in length among participants, but it was noted that numerous participants repeatedly referred to a two-year window of shock, withdrawal and depression. While despair was the prevailing negative emotion, becoming suicidal at its most acute, some participants articulated that they had experienced aggressive and obsessional thoughts associated with *Nafs Ammarah النفس الاماره*; some reported that they had very aggressive thoughts of slur, revenge, torturing and disfigurement of

family members, heath care professions or community members. Such thoughts were described as unwelcome and frightening:

> "I will feel that I have done something right, but if I would like to follow the devil's whispers, I might kill one of the kids, from my aggressive anger, or suffocate someone I don't know. …
>
> "I might slur other people, or I harm others, or become a thief, or start drinking alcohol and become drunk when I am healthy [….] you will see many people slur others and suddenly collapse and die, when he is slurring others, what benefit has he gained?". (Abo Sofyan)
>
> "It was like what you can say is… it was like a reaction of a wounded revenge person[….]For example, the urologist people, if I have a chance now, I will take a knife to take them one by one, I wouldn't delay… this catastrophe condition that I'm in now is their fault." (Abo Ows).
>
> "… It is frustration itself, I think the frustration is more appropriate to use […] But because you are a Muslim, you are not allowed to hurt him and reply to him, you are only allowed to say '*Allah Ysamhak*' or '*Allah yehdik*' then he will reply ' because you are a patient, otherwise I would show you!!'. [….] In this, you will find the "spirituality or الروحانيه" will have an important impact, as it will have impact on you worse than the illness itself, as the organic illness… is fine, but how people deal with you in all levels, without ethics, will be disastrous". (Abo Obada)

Such frustration led to feelings of despair, depression, suicidal ideation or aggression; in some cases patients frequently cited experiencing hallucinations and imaginations associated with paranoia which disappeared again after receiving the spiritual dose (as I explained in previous themes) that enhanced their emptiness status:

> "To prevent the patients from feeling emptiness [….] sitting at home and going to dialysis, so he will have strange thoughts that run in his mind, and it can lead one day to affecting his life as person [….]

> imaginations and hallucinations will come to the ESRF patient because he is not working". (Abo Eizz)

Abo Eizz concurred with Abo Khalid that such paranoid and fanciful thoughts could lead to harming relationships with close family members and jealousy:

> "First of all "spiritually روحانيا, you will have in pain your chest, which is connected with your health, as you are continuously thinking, and such thinking will transfer to your emotions, your emotions toward a certain person [….] For example, to say that 'I am a patient me?'". (Abo Eizz)

Indeed, the marital implications of despair were cited by all married participants and the negative implications of delirium in particular were common among them:

> "It will affect your relationship with your wife… It will affect your relations with your kids… And with the people around you, as you are to them as a piece of furniture placed in the house, nothing more, as long as you're not productive despite the fact you are able to be productive". (Abo Omer

Differently, for Abo Ows, his experience of the frustration of dialysis treatment itself presents a microcosm of the overall ESRF spiritual experience, a trial overcome only by improving his connection with Allah. In addition, this could be related to a general frustration felt with the healthcare services he received and the feeling that some health professionals did not care, from general perceptions to specific instances of insensitive communication concerning marital issues:

> "I feel frustration in myself, I feel myself being destroyed, and my life is ended, as the community may picture your life has ended, and at any time you may die, you may die now" . (Abo Saber)

As noted from the above quotes, participants suffered psychiatric symptoms which had very traumatic effects on their "spirituality or الروحانيه", especially given the restricted environment in which ESRF patients exist, limited in many cases to the hospital and their homes, leading them to experience a sense of emptiness. All of the spiritual signs such as lack of tolerance, sense of detachment from marital relationships and experiencing psychological symptoms are present. Thus, the

feelings of emptiness were uncovered as a sign of spiritual distress. This mainly related to the home and community environments. Suddenly going from normal life to being an ESRF patient caused a feeling of emptiness among most patients, who lamented the loss of the ability to "come and go". Previously, many of the participants had been accustomed to particularly active lives, whether as busy workers and professionals or experienced refugees. How ESRF patients reported such feelings of emptiness revealed a great deal about how he or she lived. Their "spirituality or الروحانيه" manifested during the process of the treatment reflected ESRF "spirituality or الروحانيه" during their life. For those individuals who adhered to religious commitments during their life, "spirituality or الروحانيه" helped their experience with ESRF to be a pleasing and rewarding purification from their mistakes, as disclosed earlier in the section on religion. Indeed it could be argued that those participants find the meaning of life through religious foundations. ESRF participants who hadn't had religious commitments, or found a meaning or goal in their life experienced a more profound sense of emptiness. For example, some dealt with the feeling of emptiness by simply accepting it as fate and not striving (or hoping) for any change or activities as stated by Abo Shahab:

> "There is a reality for the human being and he shouldn't escape from his reality, and I am convinced that I'm doing three times dialysis per week, that's it, end of story". (Abo Shehab)

However, the general emptiness was compounded by the loss of friends, whether this was due to self-isolation and withdrawal on the part of participants or actual abandonment due to being unable to participate in social activities as they had before ESRF diagnosis, as this were reported by many participants.

> "Even your close friend which whom you used to go [….] you are just a burden for them, which is a wrong feeling, and I haven't changed, but the feeling that you may be a burden to them". (Abo Sara)

The concept of feeling like a burden to the community was repeatedly reported by participants, who generally experienced some measure of social exclusion. Ironically, social mores surrounding illness, intended to comfort and help the patients, was a chief source of frustration and feeling empty, as participants reported

feeling stifled and belittled by the pity of those around them. Such feelings were exacerbating spiritual distress. Many participants revealed that:

> "Unfortunately, within the Arabic culture, the society does not look to the patient as normal! They look to the patient only in terms of *shafaqa*, which will make patients' self-esteem ultimately deteriorate". (Abo Sayef)

Abo Sayef explicitly described patterns that ESRF patients endured. Despite the fact that he was the only participant to correlate self-esteem directly with "spirituality or الروحانيه", he indicated that self-esteem, sense of losing hope, and isolation are all signs that could cause frustration and anger. O'Brian (2003) stated the importance of providing care for emotional sequel as this can have implications for patients' spiritual wellbeing in chronic illness. Abo Sayef also indicated that being with other ESRF patients, listening to him and giving him hope, were strategies that enhanced and integrated his "spirituality or الروحانيه" into coping behaviours that will help him to re-emerge in his role back in the community. But, other participants reported feeling a sense of catharsis and tranquility after the anger and frustration peaked ("erupted"). Some participants suggested that awareness of how to deal with ESRF patients should be promoted among their families to prevent stifling and irritating the patient and to help avoid the isolation and social alienation that can cause spiritual despair. The reason participants emphasised the emptiness of isolation might be because it stopped them interacting with others and undermined their self-esteem:

> "The first transplantation was really very bad very bad, as all symptoms I mentioned to you – I went through them one by one, as I became isolated, I stopped going out, coming and going; I developed unbelievably low self-esteem". (Abo Sayef)

As revealed previously, engagement in challenging and goal-setting behaviours such as exercise and studying were found to alleviate the feelings of emptiness among some participants. Where patients lacked such constructive objectives, they typically reported falling back on watching TV and staying in the house, feeling empty:

> "Your body becomes weakened, and the laziness increases, and as you can say I will develop a gap, and in this I would watch TV, and

> you try to do something, or going out for example, you will complain from an emptiness". (Abo Rami)

Moreover, the absence of some form of meaningful activity (e.g. work or study) was reported by participants to have a negative impact on their *"Nafs النفس"* and spiritual wellbeing, especially when associated with lack of knowledge about ESRF. Some participants equated the feeling of emptiness at home with being dead:

> "Not only passive, but to become dead, even in the initial period. I personally don't generalise here, my nature, I would like to suffer a bit longer more than the people around me, and once I feel the people around me start to be weakened, then I will collapse". (Abo Ows)

When patients were coddled and prevented from living as normally as possible. some reported a sense of feeling bad tempered, which made relations in the home strained. Abo Eizz made reference to other patients to illustrate the theme of the dangers of isolation and negative thinking within the home, leading to paranoia and suspicion of family members as a result of low "spirituality or الروحانيه" arising from experiencing that sense of emptiness:

> "ESRF patients must get rid of the emptiness feeling… see this patient Abo Sofyan, I invited him and other patients to come and visit me at home [….] if he would like to go out in the afternoon, he will sit out for a short period alone, such sitting outside alone will bring to him *"Balaa' بلاء"* · (Abo Eizz).

Abo Eizz and others also mentioned the important role of employment on the psyche and spiritual wellbeing of ESRF patients. Likewise, other participants emphasised the important role of the family in lifting patients' morale and promoting hope (as described earlier, in relationship theme):

> "Trying to lift his morale up and try not letting him feel that his condition is difficult". (Abo Sayef)

However, this requires great delicacy on the part of families: while the role of the family in providing spiritual support for ESRF patients is obvious, the majority of participants more frequently reported the negative impacts of over-protection. Indeed, some participants stated a wish to die rather than starting dialysis and living

as a “patient”. As already mentioned, patients have been known to refuse treatment due to despair, and consequently died. While most participants reported overcoming such negative thoughts and emotions, they were nevertheless universally experienced. Thus, in caring for the feelings of emptiness and despair “spiritually روحانيا”, many participants fundamentally cited the importance of accepting their condition and returning to Allah. Significantly, it was also mentioned by many participants that spiritual dialogue (including participating in the study interviews) could help in improving spiritual care by increasing self-efficacy and lifting morale. Although many participants initially felt that the health staff had no role in spiritual care, they later modified this view during the course of the interviews. It was primarily considered to be a nursing role to provide such care, whilst others cited the role of psychiatry and family. It has already been identified in the Religion theme that praying and patience, along with other Islamic concepts such as pilgrimage and reading the Qur’an, were regarded as useful strategies in enhancing spiritual care for emptiness, leading to improved relations with others and lifting general morale. Related to praying, the concept of *dhikr* was very important for patients, and they felt the hospital should play a more active role in promoting this for those who would benefit from it. Furthermore, As uncovered previously, being constructively engaged was important to prevent feelings of emptiness and despair:

> “spiritually روحانيا”, the patient must not have an emptiness status; once he has an emptiness status, he will start his own obsessions… and “spiritually روحانيا”, it’s really easy to fulfil this emptiness status.... Being Muslim [….] this comes from remembering Allah, reading the Qur’an… Performing *salah*… Away from the dialysis machine, ESRF patients can perform *salah*, socialise and visit relatives” (Abo Khalid)

In addition, the interviews revealed that ESRF treatment is associated with a number of fears, such as losing consciousness during dialysis. Such sense of fear was uncovered to have significant implications in patients’ “spirituality or الروحانيه”. During the treatment, one participant employed spiritual coping strategies, mentioned above, to deal with such fears. As well as specific fears such as losing consciousness, some patients reported fears of medical procedures in general, including a strong aversion to hospital in the initial period as well as the intense pain of needling, and phobia of injections:

> "During the dialysis, everyone has a kind of horror and fear… especially when I was discharged from the ICU, I developed a kind of phobia of injections…. I started feeling tiredness and tightness when I saw needles". (Abo Ows)

The analysis of participants' interviews revealed that these fears were related to lack of knowledge of the condition and of treatment methods: many participants found it very difficult "spiritually روحانيا to cope with an illness that they hadn't heard about before:

> "The lack of knowledge about dialysis makes the patient refuse the advice of the doctors sometimes […] this doctor told me 'Don't allow anyone to take blood from your left hand'. I asked him 'Why?' and he told me that this is the plan for the fistula. I was frightened from him, I don't go back to him, I told him" (Abo Sara)

Further, the analysis showed for some participants that their complete ignorance of the ESRF treatment caused psychological distress followed by acute pain and shock at receiving treatments they had not anticipated such as needling. Such psychological distress appeared to have implications on ESRF "spirituality or الروحانيه", as many participants reported such distress:

> "I remembered what dialysis means, I thought they were going to open my abdomen and take my kidney out and wash it and put it back again [….] the needling was really very painful and I hated it [interruption by staff]". (Maha)

Additionally, it appeared that fear of living constantly in a condition of illness undermined the general psychological condition of some patients, particularly those diagnosed with ESRF at a young age, who felt they would be continuously ill, in hospital and bored due to being unable to live a normal life. This had huge implications on their "spirituality or الروحانيه", as many participants reported having a conflict between accepting and predicting such an illness.

It is important now to explore the reasons behind deterioration in ESRF patients' "spirituality or الروحانيه". The interviews revealed that there is a relationship between acceptance and rejection of the *"Balaa' بلاء"* of ESRF according to the patient's own

capability and experience of "spirituality or الروحانيه". Twenty participants experienced desperation during their illness. ESRF participants reported that their suffering from the illness increased every time they felt or experienced social stigma, isolation, false perception and lack of knowledge (for both participants and their families), lack of psychological care (despite the psychiatric symptoms they addressed themselves), lost employability due to ESRF or felt they were a burden. Nevertheless, the general impact of society was to make patients feel worse due to the pity and focus on the illness rather than the patient as a whole person. Such a view had substantial implications for patients' "spirituality or الروحانيه" and upon their *"Nafs النفس"* during ESRF and many participants reported the consequences of the culture on them:

> "He will feel that he lost everything, but if he understood properly he would realise that his illness is a win for him, as the patient when he is patient and copes with [endures] his illness for the sake of Allah, Allah will compensate him with many things and once he believes in this thing he will become comfortable in his *"Nafs النفس"* very much". (Abo Ahmad)

Abo Ahmad stated that patients would be despairing and unable to cope without adequate "spirituality or الروحانيه", but that some despairing patients will have built an internal block, so special care is needed to address them "spiritually روحانيا. He emphasized that one should avoid "confronting" patients.

On the other hand, all participants reported that they had a sense of being a burden by either the community or their family or even both. The analysis of the interviews showed such perception of either being a burden or discriminated against them of being ESRF patient. As they reported, to some extent their relationships with others had been changed. This change was a reflected in their narratives as a sign of deterioration in their "spirituality or الروحانيه". Almost all of them narrated their stories with rich expressions of sadness, frustrations and spiritual anger arising from such experiences. Participants were often in tears when they narrated these accounts:

> "I have been affected… As when they suspended me from working… I started to realise that life is full of darkness [….] why didn't they let

> us work? For example, do we have to eject any person who is in dialysis and make him a burden?!". (Abo Omer)

Such narratives seem to be related to the lack of public awareness of ESRF, the resultant important consequences of community and families upon patients' "spirituality or الروحانيه" and how this affects the overall outcome of patients' in coping with their illness.

In addition, ESRF participants recounted significant symptoms of social stigma and isolation either from family members, healthcare staff, or the wider community. Despite the Islamic ethos on caring for the ill, it became apparent while conducting the research that the community badly failed ESRF patients.

The community response was generally manifested in social ignorance, abuse, undermining the inner strength of patients, tagging them negatively and condescendingly (*shafaqa* looks), discriminating against them and causing them to become isolated:

> "To be honest with you they [community] shouldn't socially isolate you from the community, as you are not able to get work or no one allows you to do work for them [….]it will affect you "spiritually روحانيا… In your *"Nafs النفس"* it will have effects…In your social life it will have effects, it will have effects on everything". (Abo Omar)

As a result of social stigma and social isolation, five participants reported that such ignorance developed a sense of being destroyed which appeared to correlate with their "spirituality or الروحانيه":

> "I use to feel destroyed when I saw people in dialysis unit, I felt myself… That the people will say that my life is destroyed by this illness [….] they will make you feel that your life has already finished". (Abo Khalil)

Some participants stated that social stigma and withdrawal caused a sense of their inner strengths weakening, causing spiritual deterioration and distress, as for example in the popular misconceptions of ESRF causing patients to be "disabled sexually" (despite popular ignorance of the nature of the illness) and the association between ESRF and alcoholism:

> "It's [ESRF] because you are a heavy drinker that you developed this illness, this was the view of the community, and if you are of my family, and my family-in-law, they were frightened". (Abo Saber)

As reflected in the above quote, participants in this study viewed themselves as being be disadvantage in a number of ways as ESRF patients with respect to the community and family overview of them. Almost a half of the participants described "the community *shafaqa* look towards ESRF patients" as being one of the reasons that affected their "spirituality or الروحانيه" negatively, thus giving them a sense of unhappiness and dissatisfaction about their conditions. They also presented the community surrounding them as disadvantage in the sense that it created an unhelpful environment "spiritually روحانيا", not providing better cope and support and making it difficult for them to avoid the isolation and sense of emptiness. Participants' narratives revealed that the role of the community and its responsibility toward the ESRF patients might have possible implications on the ESRF patients' "spirituality or الروحانيه", with participants reporting negative influences on their *"Nafs النفس"*, emotions and on their spiritual experience as a result of their illness:

> "As a patient… And for example if I need to do anything… at home, in the street, or anywhere - they will view me as a patient". (Abo Shehab)

> "The community looks to the patient as very, very, very bad; the community will make you despair". (Abo Saber)

> "The community will step on you if they know you are a patient, no there is nothing…. Nothing" (Abo Obada)

Furthermore, three participants narrated other negative experiences such as discrimination against them as a result of their illness. Analysis of participants' accounts revealed that they had a perception of being discriminated against with respect to their right to work or residency as reported.

> "For example, I lost my residency rights as a result of this illness, you will feel yourself that you become a weaker person, you don't feel

> that you as yourself again, as a result the ESRF patient will start to interpret things around him mistakenly". (Abo Obad)

Other participants likened their dialysis treatment to being in jail, repeatedly stating that such feeling led to their "spirituality or الروحانيه" deteriorating. Unfortunately, there are no facilities in the Jordanian healthcare system to facilitate patient's dialysis if they wish to go to different cities or different countries. At least one participant stated that not having such service affected his "spirituality or الروحانيه" directly.

Some participants developed a sense of being a trapped on dialysis which limited their ability to cope with the illness, since their income was stopped as a result of their illness and there was no other help or support they could receive. All the emotions expressed above contributed to ESRF patients to developing a sense of isolation resulting from the social stigma and sense of being a burden as previously discussed. More than half of the study sample experienced such a sense of isolation.

> "If the patient becomes isolated he will never ever go out from his house, and he will not ask anyone to help, and this will affect his *"Nafs النفس"* and his body as well". (Abo Yasser)

Furthermore, many participants expressed their dissatisfaction with the way that they lost their employability due to ESRF. This helped to create a feeling of being inactive within the community they lived in. Participants highlighted the different experiences of men and woman due to the social constructs in Islam where men are expected to work and earn (see Chapter One); the obligation being on men to support women and their family, while the women are not expected to provide for the family. This indeed add extra challenges for ESRF patients to cope with, especially when more than half of the participants reported that losing employability was one of the significant factors that affected their "spirituality or الروحانيه". This negative experience led to them to feeling that they had been discriminated against due to their illness. The analysis of the interviews reflected that many of the participants experienced such perception in respect of work and employment.

> "I felt shock as I wasn't prepared for it to reach me at that stage, as I had a new contract with that hospital, and as you know if they discovered this they would have sacked me". (Abo Omer)

> "The work itself makes you feel that you are still alive, "spiritually روحانيا" and mentally and everything". (Abo Saad).

As a result of losing the chance to be employed again, life for some participants become colourless:

> "As when they suspended me from working… I started to realise that life is full of darkness, that's it[….] why didn't they let us work? For example, do we have to eject any person who is in dialysis and make him a burden?!! No... We have to gain benefit from him, if he is able to work". (Abo Omer)

Thus the importance of work and employment in promoting self-esteem and spiritual fulfilment was evident in the analyses of the interviews with many participants highlighting the importance of this for their "spirituality or الروحانيه".

Finally, many participants highlighted spiritual needs that could have been addressed through psychological care. Participants reported that the lack of psychological care affected their "spirituality or الروحانيه". In the literature review it was revealed that there is wealth of literature to support the assumption that "spirituality or الروحانيه" can be enhanced through providing psychological care. It emerged strongly throughout the interviews that when participants expressed their mental state as being comfortable and less stressed; their "spirituality or الروحانيه" appeared to be tranquil and vice versa.

> "Beside physical care the patient requires psychological care, and when I say psychological care, I mean "spiritually روحانيا, so the patient requires spiritual care, and all are agreed that the spiritual care is much more important than physical care, as in medicine, if you give someone an illusion by giving him a tablet or injection [placebo], he will get recovered [….] We don't need to say it's parallel with the medical treatment; it is more important than the medical treatment" (Abo Obada)

It was also observed that staff need to be educated further about the 'psychology of medicine' in order to understand patients' needs (e.g. new patients will be highly disturbed if the dialysis machine alarm goes off, while experienced patients and staff

view it more nonchalantly). It was also suggested that staff should remain with new patients throughout their dialysis session:

> "If you would like really the staff to help patients, the staff has to have the psychology of the medicine before they deal with the patient, as they need to understand his *"Nafs النفس"*, as when I started if the staff did not give me enough attention when the dialysis machine was alarming I would become very nervous, especially when I was a new patient, as they are not allowed to leave the patient". (Abo Ahmed)

Thus, analysis of the interviews uncovered that participants experienced spiritual distress in a number of ways: as a result of being a burden, through social stigma and social isolation, losing employability due to their illness and from lack of knowledge and psychological support.

In addition, analysis of the narratives showed that five participants appreciated their wife's role in their "spirituality or الروحانيه". Hence, the death of one's spouse was uncovered to be a traumatic event for an ESRF patient. This has been categorised as emotionally overwhelming and the most devastating human loss possible (cited from O'Brien, 2003, p283). One participant, Abo Rajab, narrated that he was badly affected "spiritually روحانيا" by losing his wife during his illness. His wife for him was everything, but once he lost his wife; his self-image appeared to be shaken as well as his physical abilities, and this generated a sense of helplessness. From his interview, his wife was a source that gave him meaning in life. However his sons and daughters supported him in overcoming his loss and provided bereavement care for the feelings of discomfort he experienced. Both his wife and brother had died suddenly from illness; and this reinforced his view of the transience of life. Culturally, "spirituality or الروحانيه" and religious belief are important factors that must be considered when providing bereavement care.

> "At 9:30 they called me to inform me that my brother passed away - it was barely fifteen minutes, and my wife - during one month a cancer ate her from inside". (Abo Rajab)

As Koenig (1994, p405) stated, religious beliefs can be used as a tool in defining rights or acceptance attitudes and behaviour in relation to bereavement care. However, Cullinan (1993) described providing spiritual care for the bereaved as a

"sacred art". According to Cullinan (p197), "spirituality was reviewed as undergirded and influenced by faith, cultural, background, religion and domination afflation of the practice". He argued that such factors could assist the bereaved individual with the his/her loss to cope in more positive approach.

> "…You will find the patient will stop moaning… stop being problematic… and complaining… and so on. The patient will remain connected with Allah". (Abo Khalid)

The narratives from participants revealed that sometimes despairing ESRF patients build an internal block which requires special care when addressing their "spiritually *روحانيا*". In this respect staffs have to avoid confronting patients when initiating spiritual dialogue or providing spiritual care for them. Abo Ahmed raised concerns for despairing ESRF patients by describing:

> "Yes… When I see the patient who is fed up already… And let us say that he is almost at the stage of *Yakfor*, you need to bring him the talk that is going to let religion and the belief into to his heart gradually [….] it will need time as well, and it needs tenderness, and it needs mercy, it will not work if you try to show him that this is right or wrong [….] you need someone who understands, a very strong believer". (Abo Ahmad)

Rejection

The analysis of participants' interviews revealed that many participants developed a sense of rejection as a sign of the desperation status that they went through in their illness. As presented earlier in Chapter 2 and in the first theme (Religion), Muslims are urged to seek remedy according to the orthodox and traditional interpretations of Islam; furthermore, the *"Balaa' بلاء"* concept is a form of spiritual coping which helps to enable ESRF treatment. Rejecting treatment due to belief in Allah's decision is an idiosyncratic aberration; thus, patients rejecting treatment have likely reached the desperation stage and require critical spiritual doses, care and support:

> "It means that the patient I'm talking to is not a believer; the patient should fear Allah, trust in Allah, and ask Allah for recovery, and to follow up their illness normally and to accepted with patience; it will

be *haram* to reject whatever Allah has sent to them. This is something they haven't brought to themselves and thanks to Allah…

"The educated person will accept everything, and he will be happy anyhow". (Abo Sara)

"When the patient's *"Nafs النفس"* is sick, and he does not accept his illness". (Abo Ali)

"He mustn't suffer in silence… especially when his mentality becomes tired… where he is going to start refusing and ignoring advices provided by doctors or nurses… where he will start debating with himself". (Abo Khalid)

"The patient will reject this condition initially not because he rejected the illness itself, but because he used to be in certain position before of the illness, such as this patient [points to the next patient], he used to do certain things, and suddenly he found himself sitting on this chair". (Abo Eizz)

On the other hand, many participants stated that lack of financial support and lack facilities within the dialysis unit, such as transport provision, factors that contributed to reaching this stage. The analysis showed that many participants had the perception of rejecting the ESRF treatment due to lack of financial support as they struggled to attend for dialysis or even buying the remaining treatment for themselves. The participants always compromised their needs as ESRF patients and their family needs. As a consequence, many participants stated that this had affected them "spiritually روحانيا", leading to them experiencing a sense of rejection of the treatment.

"I suggested to have special people in the hospital to walk around the patients to talk with them, to provide support for them, as I have missed some dialysis sessions because I didn't have the money to go there; what about giving the patient a lift or asking him what he needs, or giving whatever he can give, and asking him whatever he can do, and asking the patient if he can come to hospital comfortably, or

sending transport, or sending an ambulance to bring you in and out". (Abo Omr)

Another perception that affected most participants "spiritually روحانيا" that is deserving of extra attention was the lack of knowledge about their illness. Although, the majority of participants were educated (see table 4.1), when they faced their illness with no knowledge about it; it appeared that they underestimated the risk of rejecting their treatment.

> "Well let me tell you that I personally when I had ESRF I knew nothing about it [….] no one was conscious about what I would do or what I should avoid". (Abo Yasser)

> "When the day came that I had to start dialysis, it was a miserable day for me [. …] I am seeing not physically a problem but social problems". (Abo Sara)

> "The important thing you see is education [….]education committee or whatever [….] our TV needs someone to talk anyhow… You know…. To explain to the public … the newspaper, a small textbook typed nicely [….] Nothing exists like that about dialysis". (Abo Sara)

> "The community, they will not understand what chronic renal failure means". (Abo Sofyan)

> "I felt myself *jahil*, and I feel like I am in a deep Hell (*fajwah*), which has an effect on me and my life [….] I became frustrated, I became stressed, I became very nervous … I felt restricted by other people's talk" (Abo Saber).

Summary

The participants' narratives presented in this study provided me with a complex view into "spirituality or الروحانيه" during ESRF. It also demonstrated that ESRF "spirituality or الروحانيه" experiences cannot be separated from the daily living experience. Religion and relationships played a crucial role in enhancing patients' "spirituality or الروحانيه". In addition, it was highlighted that the participants with low "spirituality or الروحانيه" experience desperation in their "spirituality or الروحانيه" and can develop suicidal thoughts. This reinforced with me the importance of spiritual propagation during ESRF and the need for appropriate strategies tailored to patients' interests. Participants repeatedly emphasised the importance of social stigma and social isolation and social ignorance of ESRF and dialysis. This appeared to be an important factor in their "spirituality or الروحانيه" deteriorating. As a result, participants experienced a sense of helplessness. Participants also suggested psychological support as being very to the patient to conceptualise his condition positively. In the absence of this in the nurses' role, they suggested provision of a psychological adviser/counsellor to help with their strange thoughts.

CHAPTER 6: Discussion

Introduction

The analysis in the previous chapter illustrated how the phenomenon of "spirituality or الروحانيه" was uncovered according to participants' accounts and my own interpretations of these. I consequently identified three main themes: religion, relationships and desperation. Although the themes were presented as three distinct domains, I noticed a large degree of overlap between them. It was manifested that both religion and relationships play an important role in an individual's spirituality, and a deficiency in either frequently may led to desperation. Furthermore, the themes were interrelated with a number of consecutive steps identified as part of a synchronised journey that many participants underwent to achieve the best outcomes in relation to spirituality and spiritual care.

This chapter discusses what the participants shared with me about their spirituality and my interpretations of their experiences during ESRF in the context of the wider literature on spiritual phenomena and care. This chapter draws together all previous themes illustrated in my study and addresses the main research question, "How is spirituality experienced by Jordanian patients with ESRF?" The chapter shifts from descriptive data and the interpretive practices of hermeneutic phenomenology to an integrative consciousness of understanding the phenomenon of spirituality during ESRF in Jordan. Reflecting on Neuman's systems model and Rogers's science of unitary of human beings, assumptions regarding how individuals interact with their environment were the basic consciousness (Kreitzer and Koithan, 2014). Consciousness can refer "to experience itself. Rather than being exemplified by a particular thing that we observe or experience, it is exemplified by all the things that we observe or experience", and it creates the power to enhance our spiritual experience (Gilbert, 2011; Velmans, 2009, p139). However, Kreitzer and Koithan (2014) argued that the integrative consciousness of understanding the phenomenon represents compassion in providing care for individuals by health care providers.

I will explore how my own views and understanding of spirituality changed and developed during the process of undertaking this research. This is an important aspect of phenomenology and reflexivity.

Collier-Reed et al. (2009) suggest that to ensure the trustworthiness of phenomenological studies, the researcher must relate to the internal horizon (the study's findings), and compare this with the external horizon of what others in the field experienced. Such wider consideration suggests in turn how spirituality experienced during ESRF could influence further research and add to formal theory in the area of study. Although, existing literature has already discussed few of my findings, such as the impact of social support in ESRF patients' spirituality, my study uncovers a crucial essence – Religion – for Muslim ESRF patients which has not previously been fully considered. Thus, it is hoped that the discussion will enhance the understanding of healthcare providers in Jordan to deal with ESRF spirituality and enable healthcare providers to utilise the phenomenon of spirituality as a tool to manage long-term ESRF spiritual care. Finally, I will reflect on my research process, other methodological aspects and the limitations that I have faced, which might possibly be of assistance to future researchers. For clarity, I will point out the main findings in each theme.

The Cultural Context in the Search for Meanings of Spirituality

The participants' accounts of spirituality were classified into three main themes which echoed the framework of (Stoll, 1989). Stoll illustrated how spiritual well-being can be achieved throughout the vertical and horizontal connections in which love, forgiveness and hope can be expressed. However, the findings from this study uncovered that cultural and religious concepts such as *"Balaa' بلاء"*, *Nafs*, *Iman*, and *Qadr* differ from those of the English-language studies found in the literature review. The following section discusses how religion in Jordan has important multiple platforms for individual's spirituality.

There has been a great deal of debate in the literature concerning the relationship between spirituality and religion, and whether they are separate entities or indeed conceptual entities in themselves (Ameling and Povilonis, 2001; Elizabeth Rippentrop et al., 2005; Fry, 2000; Krause and Wulff, 2004; Lagman et al., 2014; Nelson et al., 2002; Paley, 2008). Numerous studies have offered definitions of spirituality (see Table 3.3), and they can be categorised as either protagonist or antagonist. The supports the notion that spirituality is not part of religion, while the latter takes the opposite view. I became acutely aware during the fieldwork during this research that religion is the bedrock of spirituality for Jordanian ESRF

participants. Indeed, when I questioned the participants directly about spirituality, the participants had no understanding of the term 'spirituality or الروحانيه" or its underlying concept in the absence of religion. Religion was the main source of meaning and purpose throughout the different stages of their illness. As participants stated, "spirituality is something to do with religion itself and hasn't got any other sides". This is an important finding, since a lot of the Western healthcare literature emphasises a "secular" concept of spirituality (McSherry, 1997; Paley, 2008). My study findings suggest that such a "secular" concept of spirituality had no meaning for the Jordanian Muslim participants in the absence of religion, which has consequences for the use of spirituality in multi-cultural settings in Western countries.

I discovered that participants understood their depressive symptoms (extending to suicidal ideation in the worst cases), their coping abilities and behaviour (spiritual self-efficacy), and their long-term psycho-social wellbeing purely in terms of spirituality and religiousness, and as a distinct entity from their biomedical treatment (i.e. dialysis and medications), except with regarded to how dialysis contributed towards their main spiritual angst (e.g. about providing for their families, and their feelings of worth). This is consistent with the findings of previous studies from Western cultures which found that religion generally plays an important role in individuals' spirituality (Albaugh, 2003; Fry, 2000; O'Brien, 1982; Tanyi and Werner, 2003; Walton, 2002; Walton, 2007). The reason for this is not clear, but it may be related to what religion and culture can offer followers in terms of finding meaning and purpose and enhancing inner strength and hope in their illness.

Jaspers claimed that "humans are always in situations; some situations we can influence and change, others cannot be changed no matter what we can do about them" (Fuchs et al., 2013; Smith et al., 2013). Based upon the 'human becoming' theory, Parse (2007) suggested that individuals are free to choose their own unique meanings in any situations they face. As seen in previous chapters, what was uncovered in my study was that ESRF patients turned to religion, citing Qur'anic verses and Prophetic Hadiths to extract meanings through different stages of their illness. This was highlighted by participants' perceptions of spiritual needs as being related to the need for "shelter" and "rescue" in many aspects of their day-to-day lives.

An ubiquitous characteristic among participants was their understanding of illness in terms of the *"Balaa' بلاء"* concept, which seemed to have important implications for ESRF patients' spirituality; participants reported this gave them meaning and purpose in terms of their perception of their illness – they reported being comfortable, stabilised, in control, and feeling tested, rewarded and purified; they had the sense of being loved, hopeful, and trusting in Allah and they experienced tranquility and enhanced connectedness with Allah. Their inner strength was enhanced and their spirituality empowered from their understanding of this concept. However, during the initial period of diagnosis, *"Balaa' بلاء"* was associated with negative implications for participants' spirituality, and they recounted feelings of tightness and tiredness, being weaker and losing control and direction in life, being destroyed and suffocated. This was characterised by questioning, 'Why me?', which was followed in the typical narrative by a process of introspection and acceptance that ultimately led to the internalisation of the *"Balaa' بلاء"* and its positive role as a concept to aid acceptance. The findings suggest that all participants compared their relationship with Allah before and after being diagnosed with ESRF, whereupon they discovered a gap in their spiritual and religious commitments. Almost all participants developed a sense of rebuilding their relationship with Allah by increasing their spiritual and religious practices. These results consistent with those observed in earlier studies (Tanyi and Werner, 2008; Tanyi et al., 2006; Tarakeshwar et al., 2006; Walton, 2007). It is possible therefore; that participants might develop a sense of transcending vertical relationships as a result of a lack of horizontal relationships. Further research is required to establish this. The above finding is remarkable though, as it demonstrates a "journey" in a relationship with Allah through the illness journey, and becomes a way of combining a notion of spirituality with finding meaning, but within the context of a specifically religious relationship. Thus, the vertical relationship leads to spiritual development for this journey. However, the journey with Allah requires direction and needs to be guided with rules. These results agree with the findings of other studies in which religious practices have provided the framework for achieving spiritual development in individuals' journeys within their cultural framework (Aldridge, 2000). In addition, the ACCESS model suggests a useful framework for nurses implementing transcultural care practice (Narayanasamy, 2002).

The *"Balaa' بلاء"* concept appeared to be an important aspect in establishing rules for nursing care: participants stated that nurses could offer a spiritual 'dose', or empower patient spirituality by behaviours that address patients' spiritual needs such as: being patient, tranquil and *mostakeen*, encouraging acceptance and being appreciative, providing comfort, being stabilised and in control, and enhancing inner strength and an empowering sense of spirituality that encompass their whole outlook on life and the world. Again, these results are consistent with those of other studies and suggest that addressing patients' spiritual needs may enhance spiritual well-being (Baldacchino, 2010). These findings also seem to be consistent with the transactional model of stress and coping (Lazarus & Folkman, 1984), with special reference to the above domains of religious behaviours attributed to ESRF patients' experiences and the importance they attach to religion and being connected to Allah, known as the transcendent connection (Stoll, 1989). This has an important implication for nursing educators in Jordan in developing a nursing model that can examine and support nurses and other healthcare professionals' behaviours and attitudes in order to address the above spiritual needs. Since it has been established that patients' spiritual well-being and nurses' spiritual well-being are interrelated, a further study with more focus on nurses' spiritual well-being is therefore suggested. I would argue here that my findings may have relevance beyond the Jordanian context in educating nurses' on the importance of appreciating the religious dimension to the spirituality of their patients.

A possible barrier to undertaking research on spirituality among Arabic-Muslim patients may be the cultural sensitivity of discussing religious concepts in a healthcare context in which, as I stated earlier, the traditional biomedical healthcare paradigm remains dominant. I personally experienced that many participants initially did not understand the relevance of spirituality to their health condition. It is notable that the limited research of Muslim patients' spirituality has mainly been conducted in Western countries (notably the UK), where healthcare systems are more sensitive to patients' multi-faceted needs, rather than in the Muslim-majority countries, where care remains focused on physical illness and medical treatment. Thus, there is an urgent need for the extension of spiritual care studies into targeting care for individuals of particular faiths. This can help healthcare professionals to address Jordanian ESRF patients' spiritual needs in order to provide holistic care and importantly to provide a balance between Body (البدن), Spirit (الروح) and *Nafs* (النفس).

These findings further support the idea that finding a balance in ESRF patients' needs can enhance their spirituality (Walton, 2002).

An important contribution of this study has been the identification of the *"Nafs النفس"* concept as a fundamental index of Muslim patients' spiritual wellbeing. Without any prompting from me, patients unanimously described their spiritual status (whether negative or positive) in terms of *"Nafs النفس"*, outlining how it changed from one pattern to another, mobilised, and ultimately became "Tranquil *Nafs* النفس المطمئنه" at the end of a long period of soul-searching (i.e. a change to spiritual self-efficacy). Furthermore, this transformation in *"Nafs النفس"* patterns helped the ESRF participants to rectify all the negative thoughts and behaviours they had hitherto held either against themselves or others, or indeed toward accepting their illness. Thus, reaching the "Tranquil *Nafs* النفس المطمئنه" was considered to be the ultimate goal of spirituality for the participants. The identification of this concept may have implications for other fields and could be explored by future studies. Furthermore, all of the participants in this study recalled their period(s) of despair retrospectively, having undergone an autonomous spiritual journey; it would be useful for future research to analyse the spiritual status of patients likely to be in a condition of despair (i.e. during the initial period following diagnosis) in order to investigate how they conceptualise their *"Nafs النفس"*, and to analyse their spiritual status generally at this stage. This finding is important, as elaborated on the *"Nafs النفس"*concept in Chapter 5 where it was shown that *"Nafs النفس"* included a religious dimension and a relationship to the inner self that includes negotiation with Allah.

Stoll (1989) suggested in his model that "self" is the centre of spirituality, in which both vertical and horizontal dimensions are united. Any lack or disturbance in those dimensions resulting from separating the self from such an amalgam is where the individual starts to experience spiritual distress (Yang et al., 2012). Nevertheless, ESRF patients in the present study stated that there was a "U" turning point in their '*Nafs'* patterns that helped them to overcome spiritual distress or deterioration, accepting their illness and letting their *Nafs* return to the above amalgam, and helping them to continue finding meaning and purpose in their life. The participants in this study stressed the importance of such a point in their spiritual journey with the illness. This result is in accord with the findings of Yang et al. (2012), who showed that spiritual distress/pain was the cornerstone of their patients' spiritual growth.

Yeh (2006) cited (Yang, 2009) argued that meaning and purpose in life could be enhanced by strengthening their sense of self-awareness. Unfortunately, the participants in my study experienced a lack of self-awareness when initially diagnosed with ESRF, especially when faced with restrictions from the community in their day to day lives. As a result, they stated that their strengths and weakness and *Nafs* patterns were assisted in overcoming such restrictions. They all started by self-motivating themselves and spiritually growing beyond their restrictions. Such spiritual growth develops a motivational or "fighting" spirit leading many participants to consciously regain power and control in their life and to become an active member in their community. Further, it has even given some participants a sense of victory over the healthy person. Overall, this spirit has enhanced ESRF patients' spirituality, providing a sense of achievement in their lives and maintaining the hope that enhanced their spiritual well-being, and helped them to overcome the fear of being lost from the moment they were diagnosed with ESRF. The present findings seem to be consistent with other research which found fighting spirit was significantly associated with spirituality and spiritual well-being in patients (Travado et al., 2010; Whitford et al., 2008). These findings further support the idea of the importance of self-awareness and self-concept in self-esteem, and in maintaining hopefulness (Ritchie, 2001). However, participants stated that they still needed help and support to overcome the restrictions in their life. In a broader prospective, this is in agreement with the findings of other studies, in which helping an individual to get back on track with their life was found to be advantageous in improving their spirituality and spiritual well-being (Al-Arabi, 2006; Albaugh, 2003; Wilding et al., 2005; Yang et al., 2012; Yang et al., 2010).

The present study revealed that *The Iman* was identified as a key aspect of spirituality. Many participants themselves defined their level of *Iman*, which they equated with their level of spirituality. I understood from participants' responses that they attempted to assay their spiritual status and condition in terms of fluctuations in their level of *Iman*. Thus the initial despair was associated with a low level of *iman* (or latent *iman*) followed by acknowledgement and acceptance of ESRF as a *"Balaa' بلاء"* from Allah, representing an increase (or mobilisation) of *Iman*, enabled by the corresponding belief in and acceptance of *qadr* (as seen in Chapters Two and five). It is natural that participants in this study would understand their spiritual condition in terms of *Iman* as this is one of the fundamental concepts

of Islamic religion (e.g. the six pillars of *iman*), which promoted acceptance and was fundamental in shaping how their spirituality enabled self-development (i.e. preparing their *"Nafs النفس"*) to deal with the illness. Participants stated that "spirituality or الروحانيه" for them is *qadr* and acceptance thereof: "Spirituality or الروحانيه" to me is *qadr*". These findings further support the relationships between spirituality and fatalism which appear to be important in Jordanian ESRF spirituality (Travado et al., 2010). This finding suggests that *Iman* and *qadr* influence participants' interpretations of the meanings they extracted from their illness. In Islamic cultures, *Iman* and *qudr* are used to answer and explain, "Why is this happening to me?" and, "What do I do?" Littlewood and Dein (2013) found that fatalism was used to verbalise the way in which Muslim patients indicated acceptance and submission to Allah's will regarding their having an illness. According to my participants, these concepts were also used to resist "giving up" too soon and instead to reflect their true faith in accepting their illness with a resilient attitude. Although, fatalism appeared to be central in Jordanian ESRF patients' spirituality, there can be adverse effects to such an attitude in giving false hope, or in some situations no hope at all, where patients leave everything to Allah. Nevertheless, hope appears to be an important element in spirituality (Baldacchino, 2010; Coyle, 2002; Nabolsi and Carson, 2011; Stoll, 1989). Hope has been recognized in the literature as multifaceted phenomenon that is important to the process of coping with internal and external stressors and life threatening illness (Aldridge, 2000; Gaeeni et al., 2014). By drawing on the concept of hope, Buckley and Herth (2004) have been able to investigate meanings of hope and the fostering of hope in terminally ill patients. They defined it as "an inner power directed towards enrichment of 'being' ". This inner power, according to Lazarus and Folkman (1984) and Frankl (1984), was important in the coping process and in surviving both internal and external pressures. As stated earlier, the Prophet (Peace be upon Him) urged Muslims to seek remedy for any illness and did not ask them to leave everything to Allah (Tseng and Streltzer, 2008). In doing so, I would argue that this involves multiple interactions between patients and others i.e. healthcare professionals, family members, the community, and even with Allah, in which those interactions may provide and maintain hope for ESRF patients on different levels. This is an important notion – as it may lead to a refinement of the concept of "fatalism", which is almost a prejudicial view of Islam in the West, where it is often

regarded as a “fatalistic” or “submissive” religion (Santesso, 2013; Shinar, 2004; Tsuḳerman, 2002). The study findings suggest a view of “fatalism” that sees it as a negotiation, an acceptance that arises only after a negotiation, or even a negotiation with Allah. Further studies, which take these variables into account, will need to be undertaken.

It is important to note that participants reported that pain in general could be controlled through enhancing their levels of spirituality. The participants related deficiencies in their spiritual status (self-perceived) to expressions of physical pain such as: “tightness in chest”, “tiredness”, “pain” and “spiritual pain”. Although spiritual pain may come in different shapes and forms and is not necessarily expressed in the form of religion (Taylor, 2002), participants associated physical and psychological pain with their spiritual levels, in terms of their religious commitments. In other words, patients expressed that a high level of spirituality and of religious observance/ideation was related with experiencing less pain and being better able to cope with pain. This finding is in agreement with those of O'Brien (1982), which showed spiritual pain was experienced as a sense of discomfort, arising from a lack of spiritual fulfilment or religious commitment. Spiritual pain has also been experienced through physical and psychological symptoms (Mako et al., 2006). For example, in terms of psychological pain, Delgado-Guay et al’s (2011) cross-sectional study in the USA found that spiritual pain was significantly associated with lower self-perceived religiosity among terminally ill patients. It is encouraging to compare this finding with Koenig et al. (2001) who concluded that religious beliefs and practices can relieve stress, help a patient retain a sense of control, and maintain hope and a sense of meaning and purpose in life. Similarly, Lago-Rizzardi et al. (2014) concluded that individuals with a high score of spirituality had less pain and fewer complaints. In contrast, others did not find any relationship between physical and spiritual pain (Delgado-Guay et al., 2011; Koenig et al., 2001; Mako et al., 2006). Whilst the literature suggests that there appears to be overlap between physical pain, psychological pain and spiritual pain, the participants in my study suggested that spiritual pain can be distinguished from other types of pain mentioned above. This difference is vital, as the treatment for physical pain and psychological pain are quite different from the treatment of spiritual pain. Participants in my study highlighted that spiritual pain cannot be treated by means of medication or just psychological support: it may require the use of different

techniques mentioned in the previous chapter. This finding was in line with that of other researchers in palliative care, and corroborates the ideas of Mako et al. (2006), who doubted that spiritual pain can be alleviated by psychopharmacological treatment. In discussing spiritual pain in palliative patients, Satterly (2001) reported that spiritual/ religious pain can add an extra struggle to many terminally ill patients. According to Satterly, spiritual pain is manifested through the sensing of shame which can be progress further until it ultimately leads to loss of hope in God completely. As revealed above, the participants in this study stressed that it was the inevitability of such spiritual pain in their experience with ESRF which was a turning point for them. These findings match those observed in earlier studies (Yang, 2009; Yang et al., 2012; Yang et al., 2010). Also, the findings in this study echo those of Taylor (2007) who suggested seven principal errors which healthcare professionals need to avoid in dealing with the spiritual pain of individuals: (1) changing the topic when patients experience it, (2) giving a superficial answer, (3) trying to make the topic funny, (4) imposing a positive turn, (5) minimising the seriousness of the topic, (6) showing fake interest, and (7) showing muted anger with sarcasm. However, more research on spiritual pain needs to be undertaken before the association between spiritual, physical and psychological pain is more understood for Jordanian ESRF patients.

The results of the study indicated that multiple fears and uncertainties were expressed by participants from the time of ESRF diagnosis which were related directly to their spirituality levels. For example, participants reported fears of confronting dialysis, physical and psychological limitations, losing income and employability, family and social roles and status, losing friends, needling for dialysis, uncertainty and being useless. Such fears are common among ESRF patients (although the particular emphasis on socio-economic roles in this study is indicative of Arab-Islamic culture and gender roles), but it is remarkable to note that all participants reported this to be an indication of low level of spirituality, level of *Iman* and lack of knowledge, even when the participant was otherwise educated. This is important because spirituality was the main “rescuer” that helped the participants comes to terms with what was happening to them. It shows how important spirituality is at all stages of the patient journey, not just during assessment or interview. Again, these results agree with the findings of other

studies, in which spirituality is seen as life-sustaining (Al-Arabi, 2006; Clarkson and Robinson, 2010; Herlin and Wann-Hansson, 2010; Walton, 2002; Walton, 2007).

In the context of this study, the findings uncover erroneous beliefs about ESRF and dialysis, which might be largely attributable to the prevailing nursing model in Jordan which remains focused on physical needs (Nawafleh et al., 2005). Since the majority of healthcare providers in Jordan are private hospitals, as in most developing countries, the nursing model in Jordan remains underdeveloped in terms of working autonomously in addressing patients' needs. Nurses remain task aligned and task oriented with their roles always led by medical staff. It seems that nurses play a less constructive role for ESRF patients and their families during the pre-dialysis phase than in Western countries. This may represent a failure to address patients' fears and lack of awareness, both of which undermine their spiritual wellbeing, as reported by participants when they stated that spiritual distress/pain affected their overall spiritual wellbeing. This is why I think policy makers as well as healthcare providers need to integrate the notion of spirituality into ESRF patient care all the way through, from diagnosis to palliative care; indeed, the most acute spiritual crisis was unanimously reported to have occurred during the first two years following diagnosis, with patients being particularly vulnerable in the initial period. Reflecting on my own experience – which is of course, a key element of hermeneutic phenomenological approach, I personally met with similar fears in the absence of spirituality, where this fear later developed into spiritual pain. Just as I experienced the fears echoed in the participants' accounts, these fears were relieved using spiritual/religious forms of coping rather than via psychological support or by psychiatric interventions. This resonates with Aldridge's discourse that diagnosis can be a critical juncture in chronically ill patients which can trigger a spiritual quest (Aldridge, 2000). The findings from this study prompt us to look at the important role pre-dialysis nurses can play in improving and addressing spiritual needs, increasing awareness, and educating patients, their families and the public in the early stages of ESRF.

Another important aspect of spirituality to emerge was engagement with religious practices (e.g. reading the Qur'an, *duaa'*, *dhikr*, *Tasbih*, *Istighfar*, praying and fasting, donation, religious trips and engagement with spiritual dialogues). This was revealed as a source of spiritual comfort and inner power, and promoted a sense of

tranquility. This finding is consistent with the findings of previous research that indicate the important roles of spiritual engagement in meeting the spiritual needs of patients (Narayanasamy and Narayanasamy, 2008; Tanyi et al., 2006; Walton, 2007). Participants highlighted the importance of such spiritual practices and spiritual propagation, and expressed a desire for appropriate strategies tailored to patients' interests in order to identify their spiritual needs and to provide them with a "spiritual dose". In the context of being on dialysis (i.e. the dialysis unit culture), research participants suggested that the culture in the dialysis unit should be redefined in a way conducive to realising individuals' spiritual needs. It was recommended by participants that ESRF patients would like to find verses of the Qur'an or Hadiths to reconnect them to the transcending power of Allah and to refocus on the role of religion. This has been a common feature of the aesthetic culture of the Middle East for millennia (i.e. religious inscriptions in public view); in terms of Heidegger's terminology, such manifestations prompt participants to have the opportunity to *Do* a more effective role, in facing ESRF authentically. As can be seen in the previous chapter, a *strong sense of being* was developed by immersion in spiritual activities, which were viewed by participants as requiring minimal effort while offering highly effective benefits. The hanging of spiritual texts (i.e. inscriptions, paintings or tapestries) represents a cost efficient way of promoting "spiritually روحانيا" beneficial, self-efficacious behaviours among ESRF patients (i.e. displaying reminders of spiritual activities encourages positive behaviours without necessitating healthcare staff intervention). The present findings seem to be consistent with other research which found that religious sources, such as prayer and scripture reading in particular, which have been identified as important spiritual activities, were important to support patients in facing spiritual distress (Narayanasamy, 2002; Tanyi et al., 2006; Yang et al., 2012). The study findings highlight an important emphasis on the practice of spirituality for Muslim ESRF patients which are often under estimated in the literature.

This study has highlighted some important implications for dialysis unit managers to consider, and draws the attention of stakeholders in hospitals to set up their ESRF units with mechanisms for identifying spiritual needs and religious practices. The participants recommended spiritual dialogues (among themselves and with staff members) to enhance their spirituality and spiritual well-being. However, some participants criticised the lack of spiritual expression by healthcare professionals in

the dialysis unit. As a consequence, they stated there was an adverse effect on their spirituality. Numerous studies have identified the positive role of religious beliefs and behaviours in promoting coping with many forms of chronic illness, including hypertension, pulmonary disease, diabetes, chronic renal failure, surgery, rheumatoid arthritis, multiple sclerosis, HIV/AIDS, polio and addictive illnesses (Kaye and Raghavan, 2002); with cardiac patients (Baldacchino, 2002); in children (Campbell, 2006; Cotton et al., 2012); in palliative care (Ekedahl and Wengström, 2010; Hayden, 2011); with psychiatric patients with personality disorders (Liu et al., 2011); with cancer patients (Nixon and Narayanasamy, 2010; Swinton et al., 2011) and renal patients (Molzahn et al., 2008). My study addresses some of the important questions raised by previous researchers of spirituality in terms of Muslim spirituality in particular (Clarke, 2009), and can potentially help non-Muslim chaplaincies in Western cultures to be better prepared to address Muslim patients' spiritual needs (Abu-Ras and Laird, 2011). I think this is important, and education on these key concepts of Muslims' spirituality is a particularly important contribution of my study..

One unanticipated finding concerned the role of music in spirituality. Participants who had tried music as part of spiritual self-efficacy told me that it had a spiritual effect, but that that it was generally a negative one. The ESRF patients expressed that music was not a cause for calmness or tranquility but rather of distraction and depression (which they related to satanic *waswas*). Therefore, music was an undermining force in their spirituality. Hence, although some participants stated that listening to music helped them to temporarily forget the illness, this was perceived by them to be a form of avoidance that prevented their authentic spiritual coping with the illness and it resulted in an absence of "tranquility" in their *Nafs*; in addition, intermittent feelings of sadness were often engendered by music.

This is in sharp contrast to the findings of previous studies conducted in a Western context (Atkins and Schubert, 2014; Cook and Silverman, 2013; Darmon, 2015; Driver and Bennett, 2015; Westermeyer, 2013), which frequently highlighted the benefits of music in spiritual therapy. The most likely explanation for this discordance is that participants in this study cited the benefits of listening to and/or reading the Qur'an as being a source of comfort and tranquility (i.e. spiritual care). The Qur'an is understood in Arab-Islamic tradition to comprise a "Recitation" (the

literal translation), not a physical book; thus, unlike the Bible, which is predominantly *read* in the Anglo-Saxon/Protestant tradition, the Qur'an is *heard*, thus music is perceived to be a "spiritually روحانيا" inferior alternative to the Qur'an among Arab-Islamic patients. This also relates to the cultural diversity of the use of music between Western culture and others; while music has a history of spiritual application in the European/Christian tradition (e.g. church bells, music and hymns), this is relatively unique; while Jews occasionally use a shofar (horn), music *per se* is not a part of religious observance in the other Abrahamic religions. Islamic culture particularly abhors the use of wind and stringed instruments. Albeit that the muezzin's call is comparable to chanting, and drums have been used on occasion in some Islamic traditions, music as it is commonly understood is not perceived as a "spiritually روحانيا" helpful phenomenon in the Arab-Islamic tradition. Such findings may prompt healthcare providers and policymakers to consider that music should not be presumed to be a universally applicable part of spiritual care strategies within dialysis units.

Furthermore, music is a matter of taste, and it has numerous varied psychological impacts. Indeed, the same piece of music can be 'heard' differently by different listeners, having different behavioural and neural impacts (Virtala et al., 2014). Even in cases when music can be assumed to benefit patients (e.g. people with motor diseases), the "overflow of music into the motor system, can easily go too far, becoming irresistible and perhaps even coercive" (Sacks, 2006 ,p129). These complex considerations indicate that any attempt to use 'music' in a therapeutic context is fraught with the possibility of failure, undermining its efficacy as a practical therapy in spiritual care. This might serve as a prompt for further research to be done to investigate the implications of music in particular cultural and medical contexts, such as Muslim ESRF patients' spirituality.

In contrast to my study findings, two studies exploring the perceptions of spirituality and spiritual care among NHS nurses in the UK argued that spirituality can be separated from religion (McSherry, 1997; McSherry and Jamieson, 2011). However, analysis of their argument exposes serious weaknesses. Firstly, McSherry (1997) states that belief in God is no longer important to individuals, but such crude generalisations are not applicable far beyond McSherry's own Christian modernist/secular setting in the West, and are obviously irrelevant and meaningless

for the billions of people worldwide for whom belief in the Divine is a central part of their identity. Participants in this study highlighted that belief in Allah is fundamental in shaping their spirituality. Both Heidegger and Stoll referred to belief in God/a higher power as part of being-in-the-world and an important element in spirituality (Heidegger, 1962; Stoll, 1989). In addition, the participants in my study stressed the importance of such a belief, viewing it as a source to maintain concepts and qualities such as: patience, purity, reward, trust, surrender and conviction, acceptance and being appreciative, rescue and shelter, hope, meaning and purpose. Furthermore, participants themselves stated that spirituality cannot be divorced from religion.

A different approach which held that religion and spirituality can be separated was espoused by Paley (2008), who argued that spirituality can lend itself to psychology and a naturalistic approach. This could be attributed to a number of reasons not necessarily applicable to my study. Paley built his argument upon the Christian view of spirituality , and the expediency of a non-religious spirituality for spiritual care in secular Western societies (Baldacchino and Draper, 2001; Narayanasamy, 2006), particularly in Europe; only 7.5% of people attend religious activities in the UK compared to 30% in the USA (Paley, 2008). The socio-cultural milieu is markedly less secular in the Middle East. As I mentioned earlier, in Jordan, 95% of the population are Sunni Muslims, who equate spirituality with religion, thus it was unsurprising that participants extracted meaning and purpose from religion throughout the different stages of ESRF. Participants showed how spirituality was for them as individuals an authentic experience of being-in-the-world; all participants turned to religion to maintain their psychological comfort, imbuing the platform of spirituality with aspects of purpose, hope, inner strength, inner comfort and inner peace in order to reach the ultimate goal of spiritual wellbeing (tranquility/tranquil *"Nafs النفس"*).

As witnessed in the previous chapter, the thickness and complexity of my participants' accounts showed how spirituality manifested during ESRF as a fundamental way to promote acceptance of their illness. This was facilitated by religious belief in Allah, the Day of Judgement and the Afterlife, which provided them with a sense of hope that was essential to motivate them and to provide meaning and purpose throughout their illness. They also stated that religion could

enhance and empower their spirituality and their emotional feelings toward their illness. It was also noted that a sense of hope was embedded in religious concepts, notably leading to the exclusion of hope from the realm of medical science by some participants (although this did not undermine compliance with medical treatment regimens). This finding was in-line with a growing body of literature highlighting the importance of hope during illness (Davison and Simpson, 2006; Herlin and Wann-Hansson, 2010; Johnson, 2007; Matthews, 1998; Moran et al., 2011; White, 2006; Wright, 2002). Hope fundamentally affects coping, self-efficacy and ultimately psychological and biomedical wellbeing and shapes individual values (Davison and Simpson, 2006; White, 2006). Yet, motivating hope for ESRF patients in Jordan is difficult.

According to the participants from my study, hopefulness was associated with being away from dialysis, having renal transplantation, being productive, being engaged with spiritual dialogue, being mentally occupied, being motivated in and out of the dialysis unit, being able to travel and receiving dialysis abroad, being valued and being supported to become independent.

On the other hand, data from several sources have identified that losing hope is associated with losing the sense of self (Yang et al., 2012), and for ESRF patients a sense of losing self is associated with becoming hopeless (Yeh and Yeh, 2007). The participants in my study suggested visible signs for losing self and becoming hopeless such as: anger at home or at the dialysis unit, pretending they are sleeping during dialysis, avoiding eye contact, non-compliance with treatment, and missing dialysis sessions, being fastidious (natty gritty), and developing negative thoughts. Participants stated that their overall spirituality and spiritual well-being were influenced by a constant struggle between feeling hopeful and hopelessness. These findings are endorsed by Whitford *et al.* who found that a lack of spiritual wellbeing was significantly associated with a sense of hopelessness (Whitford et al., 2008).

My study suggests that maintaining hope and ambitions for Jordanian ESRF patients in a dialysis unit, through spiritual/religious engagement and through participating in discussions and lectures, may assist them in their search for new meaning and purpose in life that could help them to mobilise their *Nafs* to move from *Nafs Ammarah* to tranquil *Nafs*, thereby promoting their positive emotions. Aldridge (2000) suggested that maintaining positive emotions including hope and

unconditional love are an advantage to patients' coping process during the diagnosis period and postoperatively. Therefore the spirituality discourse of previous studies related to this field needs to be reconciled with the spiritual meanings that Muslim patients attach to their illness and healthcare.

Reflecting on Paley (2008) who challenged nursing literature to show how "spiritual concern" applies to patients asking the question, "Why me?", I might agree on a personal level that this might apply if we were to discuss spirituality in a Western cultural context. However, in the Jordanian context, all participants reported initial feelings of "Why me?" during their initial reaction to ESRF diagnosis, questioning why Allah had afflicted them with the illness, which they subsequently (sometimes after many months or years) attributed to a weak level of spirituality. Similarly, Paley's claim has been criticised by a number of other researchers. For example, Pesut (2008) pointed out that the religious perspective has important elements in offering ideas for spirituality in nursing. The participants in my study ultimately regarded such questioning as evidence of a lack of true belief, and weakened spiritual status related to a lack of trust in Allah, which caused the *"Balaa' بلاء"* to be perceived as something beyond endurance. In addition, the participants in my study suggested that spirituality and religious practices function as consecutive steps, not only to answer such questions but also to strengthen their spirituality, providing them with "spiritual doses" and mobilising their *"Nafs النفس"* in order to reach tranquility. This represents an original contribution to the existing body of knowledge. Another notable finding I identified from participants' accounts regarding psycho-spiritual causality was that spiritual activities enhanced their psychological wellbeing, rather than vice-versa (i.e. increased spiritual activity activated feelings of tranquility). The findings of the current study are consistent with those of O'Connell and Skevington (2010), and (Fry, 2000), who found that spirituality and religious values and beliefs are different to psychological needs, and are important for an individual's wellbeing. Thus my study presents relevant findings to the existing arguments, making a further important contribution to the debate on spirituality.

Taken together, the discussion about the theme of religion and how spirituality manifested during ESRF in Jordan shows a resemblance with the existing literature conducted within Western culture that showed how religion is intertwined with

spirituality. The Jordanian ESRF patients who participated in this study represented a diverse group of the Jordanian community in terms of age group, marital status, parental status and dependents/dependency, income, employment, education, duration of ESRF and renal transplantation status. They unanimously experienced the spiritual aspect of their illness in terms of three religious concepts: *"Balaa' بلاء"*, *"Nafs النفس"* and *qadr*. These concepts, which they knew academically, were activated by the spiritual distress they experienced and enabled them to cope with the long and dangerous journey of ESRF spirituality in an unstructured way (i.e. with no formal or structured spiritual support from the healthcare system).

Thus, the trite contention that Muslim patients are indoctrinated with their religion and this is why spirituality turns out to be so closely aligned with religion compared with other contexts is easily exposed as false; the area and people of Jordan has been continuously following Abrahamic values and beliefs for approximately two thousand years (particularly Christianity and Islam), hence religious beliefs are the core of important life activities surrounding birth, marriage and death, yet the religious concepts mentioned by participants in this study were not activated or experienced until they experienced their illness, after a period of profound spiritual angst. This is very important contribution – so, in a way, the crisis activated a previously tacit set of concepts by mobilising and giving meaning to a tradition in a "lived" way. This finding supports previous research into religious activities and spiritual self-efficacy behaviours which are significant for Muslim patients in countries where Islam has been actively suppressed for many years (e.g. Turkey) (Ozbasaran et al., 2011).

Regardless of *why* participants believe in the efficacy of religious values and practices as part of spiritual wellbeing, the fact is that they *do*, and it is incumbent upon healthcare providers to cater for their spiritual care needs accordingly. As Heidegger (1962) contended, we all come to the world and we do not chose who we are; in the notion of *Das Man* or "the They". He identified that the individual mirrors what other people are doing, which reflects on behaviour and attitudes as being in the world and how we perceive various things around us. This is related to the spiritual perceptions of the participants in this study within their milieu and to the reaction of an outsider reading this paper, either with objective and open-minded consideration of the spiritual care needs of Jordanian ESRF patients, or with

parochial disdain for the association between spirituality and religion (specifically Islam) that I have identified from the data. Some however could argue that this might be seen as a distorted aspect of Heidegger's *Das Man*, in the sense that people tend to go with the crowd and follow what religion tells them to do (Heidegger, 1962). Nevertheless, this comes to the fore in all the interviews and cannot be ignored for Jordanian ESRF patients who, having a high level of commitment toward the Islamic religion, will be seen in this way. Reflecting on what I wrote in Chapter Three about Heidegger and the application of *Das Man* in my study, it was revealed that participants cannot be detached from either their religion or their cultural beliefs. As both of these elements have shaped individual spirituality, ESRF participants responded and coped with their illness in the same way everybody else was expected to.

This study has been unable to demonstrate that spirituality can be regarded in the modern sense of a deep dimension separated from religion, and in this sense it draws parallels with Heidegger's philosophy whereby *Das Man* is related to authenticity and inauthenticity. For Heidegger, authenticity doesn't arise through a totally free choice (as in Sartre) but in authentically assuming or living your commitments so that one truly assumes responsibility for a life, rather than just "performing" a life. In a way, the participants' accounts chime with Heidegger here, as they talk of the crisis of illness triggering an authentic "lived" relationship to a tradition that was previously just assumed (lived inauthentically as *Das Man*). Heidegger talks of experiences such as anxiety as triggering an authentic responsibility for existence: this notion has been subject to much critique though, as it is seen as fatalistic, as not being critical, and some have tied it to Heidegger's disastrous political commitments in the 1930's. Aldridge (2000) addressed the tension in modern communities between institutions and individual freedom in which each individual has their unique "way of life" that can be distanced from the notion of a transcending dimension i.e. religion. However, it is not apparent in Islamic cultures such as Jordan that individuals live their own way of life apart from Arabic-Islamic values and beliefs. The participants in this study experienced a constant struggle when either their religious or cultural commitments were not met. Both religion and culture form the identity that transforms their experiences of day-to-day activities. In other words, religion and culture were seen by participants as important elements in coping with ESRF.

Baldacchino (2010) views religion as a set of practices, values and beliefs that are shared by a community of people as necessary to establish a relation to the deity, or to be in harmony with ultimate reality necessary to establish a relation the deity, or to be in harmony with ultimate reality. A religion maintains power for itself by offering a critique to alternative systems of power (Aldridge, 2000). In a limiting situation such as being diagnosed with ESRF, such sets of practices, values and beliefs have given participants power by being with others in praying and in fulfilling religious obligations. The participants stressed that maintaining such an identity had added new meaning and purpose to their life. Secularism of spirituality is seen in the literature as an ideology that supports a particular power structure and tries to insulate a political elite from moral critique (Aldridge, 2000). In other words, secularism of spirituality attempts to move analysis above power away from moral responsibility and the values and beliefs of a religion. However, as discussed in Chapter Two, in Jordan religion and culture transform each other and the participants in this study immediately uncovered meaning and purpose from such values and beliefs in their lives that empowered their spirituality and enhanced their spiritual well-being. As such, the findings from this study suggest that religion and culture should be integrated with spiritual care. This is in agreement with a longitudinal study of the relationship with religious faith by O'Brien (2003), who reports the importance of religious faith in coping with ESRF and dialysis. The results in my study also raise intriguing questions regarding the nature and extent of spirituality for Jordanian ESRF patients and how the secularism of spirituality could impact on Jordanian ESRF patients' spirituality. However, further study is required to establish a deeper understanding of this.

The use of the phenomenon of Relationships (with family, community, other ESRF patients, medical staff, and trust) displays how ESRF participants put emphasis upon their relationships with the surrounding environment. Such relationships were stressed throughout all participants' accounts and appeared to be related to their spirituality, affecting the overall acceptance status toward their illness. It became particularly clear that participants initially started to examine and compare their relationships before and after having ESRF. In essence, they described discovering that they had spiritual disequilibrium. Like the previous phenomenon of Religion, Relationships unfolds another layer toward a better understanding of how spirituality is manifest during ESRF. This takes the main aim of this study forward and moves

the notion of spirituality from chronic illness to the more specific condition of being ESRF patients, as the world of the participants was fundamentally changed by ESRF and became uncertain in many aspects. Such uncertainty was challenged through their relationships. These findings further support the idea that spirituality is experienced through relationships and connectedness (Dossey and Keegan, 2008; Miner-Williams, 2006; Mok et al., 2010). In this context, the present findings seem to be consistent with other research which found spirituality belongs to everyone as a place where inner peace, inner strength, love and hope can be maintained (Baldacchino and Draper, 2001; Narayanasamy, 2006; Narayanasamy, 2006; Taylor, 2002).

Spiritual Challenges for ESRF

The results from this study show that family connectedness and collectiveness are central to Jordanian culture and to a participant's spirituality. Participants addressed how such connectedness enhanced their spirituality and promoted the tranquil *Nafs* for longer. However, participants also drew attention to how this connectedness became weaker and looser and for many participants, the connectedness even became disconnected. This disconnection caused participants' *Nafs* to deteriorate quicker from being tranquil *Nafs* to becoming *Nafs Ammarah*, where spiritual distress and spiritual pain were experienced, which influenced overall spirituality and spiritual well-being.

Participants also experienced "*Shafaqa* look شفقة" and felt abandonment from the family as a result from such disconnection. This created constant negative thoughts and negative emotions for the participants toward their families. It can thus be suggested that families should continuously express connectedness, love and forgiveness to their ESRF relatives. This finding is in agreement with the spiritual model of Stoll (1989) that suggests expressions of love, hope and forgiveness from family are important to an individual's spirituality, especially if participants experience a sense of disconnection and detachment from the family during their illness.

Molzahn (1998) described three important stages that patients undergo during ESRF. The first stage is when the patient experiences a "honeymoon period" of initial physical improvement; in the second, the patient experiences disenchantment and

lack of support to cope with a number of stressors such as: limitation of their physical abilities; fluid restrictions; dialysis; decreased sex drive; and low income and in the final stage, the patient starts to struggle with issues such as loneliness and long-term adaptation. In my study, the participants agonised over the deep worries that affected their spirituality and mentality. Participants reflected how their family relationships had changed i.e. parental roles, respect, social isolation and change in family boundaries. This finding supports previous studies into the importance of connectedness and collectiveness of family members with the patients, which influence patients' spirituality and mentality (Lin and Bauer-Wu, 2003; Tanyi et al., 2006).

The results revealed that the role of being a father in Jordanian culture involves numerous responsibilities that participants used to fulfil before suffering from ESRF. Participants stated a constant struggle to maintain their personal value, balanced between being worthy and of value to their family, or being devalued and worthless. In line with Roy's Adaptation Model, which focuses on the adaptive needs of the ill person and their family, including the self-ideal and the moral-ethical-spiritual self (O'Brien, 2003; Parker, 1998), participants recurrently stated that their individual needs were strongly associated with their family needs. An implication of this is the possibility that healthcare providers might need to consider the spiritual needs of the entire family of the ESRF patient (O'Brien, 2011). This observation may support the hypothesis that Jordanian nurses should allow patients to be with their family at any time they want to, in which case the policy for visiting times during dialysis would need to be changed. Meeting the above needs might help family members to empower the individual patient's spirituality, in order for them to cope better and for the family to be more supportive to their relative.

As discussed above, this struggle was the turning point in the motivation of those participants who were successful in finding a new job or those who were able to work independently. In Jordan, the support system for ESRF patients is still limited to providing dialysis sessions at low cost. Participants stated how difficult it was to lose their employability as a result of such illness, leading in many cases to social isolation and exclusion. A key policy priority should therefore be a plan from government to improve the existing support system, and to provide a rehabilitation

program for ESRF patients that can reconnect patients in long-term care, and their families, with the community.

The results from this study also suggested that the detachment which occurs between patients and their families made the participants experience a sense of hopelessness and powerlessness. Hopelessness and other passive means of coping (i.e. helplessness) were reported in literature to be common amongst ESRF patients (Perales-Montilla et al., 2013; Yeh and Yeh, 2007). Participants highlighted that losing hope in being a productive member of the family was one reason for their sense of powerlessness. Consequently, dialysis patients recounted how this impacted negatively upon their spirituality by turning their *Nafs* to be *Nafs Ammarah* and by devaluing their self-concept to a point where they started to experience spiritual distress. There are similarities between the attitudes expressed by ESRF patients in this study and other studies which have conclusively shown that senses of hopelessness and powerlessness impact upon a patient's self-concept and self-value (Hoffmann et al., 2000; Lin and Bauer-Wu, 2003; Yang et al., 2012). Hope for the ESRF participants meant finding a way to regain their role in the family by finding a job and being able to contribute to their basic family and extended family commitments, i.e. by supporting eating, drinking, socialising, parties and travelling. According to Abdollahi and Abu Talib (2015 ,p 13), commitments can be defined as " a person's dedication to activities that are meaningful and interesting to him or her". However, in this study, participants had to come to terms with choosing between such commitments and their ongoing treatment costs. For some participants, they chose to miss their treatment and not to have dialysis sessions and instead fulfilled more meaningful roles in their social life. Their sense of spiritual connectedness involved both receiving and giving (Dossey and Keegan, 2008). Therefore, finding work was not only an indication of hope; it was also acknowledged by the Jordanian participants to be a sign of being an active member in their family and in their social life and was a way to regain power to meet their family commitments. Work was also a way to prove to themselves and their families that their role was not yet finished, and they still existed physically, mentally and spiritually regardless of their illness. Finally, work was an opportunity to develop a sense of being engaged, responsible, and independent which helped them to overcome a sense of emptiness and of being a burden on their families. The findings of the current study are consistent with those of Sunderrajan and Swaminathan

(2011), who found patients' spirituality correlated positively with individual employability status. Nevertheless, as seen in Table 4.1, the majority of participants were unable to maintain hope through their employability status due to the time requirements and restrictions of dialysis. Hence, it could be hypothesised that ESRF patients would inevitably become hopeless and powerless and indeed participants stated that they experienced a sense of losing power and control in their life.

This study found how participants had unique and diverse experiences that related to individuals' interactions with the surrounding environment. These interactions were later conceptualised as a spiritual support system for ESRF patients. This was one way to interact and react with others and consequently to enhance participants' spirituality. Family relationships in particular were associated with special elements such as patients being loved, being supported, being offered hope, and receiving attention. This study supports previous literature identifying the family as a key input in individuals' spirituality that was empowered and enhanced from the family's role (Acton and Miller, 2003; Hsiao et al., 2010; Lundberg and Kerdonfag, 2010; Paula et al., 2009; Tanyi, 2006). Participants in the present study utilised both family structure and extended family structure as important resources to strengthen and empower their individual spirituality in every moment that they experienced reunion with their family members, either being visited in the dialysis unit or meeting family outside. The sense of being visited was identified by participants as a crucial dimension of their spirituality: those who had regular visits appeared to have higher levels of spirituality than those who did not. As discussed in Chapters Three and Five, visiting the ill is particularly emphasised in Islamic religion. The findings observed in this study mirror those of previous studies that examined the effect of family and social support on ESRF individuals' spirituality (Spinale et al., 2008). These findings may help us to understand the importance of visiting the ill by family in terms of empowering the patient's spirituality.

Although the participants reported that they had support from their families (including their extended families) and inclusion in social events, the community as a whole was not considered to have a supportive role in participants' spirituality. This is no doubt related to the phenomenon mentioned by all participants whereby their social role and status in the community changed due to being perceived to be ill. The majority of participants highlighted the inauthenticity of socialisation after

ESRF diagnosis, which caused their spirituality to deteriorate and their *Nafs* to remain in the *Nafs Ammarah* pattern, even though in Jordan they had the asset of the Islamic-Arabic cultural values and beliefs which should have transformed attitudes toward ill persons. However, participants in this study experienced a constant tension between purported Islamic-Arabic cultural values and beliefs and how they were treated in reality. Experiencing a sense of social stigma, social isolation, social discrimination and "*Shafaqa* look" were reasons given by participants in this study for these tensions. This tension was even more complicated in real-life as it reflected the conflicts in an amalgam of values and beliefs from religion, culture and the moral system in Jordan as to how ESRF patients should be treated. According to Goffman (2009) theory of Dramaturgy, stigmas are collective signs that indicate something unusual and bad in respect of the moral system of the signifier. Stigmas can be classified in three different forms based on physical abnormalities, deviations in personal characteristics, and tribal stigmas that refer to ethnic groups, nationality, or religion (Goffman, 2009). Numerous studies have highlighted how stigma impacts negatively on individuals and their families, both mentally and spiritually (Aldridge, 2000; Corrigan, 2005; Goffman, 2009; Liamputtong, 2013; Reed and Baker, 1996; Sartorius et al., 2005). Participants in my study suffered deeply from the three types of stigma mentioned above. The reasons for stigma toward them were not clear but, may be due to a lack of adequate knowledge about ESRF in general for both patients and communities. For instance, when participants were told that they had ESRF and had to start dialysis, some of them were shocked by the very term "renal dialysis". Although both patients and community thought that ESRF was a minor ailment, many thought dialysis meant "kidney washing", which was interpreted by many of them as the nurse removing and literally bathing their kidneys. These results match those observed in earlier studies (Krespi et al., 2004; Lin et al., 2005).

Another possible explanation for this stigma was the cultural misconception highlighted by participants which linked ESRF with alcoholism or drug abuse, a belief that appeared to be widespread among families and community. As a result, participants stated a sense of negative labelling from their community. The findings from this study uncovered how this labelling appeared to be "the new virtual social identity" of ESRF patients, which added extra challenges and restrictions into their life in teams of accepting or rejecting their illness. This new virtual social identity for ESRF patients created an important conflict in their life, in their *Nafs*, and with

their true social identities in terms of accepting or rejecting the illness. Participants referred to a constant struggle with such conflict which was a reason for them becoming socially isolated and avoiding social interactions. This finding is in agreement with Goffman (2009) findings which showed the impact of virtual social identities on an individual's self-esteem. As a consequence, participants reported that stigma led them to devalue their *Nafs* and their family. Seen in terms of Goffman's theory of stigma (Goffman, 2009), attending three times a week for dialysis was traumatising for participants in the sense that they experienced how society started to evaluate their abilities. Culturally in Jordan, this meant that the society virtually identified ESRF patients as: disabled, weaker, and as people for whom their life is already finished. Consequently, as suggested by this study, ESRF patients turn to their *Nafs* internally when the outside world stigmatises them, where their *Nafs* turned from tranquil *Nafs* to *Nafs Ammarah*. In summary, they faced social isolation and spiritual disturbance of their Nafs.

According to Carlisle et al. (2005), discrimination and prejudice in any form serve to separate and exclude individuals from society. This study poses a major criticism of the attitude of the Jordanian community toward ESRF since Arab-Islamic values and beliefs consider it sinful and forbidden to foment such stigma and discrimination (Ashraf, 2008). The Prophet (Peace be upon Him) urged Muslims to tackle such evil actions. It is narrated that "Whoever among you sees an evil action, then let him change it with his hand, if he cannot, then with his tongue, and if he cannot, then with his heart and that is the weakest of faith." (Patel, 2011). The results of this study are in keeping with previous observational studies which found that stigma and discrimination are main concerns for patients in Jordan and elsewhere (Abu-Moghli et al., 2010; Alqaissi and Dickerson, 2010; Walton, 2011).

It seems possible that feelings of both stigma and discrimination among ESRF patients indicate lack of support, calling for changes in the community attitudes and care for ESRF patients and their families. In confronting such stigma, combined efforts among healthcare providers, politicians and policy makers, the media, and religious leaders can shape social, cultural and emotional responses to ESRF patients and their families. The media appears to have an important role in reducing stigma and in changing public attitude (Corrigan, 2005). ESRF anti-stigma-programmes and stigma reduction programmes are also recommended to enhance connectedness

and collectiveness of ESRF patients with families and community, as advocated by (Sartorius et al., 2005; Walton, 2011). Participants highlighted the need for public awareness campaigns about this subject. In addition, improving communications and changing the language around ESRF between patients and community suggests an effective way of diffusing both stigma and discrimination and improving the language of illness (Carlisle et al., 2005; Smith, 2012). This is another important issue for future research.

In this study, several ESRF participants described how the above external stigmas had negatively affected them, especially when they faced physical and verbal challenges. These challenges strengthened internal stigma particularly for male participants for whom cultural roles and masculine identities were altered as a result of having ESRF. This is in agreement with the findings of other studies, in which self-stigma/ internal stigma was found to be challenging for ESRF and other patients and their families (Carlisle et al., 2005; Richard and Engebretson, 2010). This also resonates with Goffman (1963) and Goffman (2009), who suggested that families who cared for an individual experienced similar consequences of stigma, known as "courtesy stigma".

Reflecting on Stoll (1989) spiritual model, I would argue that the implications of both internal and external stigmas upon ESRF patients in this study may have changed meaning to the "self", in a way that the "self" in above mentioned model has been marginalised from the centre. In other words, both ESRF patients and their families started to re-identify themselves in a way that emerged from the external stigma, leading them to interpret themselves through the negative concepts that had been given to them from others. As a result of such marginalisation of the "self", participants in this study illustrated how the "self" became a sponge that attracted and absorbed all negative thoughts and emotions towards themselves and their family. For them, this created a conflict in their *Nafs* and caused spiritual distress, especially when compared their overall condition before and after they had ESRF and discovered the inauthenticity of their cultural values and moral system. This conflict appeared to produce two important stages. The first involved loss of meaning and purpose in life characterised by negative evaluations of being in the world. This is in agreement with Goffman (1963) who showed the impact of stigma upon individual's, in showing this stigma for ESRF; it could be argued that

participants in this study could not alter or adjust the stigma of being ESRF patients. For example, patients reported their senses of being weaker, being worthless and viewing their tasks in life as finished due to having been stigmatised. However, in this stage participants concealed both the fact that they were ESRF patients and the stigma they felt from others, and further isolated themselves from family events and society in order to avoid such senses of stigma. As a consequence of this, participants possibly limited the opportunities for receiving support in their isolation, and so became hopeless and powerless. There are similarities between the attitudes expressed by participants in this study and those described by (Martin-McDonald and Biernoff, 2002; Richard and Engebretson, 2010). The second stage was positive, where ESRF patients started to develop "a new self-concept" and become more appreciative of their overall condition, especially when they started to compare their illness with those who had worse illnesses, such as cancer, diabetes, or with those whose ESRF condition was worse than theirs. It was found that this stage appeared spiritually important for participants not only in order to face the challenges of both internal and external stigma, but also in creating new meanings that could replace meanings they lost as a result of stigma. This comparison helped participants to cope resiliently and grow spiritually beyond their illness and sense of negative being. This stage helped participants to mobilise their *Nafs* to become Tranquil *Nafs* and it further showed the desire that ESRF patients have to live their life meaningfully.

These results match those observed in earlier studies (Bullard, 2004; Tanyi and Werner, 2003; Tanyi and Werner, 2007; Tanyi and Werner, 2008; Tanyi et al., 2006; Walton, 2002) whilst also being consistent with the finding of Goffman (1963) in that ESRF patients would like to see themselves as normal or "passing". The participants explained passing as being viewed in the same way as a "normal" person suffering from headache would require paracetamol, just as they required dialysis. This helped them to regain power, which enhanced their inner strength of spiritual being and facilitated reflection on meaning and doing, undertaking tasks either at the dialysis unit (helping in lining and priming the machines and helping other patients), or at home (tidying their rooms, helping in preparing food and in shopping) in which the "self" is shifted back to the centre in Stoll's (1989) spiritual framework. This finding is in agreement with findings of other studies which showed how ESRF patients would nurse incorporate their spirituality during dialysis (Tanyi et al., 2006; Walton, 2002). This draws a comparison with the concept of recovery that has been

developed in mental healthcare – recovery is not about cure or a return to a previous state, but the growth of a new self that arises through coping with ongoing illness and surviving stigma.

Applying Heidegger's thoughts of "authenticity and inauthenticity" (Heidegger, 1962) to my interpretations of participants accounts, I suggest that some participants developed a powerful *sense of authentic being*, which later reflected upon their spirituality as *spiritual being*. As a result, these participants were able to assume more effective roles in the community, becoming enabled, in different ways to meet their family commitments and re-connect themselves with their communities, and indeed to live authentically in facing the challenges that ESRF patients face: in another words, that one only finds authenticity *through* inauthenticity. Although all participants stated that they felt some degree of social stigma and isolation, they felt they could overcome this by their *spiritual being*. Participants stated how they felt and connected their spiritual being with others through daily activities, work or even gathering in the *masjid* to pray; doing such actions was found to be a relatively easy way to reconnect with the world and engage with their communities, thus overcoming the spiritual distress they reported from community stigma and marginalisation. The present findings thus corroborate with previous research, which found spirituality to be a form of being from which actions significant for the individual can emerge (Wilding et al., 2005). Therefore, in order to enhance ESRF patients' spirituality, policy makers and hospitals could facilitate meaningful *doing* for ESRF patients that first connects them with religion, as discussed earlier, and then with rehabilitation programmes that can re-introduce them to the community and overcome the cultural stigma and isolation from society.

In Arab-Islamic societies such as Jordan, males are expected to be breadwinners; thus the majority of male ESRF patients told me of their concerns about employment and the negative effect those concerns had in decreasing their level of spirituality. The male ESRF patients experienced spiritual distress by losing their employability, which brought to surface a sense of struggling to meet family requirements, being labelled negatively by the community, a sense of guilt and shame and even the experience of being abused. On the other hand, within the same culture, females in general have religious permission during their menstrual periods not to perform some religious practices i.e. prayers (Katz, 2013). Since prayers are significantly

associated in enhancing individual spirituality (Cotton et al., 2012; Narayanasamy, 2006; Narayanasamy and Narayanasamy, 2008; Walton, 2007), by reflecting on Stoll's framework of spirituality (Stoll, 1989); it is possible to hypothesise that females with these conditions are more likely to compromise their vertical connections, and will therefore, requires extra emphasis on the horizontal dimensions in order to redress the balance. The literature suggests that women and men differ not only in physical, psychological needs but also in the way in which they experience spirituality (Bouckaert and Zsolnai, 2011; Bryant, 2007). Bryant (2007) and Thompson and Remmes (2002) indicated using a quantitative approach that females appeared to be more spiritual than males. However, the female ESRF patients in the present study did not show any different spiritual experiences from male participants. This finding is in agreement with Rich (2012) findings which showed no significant differences were found between male and female in scoring on the spirituality scale. However, as uncovered in the previous chapter, for male ESRF patients, developing a sense of being busy with an activity not related to dialysis, provided them with spiritual comfort that later developed their sense of being responsible and being in control of something in their lives. They perceived the sustenance of themselves and their families as a dimension of spirituality, thus the inhibition of their ability to provide due to ESRF undermined their QoL. Economically and "spiritually or الروحانيه", this is an important finding that should not be ignored. Further research should be done to investigate the interaction between gender and spirituality.

Rambod and Rafii (2010) also found significant associations between social support and QoL for ESRF patients. Similarly, Cordeiro et al. (2009) reported that ESRF patients who lose their employability status and social support had lower QoL. There is scope for further research to explore what type of social support (i.e. occupational/employment assistance) can be provided to Jordanian ESRF patients to meet their spiritual needs.

Although participants told me that healthcare providers were in the best position to elevate their spiritual level, they specified that nurses were more effective in achieving this than other healthcare providers. As discussed in the previous chapter, nurses played a role in enhancing ESRF patients' spirituality. This was evident every time patients experienced compassionate and genuine care and required nurses

being informed, being confident, being responsible and accountable, *ajer*, inspiring hope and ambition, being thankful and "spiritually روحانيا engaged with the patients, re-connecting them with religious rituals and concepts, and listening to their individual needs. Participants reported that all these of elements were important to enhance their spirituality during dialysis, and appeared to facilitate acceptance of the illness and enhance their coping mechanisms. This finding corroborates the results of Tanyi et al. (2006), who found that patients appreciated nurses exhibiting genuine care, including listening, presence, humour, friendliness, understanding, sympathy, reassurance, and explaining procedures. Several studies have revealed the inspiring role of the nurse in enhancing patients spirituality (Baldacchino, 2010; McSherry, 2007; Taylor, 2007). The findings from this study indicated that respect and care with compassion were important concepts in addressing participants' spiritual needs and in providing spiritual care. Therefore, it is argued that nurse educators may adapt a model of nursing that can show such important elements in nurse-patient relationships in Jordan. Participants expressed a sense of being that enhanced their self-esteem and helped them to mobilise their *Nafs* to become tranquil Nafs when these concepts were shown in their interactions with nurses and other healthcare providers. Unfortunately, this was not the case for the majority.

The participants in this study highlighted the importance of their spiritual needs being understood during dialysis, since this motivated the patients and maintained their feeling of being respected. For them, being understood could be expressed in nurse-patient relations through communication and engaging with spiritual dialogues. According to Swinton (2001) and Waaijman and Vriend (2002) spirituality is a language in which spiritual needs can be expressed through that language and culture. This requires the nurse to be an active listener to what their patient needs. Hence, Aldridge (2000) urges nurses to expand their spiritual vocabularies to include deeper understanding of terms such as: transcendence, forgiveness, reconciliations, redemption and sacrament. These concepts appeared to be important in the patient's journey with the illness. Aldridge (2000, p197) "did not call to abundant individual's vocabulary of science, but to enrich the vocabulary of healing even so far that we speak not only of mind and body, but also spirit".

Reflecting on Stoll's spiritual model (Stoll, 1989), and without enriching the language, I would argue that both vertical and horizontal dimensions will not be achieved and therefore the "Self" will be again marginalised and individuals will become disconnected. Participants in this study suffered from such disconnections and marginalised their inner self as a result of a lack in communication between themselves and their nurses. This contributed to them to develop a negative sense of being discriminated against, even in the dialysis unit, and as a result of nurses misunderstanding their spiritual needs, patients expressed symptoms of spiritual distress i.e. anger, avoiding any interactions with nurses and pretending they were sleeping during dialysis, thus their Nafs remained Nafs Ammarah. Participants felt as they reach the complete Isolation cycle Home-Street-Dialysis unit. They developed a sense of emptiness. This finding is in agreement with O'Brien (2003) findings which showed that loneliness can be trigger for spiritual distress and a cause of serious problems to those who suffer from it. However, ESRF patients in the present study reported that nurses could prevent such feelings of loneliness and senses of emptiness through mobilising spiritual activities e.g.: by engaging with hadiths and Qur'anic stories and reminding them to perform spiritual practices as explained in the previous chapter. These results reiterate the suggestions made in other studies that religious practices and scriptures are important resources in spiritual coping among chronically ill patients (Lagman et al., 2014; Latifnejad Roudsari et al., 2014; Narayanasamy, 2002; Walton, 2007). Thus, the findings suggest that using Narayanasamy Models ACCESS (2002) and ASSET (1999) may provide answers to how nurse-patient communications could be improved in order to address patients' spiritual needs effectively. It is also worth noting that the Jordanian ESRF patients identified nurses' characteristics as important in addressing their spirituality. The majority of participants told me that nurses should be spiritual and have a good spirituality before they can address individual spiritual needs. For example, participants were reluctant to accept any spiritual engagements from a nurse who ostentatiously disregarded Islamic behaviour (e.g. female nurses dressing in a beguiling way or wearing excessive make-up, and nurses who ate and drank during Ramadan or when patients were undergoing dialysis, which patients cited as signs of a low spiritual level.

This finding supports the results of previous interpretive studies into the relationship between nurses' characteristics and patients' spirituality (Tanyi et al., 2006). It is suggested that the association of these factors be investigated in future studies. It initially seemed to me that such subjective judgements cannot be incorporated into ward policies and behaviours, but on subsequent reflection it seems that it is common decency to respect the position of ESRF patients by not eating in front of them or treating them discourteously, and generally speaking healthcare professionals worldwide are assumed to adopt a position of respect and ethical obligation.

Suicidal Thoughts That Reflect Low Spirituality in ESRF

The participants reported that during their experience of living with ESRF they faced numerous challenges associated with negative feelings and thoughts that later manifested as spiritual distress, expressed as: tightness, emptiness, loneliness, social stigma and social isolation, being a burden, non-compliance with treatment, harming self or others, poor connection with religious practices and others, lack of role in society, losing employability, lack of tolerance, sense of detachment from marital or family or community and other psychological disorders. As a result, numerous participants stated that suicidal ideation permeated their thinking during the initial critical period, and they were aware of other ESRF patients who had already committed suicide. However, they also stated that spirituality was for them a direct antidote to suicidal thoughts and negative feelings. Rasic et al. (2009) also concluded that patients with religious commitments and practices exhibited reduced risk of suicidal ideation during the twelve-month period of their study. Similarly, Garroutte et al. (2003) qualitatively investigated the association between spirituality and life prevalence of attempting suicide among American Indians, concluding that cultural and spiritual orientation was significantly associated with a reduction in attempted suicide. Although suicide in all forms is prohibited in Arabic-Islamic culture (Zaidi, 2013), I witnessed how for some ESRF patients the development of such thoughts was an indicator for the deterioration of their spirituality and for their Nafs. Reflecting on Stoll's spiritual framework, it can therefore be assumed that ESRF participants did not develop such thoughts because they were serious about killing themselves, but it was an expression they used to "ring the bell" to notify others that they had lost: meanings and purpose in life, unity, love, respect,

wholeness and forgiveness. In this study, I would argue that participants who had such thoughts might have lost both the vertical dimensions and the horizontal dimensions. This finding corroborates the ideas of Aldridge (2000), who suggested that suicidal thoughts result in the sensing of hopelessness, loneliness and losing unity and meanings.

However, during their period of intense spiritual distress following diagnosis (and after intense visitation tailed off), ESRF participants reported they suffered from feelings of emptiness associated with a sense of detachment from marital, family and community life. There are similarities between the attitudes expressed by participants in this study and those described earlier by (Frankl, 1984; Frankl, 2006). Frankl reported exclusively about his experience during the death camp and illustrated how humans can become dehumanised through the breakdown of an individual's identity of being human and through removing the individual from the collective setting – a social framework – such that the individual no longer belongs to that human society. All victims in the holocaust were not only denied as worthy human beings but also denied their collective (Frankl, 1984; Frankl, 2006). Similarly, the same construct was highlighted by the ESRF participants when they expressed their meaningless and hopelessness through feelings of: isolation and loneliness, being socially isolated and neglected by their communities. Regrettably these were the new realities for all ESRF patients as they discovered to some extent the inauthenticity of their previous relationships with others. As exposed in Chapter Three, The Das Man of Heidegger (Heidegger, 1962) could explain how the concept of Being-in-the-world could influence ESRF participants' spirituality. The surrounding environment was not helpful in enhancing participants' spirituality, especially when the community observed their journey and did nothing except tagging ESRF patients negatively and piteously. The bystander effect of the community against ESRF patients impacted negatively on participants' spirituality and ecouraged their suicidal thoughts further. Participants highlighted the stereotype of Jordanian people's behaviours against them in public places despite the Islamic rules emphasising how to treat ill persons, i.e. showing and protecting the respect and dignity of the individual (Rassool, 2014). Reflecting on Stoll's spiritual model (Stoll, 1989), such attitudes helped only to marginalise the "self" from the centre whereby ESRF patients felt alienated from others. As a result, therefore, participants isolated themselves from any social interactions in public places and became lonely

after their individual and collective identities were broken down and disconnected from the horizontal dimension. Furthermore, ESRF participant's sensed that the community's responsibilities toward them were inhibited, limited and diminished because of people's false perception of ESRF patients. Diffusion of responsibility refers to "the belief that others will or should take the responsibility for providing the assistance to a person in need" (Kassin et al., 2010 p,409).

As seen in the above hadith, the Prophet (Peace be upon Him) urged Muslims to tackle such evil actions. It is narrated that "Whoever among you sees an evil action, then let him change it with his hand, if he cannot, then with his tongue, and if he cannot, then with his heart and that is the weakest of faith." (Patel, 2011), meaning that everyone has an individual obligation to prohibit any evil actions. Adopting the bystander attitude may have negative implications for both people and patients. A real example of how the bystander effect can lead to spiritual desperation and then to suicide is provided by the South African photographer Keven Carter (1983). Carter was awarded a Pulitzer Prize in 1994 for a photograph that captured a starved Sudanese toddler trying to reach a feeding camp when a hen hooded vulture landed nearby (MacLeod, 1994). But after winning the prize, people started to query why he had not stopped to help the little girl instead of taking the picture. People started to stigmatise him negatively as he had at least 20 minutes before the United Nations team have to leave that camp. This event was well documented by people who asked Carter about the picture: Carter responded that he had not wanted to get involved in the situation. He stated that "Being a witness to something this horrible wasn't necessarily such a bad thing to do" (Smart, 2012 ,p177). As a consequence of both stigma and the bystander effect, Carter developed depression and three months after receiving his award committed suicide. However, I would like to argue that Allah has created us in a way that we can recognise each other as human beings. One specific hadith that The Prophet (Peace be upon Him) narrated for this situation was " whoever abandons a believer at the time when he needs help, Allah will abandon him when he needs Allah's help the most" (Karoub, 2006). Taken together, it is everyone's responsibility to stop evil actions according to their capabilities. These findings may help us to understand some of the reasons why ESRF patients have committed suicide. This finding has important implications for policy makers, educationists and healthcare providers to be able to detect such behaviours and develop programmes to increase the awareness toward ESRF.

Results from my study uncovered ESRF patients' self-perception as being bounded and being neglected, which came as a unique experience for each patient. However, religious practices were perceived as one way to dispel all the negative thoughts and emptiness feelings. These findings was consistent with other studies that highlighted the importance of spirituality in African women recovering from abuse (Wright, 2003). It seems possible that this observation is a result of the meaning and purpose in life that religions can confer on their followers (Rambod and Rafii (2010).

Based on the preceding discussion, it appears to surface that Jordanian ESRF patients' experienced multifaceted challenges that weakened their spirituality. This low level of spirituality was associated with the *Nafs Ammarah النفس الاماره*. As a result, they experienced many limited situations and suicidal ideation,. However, participants stated that they were able to recover through enhancing their spirituality and re-connecting themselves to religious practices and their relationships. This provided them with a spiritual dose and a sense of comfort and tranquility that promoted their surrender and conviction status toward their illness. This ultimately changed their *"Nafs النفس"* from one pattern to another to reach the Tranquil Nafs النفس المطمئنه.

I soon realised that the large volume of data-richness and thematically complex responses I received from patients would be impossible to contain within this study due to word count limitations. Furthermore, I do not claim to have reached some kind of ultimate understanding of spirituality among ESRF patients in Jordan; this is nursing research about spirituality, not a dedicated psychological study of spirituality in Jordan. The notion of "ultimate understanding" would be a myth for any phenomenological analysis (Fuchs, 2012) However, conducting the interviews provided me with a deep understanding and more insight into the phenomenon of spirituality and added other layers to its complexity by raising a number of questions that can be explored in future studies. Since this is the first hermeneutic study conducted in Jordan to explore the meaning of spirituality in ESRF, I feel I am at a stage in the hermeneutic cycle where I am prepared to progress to the next level of understanding and uncovering. The thing that strikes me most in answering the research question is the way in which ESRF patients interacted with and were treated by their surroundings and community, and how the socio-economic feature of losing their employability due to ESRF caused an acute spiritual crisis extending to suicidal

ideation. This study provides a new of understanding of spirituality among Arab-Islamic patients in terms of coping mechanisms that I would like to explore and perhaps compare in the context of different illnesses and different cultures in the future.

Summary

This chapter discussed the results that have been extracted from the Jordanian ESRF participants' interviews and compared them with the wider literature to show how "spirituality or الروحانيه" manifested during the illnesses. The chapter produced new knowledge about spirituality and spiritual care of ESRF patients on dialysis. This chapter has argued that a "secular" concept of spirituality had no meaning for the study participants in the absence of religion. It appeared that spirituality was experienced fundamentally as part of religion and vice versa, contradicting the debate by Paley (2008) that spirituality is a secular dimension. Thus, the findings from this study may have consequences for the use of spirituality in multi-cultural settings in Western countries. Additionally, findings highlighted an important emphasis for Arab-Muslim Jordanian patients on the practice of spirituality that has often been underestimated in the previous literature.

The study findings contribute to the existing gap in knowledge regarding how Arab-Muslim Jordanian ESRF patients experience spirituality during their illness. It provides valuable insights into the importance of spirituality for this patient group and suggests how nurses, educators and policy makers might help address ESRF patients' spirituality and spiritual needs in order to provide appropriate spiritual care. The study suggests the findings may have relevance beyond the Jordanian context in educating nurses on the importance of appreciating the religious dimension of spirituality. The findings may contribute to clinical practice, and be applied to educational programs and policy makers. Recommendations for further studies are made.

CHAPTER 7: Conclusions

Introduction

This chapter presents the conclusion of my study. It highlights the important contributions of this research to knowledge and practice concerning care for ESRF individuals in light of their experiences of "spirituality or الروحانيه" as revealed in my study. I found that spirituality greatly affected the participants' physical, psychological, social and emotional conditions and their overall well-being. This study has enlarged my understanding of spirituality and how it relates to care, and has implications for healthcare providers, carers, family members and even individuals who know someone with ESRF. All stakeholders have the opportunity and, in the case of healthcare professionals, the duty of care to enhance patients' spirituality. A failure to acknowledge the spiritual aspect of care represents negligence on our part as health providers, reinforcing the general social stigma and isolation I found ubiquitously reported by ESRF patients in the study. In this chapter I present my own reflexive account of my study and how my role as a nurse from an Arab-Islamic culture affected my interpretations of the participant's accounts. As mentioned in Chapter Three, I will explain how my field notes helped me to question every step in my PhD journey. Finally all the challenges I faced in my research are highlighted to help future researchers.

Study Contributions

The study specific aim and objectives have been addressed in chapters 5 and 6. The first four objectives were achieved in the theme of religion and relationships. I presented and discussed how patients' beliefs and practices toward spirituality, how Jordanian ESRF patients characterise their spirituality, I described spirituality as depicted by the experience of Jordanian ESRF patients, I explored and identified the spiritual resources that ESRF patients can use to enhance their spirituality and I explained how spiritual dialogue has enhanced patients' spirituality. The findings from my study make several contributions to the current literature in this field. to date this is the first time that spirituality has been used to explore individual healthcare experiences in Jordan and Middle East countries generally, it extends our knowledge about how "spirituality or الروحانيه" is experienced among Jordanian ESRF patients and among Arab-Islamic patients with serious illness more generally.

It gives a deeper understanding and greater insight into how ESRF patients feel their spirituality and spiritual needs can be addressed. This is a unique contribution to the existing body of knowledge and growing body of literature on Islam and spirituality, and my research will hopefully serve as a basis for future studies.

To date this is the first hermeneutic phenomenological study to explore the meanings associated with spirituality as phenomenon of care for ESRF patients and during the course of this research my understanding of the phenomenon of spirituality has grown. Special consideration was given to the methodology of this research and I was fortunate to be able to access valuable advice and clarification from one of the leading phenomenologists at the University of Nottingham whenever the study faced challenges. For example, as explained in Chapter Three, I faced a number of obstacles in obtaining ethical approval from one of the hospitals, where I discovered that a lack of understanding of my study methodology was being cited as the reason for refusing to give my permission. Thus, I was able to organise a workshop with one of the leading universities in Jordan, where we worked with Jordanian educators and practitioners, including some from this hospital, in order to increase their knowledge about such an important methodology. Also, this particular interest in phenomenology led me to create a phenomenological forum at the University of Nottingham that focused on providing help and support for new postgraduate researchers; this forum is now growing in membership and is becoming a weekly event.

My new level of understanding of the phenomenon of spirituality has been helpful in developing (with several university and private hospitals) a group called *The Friends of End Stage Renal Failure Patients*, whose main aim is to address spirituality and to help and support general aspects of life for ESRF patients and their families. Since the aim in a phenomenological study is to search for better understandings of a phenomenon, my study aim was achieved by determining and exploring the three major themes which emerged from my interpretation of participants' accounts of their understanding of spirituality. Reaching this phase in my study, I consider that what I have achieved merely scratches the surface in understanding spirituality in ESRF, providing only a single piece of a complex mosaic that connects to national and international studies on spirituality to uncover the phenomenon of caring for patients with ESRF.

The present study provides additional evidence with respect to the connection between spirituality, religion and culture as demonstrated by the ESRF participants whose experiences of spirituality confirmed that it cannot be separated from religion in the Jordanian context. The *"Nafs النفس"*, *"Balaa' بلاء"* and *iman* concepts that I identified in my study represent an important contribution to existing knowledge. Although all participants had unique experiences of these concepts, the framework assists our understanding of how spirituality was an indication of the transformation and development of these concepts during their illness journey.

My study responded to the recommendations of previous research to explore the Islamic view of spirituality and spiritual care (Clarke, 2009). Given the limited knowledge available in nursing literature on Islamic spirituality, the study provides more insight into Muslim patients' particular needs and suggests evidence-based strategies to assist chaplaincy for Muslim patients, whether in Arab-Islamic or other contexts; particular where specific barriers and constant struggles are encountered in addressing Muslim patients' spirituality such as in Western healthcare settings (Abu-Ras and Laird, 2011). It also provides evidence-based guidelines for non-Arab-Muslim healthcare professionals in Western cultures to provide cross-cultural competent care for ESRF patients, and possibly for other patients as well, as recommended by (Kulwicki et al., 2000). Thus, my study has the potential to close the gap in the existing body of knowledge whilst also providing very important information for Jordanian nephrology nursing practitioners, educators and administrators in leading healthcare professionals to incorporate spirituality in their patient care.

My findings suggest that Jordanian ESRF patients commonly experienced an acute spiritual crisis during the initial period after diagnosis, which had a tendency to cause suicidal ideation. This warrants the urgent attention of healthcare providers at all levels, including the Jordanian Government, policy makers and educators to increase public awareness about this illness and to re-engage ESRF participants in the community to be active and valued members of society. Such positive reinforcement at community level would be the most effective and highest quality spiritual care that nursing could provide for such patients. Thus, the key strengths of my study are its suggestions for appropriate and spiritual care that promotes the coping mechanisms

of ESRF patients at the immediate and individual level as well as the long-term, community level.

The analysis of ESRF patients' spirituality undertaken in my study has extended our knowledge and awareness of the lack of support linked to Jordanian MoH policies. Participants reported continuous struggling and relentless compromise between keeping up with the ESRF treatments and meeting their family obligations. This dichotomy increased individuals' spiritual distress and participants with greater family commitments (e.g. breadwinners) were quicker to reach the desperation stage. Thus, my study contributes significantly in highlighting those challenges and difficulties.

Although, participants in this study shown a great commitments, willingness and made a considerable efforts to adhere to their treatment program and dialysis sessions. However, my study also indicates that the previous assessment of the needs and requirements of ESRF patients by the Ministry of Health should urgently re-consider the particular needs of those ESRF participants who are underprivileged, as they experience financial difficulties and often cannot afford transportation, meaning that some miss their dialysis, while others come for dialysis merely to receive the free sandwich as they might be underprivileged to have food at home with same quality. Serious considerations were uncovered from the participants' accounts in my study, which is the first study in Jordan reporting the advantages of the role of financial stability in ESRF patients' spirituality.

According to Green and Thorogood (2009), the dissemination of a study can be achieved in a numbers of different settings and styles. I have taken my understanding of the phenomenon of spirituality to it is next level in presenting my study to staff members and postgraduate and undergraduate students at University of Nottingham seminars, and I was able to develop a poster which was widely presented at a national conference, Saturday research meetings and in dialysis units in Jordan. It is hoped that my findings will be used to help patients, nurse educators, nephrology nurses, doctors and other healthcare professionals involved in caring for ESRF patients to gain a better understanding of spirituality in ESRF and how it is manifest in the lives of Jordanian patients.

In addition, I am devising a leaflet entitled *Spirituality in ESRF* highlighting the essential outcomes and how this may enhance spirituality for Jordanian ESRF patients. This leaflet and ancillary posters may support nurses and other healthcare professionals in the pre-dialysis phase to promote better understanding and make better use of spirituality in the care they provide. By disseminating leaflets and posters in dialysis units and renal clinics, and potentially publishing aspects of this research in nursing journals, I hope to be able to increase awareness of ESRF and spirituality as a phenomenon of care in Jordan.

It is also hoped that the results of my study will increase the awareness of spiritual care and the spiritual dimension of holism generally, since I found that this can significantly affect patients both positively and negatively, yet it is not primarily understood as a related aspect of health and care in Jordan, despite this being an essentially religious country. The findings from this study will be presented to the five participating hospitals, across different sectors, for the information of staff and the consideration of policy makers. It is hoped that the findings will provide information to inform evidence-based practice to facilitate the spiritual dimension in the care of ESRF patients. Additionally, I will present the important findings of my study in a range of different settings, such as to patients in dialysis units, in nursing group discussions, in meetings, seminars, lectures and conferences, and the study will also be available in journals for interested healthcare professionals. The disseminated findings will include my correspondence addresses for further information.

Study Implications

I acknowledge the fact that one piece of research cannot solve all the problems I identified from participants' needs. However, as far as the implications are concerned, the knowledge I gathered from studying the phenomenon of spirituality in ESRF can help to put the pieces of the jigsaw together to allow educators, healthcare providers and policy makers in Jordan to improve and maintain a positive environment and have clear picture in respect of Jordanian ESRF patients' spirituality. The study has important implications for the following stakeholders.

Jordanian Nursing Educators

The results from my findings can provide substructures for Jordanian educational institutions to develop training programs that can address spirituality and spiritual needs for ESRF patients from early stages. The study findings can also help educators in Jordan to design programs to enhance health education for both ESRF patients and their families in hospital settings where patients have their dialysis and by providing lectures within their educational institutions and inviting ESRF patients and their families to participate in them. In addition, educators are in the best position to increase public awareness to change community perceptions of ESRF and related attitudes toward patients. This may involve using presentations in the public media and will help to tackle the social isolation and stigma from which ESRF patients and their families suffer.

Jordanian Nephrology Nurses

The results from my study highlighted the important roles that Jordanian nephrology nurses have in ESRF patients' spirituality, indicating the importance of spiritual intervention and the need for appropriate strategies tailored to patient interests. Thus, nurses can be inspired to be "spiritually or روحانيا" engaged with ESRF patients through spiritual dialogue, especially when meeting the patients and conducting routine techniques such as connecting patients to dialysis, actively listening, and addressing the spiritual needs of patients in a friendly manner. The Jordanian nurses should feel comfortable to address such needs, especially when they share the same religious background as their ESRF patients.

My study findings showed that religiosity is a signal for individual spirituality. Therefore, nurses treating Muslim patients need to understand important concepts such as *"Nafs النفس"*, *"Balaa' بلاء"*, *iman*, spiritual-religious coping practices and the influences these can have on ESRF spirituality. In addition, nurses must also show respect and companionship in caring for ESRF patients during dialysis and should offer options for patients to maintain a sense of being in control and being responsible. Nurses also have a key role in providing advice to patients and their families in encouraging them to be active at home, so as to prevent unnecessarily overwhelming attention which I discovered can lead to withdrawal and isolation.

Organisational help and financial support should also be provided to nurses to help them to organise social activities and trips for ESRF patients and their families so as to enhance the feeling of being connected to others. This could enhance the overall patient-nurse relationship and facilitate the integration of spirituality into the existing care of ESRF patients. From such relationships, patients can sense the compassionate care from nurses that can negate senses of loneliness and feelings of being neglected. One of the important implications of my study is its identification of the important role of nurses' characteristics in approaches to spiritual care.

Policy Makers

Although the current study is based on a small sample of participants, it has provided a platform for a population which has never felt able to raise its feelings, needs and experiences before. Thus, the findings suggest some evidence-based guidelines for policy-makers to address ESRF spirituality. Unlike in Western countries, there are no roles for nurses in the Jordanian healthcare system to address patients' spirituality during the pre-dialysis phase. Developing such a role to extend nursing care for ESRF patients before they start dialysis may promote patients' physical, psychological, spiritual and social wellbeing, and most importantly minimise the knowledge gap that all participants stated they suffered from. Also, the culture in the dialysis unit should be redefined in a way conducive to realising individuals' spiritual needs. Participants told me that they would expect to find verses of the Qur'an or hadiths displayed in the ward to reconnect them to the transcending power of Allah and to refocus on the role of religion (extending the common living room practice of Arab-Islamic and indeed many Christian cultures to the hospital setting).

Future Research

Despite the fact my study has answered the research question, -*How does spirituality manifest in the lives of Jordanian patients in End Stage Renal Failure*? - and has generated a substantial volume of information, the main contribution of the study has been to highlight the importance of spirituality and its complete absence in the Jordanian healthcare system, thereby alerting researchers to the urgent need to understand the phenomenon of spirituality in care in more depth. It is further proposed that similar studies should be conducted with different participants (i.e. in terms of illness, demographic characteristics, and national and religious cultures)

nationally and internationally so that a clearer picture can emerge of spiritual care needs. Further research is also required in a number of other areas e.g. understanding the role of music in ESRF participants' spirituality, the role of social support systems in Jordan in enhancing spirituality, increasing understanding of spiritual pain in ESRF patients, and the implications of spirituality on individual psychology during ESRF and vice-versa.

Study limitations

My study has a number of limitations that must be acknowledged.

Suggestions on how to incorporate spirituality when caring for patients with ESRD receiving dialysis were offered by 27 participants from four dialysis units located in Amman. However, individuals from other dialysis units may offer different suggestions; thus the findings in this study must be made with caution.

I was clear about my ontological position from chapter one as I stated this in Chapter One. In addition, against my own ontological position, I began to explore spirituality and nurses' roles in spiritual care for patients in general, and for ESRF patients in particular. I was open minded to any meanings of spirituality that may have either positive and negative influences upon ESRF participants in this study. I, as Arabic, Muslim, nurse, bilingual, Father, ESRF patient and researcher I came to recognise the world through different lens, indeed, influencing how the analysis and findings have been formulated. It might, therefore, be perceived as detracting from ESRF participants' stories and instead telling my own story. Although I do not disprove that insight that have been emerged from the analysis are influenced by my own prospective. This was undertaken critically with the methods. I have constantly committed to conducting a moral, ethical, reflexive account, relational enquiry and leave audit trial to the reader of which this study is product. Thus, the understanding of the phenomenon results from the co-creation of a new level of understanding that involves both the researchers and the participants' interpretations, and not just the individual interpretation of either one (Flood, 2010). Mandating the quality of this study has been vital and, therefore, in order to the authenticity and credibility, my own reflexive account and processes have been presented throughout this study.

Another limitation is that composition of the study sample in relation to the gender. Although, the pilot study conducted prior to the data collection suggested that there

were no issues in recruiting both male and female participants equally. However, the participants in this study appeared lacked diversity between male and female participants. Male participants who experienced spirituality during ESRF were highly representative. This lack diversity in the sample could limit the insight. A possible explanation for this may be the lack of adequate female patients in the selected dialysis units. Another possible explanation for this is that the distribution of ESRF in male more than female or there might be a cultural factors that stopped female patients to come forward and participate in this study. Therefore, the results and conclusion drawn in this study need to be interpreted with cautions.

The Reflexivity of My Journey

> "Those who do not know history are condemned to repeat it".
> Edmund Burke (McClellan, 2015)

As seen in Chapter Three, one of the main criteria that enhanced the rigour of my study was being reflexive throughout every step of the research. Being reflexive has enhanced and transformed every decision I have made so far, and is still doing so. Despite the fact I disclosed my reflexivity at the end of my project, the reflexivity itself has been a constant process from the inception of this research. In actual fact, the reflexivity started from the moment I started to think what I would really like to do in my PhD study and was manifested in my searching for the best location to study and the best experts with whom to discuss my thoughts about spirituality. It continued throughout all the stages of this thesis and will continue for the rest of my life.

My motivations and previous engagements with this topic (i.e. my knowledge of the literature and my previous experience and background) led me to start correspondence with the expert in this field, Dr. Narayanasamy. However, after submitting my CV I did not receive any subsequent correspondence, thus I started to question: Why, How, Where and When, and What I could do. Although I did apply directly to the doctoral programme, for reasons unknown at the time I ended up in an "Integrated PhD"; a new programme that enrolled only three postgraduate students (including myself). I acknowledged that my selection for the Integrated PhD was based upon the University of Nottingham admissions procedures.

Dr. Sheila Greatrex-White and Dr. Aru Narayanasamy were appointed to be my supervisors. Despite being competent in the modules I was required to undertake in this programme, I again questioned why and how this had occurred after I had specifically applied for a PhD programme, and I felt able to approach my supervisors to raise my concerns. After a long discussion about this issue I was able to transfer to the normal PhD. I saw this as an opportunity that enhanced my thoughts and which no doubt has influenced my research.

As explained in the introduction, this study was originally motivated and inspired by my own need to answer personal questions about the phenomenon of spirituality that arose as a result of being both an ESRF patient as well as a nurse confronted by innumerable spirituality-related experiences during the previous 18 years of my clinical experience with ESRF patients in Iraq, Jordan and the UK. At that time, I hoped I could give patients the same "spiritual dose" that I had experienced from my family, and which some participants in my current study had also experienced. However, prior to conducting this study, I had found it difficult and even impossible to systematically address the spiritual needs of ESRF patients.

I used to spend much of my working time in the dialysis unit talking with patients, and later, looking back on spiritual engagements with ESRF patients in the context of my own spiritual experience: I felt such discussions were mutually beneficial for both of us. However, it was not obvious at that stage that I was involved with spiritual care. In addition, in Chapter Two, I was aware of incidents that split the nation's opinions about spirituality. Thus, I was cautious and very careful not to be suspended from my own work as a result of such engagements. My concerns at that time were not limited to spirituality when patients first started dialysis, but also to the other stages of ESRF. Thus, by conducting my research, I had the best opportunity to see the clearest picture of the phenomenon of spirituality from my own perspective and the viewpoints of other stakeholders. This was particularly enhanced by the keen engagement and enthusiasm of most ESRF patients to share their stories and spiritual experiences, which identified three themes and areas for future research.

Reflecting on my initial thoughts about how I would conduct my study, the aim at that time was to provide spiritual care for the ESRF patients within a structural, positivist paradigm. However, the transitional process in the supervision meetings

led me to question myself more and more about how I could achieve this aim without also discovering how spirituality manifested during ESRF. It became increasingly that I needed to discover what it 'means' before knowing how to deliver it. As one of the participants later remarked: "How can someone give something he does not own?". From discussions with my supervisors and with their advice, I refined my way of thinking and adopted an interpretivist epistemology to explore and choose the best possible methodology for my research, to gain the widest view possible of ESRF participants' experiences so as to show all possible aspects of the phenomenon of spirituality in order to see the similarities as well as the differences within the participants' experiences. Thus, I chose phenomenology as my methodology.

The review of existing literature was initially very difficult to digest, despite my prior belief that this would be the most straightforward part of the study. It turned out to be problematic for me to systematically search for the phenomena of interest. I ultimately had a total of 900 studies in my Endnote library. Further self-questioning, reading and discussions in the supervision meetings helped me to understand the essence of a literature search, honing my review of existing studies and enabling me to identify gaps in the existing literature. This was a major strength I gained from conducting this study.

As far as being an 'insider' is concerned, I acknowledged my previous ontological positioning. Being male, speaking Arabic, being experienced in nursing in Jordan, being an ESRF patient, and knowing the culture and the context of the study could be considered influential factors that might colour the participants' responses and the way they chose to answer the questions. It could be argued that my results would have been more valid if I bracketed out all those factors. However, I feel that correlating my own experience as a person from the same socio-cultural milieu as the participants, together with my healthcare knowledge and experience of ESRF as a patient as well as a nurse, enabled me to interpret the data in a uniquely deep and comprehensive way. These influential factors in my view represented an accumulative knowledge and experience built up through many years that were immensely beneficial for my study, especially when the aim of the study was to gain a deeper understanding of complex concepts such as spirituality in multiple realities.

It is evident in the literature that being an insider can enable the researcher to be in a better position to understand the phenomenon's terminology, the care pathway and process, the experience, and the knowledge of the phenomenon of spirituality from complex dimensions (Hayman et al., 2012). My understanding of spirituality and of ESRF as an illness greatly enhanced the process of building trust and rapport with participants, enabling them to open up and divulge extensive data to me, much of it highly sensitive in the conservative culture of Jordan. The sense of connectedness and comfort exhibited by my participants was accrued because of my status as an insider (Hayman et al., 2012; Pringle et al., 2011). This view is also supported by previous studies arguing that we are all embedded in a historical context and we are powerless to purge ourselves of it completely, despite the ideals of the positivist paradigm (Koch, 1995; Koch, 1996). Thus, although bracketing is one way to maintain the objectivity of the researcher, I refused to adopt this stance as it contradicts the subjectivity of the specific methodology I chose (i.e. phenomenology), to answer my study question (Greatrex-White, 2004; Koch, 1995; Pringle et al., 2011).

As pointed out throughout my thesis regarding reflectivity, during the data collection phase I conducted four interviews as a pilot, all of which were video-recorded. Studying, critiquing and reflecting on these interviews then enabled me to identify and discuss (with my supervisors) what was wrong and what might go wrong during fieldwork, in order to overcome any weakness when conducting the actual interviews. For example, the unnecessary and unnatural interactions of interviewees when they saw the camera were causing too many interruptions. I questioned this with myself, then discussed it with my supervisors who advised me not to video-record interviews. In addition, some staff was not familiar with the video-recorder and they kept interfering to ask about the instrument.

I also faced significant challenges in gaining access to hospitals (or rather one hospital in particular, as explained previously). Furthermore, I was unable to recruit a Christian woman I had hoped to interview due to issues of cultural sensitivity. All of these issues were resolved in the main data collection phase. However, I faced other challenges that I did not expect from the pilot study and I felt powerless to deal with them. For example, the confidentiality clause in the information sheet, while essential to comply with ethical requirements in academic studies, was viewed with

suspicion and apprehension by some participants who felt that the emphasis on confidentiality implied the likelihood of some misdemeanour on their part. As potential participants kept calling and repeatedly asking me to clarify this during the recruitment process, I constantly reiterated as best I could that the confidentiality issues posed no harm to them, but were there to protect them, and as such were a requirement for me to obtain ethical approval to conduct the study. Nevertheless, one participant withdrew from the study as a result of the confidentiality issue. Future researchers might need to consider this point as an issue of cultural sensitivity in Arab countries.

As discussed above and throughout my thesis, my own experience as a novice phenomenological researcher, as a nurse and as an ESRF patient reviewing the phenomenon of spirituality during ESRF, made it incredibly difficult to rectify my ontological positioning within this study, but it was clear that my position was important in interpreting the ESRF patients' accounts of the phenomenon of spirituality. Although I began this study based on my own experiences, during fieldwork and writing up this study, and reflecting on my journey throughout, I came to see that my baseline knowledge and understanding were very limited, and new levels of understanding unfolded as the study progressed and as I learned from patients' experiences. My understanding of spirituality now is a co-creation of a new picture that contains multiple pieces in a jigsaw that includes my own understanding as well as participants' understandings. Nevertheless, I cannot comprehend the form and shape that will be given to this study by the final piece of the jigsaw – i.e. the reader and their understanding.

It is important to reflect upon the most painful experience in I had during writing my study. This happened after I had completed the Findings chapter, which reached over 143,000 words. The University of Nottingham regulations state that theses should not exceed 100,000 words; the consequent process of slashing reams of rich and personally important data from the study was heart breaking and the most traumatic experience of my life, and is something that potential phenomenological researchers should seriously consider. I had a continuous feeling of guilt that I was letting my participants down, participants who had been very enthusiastic to entrust me with their experiences. In short, I felt I was failing in my personal obligation to the ESRF patients who participated in my study. Whilst at this low ebb I had a

major car accident on a motorway in the UK and almost died, but over the ensuing days I had the opportunity to reflect that the best way to help ESRF patients and keep fidelity with my interviewees was to complete my study and improve spiritual care for ESRF patients in Jordan in my future career. Furthermore, I will always carry their stories with me wherever I go.

On the other hand, in spite of this negative aspect of the phenomenological method, the implications of using hermeneutic phenomenology proved to be a transforming process for me personally. Looking back, when I embarked on my learning journey at Nottingham University, I had exclusively experienced traditional positivist research. During supervision meetings, I unwittingly became more interpretivist due to my own reasoning and my supervisors' questioning concerning the research. This ultimately opened a new set of transferable skills and knowledge that Dr. Sheila Greatrex-White and Dr. Aru Narayanasamy shared with me. This has given me an insight into my selected approach that I simply did not have when I started four years earlier. I attended an international conference recently where I critically analysed every single study presented. My supervisors were subsequently notified (without my knowledge) of my critical and rich participation in this conference. Indeed, I was also approached by many scholars and students enquiring where and who my supervisors were due to their appreciation of my contributions. This would not have happened three years ago.

Although the implications of phenomenology in applied science have been critiqued in the literature, I argue that my study has provided a new understanding of the phenomenon of spirituality during ESRF. In addition, it has provided evidence-based guidelines and procedures for Jordanian educators, nurses, policy makers and future researchers to explore and understand further. As can be noted throughout the study, I do not claim that I have reached the ultimate truth for the entire ESRF patient community in Jordan, and what emerged from my study cannot be held to be universally representative of them and I acknowledge that the root aim to understanding spirituality requires far more extensive research.

The methodology I employed in this study has been useful for me personally and for the existing body of knowledge concerning the research phenomenon. The early chapters in this thesis, highlighted the dichotomy of why the existing knowledge regarding spirituality in Western culture was missing major elements, when different

cultures and traditions such as the Arab-Islamic one, or particular subject groups such as ESRF patients, were under-represented. This study makes a fundamental contribution in each of these contexts.

Appendix 1: References

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Appendix 2: Map of Jordan

Appendix 3: Research Studies Analysis

Author/s (year)/ title/ country	Aim/purpose	Research participant/ setting	Method	Area	Main findings
White, Y. and B. F. S. Grenyer (1999). The biopsychosocial impact of end-stage renal disease: the experience of dialysis patients and their partners." Journal of Advanced Nursing 30(6): 1312-1320. Australia	To investigate the impact dialysis patients and their partners.	N= 44	Phenomenology	Dialysis	Seven themes emerged: Anxiety about the uncertainty of their health, Major changes in life-style since the commencement of dialysis, Negative emotional responses to dialysis, Positive aspects of their relationship, A sense of indebtedness to their partners, Lifestyle changes since the commencement of dialysis, Fatigue. This study gives a unique perspective on the negative impact which dialysis can have on couples, yet it also suggests that some are able to cope in a positive way despite the many life-style adjustments required by dialysis. The results of this study indicate that nurses need to recognize and respond to the tremendous emotional impact that chronic illness and its treatment can have on families in an era where it is possible to sustain life for years with the use of life support technology. Nursing management should also encourage nephrology nurses to develop advanced counselling skills and to develop a family centred approach to the care of the patient with ESRD.
Ndlovu, P. and J. Louw (1998). Making sense of kidney transplantation: view from African recipients. Clinical Transplantation 12(3): 250-255	To investigate the experiences of African patients who have undergone a kidney transplant from a live donor or from a cadaver	N=14	Qualitative	Transplant	Several themes accounted for the frameworks of meaning that patients attributed to the transplant process. These are: religion and indigenous belief systems; the role of the extended family; patients' respective routes to the hospital; feelings about the transplant; and experiences in the hospital.

Author/s (year)/ title/ country	Aim/purpose	Research participant/ setting	Method	Area	Main findings
Sussmann, K. (2001). Patients' experiences of a dialysis diet and their implications for the role of the dietitian." Journal of Renal Nutrition 11(3): 172-177 UK	To examine, the experiences and difficulties of patients on hemodialysis who follow dietary restrictions.	N= 8	Qualitative	dialysis	Findings showed a variety of physical, social, and psychological difficulties that can result from the onset of illness, commencement of dialysis, and the imposition of dietary restrictions. A loss of autonomy was an underlying theme. Greater understanding, hope, support from others, individual activity, and personal responsibility on the part of patients helped them to cope more positively with the changes in life.
Fry, P. S. (2000). Religious involvement, spirituality and personal meaning for life: existential predictors of psychological wellbeing in community-residing and institutional care elders." Aging & Mental Health 4(4): 375-387 Canada	To exam the unique and combined contribution of special dimensions of religiosity, spirituality and personal meaning in life as predictors of wellbeing in samples of community residing and institutionalized older adults	N= 340	Quantitative	Community	The findings confirmed that existential measures of personal meaning, religiosity and spirituality contributed more significantly to the variance in wellbeing than did demographic variables or other traditional measures such as social resources, physical health or negative life events. The importance of existential constructs of religiosity, spirituality and personal meaning in helping older adults to transcend old age stresses and sustain wellbeing
Walton, J. (2002). Finding a balance: a grounded theory study of spirituality in hemodialysis patients." Nephrology nursing journal : journal of the American Nephrology Nurses' Association 29(5): 447-457. USA	To discover what spirituality means to hemodialysis patients and how it influences their lives	N= 11	Qualitative	Dialysis	Participants described spirituality as a life-giving force from within, full of awe, wonder, and solitude, that inspires one to strive for balance in life. Participants validated the description of spirituality, categories, and phases to assure that it captured their person experiences. The results of this study provide a theoretical framework to guide nursing practice as well as an understanding of what spirituality means to hemodialysis patients and how it influences their lives.

Author/s (year)/ title/ country	Aim/purpose	Research participant/ setting	Method	Area	Main findings
625Curtin, R. B., H. K. Johnson, et al. (2004). The peritoneal dialysis experience: insights from long-term patients." Nephrology Nursing Journal 31(6): 615- USA	To identify the domains and dimensions of self-management experienced by peritoneal dialysis (PD) patients who have been on PD tor more than 4 years.	N= 18	Quantitative	dialysis	Autonomy/control was comprised of three specific dimensions: partnership in care, self-care, and self-care self-efficacy. Normality in everyday life included the dimensions of flexibility/freedom, interpretation of illness severity, and perception of body image. Such insights lay the groundwork for development of interventions to facilitate informed decision-making regarding dialysis modality, to teach tactics for effective self-management on PD, and to help health care professionals to support the self-management efforts of patients on PD.
Polaschek, N. (2003). The experience of living on dialysis: a literature review." Nephrology Nursing Journal 30(3): 303 NewZealand	literature review				
Martin-McDonald, K. and D. Biernoff (2002). Initiation into a dialysis-dependent life: an examination of rites of passage... including commentary by Frauman AC with author response." Nephrology Nursing Journal 29(4): 347 Australia	To explore the conceptual and empirical application of the rites of passage model in contemporary health care for those who are dialysis dependent.	N=10	Mixed	dialysis	The findings illuminated the three stages of rites of passage (ROP), separation, liminality, and reincorporation, with each stage evident in the participants' stories. Commencing dialysis is an initiation that delineates the transition from one social status to another. It is argued that there is a metaphoric usefulness of the application of the ROP model that might influence the quality of care to dialysis initiates.

Author/s (year)/ title/ country	Aim/purpose	Research participant/ setting	Method	Area	Main findings
Al-Arabi, S. a. (2006). Quality of life: Subjective descriptions of challenges to patients with end stage renal disease." Nephrology Nursing Journal 33(3): 285-292. USA	To describe how persons with end stage renal disease (ESRD) experience and manage the quality of their daily lives.	N= 80	Qualitative	Dialysis	The three emergent conceptual categories that describe the quality of everyday life among the study group were: 1) Life Restricted with sub-themes "tied down," "left out, " and "doing without;" 2) Staying Alive with sub-themes "love from others," "accept it as part of life, " and "trust in God;" and 3) Feeling Good with sub-themes "personal satisfaction" and "being happy."
Lin, C. C., B. O. Lee, et al. (2005). The phenomenology of deciding about hemodialysis among Taiwanese." Western Journal of Nursing Research 27(7): 915-929. Taiwanese	To describe the experience of making hemodialysis choices among Taiwanese with end-stage renal disease (ESRD).	N= 12	Phenomenology	Dialysis	Three themes emerged: getting opinions of family members, seeking professional confirmation, and exploring alternative treatments. The third category, living with dialysis, included three themes: worsening symptoms, support of the family, and law of causation. These categories and themes revealed the difficulties that ESRD patients dealt with and the influence these difficulties and their culture had on the treatment choice.
Giaramazidou, T., A. Giovreki, et al. (2005). A study of dietary knowledge and its religious relationship in patients receiving haemodialysis." EDTNA/ERCA Journal of Renal Care 31(4): 199-202 Greece	To explore the relationship between patient dietary compliance and religion and educational level	N =70	Mixed	dialysis	Patients did not acquire the necessary dietary knowledge but despite insufficient knowledge, they had a low incidence of fluid overload, hyperkalaemia and hyperphosphataemia. The Christians, despite superior knowledge, compared to the Muslims had more episodes of fluid overload.

Author/s (year)/ title/ country	Aim/purpose	Research participant/ setting	Method	Area	Main findings
Vélez, E. and M. Ramasco (2006). Meaning of illness and illness representations, crucial factors to integral care." EDTNA/ERCA Journal of Renal Care 32(2): 81-85. Spain	To Identify and characterize the attributed meanings of ESRD and HD as articulated by patients.	N=12	Qualitative	dialysis	It is not enough to provide the patient with scientific information considered essential for the successful management of illness. How this information is received and understood should be investigated further. The lack of effectiveness of pre-dialysis clinics as an educational period for the patient suggests the need to revisit this area.
Tarakeshwar, N., L. C. Vanderwerker, et al. (2006). Religious coping is associated with the quality of life of patients with advanced cancer." Journal of Palliative Medicine 9(3): 646-657. USA	To examine the association between religious coping and QOL	N=170	Mixed	Cancer	Findings show that religious coping plays an important role for the QOL of patients and the types of religious coping strategies used are related to better or poorer QOL.
Fowler, C. and L. S. Baas (2006). Illness representations in patients with chronic kidney disease on maintenance hemodialysis." Nephrology Nursing Journal 33(2): 173. USA	To explore the relationship between illness perception and quality of life	N= 42	Quantitative	Dialysis	Nephrology nurses are in an optimal position to identify the illness perceptions of patients on chronic hemodialysis and can introduce specific coping mechanisms to enhance overall well-being. As well nephrology nurses can function as part of the overall health care team to identify the resources available to minimize the perceived consequences of chronic kidney disease.

Author/s (year)/ title/ country	Aim/purpose	Research participant/ setting	Method	Area	Main findings
Campos, C. J. G. (2007). The experience of person with chronic renal disease in hemodialysis: meanings attributed for the patients." Online Brazilian Journal of Nursing 6(3): 16-16. Brazil	To show how renal patients experience disease and hemodialysis treatment in a specialized service of a State University Hospital.	N=7	Qualitative	Dialysis	Chronic renal patient attributes diverse meanings to hemodialysis treatment and that survival appeared as the main meaning for such event. The renal disease and hemodialysis treatment cause individual emotional alterations in different degrees that can interfere in the treatment evolution. Patients have difficulties in social and professional life, relations with friends and family members besides somewhat social discrimination. On the interpersonal relation with the health team, patients indicate the need for more attention and willingness to be listened more.
Walton, J. (2007). Prayer warriors: a grounded theory study of American Indians receiving hemodialysis." Nephrology nursing journal : journal of the American Nephrology Nurses' Association 34(4): 377-387 USA	To explore what spirituality means to individuals who are American Indians receiving hemodialysis	N=21	Ground theory	dialysis	The metaphor "Prayer Warriors" described the core category of this study. Praying played a major role in the following categories: (a) suffering, (b) honouring spirit, (c) healing old wounds, and (d) connecting with community. Praying involved hard work, suffering, sweating, hunger, and passion, and was a powerful way to cope with the stress of hemodialysis.
White, Y. and G. Fitzpatrick (2006). Dialysis: prolonging life or prolonging dying? Ethical, legal and professional considerations for end of life decision making." EDTNA/ERCA Journal of Renal Care 32(2): 99-103. Austrlia	review of literature				A review of current literature was undertaken and revealed a paucity of information in regard to palliation in those with end stage renal disease who had discontinued dialysis. The fear of dying, pain, suffering, and abandonment that a patient and/or their family may perceive as being associated with death may create barriers to decisions to discontinue with dialysis treatments.

Author/s (year)/ title/ country	Aim/purpose	Research participant/ setting	Method	Area	Main findings
Brown, J. B., M. L. Karley, et al. (2008). The experience of living kidney donors." Health & Social Work 33(2): 93-100. Canada	To describes the experiences, feelings, and ideas of living kidney donors	N= 12	phenomenology	Donors	Three key themes emerged in the exploration of the living kidney donors' experience of donation: (1) how witnessing their loved ones' experience of illness and the threat of losing the recipient influenced the participants' decision to donate, (2) interpersonal and intrapersonal factors influencing the living kidney donor's decision to be tested as a potential donor and the actual process of donation, and (3) the impact of giving the gift of life.
Yeh, S. and H. Yeh (2007). Using complementary therapy with a hemodialysis patient with colon cancer and a sense of hopelessness [Chinese]." Journal of Nursing 54(5): 93-98. China	To discusses a nursing experience involving a dialysis patient who also suffered from cancer had and a sense of hopelessness due to the distress caused by the two severe illnesses	N=1	Mixed method	Dialysis	The patient learned to release stress, and to ex-press his feelings, so that he could adapt to his current life, changed as it was by the illnesses, and face: he impact of those illnesses with a positive attitude.
Finkelstein, F. O., W. West, et al. (2007). Spirituality, quality of life and the dialysis patient." Nephrology Dialysis Transplantation 22(9): 2432-2434. USA	To discusses the spirituality in dialysis	Article			The relationship between spirituality and various quality of life domains is certainly worth exploring in more detail. Since it has been difficult to positively impact on the quality of life of ESRD patients, is it possible that engaging patients in discussions about their spiritual concerns and attending to their spiritual well-being may contribute to an improvement in their quality of life and medical outcome.

Author/s (year)/ title/ country	Aim/purpose	Research participant/ setting	Method	Area	Main findings
Cordeiro, J. A. B., V. V. Brasil, et al. (2009). Quality of life and hemodialytical treatment: renal insufficiency patient evaluation. Revista Eletrônica de Enfermagem 11(4): 785-793 Portugal	To evaluate the quality of life of patients with chronic renal failure under hemodialysis treatment.	N= 72	Quantitative	dialysis	The population perception was influenced by religious choices, gender, years of study, advanced age, time of treatment, family support and by work status. Researchers concluded that people under hemodialysis treatment suffer many alterations in their quality of life, showed by the lowest scores that indicate which aspects need more professional attention.
Timmers, L., M. Thong, et al. (2008). Illness perceptions in dialysis patients and their association with quality of life." Psychology & Health 23(6): 679-690 Netherlands	To explore illness perceptions of end stage renal disease (ESRD) patients and their associations with quality of life.	N= 133	Quantitative	ESRD patients	The concept of illness perceptions is useful in understanding the impact of ESRD and of dialysis treatment on quality of life. Interventions aimed at providing more knowledge about ESRD and dialysis, and provision of skills to coping with the illness and its consequences may improve quality of life in dialysis patients.
Molzahn, A. E., A. Bruce, et al. (2008). Learning from stories of people with chronic kidney disease." Nephrology Nursing Journal 35(1): 13-21. USA	To explore how people with chronic kidney disease (CKD) describe/story experiences of liminality associated with CKD and its treatment.	N= 100	Narrative inquiry	Dialysis	Six main themes emerged: The people relating the stories described a number of liminal spaces, including living/not living independence/dependence, restrictions/freedom, normal/not normal, worse off/better off and alone/connected. Awareness of the liminal spaces can help nurses provide care that addresses the complexity of CKD

Author/s (year)/ title/ country	Aim/purpose	Research participant/ setting	Method	Area	Main findings
Madar, H. and Y. Bar-Tal (2009). The experience of uncertainty among patients having peritoneal dialysis." Journal of Advanced Nursing 65(8): 1664-1669. Isreal	To examine factors (severity and duration of the disease, credible authority, social support, education) that may influence the level of uncertainty and stress in patients having peritoneal dialysis.	N= 71	Quantitative	dialysis	Level of education was found to affect both uncertainty and stress. The factors that most influenced patients' uncertainty were related to their ability to process information. Familiarity with their disease was less influential. Nurses should be aware of the fact that they can reduce their patients' uncertainty and stress by helping them to maintain hope and to view their health status.
38Krueger, L. (2009). Experiences of Hmong patients on hemodialysis and the nurses working with them." Nephrology nursing journal : journal of the American Nephrology Nurses' Association 36(4): 379 USA	To explore the experiences of Hmong patients on hemodialysis and the nurses working with them.	N= 30	Qualitative	dialysis	Overwhelming sadness was the most consistent theme. Sadness resulted, from physical symptoms of weakness and fatigue, which caused an inability to participate in activities and perform roles and responsibilities; psychosocial symptoms of uncertainty, worthlessness, hopelessness, and fear; and the dialysis treatments themselves, as well as the dietary restrictions, added to the sadness these
Hughes, J., E. Wood, et al. (2009). Exploring kidney patients' experiences of receiving individual peer support." Health Expectations 12(4): 396-406. UK	To explore kidney patients experiences of receiving individual peer support	N= 20	Qualitative	Chronic kidney patients	Four main themes were identified from the analysis: interaction with the peer supporter; perceived benefits of peer support; contrasts between peer support and other sources of Information; and the peer supporter as a role model.

Author/s (year)/ title/ country	Aim/purpose	Research participant/ setting	Method	Area	Main findings
Clarkson, K. A. and K. Robinson (2010). Life on dialysis: a lived experience. Nephrology Nursing Journal 37(1): 29-35. USA	To explore the lived experience of patients with ESRD and	N=10	phenomenology	dialysis	Five major themes emerged: Restricted Life, Limitation, Body/Mind/Spirit Challenges, Coping and Areas Lacking. Three pertinent conceptual categories emerged that described the concern in the life of patients on dialysis: 1) life changes on dialysis with sub-themes of restricted life, limitations, and hard on body; 2) coping; and 3) areas lacking with sub-themes of health management, education, and preparing the next generation.
Sinclair, P. M. and V. Parker (2009). Pictures and perspectives: a unique reflection on interdialytic weight gain." Nephrology Nursing Journal 36(6): 589-597. Australia.	To explore the perspectives of managing intradailytic weight gain for individuals on hemodialysis	N= 7	Qualitative	dialysis	Five major themes emerged: include magnitude of loss, constant struggle, and transition to acceptance. Transition to acceptance is not a linear progression to understanding and compliance but a multifaceted, tortuous struggle unique to individuals and largely dependent upon support, belief in a life worth living, and willingness to engage in surveillance and maintenance of behaviour.
Pruchno, R. A., F. P. Cartwright, et al. (2009). Effects of marital closeness on the transition from caregiving to widowhood." Aging & Mental Health 13(6): 808-817. USA	To examine the effects of marital closeness on indicators of well-being (depressive symptoms, grief, and relief) as spouses transition from the role of caregiver to that of widowed person	N=118	Quantitative	Widowhood of ESRD patient`	These data highlight differences in the experiences of grief, relief, and depressive symptoms and suggest that marital closeness plays a central role.

Author/s (year)/ title/ country	Aim/purpose	Research participant/ setting	Method	Area	Main findings
Davison, S. N. and G. S. Jhangri (2010). Existential and Supportive Care Needs Among Patients with Chronic Kidney Disease." Journal of Pain and Symptom Management 40(6): 838-843.	To describe the nature, prevalence, and predictors of spiritual and supportive care needs in CKD	N= 253	Quantitative	Chronic kidney patients	The study supports construct validity of the ESRD Spiritual Beliefs Scale as a measure of religiosity. The existential domain of spirituality was more clinically relevant to patients in this study and had a greater impact on HRQoL compared with measures of religiosity.
Jansen, D. L., M. Rijken, et al. (2010). Perceived autonomy and self-esteem in Dutch dialysis patients: the importance of illness and treatment perceptions. Psychology & Health 25(6): 733-749. Netherlands	To Explore the perceived autonomy, state self-esteem and labour participation in ESRD patients on dialysis, and the role illness and treatment perceptions play in these concepts.	N = 166	Quantitative	Dialysis	The results indicate that dialysis patients' beliefs about their illness and treatment play an important role in their perceived autonomy and self-esteem. Stimulating positive (realistic) beliefs and altering maladaptive beliefs might contribute to a greater sense of autonomy and self-esteem and to social participation in general. Interventions focusing on these beliefs may assist patients to adjust to ESRD.
Herlin, C. and C. Wann-Hansson (2010). The experience of being 30-45 years of age and depending on haemodialysis treatment: a phenomenological study. Scandinavian Journal of Caring Sciences 24(4): 693-699. Sweden	To describe how hemodialysis (HD) patients, between 30 and 45 years of age, experience their dependence on HD treatment.	N=9	Phenomenology	Dialysis	Five major themes emerged: A sense of fear, Dependence on caregivers, Feelings of loneliness, Time lost in dialysis, Being on a waiting list for kidney transplantation.

Author/s (year)/ title/ country	Aim/purpose	Research participant/ setting	Method	Area	Main findings
Moran, A., A. Scott, et al. (2011). Waiting for a kidney transplant: patients' experiences of haemodialysis therapy. Journal of Advanced Nursing 67(3): 501-509. Ireland	to exploration of the experiences of patients with end-stage kidney disease who were having hemodialysis	N= 16	phenomenology	Dialysis	Three themes: living in hope, uncertainty and being on hold. Participants described their experiences of living in hope while they waited for a kidney transplant. However, as the waiting time continued indefinitely, participants became uncertain, and this meant that they were unable to contemplate opportunities in the future. Moreover, the restrictions of hemodialysis therapy prevented them from performing many of the activities they had taken for granted in the past.
Adams-Leander, S. (2011). The Experiences of African-American Living Kidney Donors." Nephrology Nursing Journal 38(6): 499-509.	To provide an overview of the experiences of living kidney donors in the African-American population	N= 8	Phenomenology	Living kidney donors	Two major themes emerged - context of living kidney donation and work of living kidney donors. The researcher noted that influence of spiritual and religious value and practices is important factors.
Rambod, M. and F. Rafii (2010). Perceived Social Support and Quality of Life in Iranian Hemodialysis Patients. Journal of Nursing Scholarship 42(3): 242-249. Iran	To describe the relationship between perceived social support and the quality of life in hemodialysis patients from an Islamic cultural background in Iran	N= 202	Quantitative	dialysis	There were a statistically significant relationship between perceived social support and health-functioning, socioeconomic, psychological-spiritual, and family subscales of quality of life. Total quality of life was also significantly correlated with perceived social support. It is important to reflect on the impact of culture and religion of Iran on quality of life of hemodialysis patients and their perceived social support.

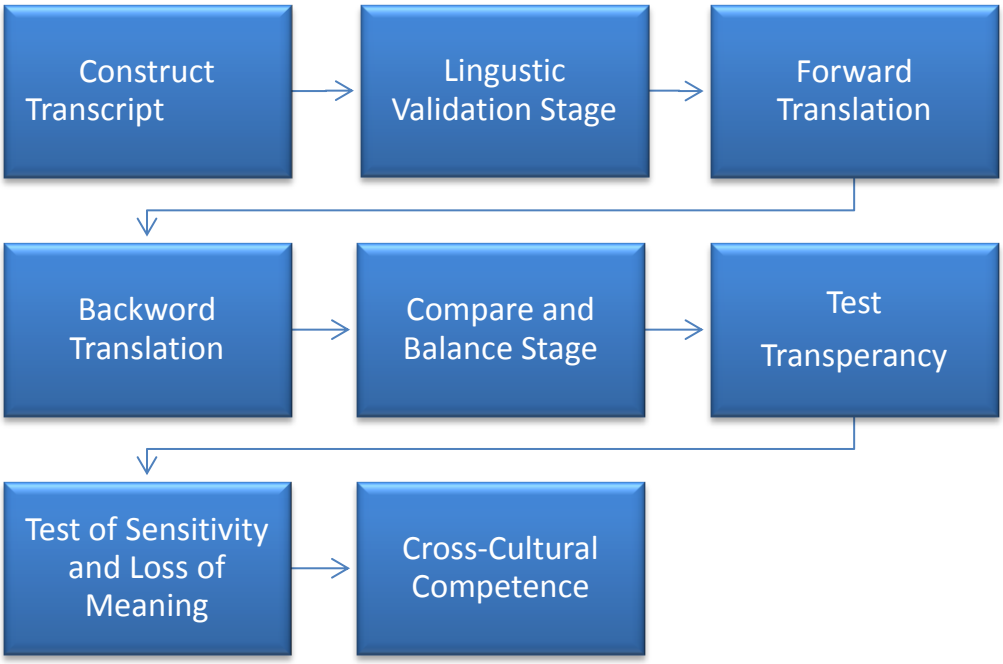
Author/s (year)/ title/ country	Aim/purpose	Research participant/ setting	Method	Area	Main findings
Birmele, B., A. Le Gall, et al. (2012). Clinical, Sociodemographic, and Psychological Correlates of Health-Related Quality of Life in Chronic Hemodialysis Patients. Psychosomatics 53(1): 30-37.Birmele, B., A. Le Gall, et al.	To examined the relation between psychosocial factors, particularly health-related locus of control (HLOC) and quality of life (QoL) in chronic hemodialysis patients	N= 300	Quantitative	Dialysis	Internal and external LOC seem to have differential impact on QoL. Increasing awareness and empowerment of the internal and external components of the LOC could help patients improving QoL.
Walsh, E. and E. Lehane (2011). An exploration of the relationship between adherence with dietary sodium restrictions and health beliefs regarding these restrictions in irish patients receiving haemodialysis for end-stage renal disease. Journal of Clinical Nursing 20(3/4): 331-340. UK	To measure adherence levels with dietary restrictions in Irish patients with end-stage renal disease receiving hemodialysis and to explore the relationships between adherence with dietary sodium restrictions and health beliefs in relation to following these restrictions in this group	N= 79	Quantitative	Dialysis	For the Irish patient, beliefs in relation to following a low sodium diet significantly affected adherence levels with this diet. This is an important finding as delineating key beliefs, particularly key barriers, facilitates an increased understanding of non-adherence for nurses.

Author/s (year)/ title/ country	Aim/purpose	Research participant/ setting	Method	Area	Main findings
Grudzen, C. R., L. D. Richardson, et al. (2010). Palliative Care Needs of Seriously Ill, Older Adults Presenting to the Emergency Department. Academic Emergency Medicine 17(11): 1253-1257 USA	To identify the palliative care needs of seriously ill, older adults in the emergency department (ED)	N=50	Mixed Methods	Emergency patients	Seriously ill, older adults in an urban ED have substantial palliative care needs that are not limited to relief of Physical and mental symptoms, but also include other problems accessing care.
Theofilou, P. (2012). Quality of life and mental health in hemodialysis and peritoneal dialysis patients: the role of health beliefs." International Urology and Nephrology 44(1): 245-253. Grease	To determine (i) whether beliefs about health differ between different renal replacement therapies in end-stage renal disease (ESRD) patients and (ii) whether these beliefs are associated with health-related quality of life (HQoL), as well as with mental health.	N= 89	Quantitative	Dialysis	The beliefs that dialysis patients hold about their illness appear to be related to the type of renal replacement therapy. These cognitions are associated with HQoL and with mental health

Author/s (year)/ title/ country	Aim/purpose	Research participant/ setting	Method	Area	Main findings
Tanyi, R. and J. Werner (2003), Adjustment, spirituality, and health in women on hemodialysis. USA	To examined levels of and relationships between adjustment, spiritual well-being, and self-perceived health in women with ESRD	N= 65	Quantitative	Dialysis	The study samples were fairly well adjusted as measured by the Psychosocial Adjustment to Illness Scale-Self-Report. They demonstrated fairly high levels of religious, existential, and overall spiritual well-being. Self-perceived health was good Spiritual well-being variables were all positively and significantly related to overall psychosocial adjustment and psychological distress adjustment. Self-perceived health variables were all positively and significantly related to overall psychosocial adjustment
Albaugh, J. A. (2003) Spirituality and life-threatening illness: a phenomenologic study. Oncology nursing forum 30(4): 593-598. USA	To examine the lived experience of individuals diagnosed with a life-threatening disease	N=7	Phenomenology	Life threating illness	Five major themes emerged: A Sense of Comfort From Aspects of Spiritual Life, Trust in God, Blessed in Many Aspects of Life, Strength From Their Spiritual Beliefs, Meaning in Life.
Burkhardt, M. A. (1993). Characteristics of spirituality in the lives of women in a rural Appalachian community, Journal of transcultural nursing : official journal of the Transcultural Nursing Society / Transcultural Nursing Society 4(2): 12-18. USA	To add to nursing's knowledge base relative to spirituality	N=5	Qualitative	women in rural area	The dominant theme which emerged relative to these relationships was that of self-reliance or inner strength. Spirituality for these women relates to the whole of life and is relational.

Author/s (year)/ title/ country	Aim/purpose	Research participant/ setting	Method	Area	Main findings
Cases, A., M. Dempster, et al. (2011). The experience of individuals with renal failure participating in home haemodialysis: An interpretative phenomenological analysis. Journal of Health Psychology 16(6): 884-894. UK	To explore the experience of individuals with renal failure undertaking home hemodialysis.	N= 6 patients	Phenomenology	Home	Three main themes were identified: (1) embracing treatment and lifestyle freedom and flexibility; (2) re-establishing a sense of self and preferred self-identity; and (3) integrating aspects of active engagement and aspects of supported, life-sustaining dependence.
Davison, S. N. and G. S. Jhangri (2010). Existential and Supportive Care Needs Among Patients with Chronic Kidney Disease." Journal of Pain and Symptom Management 40(6): 838-843.	To describe the nature, prevalence, and predictors of spiritual and supportive care needs in chronic kidney disease	N= 253	Cohort study	Chronic kidney disease	The patients had substantial spiritual and supportive care needs. There were no clear predictors of high spiritual or supportive care needs, highlighting the importance of evaluating all CKD patients for unmet needs.
Ziegert, K., B. Fridlund, et al. (2009). Time for dialysis as time to live": experiences of time in everyday life of the Swedish next of kin of hemodialysis patients. Nursing & Health Sciences 11(1): 45-50. Sweden	To explore the content of time in everyday life as experienced by the next of kin of patients on hemodialysis in Sweden	N=20	Qualitative	Next of kin home	The content of time in everyday life can be described as follows: fragmented time, vacuous time, and uninterrupted time. The findings show how everyday life time for the next of kin is minimized and that the common life space is contracted. The next of kin must be provided with supervision in order to provide them with more of their own time in everyday life, which can benefit their health.

Appendix 4: Cross-Cultural Competence



"Doing Culturally Competent Research: An Imperative for 21st Century Health Research", Papadopulos (2006).

Appendix 5: Information Sheet

Title of Project: HOW IS SPIRITUALITY EXPERIENCED BY JORDANIAN PATIENTS WITH ESRF? *A PHENOMENOLOGICAL STUDY.*

Name of Investigators: *Abdelrhman Tamimi*

Information Sheet

The Study

You are being invited to take part in a research study on the experiences of Jordanian patients on hemodialysis. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Please feel free to ask me if there is anything that is not clear or if you would like more information. Thank you for reading this.

What is the purpose of the study?

This study is part of a PhD in Nursing Studies, at the Faculty of Health and Life science, Nottingham University, England. The overall aim of this study is to understand and interpret patients' perceptions, the experiences, beliefs and practices that are associated with the use of spiritual care concept among End Stage Renal Failure patients in Jordan, with a view to extract the meanings of the multidimensional and the functionality of religion in the spiritual care in the lived experience of end stage renal failure who are in dialysis

Why have you been chosen?

You are being selected to take part in this study because you are a patients' on haemodialysis, that you required a spiritual care as a part of your holistic care. I would like to collect information about spiritual needs and meanings of spirituality to you. This information will be used to help nurses and may some other health professionals to meet your own spiritual needs.

Do you have to take part?

It is entirely up to you to decide whether to take part. If you decide to take part you are still free to withdraw at any time without giving a reason. If you decide to take part, you will be given this information sheet to keep and you will be asked to sign a consent form. If you decide to take part, you are still free to withdraw from the study at any time. You do not need to give a reason if you wish to withdraw.

What do I have to do?

Initially, I would like to ask you questions and to share with you some views about spiritual belief, practice, needs and care that you may think about. Indeed, with your permission, our conversation will record either tape recorder or camcorder.

What are the possible disadvantages and risks of taking part?

Any disadvantage or risk related to taking part in this study is extremely unlikely

What happens to the information?

All the information that will be gathered will be strictly confidential. No one will be able to identify you from the study. The answers from the questions will be put into a computer to be translated and written up to transcript then analysed. At the end of the project all the transcript will be shredded. All data will be treated in accordance with the current Data Protection Act.
Your name will not be used at all in the study. Any information from the transcript will have your name and address removed so you cannot be recognised from it. I will keep the transcript in a secure place until they are no longer needed and I will not share them with anyone other my doctoral supervisor from Nottingham University. In addition, the PhD examiners and other representatives from ethical comities may review your transcript. Furthermore, the research may be published or presented at national and international conference.

What are the potential benefits in participating in this research study?

The participation in this interview may help to develop better understanding for the spiritual care concept for haemodialysis patients in Jordan. In addition, it may develop knowledge about hemodialysis patients spiritual needs that nurses and other health care professionals are required to meet.

What if something goes wrong?

It is very unlikely to have any adverse effect. However, In the event that something does go wrong and you are harmed during the research study there are no special compensation arrangements. If you are harmed and this is due to someone's negligence then you may have grounds for a legal action for compensation against Nottingham University (who have indemnity for negligent harm), but you may have to pay your legal costs.

Who has reviewed the study?

This study has been reviewed and approved by the University of Nottingham Medical School Ethics Committee, the research and ethical committee at Jordanian Ministry of Health and the research and ethical committee in each individual hospital.

Who has reviewed the study?

This study has been reviewed and approved by the University of Nottingham Medical School Ethics Committee, the research and ethical committee at Jordanian Ministry of Health and the research and ethical committee in each individual hospital.

What if I wish further clarification?

Please raise any difficulties or questions with Abdelrhman Tamimi, School of Nursing, Faculty Of Health And Life Sciences, Nottingham University, Nottingham, NG7 2RD UK, Tel/Fax +44 01482214393 e-mail, ntxat4@nottingham.ac.uk. If he is unable to give you a satisfactory answer, please contact the research supervisor Dr. Aru Narayanasamy at Nottingham University, Aru.Narayanasamy@nottingham.ac.uk, Nottingham University, Nottingham, NG7 2RD or Dr. Sheila Greatrex Sheila.Greatrex-White@nottingham.ac.uk

Contact for Further Information

Mr. Abdelrhman TAMIMI
Mobile: 07590568983
E-mail: ntxat4@nottingham.ac.uk

Thank you for help and support in taking part in the study,

Abdelrhman Tamimi

عنوان المشروع: كيف تتجلى روحانية المرض في حياة المرضى الأردنيين في مرحلة الفشل الكلوي ؟ دراسة الظواهر

اسم الباحث: عبدالرحمن التميمي

ورقة معلومات

عزيزي/ عزيز تي

جرى دعوتك للمشاركة في هذه الدراسة البحثية لدراسة تجارب مرضى غسيل الكلى الأردنية. قبل أن تقرر اذا كنت تود المشاركه، فمن الضروري التعرف على هدف البحث وما الذي ستشمله. الرجاء اخذ الوقت الكافي لقراءة المعلومات التالية بعناية، إذا كان هناك أي شيء غير واضح أو إذا كنت ترغب في مزيد من المعلومات لك حرية السؤال والاستفسار.
أشكركم على هذه القراءة.

ما هو الهدف من الدراسة؟

هذه الدراسة هي جزء من متطلبات شهادة الدكتوراه في الدراسات التمريض في كلية العلوم الصحية والحياة، جامعة نوتنغهام، إنجلترا. ويتمثل الهدف العام من هذه الدراسة في فهم وتفسير المفاهيم المرضى، تجارب والمعتقدات والممارسات التي ترتبط مع استخدام مفهوم الروحانية بين مرضى الفشل الكلوي في الأردن. وتوفير الرعاية الشاملة لمرضى الفشل الكلوي أمر ضروري، خاصة في غسيل الكلى الذي يتطلب الرعاية الروحية كجزء من الرعاية الشاملة الخاصة بك .

لماذا تم اختيارك؟

جرى **اختيارك** للمشاركة في هذه الدراسة لأنك من مرضى الكلى/ غسيل الكلى، وأود جمع المعلومات حول تجربتك الروحانية منذ ان تم تشخيصكم بالفشل الكلوي. سوف تستخدم هذه المعلومات للمساعدة الممرضات وربما بعض غيرهم من المهنيين الصحيين لتلبية الاحتياجاتك الخاصة بك. آرائكم مهمة جدا لمساعدة هيئة التمريض والمهن الصحية الأخرى والمساعدة في فهم الصعوبات والتحديات الخاصة بك.

هل المشاركه ايجباريه ؟

لا، لك حرية القرار في المشاركه وهي تماما متروك لكم لتقرير ما إذا كنت ستشارك ام لا. إذا قررت المشاركة، لا تزال حر لسحب المشاركه في أي وقت دون أن تدلوا بأسباب. إذا قررت المشاركة، سيتم منحك هذه الورقة المعلومات للحفاظ عليها وسوف يطلب منك التوقيع على استمارة الموافقة.

ماذا علي أن أفعل؟

في البداية، أود أن أسألك الأسئلة وأن أطلعكم على بعض وجهات النظر حول المعتقد والممارسة الروحية والاحتياجات والرعاية التي قد تفكر بها . في الواقع، فان الحديث الذي سيدور بيننا سوف يسجل اما عن طريق مسجل رقمي او كاميرا الفيديو.

ما هي فائدة ممكنة من المشارك؟

نأمل، من خلال المشاركة في هذه الدراسة، ان يتم تبادل بعض وجهات النظر الخاصة بك، ومنظور، والأفكار والخبرات لاستخدامها لفهم كيفية ظهور الروحانية المرض في حياة المرضى الأردنيين في الفشل الكلوي، ولمساعدة المرضى في تجربة الرعاية الروحية جيدة.

ما هي المساوئ المحتملة ومخاطر المشاركة؟

من غير المرجح للغاية ان يكون هنالك أي عيب أو المخاطر متعلقة بالمشاركة في هذه الدراسة.

ماذا سيحدث للمعلومات التي سيتم جمعها ؟

إن جميع المعلومات التي سيتم جمعها والتعامل ستكون سرية للغاية. لن يكون أي شخص قادرا على التعرف عليك من الدراسة. وسيتم طرح الإجابات على الأسئلة من على جهاز كمبيوتر لترجمتها وكتابة ما يصل إلى نص تم تحليلها. في نهاية المشروع كل نص ، سوف يتم تمزيقه. سيتم التعامل مع كافة البيانات وفقا لقانون حماية البيانات الحالية.
لن يتم استخدام اسمك على الإطلاق في الدراسة. فإن أي معلومات من النص يكون اسمك وعنوانك ظاهرا فيها يتم ازالتها حتى لا يمكن ان يتعرف عليها احد من ذلك. سأبقي نص في مكان آمن حتى لم تعد هناك حاجة إليها. ولن اشاركها مع أي شخص آخر باستثناء مشرفي الدكتوراه من جامعة نوتنغهام. وبالإضافة إلى ذلك، قد الممتحنين الدكتوراه وممثلين آخرين من مراجعة نص لأخلاقية الخاص بك. وعلاوة على ذلك، يمكن نشر البحث في المؤتمر الوطني والدولي.

ما هي الفوائد المحتملة في المشاركة في هذه الدراسة البحثية؟

المشاركة في هذه المقابلة قد يساعد على تطوير فهم أفضل لمفهوم الروحانية للمرضى غسيل الكلى في الأردن. وبالإضافة إلى ذلك، فإنه قد وضع المعرفة حول الاحتياجات الروحية مطلوبة لمرضى غسيل الكلى والتي يتوجب من الممرضين وغيرهم من العاملين في مجال الرعاية الصحية تلبيتها.

ماذا لو حدث خطأ ما؟

من المستبعد جدا أن يكون له أي تأثير سلبي. ومع ذلك، في حالة حدوث اي خطأ والضرر لك خلال دراسة بحثية لا توجد ترتيبات التعويض الخاص. إذا كنت تتضرر وهذا يرجع إلى إهمال شخص ما تم قد يكون لديك أسباب دعوى قضائية للحصول على تعويض ضد جامعة نوتنغهام (الذين لديهم تعويض عن الضرر الإهمال)، ولكن قد تضطر إلى دفع تكاليف القانونية الخاصة بك.

هل تم مراجعة الدراسه؟

وقد استعرضت هذه الدراسة والتي وافقت عليها جامعة نوتنغهام و لجنة الأخلاقيات الطبية، والبحث واللجنة الأخلاقية في وزارة الصحة الأردنية والبحث واللجنة الأخلاقية في كل مستشفى على حدة.

ماذا لو اود الحصول على المزيد من التوضيح؟

يرجى رفع أي صعوبات أو أسئلة للباحث: **عبدالرحمن التميمي**، كلية التمريض، كلية العلوم الصحية، والحياة، جامعة نوتنغهام، نوتنغهام، NG7 2RD
المملكة المتحدة، هاتف / فاكس +44 01482214393 البريد الإلكتروني، ntxat4@nottingham.ac.uk. اذا كان غير قادر على إعطائك إجابة مرضية، يرجى الاتصال البحوث المشرف الدكتور آرو Narayanasamy في جامعة نوتنغهام، Aru. Narayanasamy nottingham.ac.uk @، جامعة نوتنغهام، نوتنغهام، الدكتور RD NG72 أو Greatrex شيلا Sheila. Greatrex - White@nottingham.ac.uk

الاتصال للحصول على مزيد من المعلومات

السيد **عبدالرحمن التميمي**
الجوال: 0787135970
البريد الإلكتروني: ntxat4@nottingham.ac.uk

أشكركم على المساعدة والدعم في المشاركة في الدراسة

Appendix 6: Consent Form

The University of Nottingham

CONSENT FORM
(Final version 1.0: 15.02.2012)

Title of Study: **How is spirituality experienced by Jordanian patients with ESRF? A phenomenological study**

REC ref: ----------

Name of Researcher: Abdelrhman Tamimi

Name of Participant: **Please initial box**

1. I confirm that I have read and understand the information sheet version number ……dated..... for the above study and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis. ☐

3. I understand that relevant sections of my medical notes and data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to participate in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐

4. I understand that the interview will be recorded and that anonymous direct quotes from the interview may be used in the study reports. ☐

5. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

3 copies: 1 for participant, 1 for the project notes and 1 for the medical notes

نموذج الموافقة

(النسخة النهائية 1.0: 2012/02/15)

عنوان المشروع: كيف تتجلى روحانية المرض في حياة المرضى الأردنيين في مرحلة الفشل الكلوي؟ دراسة الظواهر
اسم الباحث: عبدالرحمن التميمي

المرجع----------:

اسم المشارك:

1. أؤكد أن لدي قراءة وفهم النص ورقة معلومات عدد .....بتاريخ ....لدراسة أعلاه، واتيحة لي الفرصه لطرح الأسئلة.

2 . أنا أفهم أن مشاركتي طوعية وأنني حر في الانسحاب في أي وقت دون إبداء أي سبب، ودون أن تتأثر الرعاية طبية لي .أنا أفهم أنه يمكنني سحب المعلومات التي تم جمعها حتى الآن والتي لا تزال امكانية استخدامها في تحليل المشروع.

3. أنا أفهم أنه يمكن النظر في الفروع ذات الصلة من ملاحظاتي الطبية والبيانات التي تم جمعها في هذه الدراسة من قبل الأفراد من جامعة نوتنغهام، ومجموعة الأبحاث والسلطات التنظيمية ذات الصلة في هذه الدراسة .أعطي الإذن لهؤلاء الأفراد في الحصول على هذه السجلات، وجمع وتخزين وتحليل ونشر المعلومات التي تم الحصول عليها من مشاركتي في هذه الدراسة .وأنا أفهم أن سيتم الاحتفاظ بياناتي الشخصية.

4. أنا أفهم أنه يمكن استخدام تسجيل المقابلة *مجموعة /التركيز وأن يقتبس مباشرة من مجهول مقابلة أجرتها مجموعة /التركيز * *)حذف حسب مقتضى الحال (في تقارير الدراسة)

5. أنا أوافق على المشاركة في الدراسة المشار إليها أعلاه.

_____
اسم التوقيع التاريخ المشترك

_____
اسم الشخص الذي موافقة التوقيع التاريخ
ثلاث نسخ 1 :لمشارك، (1)لملاحظات المشروع و 1لتلاحظ الطبية

Appendix 7: Access Letter

To whom it may concern

Dear Sir/Madam,

I am writing to you to apply for ethical approval for my research study entitled *How does "spirituality or الروحانيه" manifest in the lives of Jordanian patients in End Stage Renal Failure?* In addition, I would like to inform you that I am Jordanian nurse studying for my PhD at the University of Nottingham to improve the nursing care for end stage renal failure in Jordan.

I attach herewith the following documents: Study Protocol, Consent Form, Information Sheet, Interview Schedule.

Should you require any further information, please do not hesitate to contact me.

Yours faithfully,

Abdelrhman Tamimi

PhD Candidate
University of Nottingham
School of Nursing, Midwifery & Physiotherapy
Queen Medical Centre (QMC) B33

Appendix 8: Ethical Approvals

Direct line/e-mail
+44 (0) 115 8231063
Louise.Sabir@nottingham.ac.uk

The University of Nottingham
Faculty of Medicine and Health Sciences

Medical School Research Ethics Committee
Division of Therapeutics & Molecular Medicine
D Floor, South Block
Queen's Medical Centre
Nottingham
NG7 2UH

Tel: +44 (0) 115 8231063
Fax: +44 (0) 115 8231059

25th July 2012

Mr Abdelrhman Tamimi
PhD Student
c/o Dr Aru Narayansamy
Associate Professor
School of Nursing Midwifery and Physiotherapy
QMC Campus
Nottingham University Hospitals

Dear Mr Tamimi

Ethics Reference No: J12072012 SNMP
Study Title: How Spirituality uncovers in the experience patient in end stage renal failure: A Phenomenological study.
Lead Investigator: Abdelrhman Tamimi, PhD Student, School of Nursing, Midwifery and Physiotherapy
Chief Investigators: Dr Aru Narayansamy, Associate Professor, Dr Sheila Greatrex-White, School of Nursing, Midwifery and Physiotherapy.
Duration of Study: 10/2012-05/2013 (6-8mths) **No of Subjects:** 20

Thank you for submitting the above application which was considered at the Medical School Research Ethics Committee at its meeting on 12th July 2012. The following documents were reviewed:

- Application form 6/7/2012
- Study Protocol 6/7/2012
- Participant Information Sheet 6/7/2012
- Consent form version 1.0 6/7/2012
- Interview schedule version 1 14/03/2-12
- Revised Application form dated 7/24/2012
- Approval letter from Ministry of Health Ethics Committee Al Bashir Hospital Jordan, Dr Esam Al Sharaidah, dated 10th July 2012 – Ethics ref/6303
- Letter of permission from HR Director Prince Hamsa Hospitals dated 22nd July 2012.

These have been reviewed and are satisfactory and the study has a favourable opinion.

A Favourable opinion is given on the understanding that all appropriate ethical and regulatory permissions are sought for each overseas project in accordance with all local laws, and that the host organisation involved also gives their permission where applicable.

Yours sincerely

Dr Clodagh Dugdale
Chair, Nottingham University Medical School Research Ethics Committee

4174025/CE/CMK

The University of Nottingham

UNITED KINGDOM · CHINA · MALAYSIA

0115 82 30894
catrin.evans@nottingham.ac.uk

Faculty of Medicine and Health Sciences
School of Nursing, Midwifery & Physiotherapy
B Floor
South Block Link
Queen's Medical Centre
Nottingham
NG7 2HA
t: +44 (0)115 823 0850
f: +44 (0)115 823 1211
Head of School::
Professor Mark Avis BA(Hons) MSc RN RNT Cert Ed

23 May 2012

To Whom It May Concern

RE: Abdelrhman TAMIMI, Date of Birth: 15/07/1975

This is to confirm that the above named is a registered PhD student at the School of Nursing, Midwifery and Physiotherapy, The University of Nottingham, UK. The course began on 01 October 2011 and the duration is 3 years of full-time study. Abdelrhman's supervisors are Dr Sheila Greatrex-White and Dr Aru Narayanasamy. The working title of his research project is: How spirituality is uncovered in the experience of patients in end stage renal failure: a phenomenological study.

As part of his PhD studies, Abdelrhman is required to undertake a period of data collection in Jordan during the academic year 2012/2013, which is between the dates of 24 September 2012 and 23 September 2013. Abdelrhman is therefore seeking ethical approval to collect research data from dialysis patients as part of his study.

During the data collection period, supervision will be ongoing and Abdelrhman will remain a registered student at The University of Nottingham. On completion of the data collection period, Abdelrhman will return to the UK to continue his PhD studies.

Please do not hesitate to contact me should you have further queries.

Yours sincerely,

Dr. Catrin Evans
MPhil/PhD Course Director
Deputy Director of Postgraduate Studies

The University of Nottingham
The University of Nottingham
School of Nursing
B Floor, Medical School
Queen's Medical Centre,
Nottingham NG7 2UH

وزارة الصحة
مستشفى الامير حمزة بن الحسين

الرقم ٣٥/٢٢/١١٦٠
التاريخ
الموافق ١٤/٥/٢٠١٣

مدير الدائرة الطبيه
مدير دائرة التمريض

تحية طيبة وبعد ،،،

إشارة لاجتماع لجنة اخلاقيات المهنة في مستشفى الامير حمزة والمنعقد بتـاريخ 2013/5/13 م فقد اطلعت اللجنة على البحث المقدم من الطالب الدكتوراه / **عبدالرحمن محمد ابراهيم التميمـي** دراسة بعنوان

(كيفه العنايه الروحانيه بمرضى الكلى)

وبعد دراسة المستفيضة حول هذا البحث قررت اللجنة الموافقة على إجراء الدراسة مع إطـلاع اللجنة على النتائج قبل النشر .

للتكرم بالاطلاع وتسهيل مهمة الباحث في إجراء البحث اعلاه .

وتفضلوا بقبول فائق الإحترام

مدير مستشفى الأمير حمزه
الدكتور علي حياصات

مستشفى الأمير حمزة
د. سعد الخرابشة
مدير دائرة الموارد البشرية

نسخة :-
- الملف العام .
ع.ا / م.أ

المملكة الاردنية الهاشمية
هاتف : ٠٠٩٦٢٦٥٠٥٣٨٢٦ فاكس : ٠٠٩٦٢٦٥٠٥٣٧٩٠ الموقع الالكتروني www.phh.gov.jo

وزارة الصحة

الرقم .....
التاريخ .....م ب ا / لجنة اخلاقيات/ ٦٣٠٣
الموافق ٢٠/٧/٢٠١٢

مدير تطوير الموارد البشريه

تحيه طيبه وبعد ،،،

اشـــاره لكتـــابكم رقـــم تطـــوير / متـــدربين /٦١٣٠ تـــاريخ ٢٠١٢/٦/٢٦ بخصوص البحث المقدم من طالب الدكتوراه عبد الرحمن محمد ابراهيم التميمي .

بعنـــــوان :
" كيفية العنايه الروحانيه بمرضى الكلى "

يرجى التكرم بالعلم بأنه" تم عرض البحث على لجنة اخلاقيات البحث العلمـــي وقد قررت اللجنه الموافقه على اجراء البحث المشار اليه اعلاه .

للتكرم بالاطلاع واجراءاتكم لطفا .

واقبلوا الاحترام

مدير مستشفى البشـــير

الدكتور عصام الفريده

ص ب /رس

٩٢٢٧

المملكة الأردنية الهاشمية
هاتف: ٥٢٠٠٢٢٠ ٦ ٩٦٢+ فاكس: ٥٦٨٨٢٧٢ ٦ ٩٦٢+ ص.ب: ٨٦ عمان ١١١١٨ الأردن. الموقع الإلكتروني: www.moh.gov.jo

بسم الله الرحمن الرحيم

THE ISLAMIC HOSPITAL
Amman - Jordan

Tel.: 5101010 Fax.:5661773
P.O.Box:925693 Amman 11190 Jordan
P.O.Box: 2414 Amman 11181 Jordan
www.islamic- hospital.org

المستشفى الإسلامي
عمان - الأردن

تلفون : ٥١٠١٠١٠ - فاكس : ٥٦٦١٧٧٣
ص.ب : ٩٢٥٦٩٣ عمان ١١١٩٠ الأردن
ص.ب ٢٤١٤ عمان ١١١٨١ الأردن
e.mail:info@islamic-hospital.org

Ref :

Date:

الرقم : ١٥/ ٢٠١٣/ ٨١٢

التاريخ: 21 شباط 2013م.

الموافق :

السيد عبد الرحمن محمد التميمي حفظه الله

الموضوع: إجراء البحث العلمي (كيفية العناية الروحية بمرضى الكلى)

السلام عليكم ورحمة الله وبركاته،

لقد جاءنا من اللجنة المؤسسية للمستشفى الإسلامي أن إجراء البحث الذي تقدمتم بطلب إجرائه على مرضى الفشل الكلوي في المستشفى الإسلامي يتطلب منك تقديم ما يلي:

(1) نموذج موافقة المرضى على المشاركة على البحث، باللغة العربية، ومعه معلومات توضيحية للمرضى تبين ما هو المطلوب منهم، وكيف يسهم البحث في تحسين العناية بهم.

(2) بروتوكول البحث.

راجياً لكم التوفيق والسداد

والسلام عليكم ورحمة الله وبركاته.

المدير العام

الدكتور عمار أبو صبح

- الملف العام.
- اللجنة المؤسسية.

S043D

وزارة الصحة

الرقم تطوير/ متوربين/ ٦٢٤ ل

التاريخ

الموافق ٢٢/٧/٢٠١٢

مدير عام مستشفى الأمير حمزة

مدير مستشفى الأمير الحسين بن عبد الله الثاني المحترم

تحية طيبة وبعد ،،،

أرفق طياً صورة عن كتاب رئيس لجنة أخلاقيات البحث العلمي رقم م ب أ / لجنة أخلاقيات / ٦٣٠٣ تاريخ ٢٠١٢/٧/١٠ بخصوص السماح لطالب الدكتوراه في التمريض عبد الرحمن محمد ابراهيم التميمي من جامعة (Nottingham) تخصص رعاية مرضى الكلى إجراء بحث بعنوان :-

(كيفية العناية الروحانية بمرضى الكلى)

وذلك عن طريق إجراء مقابلات مع مرضى الكلى المراجعين للعيادات والمقيمين في المستشفيات التابعة لوزارة الصحة .

أرجو التكرم بالإيعاز لمن يلزم تسهيل مهمة الباحث أعلاه .

واقبلوا الإحترام ،،،

مدير تطوير الموارد البشرية

الدكتورة فدوى الشوابكة

نسخة / الملف

س م

عدد الباحثين (١)

المملكة الأردنية الهاشمية
هاتف ٥٢٠٠٢٣٠ ٦ ٩٦٢+ فاكس ٥٦٨٨٢٧٣ ٦ ٩٦٢+ ص.ب ٨٦ عمان ١١١١٨ الأردن. الموقع الإلكتروني www.moh.gov.jo

وزارة الصحة

الرقم تطوير موارد بشرية/ ٦٢٤
التاريخ
الموافق ٢٢/٧/٢٠١٢

مدير عام مستشفى الأمير حمزة

مـــــدير مستشفـــى --------

تحية طيبة وبعد ،،،

أرفـــق طيـــأ صـــورة عن كتـــــاب رئيس لجنة أخلاقيـــات البحث العلمـــي رقـــم م ب أ / لجنـــة أخلاقيـــات / ٦٣٠٣ تاريـــخ ٢٠١٢/٧/١٠ بخصوص الســـماح لطالب الدكتوراه في التمريض **عبد الرحمن محمد ابراهيم التميمي** من جامعة **(Nottingham)** تخصص رعاية مرضى الكلى إجراء بحث بعنوان :-

(كيفية العناية الروحانية بمرضى الكلى)

وذلك عن طريق إجراء مقابلات مع مرضى الكلى المراجعين للعيادات والمقيمين في المستشفيات التابعة لوزارة الصحة .

أرجو التكرم بالإيعاز لمن يلزم تسهيل مهمة الباحث أعلاه ،

واقبلوا الاحترام ،،،

مدير تطوير الموارد البشرية

الدكتورة فدوى الشوابكة

نسخة / الملف
س م
عدد الباحثين (١)

المملكة الأردنية الهاشمية
هاتف: ٥٢٠٠٢٢٠ ٦ ٩٦٢+ فاكس: ٥٦٨٨٢٧٢٠ ٦ ٩٦٢+ ص.ب: ٨٦ عمان ١١١١٨ الأردن. الموقع الإلكتروني: www.moh.gov.jo

المستشفى التخصصي
THE SPECIALTY HOSPITAL

التاريخ : ٢٠١٣/٤/٢٩
الرقم : ٧٠٨٦٤/ت/١/٥

من : لجنة الآداب والسلوك الطبي I.R.B

إلى : الطالب / عبد الرحمن محمد التميمي المحترم

الموضوع : طلبكم عمل دراسة استجوابيه في المستشفى التخصصي بعنوان :
كيفية العناية الروحانية بمرضى الكلى

تحية طيبة وبعد ،،،

بناءً على الرسالة الموجهة من قبلكم لعمل الدراسة الاستجوابية أعلاه، وبعد مناقشة محتواها كما ورد في اجتماع لجنة الآداب والسلوك الطبي الأخير بتاريخ ٢٠١٣/٤/٢٩ .

يسرنا إعلامكم بأن اللجنة وافقت على إجراء المشروع أعلاه وحسب البروتوكول المرفق ، شريطة :

١. أن يتم توقيع نموذج سرية المعلومات .
٢. أن يتم إعلام اللجنة بتطور الدراسة أولاً بأول .
٣. أن يتم كتابة تعهد بإرسال نسخة من الدراسة والنتائج إلى اللجنة .
٤. أن لا يتم نشر هذه الدراسة في المحافل العلمية قبل الرجوع إلى إدارة المستشفى التخصصي .

مع تمنياتنا لكم بالتوفيق في مسعاكم

رئيس لجنة الآداب والسلوك الطبي
الدكتور / فوزي الحموري

المستشفى التخصصي
THE SPECIALTY HOSPITAL

عمان - الأردن - هاتف ٥٠٠١١١١ ٦ ٩٦٢+ - فاكس ٥٦٩٧٤٢٥ ٦ ٩٦٢+ - ص.ب ٩٣٠١٨٦ عمان ١١١٩٣
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